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Promoting Caregiver Mastery in Black American Dementia Caregivers

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Abstract

Over 6 million older Americans live with Alzheimer's disease and related dementias; Black American older adults' prevalence is more than twice that of non-Hispanic White older adults. The Black American dementia caregiving experience can be encapsulated within the Black Family Socioecological Context Model, which provides a conceptual basis for examining social determinants of health at individual, family, community, and societal levels with careful consideration for how the intersection of race, gender, and class of Black American dementia caregivers influences the multiple dimensions of their caregiving experiences. Family dynamics, community setting, and health care systems have a potentially bidirectional influence on these caregivers, which is shaped by historical and ongoing systemic and institutional racism and general disenfranchisement. This Forum article outlines how the Social Cognitive Theory offers ways for Black American dementia caregivers to achieve a sense of mastery within the complicated and fraught ecology within which their caregiving occurs. We propose a research agenda to create programs and interventions for enhancing a sense of mastery among Black American dementia caregivers. Two concepts in particular, "constraints" and "efficacy expectations," provide ways to create a systematic approach to developing successful coping strategies for the constraints perceived by individuals as they undertake and function in the caregiving role. The recognition of the complexity of the caregiving ecosystem and intersectionality of caregivers' experience and identity emphasize the importance of individualization: Each caregiver's experience of this ecosystem—and therefore each Black American dementia caregiver's way to mastery within it—will be uniquely shaped and experienced.

Keywords: African American, Caregiving, Ecosystems, Intervention, Socioecological

Black American older adults have more than double the prevalence of Alzheimer's disease and related dementias compared to non-Hispanic White older adults (Alzheimer's Association, 2021; Ortman et al., 2014), which suggests a disproportionate burden of dementia caregiving on Black Americans when compared to caregivers from other racial

groups (Farina et al., 2020; Garcia et al., 2019). Despite this disproportionate burden of dementia caregiving within Black American communities, dementia caregiver interventions are rarely culturally sensitive or culturally relevant (Butler et al., 2020). For example, few interventions account for situations such as caregiving networks encompassing

more than one caregiver, caregiver coresidence, and pooling of financial resources that are common in the informal care provided to Black American older adults (Dilworth-Anderson et al., 2004; Young et al., 2020). In addition, dementia caregivers typically spend more hours providing care and report greater emotional, physical, and financial challenges (Kasper et al., 2014). Thus, Black American dementia caregivers must learn to cope effectively with the challenges and constraints they face in societal institutions shaped by racism and discrimination while upholding their cultural values. At a minimum, coping that allows caregivers to manage their daily challenges and constraints effectively and reduce caregiver distress demands a measure of self-perceived confidence resulting in an enhanced sense of control; such coping demands caregiving mastery (Hepburn et al., 2003; Pioli, 2010).

In this Forum article, we outline a research agenda that we hope to pursue ourselves and hope others will build on to create programs and interventions for enhancing a sense of mastery—a self-acknowledged sense of confidence and competence—among Black American dementia caregivers. The first premise is grounded in the Social Cognitive Theory. In the latter part of the article, we use Social Cognitive Theory (Bandura, 2001; Pioli, 2010) to illustrate the importance of conceptual frameworks in designing interventions for developing dementia caregivers' mastery in navigating specific situations and challenges in the caregiving ecosystem. Our thinking rests on an appreciation of the effects of the entire spectrum of the social determinants of health influencing Black American dementia caregivers' experiences. The day-to-day tasks and mastery skill demands of providing care for a person living with dementia may be the same regardless of race and ethnicity. But that is where the similarities end. Black American caregivers' interactions with their social and physical environments are typically different from those of non-Hispanic White American caregivers. Woven into the fabric of American society, structural and systemic racism produces the challenges and constraints Black Americans face in providing care to older adults, and particularly those living with dementia, in an ecosystem marked by the social and health inequities embedded within social/political structures and institutions with which they must interact like health care, education, employment, lending, and housing (Yearby, 2020).

An Ecological Model to Characterize Challenges for Black American Caregivers

We employ the Black Family Socioecological Context Model (Allen, 1995) as a lens for viewing the interacting factors and multiple systems that create the challenges and constraints facing Black American dementia caregivers. The model adapts and amalgamates several earlier frameworks (Billingsley, 1988; Bosserman, 1968; Bronfenbrenner, 1979; Hill & Rodgers, 1964) that situate Black American

families within the broad sociopolitical system and consider family dynamics and changing relationships across the life span at different levels of the larger ecosystem. The model builds out two main assertions. First, it stresses the importance of interrelated ecosystems, suggesting that influences and causal relationships move not only downward, from larger systems through successively smaller systems, but bidirectionally as well (Allen, 1995). Thus, while societal institutions influence community settings, which influence family units/kinship networks, including fictive kin, which, in turn, influence individuals, the reverse is also possible. The second key assertion the model provides is that Black American families are varied and dynamic in nature. The heterogeneity within and across Black American families affects the kinds of challenges and constraints posed by other elements of the socioecological contexts and influences their optimal “outcome expectancies” (i.e., their constructions of realistically achieving optimal outcomes for their situation) and by their “efficacy expectations” (i.e., self-evaluations of their own capacity to bring about those outcomes; Bandura, 2001). The variable nature of caregiving coupled with individual responses to external stimuli supports the importance of understanding how each set of relationships across the entire socioecological system shapes the context-specific mastery demands required of Black American dementia caregivers.

Recounting the historical context within which Black American caregiving is situated is beyond the scope of this article, but it is important to acknowledge that the experiences of Black American caregivers in societal institutions are not akin to those of non-Hispanic White American caregivers. Black American caregivers' daily interactions with these societal institutions require levels of vigilance and forethought that non-Hispanic White American caregivers do not have to exert. In this context, we highlight below more specific important elements of each of the ecological levels (i.e., societal institutions, community setting, family units/kinship networks, and individual) that pose key challenges and constraints these caregivers must overcome to achieve mastery.

Societal Institutions

Three prominent realities of societal institutions shape the Black American caregiving experiences. First, historic and ongoing systematic racism—reflecting an underlying belief in Black inferiority—has produced a system that perpetuates the delivery of inferior health care and other services (Institute of Medicine, 2003; Milner & Franz, 2020; Noonan et al., 2016; Stepanikova & Oates, 2017; Warren, 2016). Second, historic and ongoing abuse and maltreatment of Black American individuals by the health care system, health care providers, and health researchers have produced an understandable distrust of health care among Black American caregivers (Bleich et al., 2019; Cuevas et al., 2016; Hughes et al., 2017; Travers et al.,

2017; Washington, 2006). Finally, historic and ongoing practice of under- and overdiagnosis of dementia and the substantial delays in accurate diagnoses of dementia in Black American older adults further justify this distrust (Alzheimer's Association, 2021; Chin et al., 2011; Dilworth-Anderson et al., 2012; Zuckerman et al., 2008). Perceived discrimination and inequities related to the social determinants of health are linked to poorer outcomes and service utilization, reduced coping options, and greater medical debt among Black Americans in a variety of conditions (Magwood et al., 2019; Rhee et al., 2021; Roth et al., 2011; Van Dyke et al., 2020; Wiltshire et al., 2016). Specific to Black American dementia caregivers, perceived discrimination has been identified as a barrier to navigating the health care system for the person living with dementia (Alzheimer's Association, 2021).

Community Setting

Three important occurrences within the community setting add constraints and challenges for Black American dementia caregivers. Communities in the United States remain largely segregated by the race and ethnicity of their members, and many Black communities are—by reason of historical oppressive economic and political policies and practices (e.g., redlining) and forced responses to them (e.g., outmigration)—depleted of resources and replete with threats (Do et al., 2017; Reynolds & Kendi, 2020). Retail and commercial disinvestment in Black communities negatively affects the health of Black Americans (Noonan et al., 2016), contributing to the development of excess comorbidities that add to the challenges of Black American dementia caregivers (Noonan et al., 2016; Thorpe et al., 2016). As the percentage of Black Americans increases in a community, the availability of supermarkets, produce stores, pharmacies, recreational facilities, parks, and dine-in restaurants—to name a few—decreases (Kwate et al., 2013; Smiley et al., 2010). When social factors including one's community of residence and health care access are held equal, health disparities in accessing health care services are significantly decreased for Black Americans (LaVeist et al., 2011). Because Black American dementia caregivers must provide care beyond their homes, the communities in which they live should be of importance when developing interventions of mastery.

Family Units/Kinship Networks

Black American family units/kinship networks can and do provide important support to Black American caregivers, support that well-designed and targeted interventions could leverage and strengthen. The family poses challenges and constraints, as well. Two particular strengths of the family bear importantly on Black American caregiving. First, strong kinship bonds—those related by common ancestry, marriage, fictive kin, friends, and/or neighbors—enable

comfortable reliance on these networks (Hill, 2003; Potter et al., 2017). The more comfortable decision to invoke this broad resource network might also, however, militate against engaging the formal health care system, thereby weakening the available, even if flawed, supports caregivers might employ. Additionally, primary, secondary, and tertiary caregivers are common in Black American dementia caregiving families (Dilworth-Anderson et al., 1999; Epps et al., 2019), so role confusion—and conflict—may be present. Second, decisions to use health care services for Black American persons living with dementia are often shared and discussed within the family until consensus is reached (Potter et al., 2017). Such role adaptability may provide support to the caregiver, but it may also add worry. This kind of decision-making process may cause caregivers to delay seeking services or increase the time needed to make health care decisions (Clutterbuck & Mahoney, 2003; Potter et al., 2017). There is an urgent need to understand the family dynamics and how these dynamics influence the sense of mastery for Black American dementia caregivers.

Individual

One of the core members of the Black caregiving ecosystem, the individual caregiver, must be understood as highly heterogeneous in terms of caregiving experience, personal characteristics, geography, socioeconomic position, and health status (Young et al., 2020), and this heterogeneity must be incorporated into intervention research (Borson et al., 2016; Harvath et al., 2020). At least three salient individual elements may have bearing on the challenges and constraints of Black American dementia caregivers. First, race itself is important, and the majority of research designed to support dementia caregivers often neglects to account for the personal characteristics of caregivers (Young et al., 2020). Second, gender and cultural expectations of gender roles further define the individual caregiver. Caregivers of Black American persons living with dementia are typically women, predominantly daughters (Alzheimer's Association, 2021; Dilworth-Anderson et al., 1999; Potter et al., 2017). Other research focused on Black American women has found unique cultural considerations that may make their caregiving experiences unique. For example, the Strong Black Woman/Superwoman Schema identified a cluster of characteristics and beliefs that reinforce a need to provide care for others without considering one's own self-care needs, which may explain why Black American women experience worse physical and mental health (Abrams et al., 2019; Woods-Giscombé, 2010). Finally, as we incorporate an appreciation for intersectionality, we recognize that individuals have multiple social and cultural identities that do not exist independently but intersect and influence one another while creating unique lived experiences, reflecting the systems and structures of oppression and privilege (Crenshaw, 1989). Caregivers who belong to a group(s) with social disadvantages and relegations to another will

experience different challenges and barriers to achieving mastery. Black American dementia caregivers experience various forms of racism every day and throughout their lives (Williams & Mohammed, 2013). The intersection of race and gender, particularly for Black Americans, is a salient example of intersectionality in the United States. Black cisgender men, Black cisgender women, Black transgender men, and Black transgender women all experience racism, various forms of marginalization, and overlapping forms of discrimination that are unique to their gender identity and far different than those experienced by their non-Hispanic White counterparts. It is important to acknowledge that the many possible permutations of these intersecting individual factors yield sets of challenges and constraints that are not homogenous; the varieties of individual caregiver identities are foundational to our appreciation of the center of Black American dementia caregiving ecology.

Further complicating this brief representation of the ecosystem of Black American caregiving is the often-overlooked fact that the Black American population is not a monolithic population. “Black American” not only includes descendants of those who were enslaved in the United States (i.e., African American) but also immigrants from Africa and the Caribbean. In 2016, there were approximately 4.2 million Black immigrants living in the United States, comprising about 18% of the overall Black American population (Anderson & López, 2018). While there are similarities across the diaspora (e.g., caregivers tending to be adult children and other family members compared to spouses, more tolerant of dementia disruptive symptoms; Anderson & López, 2018; Cooper et al., 2010; Friedemann et al., 2013), there are differences. For African Americans, historical treatment, racism, and discrimination tend to influence their distrust of health care systems and research (Institute of Medicine, 2003; Washington, 2006). On the other hand, unfamiliarity with the United States health care system, language differences, and immigration status may prevent Black immigrants from accessing health care and participating in research, which has been examined in other immigrant populations (Calderon-Rosado et al., 2002; Lara et al., 2005). By treating Black American dementia caregivers as a monolithic population, we fail to acknowledge the axes of inequity that individually affect Black American dementia caregivers (López & Gadsden, 2016). To emphasize the heterogeneity among Black American caregivers, there is a need for tailored interventions.

Developing Situation-Specific Caregiving Mastery

For all caregivers, encounters and experiences with caregiving ecosystems are shaped by the intersections of a variety of personal, interpersonal, socioeconomic, and historical structural factors that produce emotionally challenging or constraining life situations (Infurna & Mayer, 2015), which we believe are best addressed by

theory-based interventions. Here we briefly employ one theory, Social Cognitive Theory, as a conceptual model with roots in helping individuals to overcome situation-specific stresses and challenges. The theory envisions that the outcomes of a stressful situation are influenced by the coping strategies that are designed and deployed by the individual to address the specific challenges and constraints of that situation (Infurna & Mayer, 2015). In this regard, Social Cognitive Theory appreciates mastery as a situation-specific trait (Bandura, 1977, 2001). In this framework, coping strategies are informed by the individual’s outcome expectancies (Bandura, 1977). The approach is designed to develop in individuals a rich awakening to and acknowledgment of their capacities to choose successful, solution-focused behaviors to cope with a given set of challenges or constraints. However, mastery in Black American caregivers has been associated with declining psychosocial health of caregivers over time (Dilworth-Anderson et al., 2004) as well as decreased health care service use (Bonds & Lyons, 2018). Dilworth-Anderson et al. (2004) found this result may be related to Black American culture and socialization, which to the best of our knowledge has not been explored in research focused on mastery. In the next section of this Forum article, we delineate a research agenda targeted to the enhancement of caregiving mastery across a range of Black American dementia caregiving experiences with consideration of Black American culture and socialization.

An Agenda for Black American Caregiver Mastery

Below, we offer an agenda of research topics focused on the promotion of Black American dementia caregiver mastery (Table 1). The agenda is structured by the system of relationships described in the Black Family Socioecological Context Model. Within each system of relationships, we describe potential constraints, intervention focus, efficacy expectations, and outcome expectancies for Black American caregivers. Acknowledgment of and appreciation for the heterogeneous—but rather consistent disadvantage of systemic racism—nature of Black American caregiving are a theme that cross-cuts the agenda.

At the individual level, the historical context of Black American dementia caregivers should be explicitly acknowledged and explored, and caregivers’ intersecting identities individually examined. Each Black American dementia caregiver has identities of privilege and oppression. We believe it is time to move beyond the focus of programs—like the Savvy Caregiver program (Griffiths et al., 2018; Hepburn et al., 2003, 2021)—that focus almost exclusively on developing caregiver mastery in producing person-centered engagement in daily tasks and activities while avoiding or quelling the lived experiences of Black American caregivers beyond their caregiving role. To do this, we must intentionally develop targeted interventions for Black Americans from inception to dissemination (Brewster et al., 2020;

Table 1. A Research Agenda to Promote Caregiver Mastery for Black American Dementia Caregivers

Systems of relationship	Constraints	Intervention focus	Efficacy expectations	Outcome expectancies
Individual	Managing day-to-day dementia care and self-care in light of cultural expectations, racism, and discrimination	Focus on mastery development at home and beyond, including health care systems as well as other systems that are frequented by caregivers Focus on personal well-being, including considerations of intersecting identities and intersectionality as well as Strong Black Woman/Superwoman Schema characteristics that may hinder self-care	Competent and confident day-to-day caregiving in multiple settings Able to establish and pursue reasonable and grounded goals and develop strategies that enable the caregiver to successfully pursue those goals	Enhanced caregiving competence, less caregiving stress, more beneficial self-care Able to lead one's self-defined life
Family units/kinship networks	History of the family, which could include "kinship" members who are not related by blood or marriage Role expectations within the family units/kinship networks Decision-making dynamics within the family, which may be influenced by cultural norms	Consider the caregivers' history in the family units/kinship networks and how this influences the caregiving dynamics Consider how intersecting identities and intersectionality influence role expectations for the caregivers within the family units/kinship networks Consider how decisions are made within the family/kinship networks to promote optimal support for the caregivers such as determining when to use formal health care services	Able to establish a working definition of "family," which may include kinship relationships Able to establish personal identity within the family/kinship networks Able to recognize role expectation constraints and accept role expectations that align Able to establish and pursue reasonable and grounded goals for optimal support and develop strategies that enable the caregiver to successfully pursue those goals within the family units/kinship networks	Comfort with the self-defined definition of "family" Experience stronger family units/kinship support Experience reduced perceived stress within family units/kinship networks expectations and dynamics Ability to negotiate optimal support from family units/kinship network
Community setting (not a caregiver responsibility)	Identify supports and constraints that exist in the community	Strengthen the capacity of community resources/relationships to fulfill their support roles	Community resources/relationships will acknowledge and provide support for dementia family caregivers and persons living with dementia	Caregivers and persons living with dementia will experience a tangible sense of support from community resources/relationships
Societal influences (not a caregiver responsibility)	Health care system (main-tenance institution) Commercial world (normative institution)	While not responsible for or not able to bring about change in these systems, focus on skills for navigating the health care system on behalf of a person living with dementia	Able to communicate effectively with the agency in the health care environment, which may require the use of a script or additional documentation Able to engage with commercial entities in ways that ensure successful transactions	Persons living with dementia receive timely, accurate, respectful, and appropriate care Commercial transactions are safe and effective Remain physically and emotionally unharmed during and after these interactions

Cothran et al., 2020). Research should openly examine how systems of oppression create a broad array of caregiving challenges and constraints, including delegitimizing self-care activities, for Black American dementia caregivers and develop and test interventions to address this whole spectrum of challenges and constraints. Specific to mastery, interventions may need to reconceptualize caregiver mastery at the individual level and include the entire caregiving network. In addition, cultural phenomena such as the Strong Black Woman/Superwoman Schema should be considered when adapting mastery for Black American dementia caregivers as such theories can frame the research to provide a cultural understanding of research findings.

At the family unit/kinship network level, our research agenda calls for interventions to help caregivers clearly identify who is a part of their family units/kinship network and how the caregiver's place in the family, including role expectations and decision-making dynamics, affects caregiving. Caregivers need to develop mastery skills to recognize when others' role expectations for them do not align with their own expectations, identity, and personal needs and to push against them. This distinction is especially important for Black American caregivers as they are navigating health care systems for the person living with dementia. Caregivers with a greater sense of mastery may not accept care from formal health care systems because of their confidence in their own mastery and distrust of the health care system. To foster such efficacy expectations, programs will need to support these caregivers in determining when to seek services and when the family unit/kinship networks alone can provide the care.

While interventions to develop mastery may hold promise at the individual level and family units/kinship networks, there are limitations within community settings and societal institutions. Thus, we outline an agenda for the work that is needed. Interventions at the community level are needed to strengthen a community's capacity to provide support and advocacy for Black American dementia caregivers. Collaborations between researchers and community organizations like churches and other key staples in Black American communities are encouraged. Such collaborations like community-engaged initiatives that focus on promoting dementia awareness, acceptance, and support (Epps et al., 2020) can serve as models for broader community efforts that can promote an environment that endorses and encourages mastery for Black American dementia caregivers. For example, Alter is a nurse-led dementia program that has partnered with Black faith communities to bridge the gap in dementia-related disparities (<https://alterdementia.com/>). Through this partnership, faith communities are equipped to support and promote mastery for their parishioners serving in a caregiving role.

Black American caregivers live in a world of both normative societal institutions (e.g., educational, religious, mass communication, and criminal justice) and maintenance

societal institutions (e.g., political, health care, and social welfare). Broad change at the policy level is needed to make key changes within societal institutions (Dilworth-Anderson et al., 2020). However, such work may be beyond the scope of this Forum article and our academic capacities, but awareness of these forces can guide work that is within our scope to provide evidence that can enact changes in policies and practices.

Summary

This Forum article outlines a research agenda highlighting ways for interventions to explicitly consider the lived experiences of Black American dementia caregivers within all their caregiving ecosystems and not just caregiving provided in their homes. Within the proposed research agenda, there is flexibility to allow for additions or adaptations that focus on other identities of Black American dementia caregivers not highlighted in this article, such as culture (e.g., Black immigrants), sexual orientation, gender identity and expression, issues of location (e.g., rurality), and other societal institutions beyond health care. Understanding the ecosystem in which Black American dementia caregivers live, work, and provide care while considering the constraints and challenges they encounter is necessary to improve their health and well-being (Dilworth-Anderson et al., 2020; Whitfield et al., 2008). The end goal for this proposed research agenda is to draw attention to a much-needed area of focus that will support ways to strengthen individual mastery in providing care and allow for optimal outcomes for both Black American dementia caregivers and Black American persons living with dementia, thus promoting more satisfactory and self-enhancing outcomes within these various ecosystems.

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Conflict of Interest

None declared.

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