

GSA's 75th Anniversary: Forum



Dementia Caregiving Research: Expanding and Reframing the Lens of Diversity, Inclusivity, and Intersectionality

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Received: December 4, 2019; Editorial Decision Date: April 24, 2020

Decision Editor: Barbara J. Bowers, PhD

Abstract

This forum expands and reframes the lens of dementia caregiving research among diverse racial and ethnic groups to better understand the unique needs, stressors, and strengths of multicultural and racial-ethnic family caregivers in the United States. By providing more diverse and inclusive knowledge on caregiving to older adults in the United States, we can create a new path forward with regards to caregiving research. Throughout the article, major questions and answers are supported by critiquing some of the caregiving literature. Discussions are provided to help create inclusive ways of conceptualizing caregiving research and using methodological approaches to reflect the diversity of caregivers and care recipients in the United States. Expanding and reframing the conceptual and methodological lens of diversity, inclusivity and intersectionality can provide evidence to support effective policy, practice, and care in addressing the needs of diverse groups of caregivers and older adults living with dementia.

Keywords: Caregiving, Ethnicity, Inclusion, Race, Recruitment.

Several keys and highly cited articles (Cantor, 1983; George & Gwyther, 1986; Stone, Cafferata, & Sangl, 1987; Zarit, Reever, & Zarit, 1980; Zarit, Todd, & Zarit, 1986) in the 1980s provided foundational findings on sociological and psychological aspects of caregiving (e.g., burden, strain, stress, use of formal services, and profiles of caregivers and care recipients). These findings provided evidence that informed care interventions, policy, and future directions in the study of caregiving to older adults in the United States. While these findings led the emerging field of caregiver burden, stress, strain, and intervention, the inclusion of diverse racial-ethnic groups in dementia caregiving research addressing such issues became prominent over time (1990–2019), with the greatest numbers of studies between 2000 and 2009 (Liu et al., 2020). Early work that informed issues of diversity and inclusion in caregiving

research (Dilworth-Anderson & Anderson, 1994; Dilworth-Anderson, Goodwin, & Williams, 2004; Farran, Miller, Kaufman, & Davis, 1997; Picot, 1994) provided conceptual and empirical information that facilitated understanding the importance of culture and context in dementia caregiving research. Nevertheless, racial and ethnic caregiver groups, living in rural or urban areas, have not been studied enough to provide the type and volume of evidence to address their needs. This forum addresses expanding and reframing the lens of dementia caregiving research on racial and ethnic groups in order to better understand addressing the unique needs, stressors, and strengths of multicultural and racial-ethnic family caregivers in the United States. Because most of the research on dementia care has focused primarily on African Americans, Asians, Hispanics/Latino, and whites, our discussions include these groups.

In the past two decades, caregiving research has moved beyond description and empirical investigations to more “evidence-based” interventions; however, limited information (Brodaty & Arasaratnam, 2012; Gitlin, Marx, Stanley, & Hodgson, 2015; National Academy of Sciences, Engineering Medicine [NASEM], 2016) is available on how these interventions work between and within diverse groups (e.g., race/ethnicity, rural/urban, sex/gender) due to the lack of “sufficient numbers of diverse caregivers and care recipients to allow an assessment of their effectiveness for Hispanic, African American, and other ethnic and racial groups” (NASEM, 2016, p. 200). As Gitlin and colleagues (2015) noted, “there is limited evidence concerning intervention benefits for demographic subgroups (men, minority populations, rural, long-distance and multiple carers) whose prevalence is increasing” (p. 12). A recent systematic literature review of studies published from 1994 to 2015 (Gilmore-Bykovskiy, Johnson, Walljasper, Block, & Werner, 2018) reported most of the 48 caregiver intervention support studies reviewed included women and racial/ethnic minorities; however, 67% did not report results by gender or racial/ethnic group. Although required by NIH (National Institutes of Health, 1993), the review also shows that underreporting was more common for race/ethnicity than gender in the caregiver interventions. Gilmore-Bykovskiy and colleagues (2018) stated, “Ensuring NIH guideline compliance necessitates shared investments from researchers, editors, and reviewers to ensure group differences are systematically identified and reported” (p.145). Minimal rigorously tested interventions exist with diverse groups, which signals “the importance of addressing the needs of culturally and ethnically diverse caregiving populations” (NASEM, 2016, p. 9).

Where Do We Go From Here?

Three concepts are central to our discussions on our path forward: diversity, inclusivity, and intersectionality. The first discussion in this article provides demographic information that highlights the need to address the growing and ever-present numbers of older adults from diverse (racial-ethnic) backgrounds. Second, we discuss concepts and theoretical perspectives that can inform present and future dementia caregiving research from a paradigm, which is inclusive and allows for addressing the importance of intersectionality in caregiving research. Last, we discuss effective recruitment approaches to help capture the richness of diversity in caregiving samples.

What Is the Dementia Caregiving Complexity in the U.S. Aging Population?

One of the fastest growing populations in the United States is the oldest-old group (80+ years), representing 27% of the U.S. older population (65+) in 2012 with an estimated 37% in 2050, implying that more informal caregivers will need

to deal with their own aging in addition to providing care to high-need older adults (NASEM, 2016; Ortman, Velkoff, & Hogan, 2014; Schulz & Eden, 2016; Taylor & Quesnel-Vallée, 2017). The older population of the United States is not only growing older, but also increasing in diversity. For example, by 2030, 20.2 million of the 72.8 million older adults aged 65 and older are expected to be racial/ethnic minorities (Schulz & Eden, 2016). As the aging population increases, the risk for Alzheimer’s and related dementias increases, especially for minority groups. Studies show that older African Americans are about twice as likely to have Alzheimer’s or other dementias as older whites (Alzheimer’s Association, 2020; Potter et al., 2009; Rajan, Weuve, Barnes, Wilson, & Evans, 2019), and older Hispanics/Latinos are about one and one-half times as likely to have Alzheimer’s or other dementias as older whites (Haan et al., 2003; Samper-Ternent et al., 2012); however, differences may vary by specific Hispanic/Latino groups (González et al., 2019; Mehta & Yeo, 2017; Yaffe et al., 2013). This growing prevalence of dementia requires a growing need for dementia care. Two thirds of caregivers to older adults with dementia are non-Hispanic white (National Alliance for Caregiving in Partnership with the Alzheimer’s Association, 2017; Rabarison et al., 2018). Furthermore, racial/ethnic minority caregivers for people with dementia, such as Hispanic, African American, and Asian American dementia caregivers, experience higher levels of depression and more demanding informal caregiving careers (e.g., less outside help, higher caregiving hours) due to low levels of formal service use compared with white caregivers (Gilmore-Bykovskiy et al., 2018; Rote, Angel, Moon, & Markides, 2019). However, some early research (Coon et al., 2004; Haley et al., 1995; Roth, Haley, Owen, Clay, & Goode, 2001) reported that African American caregivers show more resilience and that African American and Hispanic caregivers report more positive attitudes toward caregiving compared with white caregivers.

Caregiving experiences are also understood through changes in family structure that are impacting the availability of caregivers for older adults with dementia. A sharp decline in the ratio of caregivers to older adults of 7:1 in 2010 to an estimated 4:1 in 2030 in the United States will result in higher-intensity caregiving among family caregivers (Redfoot, Feinberg, & Houser, 2013), which may result in more care burden for family caregivers of people with dementia. In general, the responsibilities of caregivers range from assisting with activities and instrumental activities of daily living to coordinating, monitoring, and even navigating health systems and delivering healthcare (National Alliance for Caregiving & AARP Public Policy Institute, 2015; Schulz & Eden, 2016). Reinhard and colleagues (2019) summarized it well: “The old paradigm—the uncomplicated world of ‘informal’ caregiving—no longer applies to millions of family members, friends, and neighbors of diverse ages and cultural backgrounds who provide complex care at home. In the current health care environment, it is presumed that every home is a potential

hospital, and every service that the person needs can be provided by an unpaid family member, with occasional visits by a primary care provider, nurse, or therapist” (p. 39). Findings also show that many caregivers have not received training to provide the current type of caregiving or preparation and face substantial financial challenges due to limited financial resources, limited paid leave, or out of pocket expenses (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Schulz & Eden, 2016). Consequently, caregivers may have difficulty adapting to their role and experience distress or burden in response to their care recipients’ needs for assistance. These strains and stresses may result in other disruptions, such as family conflict, social isolation, financial burden, occupational instability, and adverse outcomes in their own physical and mental health as well as mortality (Adelman et al., 2014; Capistrant, 2016; Pinquart & Sörensen, 2003a, 2003b; Schulz & Eden, 2016).

What Conceptual and Theoretical Views Are Needed to Capture Demographic Changes and Caregiving Complexity?

Given the demographic changes and the complexity of caregiving issues and needs described above, inclusive conceptual and theoretical models and perspectives are needed to capture, examine, and interpret this complexity. As noted by Pillemer, Suito, and Wethington (2003) almost two decades ago, the connections among theory, research, and intervention in the field of gerontology are often tenuous or nonexistent. Their reporting is still true today, not only regarding interventions but also with regards to care practices and policy (Dilworth-Anderson & Moon, 2018).

Concepts to Inform Inclusive Caregiving Theory and Research

- *History* of a “people” (native, enslaved, immigrants) provides a broad understanding how past generational experiences determine access to and use of services and trust of different kinds of services and support.
- *Culture* allows for understanding both care recipients’ and caregivers’ identity, norms, values, beliefs, and ways of “being” and “doing.”
- *Social determinants of health* provide information on both distal and proximal factors (e.g., education, income, literacy, immigrant status, discrimination) that affect the health and well-being of care recipients and caregivers.
- *Place* allows for understanding social structural (e.g., access to hospitals, pharmacies, and adequate food) aspects of care and caregiving.

Theoretical Views to Inclusive Caregiving Theory and Research

Numerous conceptualization and theoretical views can inform and help reframe the lens on diversity and inclusion in

caregiving, research, interventions, and practice. As Apeso-Varano, Tang-Feldman, Reinhard, Choula, and Young (2015) noted, we need to explore frameworks in caregiving research that go beyond stress and coping models and incorporate theoretical concepts such as sociocultural values and beliefs. Due to limitations in space for this article, we identified two theoretical perspectives that are both broad and relevant to this discussion to expand theoretical views on dementia caregiving research.

Sociocultural theory. Social-cultural theory allows us to incorporate the above-mentioned theoretical concepts of history and culture in caregiving research. Furthermore, the theory emphasizes the importance of social environment (place) and the type of environment or context in which to understand social determinants of health. Sociocultural theory also stresses that cultural norms, beliefs, and attitudes influence greatly how people learn. Learning is achieved through social relations and environmental contexts (Vygotsky, 1989). Historical events in the lives of those within a certain social-cultural group also shape learning and identity development. Thus, the “lived” experience of individuals within sociocultural context will shape perceptions, meanings, values, and beliefs about a situation. Therefore, caregiving from a social-cultural perspective is likely filtered and layered through a group’s history, cultural norms, beliefs, and values. Findings in Lindauer, Harvath, Berry, and Wros (2016) show that the meaning African American caregivers assigned to dementia-related changes in their loved ones were in relation to oppression in general, and slavery specifically. Thus, institutional, structural, and cultural factors (e.g., mistrust, lack of resources, lack of access to care, and family reciprocity; Aranda & Knight, 1997; Dilworth-Anderson, Williams, & Gibson, 2002; Haley, Levine, Brown, & Bartolucci, 1987; Hinton, Franz, Yeo, & Levkoff, 2005; Knight & Sayegh, 2010) experienced by racial/ethnic minority older adults often create high dependence on informal networks for their care.

Roth, Dilworth-Anderson, Huang, Gross, and Gitlin (2015) conducted a study to provide an understanding of how different subgroups of caregivers experience positive aspects of caregiving. Their findings show that, overall, the Positive Aspects of Caregiving (PAC) scale scores indicated that both Hispanics and African Americans experienced more PAC than whites. They noted that both African Americans and Hispanics reported more positive caregiving experiences on items that were not sensitive to cultural differences. In addition, African Americans endorsed two items at significantly higher levels that addressed feeling “enabled” to “appreciate life” and to “develop a positive attitude toward life” (p. 818). The authors noted that these items may reflect racial socialization and maintained in adulthood and later life among African Americans, especially when facing adversity or overcoming hardships. Using the Cultural Justification for Caregiving Scale

(CJCS), Dilworth-Anderson and colleagues (2005) found that African Americans had stronger cultural reasons (e.g., of sense of duty, obligation, expectations, and values) for providing care than whites. Within-group differences, however, show African Americans with higher education scored lower than their counterparts on the scale. Like gender socialization regarding caregiving in most cultures, African American females when compared with males had higher CJCS scores. White males, however, had higher CJCS scores than their female counterparts. Younger when compared with older white caregivers had higher CJCS scores. These findings show that cultural reasons for caregiving need to be interpreted within the context of race and gender socialization. Dilworth-Anderson and colleagues (2005) also noted that culture can inform social roles, and social roles, such as husband or wife, son or daughter, can have different meanings for these same roles across cultures. Thus, these interpretations of role-specific caregiving are important to consider.

Intersectionality framework. The intersectionality framework developed by Crenshaw (1994) allows for understanding how certain conditions and statuses impact on people's lives. The framework, therefore, emphasizes how people are best understood and studied through the dimensionality, co-occurrence, and interlocking factors, such as race, gender, socioeconomic status, immigrant status, and geographic location or place (Hankivsky, 2012). Intersectionality also directs us to think analytically about the lens through which we attempt to understand the "other" who may not have the same history and social location as others. It also allows for understanding how identity categories (e.g., gender, race, ethnicity, and religion) and lived reality of an individual interact to shape one's life course choices and reactions to them. Thus, intersectionality theory informs us on framing and reframing how we come to understand a person's lived experience as a caregiver that is shaped by the reality of their history, culture, social determinants of health, and place.

Furthermore, this framework subsumes many of the views of social stratification theory, role theory, and feminist perspectives regarding the social positions of people and socially assigned roles people play in a society. In their study on caregiver well-being, intersections of relationship, and gender, Chappell, Dujela, and Smith (2015) stated, "The data confirm the usefulness of the intersectionality framework for understanding occupancy of more than one status and indicate that positive cognitive well-being and negative affective well-being can be differentially related" (p. 623).

Sampling to Expand the Lens on Dementia Caregiving Research

Although dementia caregiving has included diverse samples, there still exists a need for greater representation in studies. Similarly, issues on measurement are equally important as

those on recruitment issues, but due to space limitations these issues are not discussed. Regarding recruitment issues, however, the next generation of dementia caregiving studies will need to address the selection of recruitment practices and challenges to capture the range of dementia caregiving experiences and reactions among diverse racial and ethnic groups. Challenges in recruitment of diverse populations in dementia caregiving research has been well documented during the last two decades (Aranda & Knight, 1997; Dilworth-Anderson, 2011; Dilworth-Anderson & Cohen, 2010; Dilworth-Anderson & Williams, 2004; Dilworth-Anderson et al., 2002; Gallagher-Thompson, Solano, Coon, & Arean, 2003; Gallagher-Thompson et al., 2006; Hinton, Guo, Hillygus, & Levkoff, 2000; Houde, 2002; Tarlow & Mahoney, 2000). On the one hand, the extant dementia caregiving literature identifies barriers to recruitment of dementia caregivers that may account for the low representation of diverse samples in study participation. In this category of literature, approaches or strategies are typically offered that address these barriers. On the other hand, and less frequently attended to, is the testing of recruitment strategies to ascertain if one caregiver recruitment strategy is superior to another in increasing study participation rates.

There are important consequences to the lack of representative samples as evidenced in dementia caregiving research. First, largely homogeneous samples limit external validity or the extent to which the study findings can be generalized from the specific sample studied to larger groups of subjects or populations. Second, having enough numbers of diverse groups can help identify possible subgroup differences with to research outcomes (e.g., physical and psychological) and potential mediators or moderators of said outcomes. For example, Liu and colleagues (2020) found that African American dementia caregivers had better psychological well-being than white dementia caregivers and that Hispanic/Latino dementia caregivers had worse physical well-being compared with white dementia caregivers. Third, informed by intersectionality theory, inclusion of diverse samples addresses the social justice aim of ensuring that the heterogeneity and "lived" experience is addressed especially for groups who experience high disease burden yet low benefits of scientific discoveries. Lastly, increasing diversity in caregiving samples adheres to federal regulations mandating the inclusion of women and minorities in clinical research (National Institutes of Health, 1993). Thus, the inclusion of underrepresented groups in dementia caregiving research addresses the goals of health equity, ethical principles, and tenets of rigorous science, and compliance with federal law (Aranda, 2001).

Descriptors of failed or inadequate attempts to recruit diverse samples in previous work has relied on terms such as "difficult to reach," "hard to recruit," "hidden populations," which may focus or skew the responsibility of participation on individuals and groups for their low representation in research (Rodríguez, Rodríguez, & Davis, 2006). Although

the central decision to participate in research lies with the identified caregiver, it is incumbent on researchers to refocus the discussion on how provider and organizational factors may deter participation in studies due to entrenched structural mechanisms. As stated by Redwood, Gale, and Greenfield (2012), “We subject to critical analysis the notion that certain groups, by virtue of sharing a particular identity are inaccessible to researchers—a phenomenon often problematically referred to as ‘hard to reach.’ We use the term ‘seldom heard’ to move the emphasis from a perceived innate characteristic of these groups to a consideration of the methods we choose as researchers” (p. 1).

What Are Effective Strategies to Address Recruitment Barriers?

Early attempts at recruiting diverse caregivers centered around “user-friendly,” “culturally appropriate or sensitive” strategies (Aranda, Villa, Trejo, Ramírez, & Ranney, 2003; Gallagher-Thompson et al., 2003). This typically was comprised of making study participation more attractive through attending to language of preference and cultural values and beliefs in outreach activities and program design. For example, efforts to recruit Hispanic caregivers underscored the salience of *personalismo* (high value placed on warm interpersonal exchanges in designing outreach efforts; Aranda & Morano, 2007; Aranda et al., 2003; Gallagher-Thompson et al., 2003). Notions about the meaning of memory decline are socioculturally constructed as evidenced by beliefs that said loss is attributed to indigenous groups’ cultural and spiritual interpretations (e.g., dementia symptoms represent communications with the supernatural world; Henderson & Henderson, 2002), or religious orientations to coping (Adams, Aranda, Kemp, & Takagi, 2002). Furthermore, issues of stigma related to memory loss is a central barrier to study recruitment for Chinese Americans (Hinton et al., 2000, 2005). Additionally, the term “caregiver” is not accepted by many groups due to cultural differences with how the role is perceived or used (Aranda & Morano, 2007; Karlawish et al., 2011; Whitebird et al., 2011). These perceptions can therefore affect recruitment efforts among people who do not identify with the label of caregiver.

With recognizing and understanding how the values, beliefs, and perceptions of diverse groups are key to recruitment, conducting media and community events and forming partnerships with community agencies or organizations can become effective recruitment strategies (Gallagher-Thompson et al., 2004, 2006; Mendez-Luck et al., 2011). Although forming community partnerships are viewed as a more robust strategy in increasing participation, minimal evidence exists supporting its relative effectiveness in increasing dementia caregiving research rates. One example of this is the work by Gallagher-Thompson and colleagues, which found that collaborative agency partnerships (professional referrals from agencies) were

more effective in recruiting Hispanic/Latino and white caregivers than two consumer-centered approaches: media advertisements and health fairs (Gallagher-Thompson et al., 2004). They also found that direct face-to-face contact with key community leaders generated the highest number of Chinese American participant referrals when accompanied by culture-specific factors such as building trust, and linguistic, and ethnic matching between staff and participants (Gallagher-Thompson et al., 2006). Work by Mendez-Luck and colleagues (2011) also found that partnerships with community-based organizations played a significant role in study participation rates among Mexican origin caregivers.

Other strategies to enhance racial and ethnic diverse samples include intensive interviewer training, monetary incentive, precontact letters, reminder calls, and in-person screenings to prompt immediate engagement and study participation; conceptual, rather than literal, translation of outreach materials; and attending to regionally specific social marketing strategies for minority recruitment (Nichols et al., 2004; Ofstedal & Weir, 2011), and outreach to health plan providers for referrals (Whitebird et al., 2011). Recruitment strategies for African American caregivers highlight the importance of assigning the same interviewers to study participants for prospective studies, intensive interviewer training around family dynamics and social issues within the African American community, providing toll-free phone number access to research staff, and allowing flexibility in scheduling of interviews (Dilworth-Anderson & Williams, 2004).

Knowledge generated from nondementia caregiving research can provide us with information that can be applied to dementia caregiving studies. For example, word of mouth (the “personal contact”) and using existing community resources (Rodríguez et al., 2006) were found to be of most value while relying on flyers as a sole means of recruitment was ineffective. Similar results were found for other nondementia caregiving studies which relied on developing partnerships with community advisory groups, providing intensive research personnel training, and having meetings with potential gatekeepers (Browne, Ka’opua, Jervis, Alboroto, & Trockman, 2017; Neufeld, Harrison, Hughes, Spitzer, & Stewart, 2001; Redwood et al., 2012).

The next generation of caregiving research, with a focus on dementia, will need to take into consideration the type, timing, and intensity of recruitment strategies to increase the representation of caregivers from diverse groups. Several methodological considerations come to mind: (i) The intensity and types of outreach may differ across groups when an attempt is made to aggressively reach certain subgroups that are not typically accounted for in caregiving research, and have not been accounted for in initial study recruitment attempts; (ii) Convenience sampling versus population-based sampling have their respective strengths and weaknesses (i.e., representation and generalizability) and can yield different subgroup findings (population-based vs convenience sample; site effects); and

(iii) Stakeholder input may vary with regards to preferred recruitment strategies. Researchers should describe ways in which recruitment efforts may have varied by race/ethnicity subgroups and the effects these differences may have had on the representativeness of the sample, and on the comparability of different groups.

Summary: What Are the Next Steps?

Informed by some of the work of the early foundational caregiving researchers (George, Stone, and Zarit, and their respective colleagues), future dementia caregiving research could expand this knowledge by using culturally relevant conceptual models and theoretical perspectives, and diverse and inclusive samples to understand better caregiving between and within diverse populations. Such theoretical and conceptual models can be informed by the sociocultural and intersectionality theoretical views that are discussed in this forum as well as other theoretical work that reframed the sociocultural stress and coping model (Aranda & Knight, 1997; Knight & Sayegh, 2010). Future caregiving research also needs to incorporate issues of acculturation, assimilation, cultural values, beliefs, and norms among diverse groups of caregivers and care recipients not only with respect to dementia care but research participation. To achieve such goals, larger longitudinal studies from nationally representative populations based on caregiving outcomes by culture and race/ethnicity are needed to provide a comprehensive understanding of caregiver groups at risk as well as inter- and intragroup risk factors. In addition, comparison studies on dementia caregiving outcomes should include more minority caregivers, such as Hispanic, American Indians, or Asian American caregivers and sub-cultural groups by origin within minority groups (e.g., Mexican, Puerto Rican, Cuban, Salvadoran, Dominican, Guatemalan, or Colombian among Hispanic caregivers; Korean, Filipino, Vietnamese, Chinese, Indian, and Japanese among Asian American caregivers) to gain better understanding of care processes and outcomes. In summary, to conduct research to effectively help expand and reframe the lens on diversity, inclusivity, and intersectionality in dementia caregiving research, resources (e.g., funding, diverse research teams, community relationships and support, recruitment and retention strategies) are needed. This expanding and reframing will also require that researchers and funders revise their thinking and practices in designing and conducting dementia caregiving research and knowing what is fundable. Ultimately, this expanding and reframing of dementia caregiving research will provide needed evidence to support effective policy, practice, and care in addressing the needs of diverse groups of caregivers and older adults living with dementia.

Funding

This work was supported in part by NIH grants P50 AG005142 (Chui) and P30 AG066530 (Chui/Toga/Zlokovic) (to M. P. Aranda

and by NIH National Center for Advancing Translational Sciences A18-1148-006, NC TraCS Institute CTSA award at UNC (Buse & Cary) (to P. Dilworth-Anderson).

Conflict of Interest

None reported.

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