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Feature Article

The “invisible caregiver”: multicaregiving among diabetic African-American grandmothers

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ABSTRACT

Purpose: To explore the multicaregiving roles African-American grandmothers assume while self-managing their diabetes.
Design & methods: This longitudinal, qualitative pilot study explored the challenges of self-managing diabetes among six African-American caregiving grandmothers. Data were collected at 5 times points across 18 months. Content analysis, guided by the Adaptive Leadership framework, was conducted using data matrices to facilitate within-case and cross-case analyses.
Results: Although participants initially stated they cared only for grandchildren, all had additional caregiving responsibilities. Four themes emerged which illustrated how African-American caregiving grandmothers put the care of dependent children, extended family and community before themselves. Using the Adaptive Leadership framework, technical and adaptive challenges arising from multicaregiving were described as barriers to diabetes self-management.
Implications: When assisting these women to self-manage their diabetes, clinicians must assess challenges arising from multicaregiving. This might require developing collaborative work relationships with the client to develop meaningful and attainable goals.
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Introduction

African-American older adult women are heralded as the backbone of the African-American family and community, adapting to ever-changing societal and psychosocial changes dating back to slavery.[1] These women have multiple roles in the family and community providing care as the matriarch, healer, confidant, advocate, teacher[2] and, increasingly, the primary caregiver of their grandchildren.[3] However, they are also often burdened with chronic illnesses such as diabetes which they must self-manage while serving in these multiple roles. Thus, the pathway to self-management for these women may prove challenging because of multiple caregiving roles.[4]

As the 7th leading cause of death,[5] the incidence of diabetes has soared to epidemic proportions with diabetes projected to double or triple by 2050.[6] African-Americans are 77% more likely to be diagnosed with diabetes than non-Hispanic whites.[7] Older African-American women disproportionately suffer from diabetes with 25% over the age of 55 diagnosed with the disease.[8]

African-American women have been found to have greater perceived barriers to self-management than men.[9] However, few studies examine why these barriers exist. Several studies have found that the multicaregiving role, including primary caregiving of a grandchild, serves as a barrier to diabetes self-management.[10–12] It is also well documented that primary caregiving of a grandchild may exacerbate and/or impact the self-management of chronic illnesses such as diabetes.[13–15] Primary caregiving in addition to other high-demand roles within the family and community may have serious implications on the self-management of their diabetes. However, few studies have examined how these grandmothers self-manage their diabetes, and no studies were found that examined this phenomenon in the context of multicaregiving. Therefore, the purpose of this study was to explore the multicaregiving roles these grandmothers assume while self-managing their diabetes.

Theoretical framework

We used the Adaptive Leadership framework as a lens to identify technical and adaptive challenges[16] (see Fig. 1). The framework helped us to differentiate technical challenges, those that might be

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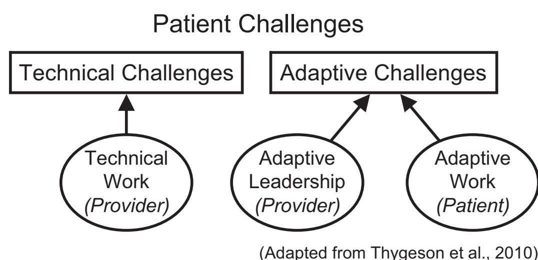

Fig. 1. Adaptive leadership framework.

addressed by technical expertise of the providers, from adaptive challenges and the adaptive work that patients must learn and perform for themselves. Technical challenges, such as an elevated Hemoglobin A1c are easily defined with clear cut solutions such as the provider prescribing medications. Adaptive challenges represent the disparity between the capabilities of familiar methods, habits or values and the demands of the present clinical circumstances.[16] Adaptive challenges require that patient adjust to a new situation and to do the work of adapting, learning, and behavior change to address the problem. Adaptive work might involve changing lifestyle to include exercise or practicing stress management; things that only patient can do for themselves. As shown in Fig. 1, providers might do technical work in response to identified technical challenges but could engage in adaptive leadership in response to identified adaptive challenges, such as supporting the patients to perform adaptive work.

Assessing the adaptive challenges of African-American caregiving grandmothers with diabetes is the first step in understanding the challenges faced by these grandmothers so that interventions might be developed to support their adaptive work. The multifaceted challenges of caregiving, intertwined with the intricate nature of diabetes self-management, require highly complex and adaptive approaches[17] which are the hallmark of the Adaptive Leadership Framework.

Methodology

This exploratory, longitudinal, qualitative pilot study was part of a larger study examining the trajectory of self-management activities among diabetic African-American primary caregiving grandmothers, Data were collected at 5 time-points across 18 months at approximately 3–4 months intervals. Qualitative interview data were used to explore the multicaregiving roles these grandmothers assumed while managing their diabetes. This study was reviewed and approved by the Institutional Review Boards of the universities of the authors.

Sample and setting

The inclusion criteria were: 1) African-American females aged 55-years or older, 2) primary caregiver of at least one grandchild under age 18, 3) diagnosed with Type-2 diabetes, and 4) English-speaking. Individuals caring for someone other than grandchildren in the home were excluded during initial screening. Although participants initially stated that they were only caring for their grandchildren, during the course of the interviews we identified that all women had additional caregiving responsibilities.

To ensure comfort and feelings of security, interviews were conducted in the participants' home or a location of their choosing. Participants selected the time of day for the interviews, and were encouraged by the principal investigator to select a time when the child was in school to ensure a quiet environment.

Recruitment

Purposive sampling was used to recruit six diabetic African-American primary caregiving grandmothers living in central North Carolina. The PI used an existing database of grandparents who had consented to be contacted for future studies from a Grandparent Center of a local university. The database indicated if the grandmother had diabetes. Potential participants were telephoned, provided information regarding the study, asked about their interest in participating in the study and screened using the inclusion/exclusion criteria. Flyers were posted throughout the Grandparent Center. We recruited four participants through the Center. Two additional participants were recruited using snowball sampling, in which participants referred others. Once a potential participant expressed interest and met the inclusion criteria, an appointment was scheduled in a location of their choosing to provide additional information regarding the study and, if they remained interested sign a consent form. All participants received a $25 Wal-mart gift card after completing each interview to compensate for their time.

Interviews

The interview guide was developed by the investigators based on a review of literature and previous pilot data. These interviews explored the context in which the participants managed their diabetes while caring for their grandchildren using the global question "Tell me what it is like to manage your diabetes while caring for your grandchildren." Probes were used to assist the grandmother in elaborating and clarifying statements. The interview guides for the five time points (Table 1) were refined throughout the study based on analysis.

Data collection

The PI conducted all interviews which were digitally recorded and lasted 45–90 min. Contextual information and details about the interview experience were documented in field notes. All members of the research team listened to recordings of the interviews and, together adjusted the interview approaches and refined questions to ensure that research questions were addressed. The research team met weekly to discuss coded data and identified areas for follow up in subsequent interviews.

Table 1
Time Points

Interview	Activity	Rationale
1	Interview to explore the lived experience of being diabetic and caring for grandchild	Pilot revealed that grandmothers wanted to discuss experiences as a caregiver before they were ready to discuss health
2	Self-management interview & survey of self-management activities	Explore lived experience and identify self-management activities
3	Same as interview 2	Same as interview 2 with addition of asking about changes in self-management trajectory
4	Same as interview 3	Same as interview 3
5	Synthesis interview	To explore any final comments from participant

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