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Factors influencing appraisal of upset in black caregivers of persons with Alzheimer disease and related dementias

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Factors Influencing Appraisal of Upset in Black Caregivers of Persons With Alzheimer Disease and Related Dementias

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Abstract: Black caregivers of persons with Alzheimer disease and related dementias (ADRD) have demonstrated significantly lower levels of stress and burden than white caregivers, as measured by instruments that assess caregiving burden and stressfulness of specific problem behaviors. However, the reasons for reported differences are unclear and cannot be attributed solely to race. This descriptive study used content analysis to compare black caregivers' descriptions and interpretations of responses to memory and behavioral issues of relatives with ADRD to 11 explanations for lower levels of upset proposed in the caregiving literature. Findings confirmed only two explanations from the literature, social support and religious orientation, as factors that influenced appraisal of upset. Two new themes emerged, categorized as *Making Sense* and *Using Strategies*, as explanatory frameworks. Findings extend current knowledge of black caregivers' emotional responses to caregiving and support the need for future study of the ways in which particular ethnic and racial groups experience caregiving. Understanding the meaning of appraisals may enable service providers and program developers to tailor services and interventions to support the efforts of black and other minority caregivers.

Key Words: caregivers, black caregivers, coping

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The majority of the approximately 4 million persons with Alzheimer disease and related dementias (ADRD) are cared for by family members at home.[1] As cognitive decline progresses in the person with ADRD, caregivers become increasingly involved in assisting the care receiver with self-care tasks such as feeding, dressing, and bathing.[2] Additionally, caregivers often must contend with problem behaviors of the care receiver such as depression, agitation, and wandering, along with secondary stressors such as family conflict, financial and work strain, and changes in self-concept.[2]

Behavior problems such as wandering and agitation are reported as more stressful by caregivers than declines in self-care. These behaviors and caregivers' responses to them have been conceptualized and measured as components of burden[3] or used as independent measures of the frequency and level of upset associated with memory and behavioral challenges.[4] Strong evidence exists for the importance of behavior problems as significant influences on caregiver health. In a review of 41 studies of caregiver health outcomes, Schulz et al[5] found that behavioral problems were consistently related to psychiatric and physical morbidity for caregivers of persons with dementia. Additionally, Gaugler et al[6] found that behavior problems significantly predicted role overload in dementia caregivers and concluded that increases in frequency of behavior problems represent the most serious effect on mental health.

Although behaviors identified as problematic in dementia have negative effects on caregiver health, they may not be experienced in the same way by different racial and ethnic groups. Many studies have found that blacks demonstrate significantly less burden and lower levels of depression than white caregivers of persons with ADRD.[7–11] Paradoxically, although black caregivers report lower levels of burden and depression, physiological measures indicating stress such as interleukin 6 are increased and may predispose the group to a variety of aged-related illnesses.[12]

Black and white caregivers have demonstrated differences in appraisal of upset in response to specific memory and behavioral issues in a number of studies.[9,13,14] For example, Gonzalez[14] studied appraisals of behavioral problems, resourcefulness, and coping in 25 white and 25 black caregivers. Results indicated that while black caregivers reported many behavioral problems of relatives with ADRD, they experienced significantly less upset than the white caregivers. Gonzalez[13] attributed the more benign appraisal of behavioral problems by black caregivers to differences in life experiences, religious orientation, and cultural background. These factors were thought to operate through the process of caregiver appraisal by influencing caregivers' interactions with their relatives in ways that decreased the incidence of behavioral problems (ie, helping caregivers modulate thoughts and feelings that would influence their modes of interaction).

Haley et al[9] used the stress process model to investigate differential levels of psychological distress between black and white caregivers. Using a sample of 74 black and 123 white

caregivers of persons with ADRD, Haley et al[9] examined the effect of appraisal, coping, and social support on caregiver well-being. They found that black caregivers had significantly less upset in response to memory and behavioral problems than white caregivers. However, race did not directly affect caregiver well-being but, instead, was mediated by caregiver appraisals and coping responses. The researchers identified four possible hypotheses for these differences in appraisal and coping between blacks and whites: greater tolerance of disturbances in family members with dementia; strong value placed on older relatives that makes cognitive decline less important; caregiving as a normative process; and previous experience with demanding life circumstances.

Miller et al[14] investigated the effect of stressor variables, including memory and behavior problems, on depression and role strain in a study of 77 black and 138 white caregivers of persons with ADRD. They found that black caregivers were significantly less upset by the memory and behavioral problems of their spouses than white caregivers and hypothesized that these differences may have been due to the different interpretations of adverse life experiences by black and white caregivers.

Lawton et al[11] also noted the importance of appraisal as an influence on psychological stress, although they did not directly examine response to behavioral problems. They conceptualized caregiving appraisal as inclusive of caregiver satisfaction, caregiving burden, caregiving as intrusion, and caregiving ideology. They proposed that the cluster of attitudes referred to as "traditional caregiving ideology" might explain the lower level of burden in black caregivers. This ideology reflected a desire to continue family traditions, to serve as role models to their children, to live according to religious principles, and to repay the care receiver for previous actions. Other researchers have identified higher levels of social support[15] as a mediator of caregiver burden and unique emotional strengths[10] as factors that may help to explain differences in responses of blacks to caregiving stress and burden.

Three limiting factors have impeded research efforts to identify black caregivers' emotional responses to caring for relatives with ADRD. First, although research has identified factors such as religiosity that may mediate caregiving distress among black caregivers, it is critical to recognize that intragroup differences also exist,[16,17] and these have not been systematically examined. Moreover, investigating cultural differences in terms of black and white dichotomies fails to uncover experiences unique to black caregiving and masks intragroup differences, which may foster development of cultural myths.[18] A second limiting factor is that current theoretical frameworks may not provide adequate means for capturing experiences unique to black caregivers because they do not account for key issues such as cultural-historical background (eg, values, beliefs, meanings) and sociopolitical influences including economic status.[19]

A third limiting factor is choice of research design. While quantitative studies have contributed useful information on stress and burden, and the importance of memory and behavioral issues as key determinants of psychosocial outcomes in caregivers, collectively they have not generated knowledge as to the different ways that specific racial and ethnic groups perceive and address memory and behavioral issues of relatives with ADRD. Research approaches that may better capture the complexity of racial and ethnic differences in appraisal include descriptive[16] and qualitative methodologies.[17,19] These designs may better capture personal interpretations rooted in cultural differences than the quantitative analysis of standardized scales. Descriptive and qualitative designs allow inclusion of multiple dimensions that influence daily life for black caregivers, such as the sociocultural, interpersonal, situational, temporal, and personal contexts described by Dilworth-Anderson and Anderson.[20] Quantitative analyses of standardized scales have limited the usefulness for comprehensive analysis of the reasons behind racial and ethnic differences. A key assumption in quantitative designs is that questions on a standard instrument hold the same meaning and significance, and researchers assume the respondent has the same understanding that they do.[21] Thus, investigating the actual interpretations behind black caregivers' responses to a standard instrument may provide an important way to understand their perceptions of memory and behavioral problems or occurrences in relatives with dementia.

The purpose of the present study was to explore factors that may influence the appraisal of upset in black caregivers of persons with dementia, in response to a relative's memory and behavior problems. The U.S. population of blacks over age 65 is expected to increase from 2.8 million in the year 2000 (U.S. Bureau of the Census[22]) to 6.5 million in 2030 (U.S. Administration on Aging[23]). Since the risk of AD increases with advancing age, the increase in elderly blacks is likely to produce a corresponding increase in the numbers of blacks with ADRD and their caregivers. Thus, it is vital to more clearly understand the factors that influence appraisal of upset, so that health and human service providers and program developers are better equipped to tailor services and interventions to support the efforts of black caregivers.

METHODS

This descriptive study used content analysis[24,25] to identify key factors influencing black caregivers' appraisal of upset with memory and behavioral occurrences in persons with ADRD. Content analysis is a systematic process of making inferences between data and the context in which data occur,[24] one purpose of which is to identify patterns within cultural groups.[25] The aim of the present study was to identify the ways in which black caregivers respond to memory and behavioral issues of relatives with ADRD and to compare response patterns to key explanations that have been offered previously in the research literature for lower reported levels of stress and burden and differential appraisal of memory and behavioral issues compared with white caregivers. Specifically, this study elicited descriptions of caregivers' responses to and interpretations of memory and behavioral issues in the family member with ADRD, to identify factors underlying appraisal of upset. Caregivers' descriptions and interpretations of memory and behavioral issues were evaluated in comparison to current explanations in the literature that attempt to explain the low levels of upset reported by black caregivers of persons with ADRD.

Participants

The study used a convenience sample of 15 black caregivers who had participated in the Philadelphia site of the National Institutes of Health Resources for Enhancing Alzheimer's Caregiver Health (REACH), an intervention study examining the effectiveness of the home environmental skill building program.[26] Participants consisted of 12 women and 3 men who completed the environmental skill building program, of whom 7 had participated in the experimental group and 8 in the control group. The participants were selected from a list of all black caregivers who had participated in the experimental or control group of the REACH study at the Philadelphia site. As part of the original REACH study, all participants had received a set of educational materials each time study variables were tested. These materials included information from the Alzheimer's Association (eg, fact sheets about dementia). Inclusion criteria for the present study were as follows: the caregiver had to be black and the primary caregiver living with a family member with dementia, and who, at the baseline interview, identified at least one memory or behavioral occurrence as "a little" upsetting on the Revised Memory and Behavior Problem Checklist (RMBPC).[5]

An announcement about the study purpose was mailed to all caregivers meeting the inclusion criteria. Following this mailing, eligible caregivers were contacted by telephone to explain the study, determine willingness to participate, and set up an in-home interview with the Principal Investigator (PI). Informed consent from caregivers, approved by the Institutional Review Board, was obtained prior to conducting the interviews. Interviews lasted from 30 minutes to one and one half hours. All interviews were audio taped and transcribed. Study participants completed the RMBPC and then elaborated on scale items using an elected probe technique.[27] The elected probe is an adaptation to the random probe technique described by Shuman,[28] which was originally designed to elicit the personal perspectives of persons responding to closed-ended questions on surveys. This technique is a cost-effective way to gain insight into the meanings respondents attribute to questions. The elected probe technique retains the advantages of the random probe but modifies the way in which the respondents' elaboration of scale items is elicited. In the elected probe technique, respondents choose items that are salient to them for elaboration instead of discussing items from the instrument that are chosen by the researcher. In the present study, the elected probe technique was used to elicit caregivers' perspectives on behaviors displayed by the person with ADRD that they considered most and least upsetting. Caregivers were asked, "Of all the things we discussed (ie, the memory and behavior problems on the RMBPC), which do you find most upsetting? Least upsetting?"

Interview transcription included the entire interaction between caregivers and the PI, including caregivers' spontaneous comments prior to and during administration of the RMBPC. The total interview time, including the RMBPC and the discussion of most and least upsetting behaviors, lasted from 30 minutes to 1.5 hours. All caregivers elaborated on personally salient RMBPC items. These caregiver elaborations ranged from clarifying sentences of less than 1 minute (eg,

stating, "There's nothing to be irritable about," when asked about the frequency of arguing, irritable, or complaining) to discussions of up to 20 minutes fully describing the family member's behavior and caregiver response to a single RMBPC item. In addition to going through each RMBPC item, the researcher used probes to clarify caregiver's comments if they were unclear. These probes consisted of active listening strategies,[29] such as restating what the caregiver said and asking for confirmation or asking, "Can you tell me more about that?" when insufficient information was provided to ascertain the precise meaning of caregiver statements.

Caregivers' spontaneous elaboration on personally salient RMBC items, in addition to the specific questions about behaviors that bothered the caregiver most and least, enabled the researcher to identify factors underlying their appraisal of upset. Summary data of the memory and behavior problems selected by participants are shown in Table 1.

Data Analysis

The 15 interviews were coded using techniques described by Weber system[25] for content analysis.

Different units of analysis such as individual words, sentence, or paragraphs are used in content analysis, depending upon the type of research question and study.[25] For this study, individual sentences from each interview transcript were considered as the unit of analysis (text units).

The initial coding system was based on key explanations proposed in the research literature to explain lower levels of stress and burden and differential appraisal of memory and behavioral issues. Relevant articles were obtaining by searching MEDLINE and CINAHL, using the key words "Alzheimer's Disease OR dementia" "Caregivers," and "African Americans OR Blacks." Eleven explanations were identified through a systematic review of caregiving literature from 1992 to 2002. These 11 explanations were organized into three explanatory paradigms or domains of concern. The 11 explanations were used as coding categories (Table 2).

Three of the 15 transcripts were used to systematize the initial coding process by standardizing the codes and creating a coding table. This systemization provided clear rules for placing text into the codes, which was important because the explanations in the literature varied in level of detail. One transcript was eliminated because of the poor quality of the audiotape and transcription. The PI and research assistants developed new categories for text that did not fit existing codes. These new codes were broadly conceptualized with Dilworth-Anderson and Anderson's ecological framework.[20] Categories were refined by condensing similar codes into more inclusive categories, through consensus between the PI and research assistants.

The procedure for standardizing the coding system was as follows. The author and two research assistants provided coding rules for placing text into the 11 categories. This included a list for each code of inclusion and exclusion criteria; and providing samples of text that might be coded into each category. Caregiver responses were counted as belonging to the category if they met the inclusion and exclusion criteria. For example, the rule for coding a text unit into the category of

TABLE 1. Most and Least Bothersome Behaviors

Most Upsetting	Frequency	Example	Least Upsetting	Frequency	Example
Concern for safety or well-being	6	If she gets depressed, she might stop eating and die.	Forgetting recent events	5	It bothered me at first, but I've outgrown it, overcome it.
Aggressiveness	3	I never know when she's gonna go berserk or when she gets provoked and we find that's easily done by others.	Not specified	7	Nothing really bothers me. I just don't think that much of it.
Doing things that negatively impact the caregiver	4	Bringing those trampy people … in this house—that is a big invasion of my privacy. When she soils her clothes, that's what really works my nerves … because I try to keep up with it every minute.	Destroying or losing objects	3	When she tears off all that toilet paper …it doesn't even phase her (laughs).
Care receiver's condition and related decline in functioning	2	I just remember the things she used to do. She used to remember, and do all these things (crying).			

social support was, "Caregiver makes explicit statement in response to either the RMBPC item or the elected probe (most upsetting/least upsetting behavior) that refers to receiving help or support from a relative, friend, or acquaintance." This category included: comments regarding reciprocal nature of social support between peers, statements about benefits of social support, and statements or descriptions of specific tasks performed by others and excludes statements about support from formal caregivers such as nurses or home health aides. A sample comment that would be coded to Social Support was "sometimes I had given her [friend] a little advice that would help with my mom and she would try it on her grandmom. It's like a buddy system."

The author and four research assistants independently coded the interviews based on the initial coding system (Table 1). Four codes (explanations for lower levels of burden) contained in the coding system were dropped because they were too vague to apply to the data without inferring the participants' intent. In particular, we found that we could not match specific text units to codes that were stated in broad terms. These codes were "More tolerant of disturbances in family members," "Cultural value placed on older adults," "Caregiving as a natural part of life," and "Have unique emotional strengths that enable them to contend with problems of care receiver with dementia." In many cases, caregivers told stories that could be interpreted as appropriate to the codes. However, after discussion, the researcher and assistants determined that excessive inference would be required to fit the text excerpts to these codes, so the codes were dropped. Four other codes were dropped because they appeared in few transcripts or achieved low interrater reliability. These codes were: "Previous experience with difficult experiences enabled development of resilience," "Caregiving as an act of love or a traditional family value," "Caregiving as a female role," and "Previous experience serving in various capacities."

To assist analysis, reports comprising all text coded to each code were generated using a qualitative software analysis program, QSR N-5.[30] This enabled all the transcribed text from each individual code to be viewed for further analysis and comparison between codes. Using N-5, the total number of text units coded to each code and percentage of documents in which they occurred were generated. A bank of verbatim quotes related to each code was obtained and interrater reliabilities were calculated.

New categories were developed for findings that did not fit specific explanations from the literature that attempt to account for black caregiver responses to memory and behavioral issues of relatives with ADRD. Dilworth-Anderson and Anderson's contextual approach to black caregiving was used as a broad framework from which to conceptualize the new categories.[20] The final coding system and text excerpts illustrating the codes are shown in Table 3. Final analysis was completed on transcripts from 11 caregiver interviews. Interrater reliability of the coding was 81%. This was calculated by dividing numbers of text units agreed upon by the total number of text units in the 11 transcripts used for the analysis.

RESULTS

Content analysis supported two of the original 11 explanations for lower levels of upset in black caregivers of persons with ADRD: social support and religious orientation. These explanations comprise elements of the interpersonal context of black caregiving, which includes relationships with family, friends, and church.[20] Two new categories were developed to capture findings that emerged from the data. These categories, Making Sense and Using Strategies, consisted of the caregivers' efforts to understand and manage the memory and behavioral issues of relatives with ADRD. The new categories were conceptualized as elements of the caregivers' personal context. The personal context comprises psychological characteristics of caregivers that influence well-being, including individual attitudes, beliefs, and coping styles.[20] In the present study, caregivers' interpretations and the ways of

TABLE 2. Proposed Explanations for Lower Levels of Stress and Burden in Black Caregivers of Persons with Dementia

Domain of Concern	Explanation from Research	Author(s)
Better equipped to cope with the problems of dementia	More tolerant of behavioral and cognitive disturbances in family members: This is evidenced by the findings that black caregivers bring in family members for initial cognitive assessment at a much later stage, when impairments are more severe, than do white caregivers.	Haley et al. (1996)[9]
	Unique emotional strengths enable adjustment to dementia-related problems. Black caregivers may believe they have inner resources and external supports that enable them to care for dementia patients in the community.	Hinrichsen and Ramirez (1992)[10]
	Previous experience with difficult experiences enabled development of resilience. Because of minority status, blacks experienced many hardships as a result of poverty, discrimination, and other life stresses; these difficult experiences may promote long-term adaptation.	Haley et al. (1996)[9]
	Previous experience in a serving role: Blacks have had considerable experience and opportunity in low wage, unskilled service occupations. As children of a servant class, caregivers learned how to serve the elderly through previous experience serving others jobs such as health aides or service workers.	Fox et al. (1999)[18]
Values and beliefs congruent with the caregiving role	Cultural value placed on older adults; with less emphasis placed on cognitive and behavioral functioning in older relatives. Older adult is valued regardless of declines in mental and behavioral functioning.	Haley et al. (1996)[9]
	Caregiving as a traditional family value: caring for family member at home is believed to be the correct course of action.	Sterrit and Pokorny (1998)[15]
	Caregiving as female role: being a caregiver is a role that is expected of women but not men.	Sterrit and Pokorny (1998)[15]
	Caregiving as an act of love, with focus on rewards of caregiving. May see caregiving as a privilege.	Sterrit and Pokorny (1998)[15]
	Caregiving seen as a natural part of life and expected by black caregivers vs. being viewed as a disruption of a time in one's life that is focused on leisure and relaxation.	Haley et al. (1996)[9]
Support systems of blacks different from those of whites	Greater reliance on religion as a source of support by blacks than by whites.	Sterrit and Pokorny (1998)[15]
	This may help to decrease level of perceived stress by viewing the situation as part of God's plan that will lead to a better ultimate outcome.	Gonzalez (1997)[13]
	Greater reliance on informal social support networks by blacks than by whites; information about AD obtained through networks of family, friends, and neighbors.	Sterrit and Pokorny (1998)[15]

responding to relatives' memory and behavioral issues were elements of the personal context.

　　Four explanations from the caregiving literature that were originally listed as codes were dropped because they were too vague, and four that appeared infrequently in transcripts or achieved low interrater reliabilities are not reported in the present paper. Explanations that were supported in the content analysis are discussed below, beginning with those derived from the caregiving literature.

Social Support

　　The importance of social support was discussed in 9 of the 11 transcripts. Types of support included both emotional support ("It helps to have someone to talk to") and instrumental support ("My daughter comes every Sunday and helps [my wife] get ready for church"). For example, L.J. (pseudonym) indicated that social support had been important way for her get to the point where none of her mother's behaviors bothered her anymore:

■ *I can't say how I got to that point other than just a lot of thinking and talking to other people who had been in this situation …I have a person at work that had been a caregiver. Her grandmother had Alzheimer. So I talked to her a lot. So, we talk about it and stuff like that and… she keeps giving me little hints, "well, try this." And basically by word of mouth to other people who have been in this situation or have family members that, you know, that are in that situation.*

　　A.Y. focused primarily on instrumental support when he was asked which of his wife's memory and behavioral

TABLE 3. Final Coding System of Explanations Related to Upset (Unsupported and Unreliable Explanations Omitted)

Domain	Topic	Example
Religious orientation	Source of strength	I pray and sing—it fortifies me for the day. I'm sure that's why [husband's behavior problems] don't bother me anymore.
	Sense of mission	God knew what He was doing. He knew she'd need someone to take care of her. So he gave me the compassion to take care of her and I take good care of her.
Social support	Importance for caregiver	[My husband] really supported me. And my daughter, she's the same way. She comes over and she helps in any way she can.
	Importance for care receiver	She looks forward to going to day care. It gives her a chance to meet other people, many with similar situations that maybe they can communicate together. I'm sure they do some kind of communication.*
Making sense of care receiver behavior	Formal knowledge	At first [her difficulty remembering significant events] bothered me because I thought she was playing me [for a fool]; I didn't understand the disease.
	Lay practitioner knowledge	I don't who these people are in her mind, but they are someone that her mind relates back to and she gets angry with them.
Using strategies	Primary control strategies	And if she's sitting here, we'll prompt her, "You're eating. [We'll say] Don't forget your food is here."
	Secondary control strategies	
	Leaving it alone	I don't see any need for forcing her. When I can get her in the shower, I'll put her in the shower.
	Not letting it bother me	I've learned to not let anything bother me now… I've made my resolution that anything you cannot change, there's no point in getting upset about it.

*Statement about her mother, who has an MMSE of 5.

problems upsets him most. He responded that his wife's aggressiveness toward him when he attempted to help her bathe or dress was most upsetting, adding that "If my daughter is not here on Sunday morning, [my wife] will not get dressed properly. But my daughter come over here, washes her hair, fixes her hair, gets her bathed. She is my right hand. I call and she's right here."

In addition to noting the benefits of social support for themselves, some caregivers discussed the importance of social support for the family member with ADRD. Transcripts from these caregivers reflected a focus on the social needs of relatives with ADRD and often reported efforts to include relatives in family and community life, such as taking a trip or going out to dinner. Their attention to their relatives' social needs appeared to be part of an overall focus on enhancing quality of life for relatives with ADRD and were congruent with a view of social support as part of the interpersonal context.

Within the interpersonal context, caregivers reported that not all interactions with family were helpful in caring for the person with ADRD. Four of the 15 caregivers stated they were disappointed with siblings because they were not supportive enough. They indicated that siblings had disappointed them by failing to help with caregiving tasks or to visit the person with ADRD. Other caregivers criticized family members who did not follow through with what they considered appropriate strategies for managing behavioral problems. As L.J. stated:

■ *To my mother [the care receiver], everything that comes out of her mouth is "no" whether she means no or not, but everything is no. You cannot ask her. You have to just go ahead and do what needs to be done.*

Religious Orientation

In 7 of the 11 transcripts used in the analysis, caregivers made statements in which they reported using religion or spirituality as a way to decrease their level of upset in response to memory and behavioral occurrences in their relatives with ADRD. This category was also viewed within the interpersonal context. Most commonly, caregivers discussed their belief that God would continue to provide strength based on the caregiver's previous experience with difficult times (eg, parent's death, disabling disease of caregiver or other family members, incarceration of a sibling). For example, after being asked what bothered her most, K.B. stated it was her mother's overall decline that was most upsetting. She reported being afraid that eventually she would have to place her mother in a nursing home but stated that "I just have to pray on that, to strengthen myself. I'm a firm believer in the Lord." With further probing by the interviewer ("Can you say more about being a believer?") she said:

■ *I just know that I'm a firm believer in my Lord. Sometimes we don't understand why or how He do things, but He works it out. I feel that He'll give me the strength to go through this. He gave me the strength to go through my mother's death.*

Acceptance of life events or a sense of mission, were also prominent in caregivers' discussions of the ways in which religion and spirituality helped them to deal with memory and behavioral occurrences of their relatives. For example, N.P. reported that

■ *God has a way that's not man's way, and not only that, that there's a way to seem as righteous unto man but it leads to destruction. So my prayer was before this year and last year*

was that the Lord have his way and not me have mine cause mine could lead to destruction or probably would. But since I didn't have my way and the Lord had his way, therefore it was right. So that's mainly the reason I stopped worrying about things. It took a long time cause there are some things you cannot change because it's not God's will. Even if your plan did work, it would be God's plan for you.

Additionally, some caregivers commented that they continued to attend church services or other church functions with the family member with ADRD. They appeared to believe that these activities helped them, and in some cases, the relative with ADRD, to remain connected with others in their community. For example, Y.R., who went to church with her mother "just about every Sunday" noted that, "The people at church say she's just adorable and sweet." A.Y. stated with pride that "people remark about how nice [my wife] looks when she goes to church" and that even though "she don't remember me, she don't remember her daughter…she can remember all the prayers, she can remember the creeds, the Apostle's creed …and all the songs."

Additional Categories Related to Appraisal of Upset

Two additional coding categories were developed to capture factors that were important influences on caregiver upset not included in the original coding system of categories from the literature. These categories, Making Sense and Using Strategies, were found in all the interviews. These categories were considered part of the caregivers' personal context and revealed the ways in which they responded to the ongoing challenges of dealing with memory and behavioral issues in relatives with ADRD.

Making Sense

Making Sense encompassed statements by caregivers related to their efforts to understand or reframe memory and behavioral issues. This category consisted of caregiver efforts to find and create meaning when dealing with challenging situations related to relatives' memory and behavioral occurrences. Transcripts revealed caregivers' attempts to decipher the meaning of their relatives' behaviors, emotions, and internal states when memory and behavioral issues occurred. These attempts to create meaning reflected an active way to build knowledge about the care receiver, to better manage memory and behavioral occurrences. Caregivers often discussed cause-effect relationships thought to occur between environmental influences and behavioral problems. They then used this knowledge to develop strategies. For example, F.H. reported that "when [my mother] does a certain kind of hum, it means she needs to have a bowel movement." This knowledge enabled her to better manage her mother's problem of incontinence, since she could predict when a bowel movement would occur and get her mother to the bathroom in time. Other caregivers appeared to use lay practitioner explanations of the family member's behaviors to change their ways of thinking about the problem behavior. For example, M.N. stated she was upset most by her father's habit of walking around at night because he was at risk for falling given neurologic problems.

However, she reported the fact that he did so completely naked with amusement and described it as "interesting" and not upsetting to family members because I think that [walking around naked] came from being on a ship [as a merchant marine].They just didn't wear clothes. So he's used to walking around like this. We all in the household have seen [his entire body].

The Making Sense category also included caregivers' use of biomedical knowledge of ADRD, in addition to insights gained from experience as a caregiver. In some transcripts, caregivers explicitly stated that they used biomedical knowledge to buffer appraisals of upset. For example, R.S. noted, "It doesn't upset me when [my mother] constantly repeats herself because I know this is part of the package of Alzheimer's." When discussing what bothered her least about her mother's memory and behavior problems, J.G. reported she was least upset when her mother did things to embarrass her, stating that "[My mother] has Alzheimer's so she really don't know what she's doing." When asked by the interviewer how that helped her to be less upset, she replied:

■ *How does that help me (knowing she has Alzheimer's)? It helps a lot. By me knowing she don't know exactly what she's doing because of her mental state, I've learned to accept it. Like if she was in her normal mind and did these things, then yeah. [I'd think] "Why are you doing something to aggravate me?" It's not on purpose. She just don't know.*

Using Strategies

The Using Strategies category included ways of exerting primary and secondary control over the memory and behavioral issues of relatives with ADRD. This category included both primary and secondary control strategies. According to some authors, control efforts are synonymous with coping.[31] Control terminology is used to emphasize the active process of managing memory and behavioral issues that caregivers described in the interviews. Primary control is taking direct action to modify a situation.[32] In this study, primary control strategies were ways in which the caregiver took direct action to deal with potentially upsetting memory or behavior problems of the care receiver. The caregivers' strategies encompassed a wide range of specific actions that they took to address memory and behavioral occurrences. Strategies included additions to the physical environment such as putting locks on doors and changes to the social environment such as changing the tone of voice in which they interacted with the care receiver, to avoid the care receiver's becoming upset or belligerent. Strategies also included ignoring problem behaviors and removing items that led to behavior challenges. For example, E.B. ignored her husband when he started yelling, stating "I go on the porch and let him holler. [When I let him holler] then he'll stop." L.C. handled the behavior problem of her mother waking others at night by removing her mother's cane from beside the bed:

■ *She used to take her walking cane. That's why I don't keep it close to the bed no more. She would just hit the bed [at night]. I go in there, "Momma what's wrong? What's the problem?*

*I say, you were hitting the bed." [Her mother said], "I was try-
ing to get that man out of my bed." She was hitting at [an
imaginary] man.*

Secondary control strategies are efforts directed at the self to manage feelings and perceptions related to stressful events.[32] Secondary control strategies in this study reflected caregivers' efforts to change the way they thought or felt about the care receiver's memory or behavior problems or their daily decisions about managing these issues. Secondary control strategies comprised two subcategories. "Leaving it alone" reflected the caregiver's active decision to refrain from intervening with the care receiver's upsetting behavior. This referred to caregivers' refraining from logical or expected actions that they would normally take. "Not letting it bother me" was also an active decision to refrain from being upset about a situation they did not have the power to change, such as a care receiver's refusal to attend church services. For example, when A.J. was asked about the things that bother her least, she stated:

■ *It bothers me the least that she can't remember. Now let's
say some of the things that really bothers me, then I have to say
to myself, 'Alright A.J., now get yourself together.' Because I
have an illness and I cannot have any stress. It would tick my
MS [multiple sclerosis] off. So, I have to think about things
that maybe she's doing that normally would get on my nerves
and drive me up the wall. Okay, so instead of letting it drive me
up the wall, what can I do, how can I think about it to keep it
from driving me up the wall, but still take care of the situation?
Those are the things I have to keep in consideration.*

Limitations of the Study

The present study was conducted using a small sample of caregivers from an urban area in the Northeast. Thus, results may not be generalized to the whole population of black caregivers of persons with ADRD or to all geographic areas. Moreover, a larger sample size may have enabled the content analysis to support additional explanations proposed in the literature that were not supported in the present study.

DISCUSSION

This content analysis identified key factors that influenced appraisal of upset in a small sample of black caregivers who were primary caregivers living with a family member with ADRD. Findings supported two explanations from the caregiving literature, social support and religious orientation, as factors that influenced appraisal of upset in response to memory and behavioral issues of relatives with ADRD. Two additional factors that influenced appraisal of upset identified in the present study were caregivers' efforts to make sense of relatives' memory and behavioral issues and their use of specific strategies to manage these issues. These key factors influencing appraisal of upset in response to memory and behavioral issues may operate by moderating appraisal of the stressfulness of the behavior. For example, efforts to make sense of the care receiver's problem behavior by fitting it within a lay practitioner's theory of care (eg, F.H.'s

comment that when her mother "does a certain kind of hum that means she's going to have a bowel movement") may make provide a greater sense of predictability to the behavior and enhance feelings of control. This in turn may make the behavior appear more benign, thus moderating its perceived stressfulness. Similarly, creating specific strategies that are used whenever certain behaviors occur may also enhance caregivers' sense of control and enable them to feel as though the memory or behavioral problem that can be managed, rather than viewing it as an insoluble problem or a source of overwhelm.

The present study supports previous research indicating that religious orientation may serve as an important resource variable for black caregivers of persons with ADRD.[33] Study findings in regard to social support demonstrate intragroup differences in this sample of black caregivers, which are thought to be present in ethnic and racial minorities. Specifically, findings from this study confirm that social support can serve as an important resource variable,[34] yet also highlighting results of other research stating that black caregivers do not necessarily have extensive informal support networks,[18,19] and may view family members as a source of stress as well as support.[18]

Findings of the present study also suggest that religious orientation, informal social support, meaning making, and the use of strategies to manage memory and behavioral issues of relatives with ADRD are a cluster of tactics used to manage emotional responses to the primary stressor of memory and behavioral disturbances and thus serve as moderators of upset, which in turn influences caregiver health. This multifaceted view of the process of coping with a relative's challenging behaviors is congruent with current views on appraisal and coping that incorporate multiple coping strategies simultaneously, instead of pitting problem- and emotion-focused coping against one other.[35] The present study also confirms findings by Gignac and Gottlieb[36] that caregivers engage in an active process of making sense of the care receiver's challenging behaviors ("Making Meaning," p.145) and developing strategies ("Managing Symptoms," p.145) in response to the specific stressor of memory and behavioral issues. This is important because it is necessary to clearly identify which stressors are associated with particular coping responses. The greater specificity gained in matching stressors and types of coping strategies enable researchers to develop more specific measures of coping[37] and may be used to provide more individualized intervention.[36]

Another contribution of the present study is that it brings into focus ways in which black caregivers integrated formal medical information with knowledge gained from experience in caring for a person with ADRD. This integration of lay practitioner and formal knowledge of AD appeared to occur through an active process of constructing meaning from the caregiving situation. Previous work by Roberts et al[38] has determined that black caregivers may have less medical knowledge and fewer sources of information about ADRD than whites. However, the ways in which caregivers synthesize formal medical knowledge with knowledge gained from caregiving experience by black caregivers has not been studied.[39] It is especially important to decipher this process in blacks, who

are sometimes thought to use folk knowledge and remedies exclusively.[18]

Findings also suggest that the elected probe methodology used in the present study can be a useful, cost-effective way to obtain data on the ways in which minority (and other) caregivers interpret commonly used scale items. This technique may be effective for investigating responses to other commonly used scales and gain greater understanding of the meanings behind appraisals.

Finally, the present study identifies a new avenue for research on intragroup and intergroup differences through a focus on strategy development and use in caregivers of persons with ADRD. Future studies might examine strategy development and use between and among different ethnic and racial groups, to further delineate its role in managing upset in response to memory and behavioral issues. Further investigation into meaning-making and strategy processes is expected to provide crucial information that will enable health and human service providers to develop programs are more individualized and better meet the needs of blacks and other ethnic and racial groups caring for relatives with ADRD.

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