

# African-American caregivers' perspectives on aggressive behaviors in dementia

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## Abstract

**Purpose:** Although African-American dementia caregivers report less upset and more confidence managing aggressive behaviors when compared to whites, their contextual experience remains unclear and this study explores that context.

**Methods:** Semi-structured interviews with 13 African-American family caregivers were analyzed using content analysis.

**Results:** Two themes emerged, “It’s the disease. . .not the person” and “You got to pick your battles.” “It’s the disease. . .not the person,” reframing aggressive behavior, included three sub-themes. Sometimes the person with dementia seemed like a stranger but caregivers remembered “In there somewhere is that person.” Aggressive behavior made this perspective difficult as they reported, “Sometimes it’s hard not to take it personal.” Premorbid dyadic conflict made caregiving difficult but caregivers remembered they were “Not who they were then.” “You got to pick your battles,” reflecting cognitive and behavioral strategies, also included three sub-themes. Participants prioritized caregiving over other commitments by reminding themselves “I got to do what I gotta do.” Preventing aggressive behaviors was most successful when “We didn’t argue. . .we didn’t insist” and caregivers remembered “Don’t put her in a position to fail” when involving the person with dementia in activities.

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**Implications:** African-American caregivers described substantial challenges when confronted by aggressive behaviors. Strategies employed by caregivers enabled them to maintain a caring perspective and the person with dementia to maintain calm. Interventions that help caregivers manage aggressive behaviors may benefit by considering the challenges, cultural values, and effective strategies used by African-Americans.

### **Keywords**

aggressive behavior, behavioral symptoms, caregiver, dementia, health disparity

## **Introduction**

Aggressive behaviors in dementia, defined Patel and Hope (1992) as “. . .an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental” (p. 212), are among the most challenging symptoms of dementia (Fauth & Gibbons, 2014; Gauthier et al., 2010). Increased institutionalization, psychotropic medication use, and physical injury have all been associated with aggressive behavior in dementia, with costly consequences (Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Kunik, Snow, Davila, McNeese, et al., 2010).

There are two distinct components of aggressive behavior highlighted by the definition provided by Patel and Hope (1992) that distinguish it from the more general term of agitated behavior. The first is the willfulness of the action, meaning that the noxious stimuli are not incidental to some other action. The second is the directionality of the action, delineated by Patel and Hope (1992) as behavior directed toward “another object, organism, or self.” We can look at one example that may be helpful in clarifying this distinction. The first case illustrating agitated behavior is a person swinging their arms about and accidentally hitting a glass of water off of a table, and the glass shatters on the floor. In this case, the water glass breaks as an incidental act, secondary to waving arms hitting the glass, and the action is neither willful nor directional. The second case illustrating aggressive behavior is a person shaking their fist, then reaching down, picking up the glass of water from the table, and throwing it at the wall, where the glass shatters. In this case, the actions preceding the glass breaking are both willful and directional.

Other similar definitions have also been used to delineate what is meant by the term aggressive behavior. Dettmore, Kolanowski, and Boustani (2009) describe aggressive behavior as “any physical or verbal behavior that has the effect of harming or repelling others, and includes behaviors such as hitting, kicking, and screaming.” The Cohen-Mansfield Agitation Inventory, Aggression Subscale and Ryden Aggression Scale are two instruments that have been developed specifically to measure aggressive behavior. They include items such as spitting, cursing, hitting, kicking, pushing, biting, scratching, and destroying property (Cohen-Mansfield, Marx, & Rosenthal, 1989; Kunik, Snow, Davila, McNeese, et al., 2010; Ryden, 1988; Whall et al., 2013).

As definitions have varied, measurement approaches have differed, and longitudinal studies have been limited, the prevalence of aggressive behavior in dementia has been difficult to estimate (Keene et al., 1999). Current estimates suggest somewhere between 30% and 50% of persons with dementia experiencing some type of aggressive behavior in

cross-sectional samples, with potentially more than 90% over the entire dementia course in longitudinal samples (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011; Keene et al., 1999; Kunik, Snow, Davila, Steele, et al., 2010; Zhao et al., 2015). As most people with dementia live at home and are cared for by their family (Alzheimer's Association, 2012; Gitlin & Schulz, 2012), caregivers are likely to encounter these behaviors at some point in their experience. Unfortunately, caregivers infrequently receive any type of formal disease-related preparation, and thus have little exposure to skills training in preventing or managing aggressive behaviors (Prince, Prina, & Guerchet, 2013).

Previous research has indicated that caregivers from different race/ethnic backgrounds experience the caregiving role differently (Alzheimer's Association, 2015; Cherry et al., 2013; Covinsky et al., 2003; Dilworth-Anderson, Williams, & Gibson, 2002; Heo & Koeske, 2013; Hilgeman et al., 2009; Kim, Chang, Rose, & Kim, 2012; O'Connor, 2012; Prince et al., 2013; Smith, Williamson, Miller, & Schulz, 2011; Sorensen & Pinquart, 2005; Vickrey et al., 2007). In particular, African-American caregivers have consistently been identified as reporting higher satisfaction levels and lower burden levels when compared to whites (Bekhet, 2015; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015; Skarupski, McCann, Bienias, & Evans, 2009). Supporting these findings, a recent study found that African-Americans reported the lowest level of upset to verbal aggression and were more confident managing aggressive behaviors overall when compared to whites and Hispanic/Latinos (Hansen, Hodgson, Budhathoki, & Gitlin, 2015). The context in which these caregivers experience aggressive behaviors by persons with dementia, however, remains largely unexplored and it is unknown why African-American caregivers have reported lower upset and greater confidence when confronted with aggressive behaviors than other race/ethnicities. This is an important area to explore as understanding caregivers' perspectives on aggressive behaviors may offer direction for future intervention development. Therefore, the purpose of this study was to explore how African-American caregivers describe their own experiences with aggressive behaviors in persons with dementia, including their reactions and management strategies.

Underpinning this study is the conceptual framework, the Stress Process Model (Haley, Lane Brown, & Levine, 1987; Lazarus & Folkman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990). Although developed over 25 years ago, the Stress Process Model continues to be widely used in caregiver research, and especially for research focusing on dementia caregivers (de Labra et al., 2015; Gaugler, Reese, & Mittelman, 2016; Grace, Allen, Ivey, Knapp, & Burgio, 2017; Grace et al., 2016; van der Lee, Bakker, Duivenvoorden, & Droes, 2014). It has been modified and adapted to incorporate additional factors that may impact on the caregiving experience, including the dyadic relationship (Hausler et al., 2016; Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016). It has even been modified for use in studies focusing on the experience of persons with dementia Judge, Menne, and Whitlatch (2010).

The Stress Process Model as laid out by Pearlin et al. (1990) includes several domains, including the background and context in which caregiving occurs, primary stressors arising from the direct caregiving activities and interactions, secondary stressors that are not directly related to the direct caregiving experience but impact the caregiver, and moderators and mediators that may buffer or intervene differentially between stress and the primary outcome of interest.

This model has been chosen as the conceptual framework for this study because it would suggest primary stressors, such as caregiving for a person with dementia who is exhibiting

aggressive behavior, and secondary stressors, such as integrating role-relationship changes into the caregiver's sense of self, may overwhelm the caregiver, eventually leading to negative health outcomes. However, this model would also suggest that strong coping mechanisms may provide a type of buffer, decreasing the stress. For example, though a caregiver may experience some upset when encountering aggressive behavior, the coping strategies used may increase confidence and decrease the level of threat that the caregiver experiences.

## **Methods**

### *Participants and recruitment*

Participants were recruited from a large metropolitan area in the Eastern United States. Participants were purposively identified from a secure database maintained by the Johns Hopkins University School of Nursing's Center for Innovative Care in Aging. Initial inclusion criteria included self-identification as African-American and caregiving for a person with dementia within the previous two years. Next, the sample was further narrowed using baseline data gathered for another study to identify those participants who had reported either aggressive or agitated behaviors by the person with dementia. All participants were notified by postal mail that the first author (BRH) would be contacting them, followed by a recruitment telephone call approximately two weeks later. Only those individuals who had previously agreed to be contacted for inclusion in future research and had either been screened for or participated in the Dementia Behavior Study (principal investigator, senior author LNG) were contacted. Seventeen individuals were contacted, with 4 declining and 13 agreeing to participate in this research study. Recruitment continued until no new themes were emerging in concurrent data analysis.

### *Data collection*

Participants were interviewed in their own homes using semi-structured interviews. The interviews used a vignette approach with three separate vignettes presenting specific types of aggressive behaviors commonly observed in dementia. The vignette approach was chosen as it has been shown to be an effective method for eliciting data about a range of topics, including socially sensitive topics such as aggressive behaviors (Spalding & Phillips, 2007). An interview guide was developed in a collaborative and iterative process with input from all authors; however, all interviews were conducted by the first author alone (see interview guide included in Supplemental Material). Interviews were digitally audio-recorded and subsequently transcribed by a qualified, third-party transcription service. Digital transcriptions were then double-checked for accuracy.

### *Ethical considerations*

Study procedures for this research with human subjects were reviewed and approved by the Johns Hopkins Medical Institutions Institutional Review Board (IRB) (IRB00037715). Informed consent procedures were conducted as approved by the IRB, with written informed consent obtained from participants. Participant confidentiality was protected by having all data securely encrypted and stored on an institutionally approved remote server. Participants were assigned an identification number and the transcripts were de-identified. The key linking the transcripts and identities was stored in an encrypted file on the remote

server. Participant information and signed informed consent forms were stored in a locked facility provided by the Center for Innovative Care in Aging. Following transcription, all audio-recordings were permanently deleted.

## Analysis

Interview transcripts were imported into MAXQDA 13 analytic software (Verbi Software – Consult – Sozialforschung GmbH, 1989). The data analysis was conducted as described by Saldaña (2009). During the First Cycle in which codes are developed and assigned to data, the first author initially used descriptive coding (Miles & Huberman, 1994; Saldaña, 2003) to capture individual topic areas arising line-by-line from the data. To complete the first cycle, the first author used process coding (Corbin & Strauss, 2008; Strauss & Corbin, 1998), to focus specifically on the processes by which caregivers addressed aggressive behaviors, and holistic coding (Dey, 1993), to assign macro-level codes to larger passages of cohesive narrative. Moving into the second cycle in which codes are combined into larger categories, pattern coding (Miles & Huberman, 1994) was used to describe the higher level patterns emerging as earlier codes were combined under an emerging conceptual schema. To complete the second cycle, themes were developed and expanded to adequately represent the totality of the constituent parts. During the process, the codes and categories were jointly reviewed and reconciled in discussion with co-authors. When discrepancies of interpretation or coding nomenclature occurred, review and discussion continued until consensus was reached by co-authors.

## Results

### Participants

As demonstrated in Table 1, participants were all African-American ( $N = 13$ ) and most were female (92.3%,  $N = 12$ ), with a mean age of 65.5 years ( $SD = 8.39$ ;  $Mdn = 67$ ,  $IQR = 9$ ). Participants had provided care for a mean of 6.35 years ( $SD = 3.86$ ;  $Mdn = 5$ ,  $IQR = 7$ ), with a range of 2.5 to 15 years, and most were caregivers for a parent (84.6%,  $N = 11$ ). At the

**Table 1.** Participant demographic characteristics.

	( $N = 13$ )
Age, years	
<i>Mdn</i> ( <i>IQR</i> )	67 (9)
<i>M</i> ( <i>SD</i> )	65.5 (8.39)
Gender % ( $N$ )	
Female	92.3 (12)
Male	7.7 (1)
Relationship of person with dementia to caregiver % ( $N$ )	
Mother	69.2 (9)
Father	15.4 (2)
Other	15.4 (2)
Years caring for person with dementia	
<i>Mdn</i> ( <i>IQR</i> )	5 (7)
<i>M</i> ( <i>SD</i> )	6.4 (3.86)

**Table 2.** Major themes and sub-themes.

- 
- |    |   |
|----|---|
| 1. | “It’s the disease. . .not the person”         |
| a. | “In there somewhere is that person”           |
| b. | “Sometimes it’s hard not to take it personal” |
| c. | “Not who they were then”                      |
| 2. | “You choose your battles”                     |
| a. | “I got to do what I gotta do”                 |
| b. | “We didn’t argue. . .we didn’t insist”        |
| c. | “Don’t put her in a position to fail”         |
- 

time of the interview, most participants were currently caring for a person with dementia (61.5%,  $N=8$ ), with the remainder having been the primary caregiver of a person with dementia within the previous two years (38.5%,  $N=5$ ). All but one of the caregivers lived with the person with dementia to provide care.

### Themes

In this exploration of African-American caregivers’ perspectives on aggressive behaviors in dementia, outlined in Table 2, themes emerged in two main areas. The first theme, “It’s the disease. . .not the person,” comprised three sub-themes, including “In there somewhere is that person,” “Sometimes it’s hard not to take it personal,” and “Not who they were then.” The second theme, “You choose your battles,” comprised three sub-themes, including “I got to do what I gotta do. . .,” “We didn’t argue. . .we didn’t insist,” and “Don’t put her in a position to fail.”

“It’s the disease. . .not the person”. In the first major theme, these caregivers described maintaining a person-centered approach to caregiving. This approach depended heavily on the caregivers’ ability to differentiate between the effects of dementia and the person for whom they were caring. Through this process of differentiation, they were able to cognitively reframe their perspective and approach caregiving with compassion and patience, despite the substantial challenges they faced.

*“In there somewhere is that person”.* As aggressive behaviors and other symptoms of dementia appeared, participants struggled to reconcile the internal image of the healthy person they had known and the person with dementia in the moment. Although participants described feeling love and a sense of responsibility to care for the person with dementia, it was as though they were constantly trying to “see through” the symptoms of dementia to reconnect with the person they had known and loved before dementia changed their relationship. As one participant stated, “There’s the lady that raised me. . .there’s the lady that I’m lookin’ at now. In there somewhere is that woman” (QE, 56). The same participant explained further, making explicit the connection between her struggle to recognize her mother through the dementia and the aggressive behaviors that her mother exhibited.

My mother, in all of my years, I had never seen her curse or cuss at people or use profanity. . . she did that. . . “I don’t want this shit. Goddamn this. Damn that.” My mother was never like that, never like that, and to see her change and say those behaviors, she became a different person. (QE, 56)

The slowly changing nature of the relationship between the caregiver and the person with dementia was distressing and the distress intensified when aggressive behaviors appeared. Dealing with this distress proved to be especially challenging as it was often not possible for these caregivers to take any extended time out from caregiving in order to integrate these changes into their own self-concept or their view of the relationship. At times it seemed that the internal dissonance became so sharp between the person the caregiver remembered and the person they cared for that the caregiver began to dissociate the two. As one participant explained,

You don't believe that your mother would actually fight you or hit you. You don't believe that your mother would take her fist and hit you, because you're trying to clean her, or you're trying to give her a bath. You don't think that they would do that... I see it as this way. This is a completely change in the personality. My mother was never that kind of person. She would never ever hit a—she wouldn't even hit us. I've never in her life heard her use bad language, and she was always kind and pleasant. To see her like that, that was not the mother that I know. Wasn't the mother I know, but this was her body. (DI, 68)

A cognitive strategy used by caregivers was to identify behaviors associated with dementia and frequently revisit that perspective, allowing them not to take it personally. Some caregivers described dementia as the “other” person but occasionally the “real” person makes an appearance, allowing for connection. A few caregivers reported that even their exposure to items from the Neuropsychiatric Inventory (Cummings, 1997) in a previous study helped them to differentiate between dementia and the real person. When describing their reactions to aggressive behavior, caregivers frequently attributed these behaviors to the other person or to the disease. Although expressing personal hurt and dismay, they would use that cognitive approach to allow them to continue to provide compassionate care by assigning the hurtful behavior to the dementia while they continued to care for the real person.

For example, one participant described her insight into the real person that still inhabited the stranger's body.

...my mother was highly intelligent, highly articulate, highly verbal, well read, self-educated and self-aware. She, even now, contains to be all of that in there within, underneath, round the side...she's in there. You see flashes of it. There are moments when she knows what she's done. She just says, “I don't know why I can't stop this. I know I ask you this. I asked you this already but what did you tell me?” Then, your heart breaks because you can see that she doesn't want to be doing this thing and if she could stop it, she would but she can't. She's compelled, if you will. (AT, 56)

*“Sometimes it's hard not to take it personal”*. Although participants described many challenges related to caregiving, encounters with aggressive behaviors seemed to be the most unexpected and disconcerting. These encounters were acutely difficult for them and they frequently described them as sad or hurtful. One participant struggling to find words to explain her first experience with the person with dementia demonstrating these behaviors stated, “It's frustrating and scary, and confusing, and overwhelming...” (RJ, 50).

Another participant, framing her own reactions to similar experiences within the context of a vignette said,

The first couple of times, when you don't recognize—when you don't know this is part of the illness—the part of the progression of the illness—if you don't recognize that at the beginning, you would feel crazy... If you knew that these were the kinds of behaviors that were going to come [you could] prepare yourself. Still, I think the first time it happens it's still a shock. (AT, 56)

These interactions seemed to demonstrate dissimilarity from their view of the person with dementia as a stranger. The caregivers seemed to feel that the behaviors were directed toward them in a personal way that was not reflected in other behaviors. As one participant stated, "I don't take it personal, but sometime it's hard not to take it personal" (EP, 70). Another participant described her experience with her mother like this,

...Then, I realized she doesn't realize what she's saying. Then, I guess the first thing you felt is heartbroken. I guess for her to think that I would take from her, and I think that was really the most heartbreaking thing, that somebody you've been helping out and taking care of for years. Then all of a sudden, it seemed like she was beginning to turn on me. Yeah, I think that was the worst part. Yeah. (PN, 67)

Another participant described the internal conflict she had until she realized that even though her mother had a premorbid personality that she found abrasive, the behaviors she was now encountering were different and arising from the progression of dementia. Coming to this realization allowed her to cognitively reframe the entire caregiving experience and the aggressive behaviors of her mother in the caregiving interactions.

When the light came on I realized, when I accepted the fact that this is the disease, see it as the disease as opposed to she's striking out at me...Then even if the thought or emotion came up I could talk to myself real quick and say, "Uh-uh, that's the disease." ... As I change...she may still do the same thing but...as I accepted the fact that, "This is not personal against you...this is the disease." Then I began handling it differently. (WB, 73)

*"Not who they were then"*. Some participants described difficult relationships with the person with dementia that dated back to earlier points in their lives. These caregivers described an additional layer of complexity surrounding the aggressive behavior and their reactions to it. As the dementia progressed, these caregivers also went through the same type of differentiation process between the dementia symptoms and the real person. However, this was made more difficult because some of the symptoms attributable to dementia were similar to behaviors that the person had demonstrated before dementia. As one participant described about her relationship with her mother,

... I always felt all my life like I couldn't please my mother... I'm carrying over from childhood into adulthood. I'm responding still like the child that nothing I do can please you. I said that to her but then when the light came on and I realized that, "...you can't take this personally this is not 1950, 1945 and she is not who she was then." ...I would think to myself, "Yeah she may



have Alzheimer's but that's who she always been." Well that personality don't change but you've gotta realize that. . .now she's at the point where she just, she don't know better, she can't do better. When my mind set changed then things changed. . .This is not a power struggle because that is what it was for mother and me for a long time, it was a power struggle. She's not gonna give up the power struggle so I have to give it up. (WB, 73)

Another participant, who had a tumultuous premorbid history with the person with dementia, described how she tried to come to terms with the verbal aggression that was new to their relationship and accompanied the dementia.

Interviewee: You can forgive, but you may not forget. You got a lot of stuff under your belt. I'm sure then that the person that has dementia also has a lot of stuff under their belt. . .

Interviewer: It sounds like it's difficult to separate out the person from the behavior that you're experiencing.

Interviewee: Yes. . .Yes. As time goes on, and they get better, then you forgive. You don't forget, but you forgive. Because then you have something to blame it on. You say, "That was what that was all about." (SL, 80)

*"You choose your battles"*. In the second major theme, these caregivers reported that they used a careful, thoughtful approach in an attempt to minimize conflict during the caregiving activities. They described how they chose when to proceed and when to wait to provide the person with dementia assistance and care. By remaining person centered in their caregiving perspective, they were able to anticipate potential areas of difficulty for the person with dementia and find alternate ways to meet the needs of the person with dementia, thus preventing and avoiding the expression of dementia-related behaviors that could have distressed the person with dementia and that the caregiver might find threatening.

*"I got to do what I gotta do. . ."*. Caregivers reported that it was important to them to rearrange all other activities to make time with the person with dementia their utmost priority. Whether rearranging work schedules, getting up earlier in the morning, or forgoing favorite activities, the caregivers stated that it was important to give the person with dementia the space and time to maintain their equanimity. Not rushing the person with dementia was one aspect that informed this perspective and hurrying the person with dementia for one's own convenience was viewed as highly disrespectful. Participants indicated that it was the caregiver's responsibility to make time for the needs of the person with dementia, even despite competing priorities. This making time for caregiving was exemplified by one participant who described her approach to melding her work life with her caregiving responsibilities.

The thing I think you have to do when you—when you're caring for someone with dementia is. . .let your employer know, because there will be times that you might be late. I think that's the first thing you need to do. . . Because they [persons with dementia] need to follow a routine, and if you get them off of the routine—. (DI, 68)

Another participant echoed this approach and explained why she felt compelled to rearrange her life for her father, stating, “I wanna help ‘em because this is—I’m looking at this is my dad. I need to do whatever I can because he was an excellent person in my life” (AE, 61). Later, she went on to expand on the urgency she felt to make caregiving the priority activity in her life, despite personal cost.

But it was my father. My job knew the situation. I told ‘em, “My dad come first.” I got to do what I gotta do for my father. That job is gonna be there. I done drop dead, the day after tomorrow you’ll find somebody to take my place and do the job. My dad needs me here now. I’ll be at work when I can. (AE, 61)

“*We didn’t argue. . .we didn’t insist*”. Caregivers in this study frequently provided examples of nonconfrontational approaches to caregiving. They explained that this was more respectful of the person with dementia and more likely to prevent aggressive behavior. Several participants also described this approach as being more productive and less time-intensive than confrontation, with many reporting that they learned this as a matter of trial and error. One participant described her morning routine with her mother, demonstrating the way she approached the hygiene and dressing aspects of caregiving.

. . .there would be times when it would take me two hours to get her dressed in the morning. Starting at five o’clock, it would take two hours. The first thing you do is you wake her up, and you just let her relax, “We’re going to get up.” Then you sit her up on the side of the bed. “Let’s stretch out our arm here, stretch an arm there.” . . .You take her to the bathroom, put her on the toilet, let her sit there. You go out of the room, you come back, because you never know. . . It was a back and forth. . . Sit her down, put on the stockings, go out, come back. “Are you ready now?” . . . It gave her time to get herself together. I would go do something else while I waited for her to get ready. For me, it was more productive for me. . .It gave me time to do other things. . . (DI, 68)

Some participants described times when they thought caregiving tasks were contributing to increased agitation for the person with dementia. Several reported that pausing the caregiving task for even five minutes was reported as being sufficient to change the dynamic and allow for successful completion of caregiving activities without further conflict. As one caregiver said, often the person with dementia “was a completely different person” (DI, 68) when allowed a brief break from the caregiving activity and was subsequently agreeable to completing the resisted activity. One participant described a typical interaction with her mother, and the way she used time, space, and even physical affection to provide an environment where her mother could return to a state of calm.

I ask, I say, “Miss Smith.” [mimicking mother’s angry, loud voice] “What?”

I say, “Oh,” so I knew just leave that alone for a minute. Come back. I ask Miss Smith again, [mimicking mother’s calm, quiet voice] “What, baby?” See, whole new turn around. But you can’t foul ‘em up. When I see Miss like that I leave her alone. I’ll come by and maybe hug ‘er, hug ‘er and kiss ‘er, and just like nothing had happened. (IB, 65)

Caregivers also identified these mini-breaks as important times for the caregivers to regain their perspective and to approach caregiving in a calmer and patient state of mind.

I might go sit out on the porch to get myself calm, and especially when I'm trying to get her to do somethin' like eat. . . When I felt my blood pressure going up, I would just go some place and do something. I might go do laundry. Go sit on the porch. Just go do something, and then. . .I'm calmed down. I come back, and approach her again. Sometimes when I came back, she was better too. I found out that the more you try to push her to do something, and she was determined she wasn't gonna do it, you just making yourself worse, so you might as well just let it go. Give her some time, and come back, and try it later. (EP, 70)

*“Don't put her in a position to fail”*. Being present and intimately familiar with the needs, behaviors, and interests of the person with dementia seemed key to preventing and addressing aggressive behaviors for these caregivers. Many described small details in their care that addressed specific preferences or aspects of the person's character that were important to preventing situations that were triggers for aggressive behavior. For example, one participant related how she tried to anticipate ways to encourage independence while also providing necessary assistance in the least intrusive way possible.

I was assuring her independence but assuring her ability to succeed. . . Why put her in that position to fail or to get frustrated or not to be able to do it and then you come and do it for her and she'll be upset. Even cutting up her food, I would cut up her food rather than put the whole chicken leg. . .she couldn't do things but she wanted that bone. . .I would cut the meat off and leave a little on the bone and put the bone on the plate. (WB, 73)

Another caregiver explained that paid caregivers in an institutional setting who cared for her mother briefly did not use the same type of patient technique and her mother's reaction was markedly different.

She hadn't did it with me, but she did threaten to kill one of the caregivers. She had never did that as long as she was with me. I think with my mom, you have to know her breakin' point. You have to know when to step back. . .I guess they didn't realize that she could blow off. That she really could come out and curse you out really. . .I felt like they didn't really handle the situation at the time correctly. She just blew up. (PN, 67)

She explained further, describing how her approach differed from other caregivers' who were not as attuned to her mother's individual needs.

. . .they went back and forward with her, which I don't do. . .I have been there recently, and I saw she opened the door. . .because she saw me at the door. The caregiver came and said, “You know you're not supposed to open that door.” She turned around and looked and said, “Don't you think I got sense enough to know who to open the door for. That's my daughter.” He said, “You're not supposed to answer.” I told the caregiver like that, “. . .you have already told her not to open the door. She knows she not supposed to open the door. . .” . . .You back off, she backs off right away. Less than five minutes, she's already forgotten about it. Why you keep goin' on and on? Because she's not gonna remember this anyway. I don't care how many times

you might tell her not to open the door, if she sees somebody at that door, and she know you, she's gonna run and open the door. That's her... (PN, 67)

## Discussion

This study identified two themes, comprising three sub-themes each, which describe these caregivers' perspectives on these behaviors. The two overarching themes that emerged were "It's the disease...not the person" and "You got to pick your battles." "It's the disease...not the person" reflected participants' attempt to reframe behaviors and to continue to provide care. The three subthemes included "In there somewhere is that person," "Sometimes it's hard not to take it personal," and "Not who they were then." Participants felt like they were taking care of a stranger but tried to remember "In there somewhere is that person." When managing aggressive behaviors, caregivers found that it was especially difficult and "Sometimes hard not to take it personal." In cases where dyadic conflicts had existed before dementia onset, aggressive behaviors added to the difficulty of caregiving, but they reminded themselves that the person with dementia was "Not who they were then." "You got to pick your battles" reflected cognitive and behavioral strategies for preventing and managing aggressive behavior. The three sub-themes included "I got to do what I gotta do," "We didn't argue...we didn't insist," and "Don't put her in a position to fail." As participants tried to balance priorities, a frequent refrain was "I got to do what I gotta do," which helped them to keep caregiving as most important. Participants reported that prevention of aggressive behaviors was more successful when "We didn't argue...we didn't insist." Additionally, caregivers who "Don't put her in a position to fail" were able to engage persons with dementia in activities without aggressive behaviors occurring. These themes demonstrate that while caregivers were constantly confronted by difficulties, they were also actively developing and practicing methods to address both the symptoms in the person with dementia and their own reactions to the symptoms.

Caregivers in this study developed two different kinds of strategies that helped them to continue to provide care after encountering these disconcerting behaviors. Of the six sub-themes, four describe cognitive strategies and two describe behavioral strategies developed by caregivers. "In there somewhere is that person," "Sometimes it's hard not to take it personal," "Not who they were then," and "I got to do what I gotta do" were cognitive reframing strategies that the caregivers used to internally cope with the rigors of caregiving when troublesome dementia symptoms were present. "We didn't argue...we didn't insist" and "Don't put her in a position to fail" were active strategies that the caregivers used in their relationship with the person with dementia to primarily prevent, but occasionally to manage, aggressive behaviors.

The strategies presented by these African-American caregivers provide valuable insight into the complex interplay between the caregiver and the person with dementia, as symptoms of dementia appear and reappear, fundamentally altering long-established patterns in the relationship. The perplexing and distressing nature of the changes shared by participants in this study echo the findings of previous studies (Evans & Lee, 2014; Large & Slinger, 2015; Lindauer & Harvath, 2015). Taken together, these studies suggest that as the person with dementia becomes increasingly impaired, caregivers experience profound grief and a struggle to redefine and reintegrate their shifting reality. At the same time, caregivers also strive to provide care that remains centered on the essential personhood of the person with

dementia, despite the feelings of increasing estrangement that may simultaneously be occurring. The findings from our study add to the literature by demonstrating that aggressive behaviors can exacerbate this internal conflict and that caregivers may struggle to adjust their caregiving strategies to accommodate new realities.

As we note that a person-centered approach was an important part of how these caregivers seemed to approach their caregiving activities, it is important to define and briefly explore what person-centered care is. Person-centered care focuses on providing care tailored to each person based on the beliefs, background, and unique biopsychosocial aspects of a person within the larger sociologic and economic context in which they live. This contrasts with models of care that are more dependent on a reductionist viewpoint to facilitate efficient and standardized interventions (McCormack, van Dulmen, Eide, Skovdahl, & Eide, 2017). Person-centered care is increasingly the focused priority of sectors in health care and health-care research. There has traditionally been an innate tension between the tailoring needed for person-centered care and developing interventions that can be widely implemented and disseminated. It is increasingly clear, however, that moving individualization of care for the person to the center of care provision is critical to promoting optimum outcomes. This is especially true for older adults, which includes all of this study's participants and their care recipients. Older adults have complex needs, are more likely to have comorbid conditions, and are likely to need highly individualized care for the best outcomes (Kogan, Wilber, & Mosqueda, 2016).

These findings suggest that interventions designed to support caregivers of persons with dementia should be sensitive to how symptoms of dementia challenge caregivers' person-centered focus. Emphasizing the concept of personhood and clearly delineating symptoms of dementia may by themselves be potent components of a supportive intervention as they may provide the caregiver with tools to feel less threatened and to regain positive regard for the person. This confirms findings from a study by Toth-Cohen (2004), conducted with a demographically similar sample, that recognizing behavioral symptoms and being able to attribute them to the pathologic processes underlying dementia helped participants to reconcile a sense of who the person with dementia was and the caregiving role.

This is consistent with recent research with a sample of African-American caregivers that found participants tended to focus on what remained of the personalities of the persons with dementia, rather than on what was lost (Lindauer, Harvath, Berry, & Wros, 2016). This perspective may be a strength that African-American caregivers draw upon to remain person centered in their caregiving activities (Lindauer & Harvath, 2015). Participants' desire to maintain love, respect, and empathy for the person with dementia was evident in this study; however, their struggle to not depersonalize the person with dementia was acutely heightened when confronted with aggressive behavior. Appraisal of the threat of aggressive behavior, and the subsequent reaction, may be attenuated by a conscious, holistic view of the person with dementia that counts what remains of the person's personality as a resource that can be leveraged to manage the behavior. By maintaining a holistic view that focuses on the remaining aspects of personality, these caregivers may have been successfully overcoming the challenge they had identified of depersonalizing the person with dementia by seeing them as a stranger.

This was even the case when the premorbid relationship between the caregiver and the person with dementia had contained significant conflict and the person with dementia had personality characteristics that the caregiver had found objectionable. For example, as participant WB (73) explained,

I would think to myself, “Yeah she may have Alzheimer’s but that’s who she always been.” Well that personality don’t change but you’ve gotta realize that. . .now she’s at the point where she just, she don’t know better, she can’t do better.

Participants’ experiences in this study suggest that the same strategies of emphasizing personhood and differentiating dementia-related behaviors may be potential strategies even in relationships burdened by a long history of discord predating the onset of dementia.

The strategy of using new information to deliberately develop a new perspective is similar to a technique used in psychotherapy called cognitive restructuring or cognitive reframing, which is used as part of cognitive behavioral therapy. A Cochrane review of interventions for caregivers of persons with dementia found that cognitive reframing has been shown to reduce psychological morbidity and perceived stress, but had no effect on the outcomes of coping or burden for caregivers (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011). In a recent systematic review of systematic reviews, Dickinson et al. (2017) found that multicomponent interventions were most effective in supporting family caregivers of persons with dementia, and that cognitive reframing is best used in combination with an educational component. As the caregivers in this study shared very similar techniques for maintaining person-centered care, it suggests that including these components may be an important way to support these caregivers.

It is important to note in light of these caregivers’ struggle to adapt to the disease-related changes in the persons with dementia that previous studies with African-American caregivers have consistently found that they report lower burden than other race/ethnic groups (Bekhet, 2015; Skarupski et al., 2009). This has been challenged as a simplistic and stereotypical view of African-Americans’ experiences with caregiving that does not capture their full experience (Dilworth-Anderson et al., 2002; Fox, Hinton, & Levkoff, 1999; Kingsberry, Saunders, & Richardson, 2010). It is possible that the degree to which burden has been associated with caregiving overall has been more broadly over-estimated than has been generally accepted in the caregiving literature, perhaps in part due to an overreliance on convenience or purposive sampling rather than on probabilistic sampling methods (R. M. Brown & Brown, 2014; Pruchno et al., 2008). This view is supported by several recent studies that suggest that caregivers have better, rather than worse, outcomes than non-caregivers on several variables (S. L. Brown et al., 2009; Roth, Dilworth-Anderson, et al., 2015; Roth, Fredman, & Haley, 2015). Further research to assess whether a more balanced and consistent measurement approach that captures both the positive and negative aspects of caregiving may eventually yield a more nuanced understanding of the caregiving experience than measuring burden alone. This may also have implications for understanding reported differences by race, ethnicity, or culture.

For caregivers in this study who were caring for a parent, their reported adroitness at avoiding conflict while delivering care may also have cultural roots. In their study of conflict engagement of African-American and European-American adults and their parents, Cichy, Lefkowitz, and Fingerma (2013) found that African-American adults were less likely to engage in conflict with their parents than were European American adults. This may suggest that these African-American caregivers held cultural values that supported a more robust approach to conflict avoidance, which led them to proactively seek caregiving strategies that minimized conflict with their parents. This may be an important building block to further explore in the development of behavioral interventions.

It was notable that almost all of these participants had a strong internal sense of how to construct their caregiving approach in ways that were specifically tailored to the needs and preferences of the person with dementia. As these participants described, they placed a strong emphasis on knowing the person with dementia well and setting them up to succeed in their daily activities. Several participants reported doing this by a trial-and-error method in which they would attempt a strategy and watch the person with dementia for signs of distress, discomfort, or displeasure.

One possible explanation for this attentiveness to disequilibrium of the person with dementia could be explored in the context of the stress and coping framework. These caregivers may have developed a method of frequent and careful appraisal as way to manage and minimize stress that may otherwise overwhelm their coping resources. When a person with dementia begins to experience discomfort or displeasure, a cascade of events may be triggered that is manifested in aggressive behaviors, as is suggested by the unmet needs model of dementia behaviors (Algase et al., 1996; Kovach, Noonan, Schlidt, & Wells, 2005). By frequently appraising the behavior of the person with dementia, it is possible that these caregivers adjusted their reactions to accommodate and address the person's needs, thereby preventing overwhelming stress to both the caregivers and persons with dementia.

While these participants described challenges to caregiving both within themselves and within the changing relationship with the person with dementia, it is important to recognize that they were happening within the larger socioeconomic context, which they identified as an additional stressor and the stress process model includes as both part of the background in which stress is experienced as well as contributing to secondary role strain in the form of economic pressure. At least one of the participants in this study seemed to have greater flexibility with her employer than may be the case for many caregivers, which may have allowed her to more readily tailor her care to her father's needs. In addition to the lack of caregiving-related resources, many participants in our study also identified their inability to take time away from the caregiving role as a challenge, which has also been shown to be an independent contributor to caregiver burden (Losada et al., 2010).

Caregivers in this sample expressed that they placed a high priority on caregiving, even at great personal cost. This emphasis on the needs of the person with dementia may be important to the person-centered approach that they consistently reported using in caregiving activities. Even when it meant early morning awakening, staying awake overnight, and working extra shifts, these participants described an approach that allowed the person with dementia sufficient time and space during caregiving activities to remain calm and relatively undisturbed. This may speak to a larger ethos in this race/ethnic community but it is unclear exactly why this might be. The Cultural Justifications for Caregiving Scale is one instrument that may be helpful in future research for elucidating this area further, building upon the work of Dilworth-Anderson et al., (2005), Powers and Whitlatch (2014), and others.

The results in our study, which suggest that these caregivers were experiencing unmet needs themselves while providing care for the person with dementia, are supported by research by Black et al. (2013) and Hughes et al. (2014). They found that, at baseline, most caregivers in the MIND at Home intervention study had unmet needs related to caregiving role support and that those needs, along with behavioral symptoms in the person with dementia, contributed significantly to the level of caregiver burden. Within the stress coping framework, these unmet needs represent different levels of stressors that

are both internal and external, which together are posited to contribute to negative caregiver outcomes, such as depression and declining health status. However, in the stress process model, coping and social support have the potential to mediate negative outcomes. This mediation was suggested by how participants described using mini-breaks by stepping into another room or out onto the porch to sit for a few minutes to help them rejuvenate. This strategy, though easy to overlook, may signal an important aspect of how these caregivers bolstered their coping resources, and thus mediating negative outcomes. This may be helpful to inform intervention development focused on supporting caregivers with limited access to social or economic resources. It is possible that even small, incremental approaches to regaining leisure time for caregivers may be helpful in decreasing distress and improving caregiver psychological outcomes.

Giving the person with dementia space to recover their equanimity was also frequently cited as an effective behavioral management strategy by participants in this study. This strategy fits well into the stress process model for individuals with dementia proposed by Judge et al. (2010) and that built upon the caregiver stress process model (Haley et al., 1987; Lazarus & Folkman, 1989; Pearlin et al., 1990). Little is known about the person with dementia's lived experience of having behavioral symptoms in dementia, especially in the mid- to late-stages of the dementia course when communication abilities are increasingly disrupted. However, the model proposed by Judge et al. would point to the immense scope of the challenges that the person with dementia is likely experiencing concurrently with the caregiver's challenges. Another model that may be helpful to consider in light of these caregivers' successful use of this strategy is the progressively lowered threshold model, which posits that persons with dementia have a reduced ability to cope with intrinsic and extrinsic stressors (Hall & Buckwalter, 1987). Stressors, such as hygiene care and other caregiving activities, are likely to place stress on the coping abilities of the person with dementia and mini-breaks during such activities may serve a restorative purpose for the person with dementia.

A contrary view to the stress process model that may help to explain these caregivers approach to caregiving may be found in the healthy caregiver hypothesis. This hypothesis suggests that healthier people may be self-selected to be caregivers and remain in that capacity for longer periods of time because they have well developed self-care approaches as well as strong prosocial tendencies (R. M. Brown & Brown, 2014; S. L. Brown, Brown, & Preston, 2012; Roth, Fredman, et al., 2015). It follows then that these caregivers may have developed coping strategies well before assuming a caregiving role and have since incorporated these strategies into the role. In the context of this model, the caregiving strategies that emerged from these caregiver interviews may reflect a lifelong approach to social interactions and attentiveness to their own needs that has prepared them well for both the demands of caregiving. Further qualitative in-depth exploration of this hypothesis in similar samples may be helpful to better understand if caregivers previously adopted approaches to interpersonal communication that laid the groundwork for the strategies identified here.

## **Limitations**

This study had limitations, in addition to its strengths. As the purpose of this research was not to provide population estimates, but rather to do an in-depth exploration of a phenomenon, the sample size was fairly small. African-American caregivers were purposively selected as our previous research had suggested that African-American caregivers reported



greater confidence managing aggressive behaviors. However, an important next step in this research would be to explore caregiver reactions to these behaviors in other race, ethnic, and cultural contexts. For example, Asian-Americans are the fastest growing race/ethnic group in the United States (A. Brown, 2014) and little research exists that examines the experiences of any segment of this group in regard to aggressive behaviors in dementia. Although the findings in this study cannot be represented as generalizable to the population of dementia caregivers as a whole, this research does provide valuable information about care challenges and strategies that this sample used dementia caregiving that may be useful to explore in other settings and samples.

The generalizability of this study may also be limited by the previous exposure these participants had to an intervention study specifically focused on behaviors in dementia. Although a few of the participants in this study had only been screened for the intervention study, the remainder had been randomly assigned and completed either the attention control protocol or the intervention protocol. For those in the attention control group, home safety and dementia education were provided by trained interventionists and for those in the intervention group, occupational therapist interventionists trained caregivers to use activities specifically tailored to the interests and abilities of the person with dementia. The exposure to dementia care best practices and caregiver resources that some of these participants may have influenced the way in which they responded to the vignettes posed in this study. However, it is important to also note that even with this previous exposure to these resources, the analysis reflected that these caregivers continued to perceive a substantial burden related to aggressive behaviors. In addition, many of the challenges and strategies they discussed appear to have predated their participation in either the intervention study or this study.

It should be noted that there was little diversity in this study as it concerns gender and relationship. There was only one male and one spousal caregiver and thus it was not possible to compare viewpoints between males and females or spouses and non-spouses. As both female gender and a spousal dementia caregiving relationship have been associated with increased caregiver burden (Chiao, Wu, & Hsiao, 2015), it would be important to consider these factors in future studies on caregiver reactions to and management of aggressive behavior in dementia.

Another potential limitation of this study is that the one person conducted both the interviews and the initial data analysis. However, subsequent to the initial phases of the data analysis, co-authors provided review and independent analysis of the data, with ongoing discussion between all co-authors, which was designed to increase the trustworthiness of the final results.

## **Conclusion**

In this study of Black/African-American caregivers of persons with dementia, participants described challenges in caregiving and the strategies that they used to manage them. Under the first overarching theme, "It's the disease...not the person," three sub-themes emerged: "In there somewhere is that person," "Sometimes it's hard not to take it personal," and "Not who they were then." Under the second overarching theme, "You got to pick your battles," three sub-themes also emerged: "I got to do what I gotta do," "We didn't argue... we didn't insist," and "Don't put her in a position to fail." Differentiating dementia-related behavior from the person underneath required participants frequently remind themselves

that “It’s the disease. . .not the person.” Although participants reported that dementia caregiving sometimes felt like taking care of a stranger, they tried to remember “In there somewhere is that person.” The sense that “Sometimes it’s hard not to take it personal” was exacerbated when aggressive behaviors occurred. Frequently they described aggressive behaviors as personally hurtful interactions between caregiver and person with dementia. Participants also reported that premorbid conflict with the person with dementia, necessitated remembering they were “Not who they were then.” “You got to pick your battles” describes the strategic approach that these caregivers used when deciding how to approach care delivery with the person with dementia. “I got to do what I gotta do” was the rationale participants used to prioritize caregiving needs of the person with dementia. “We didn’t argue. . .we didn’t insist” refers to participants’ person-centered approach that required they use the response of the person with dementia to guide the timing and execution of caregiving activities. Additionally, “Don’t put her in a position to fail” was an important concept used to describe how participants helped the person with dementia to be as independent as possible while being mindful of limitations. These insights provide important information that may be helpful to guide intervention development that is supportive of caregivers and that encourages a person-centered approach to caring for persons with dementia.

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