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You Don't Want to Burden Them:

Older Adults' Views on Family Involvement in Care

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Abstract

Burden emerged as an important concept among older adults in a study of how older adults interact with their families around care. The authors conducted 50 semistructured interviews with adults older than the age of 65 years and a spouse or adult child. The sample was stratified by ethnicity thus giving the opportunity to explore both ethnic similarities and differences. Older adults who expressed the concept of burden were more likely to be White compared with older adults who did not express burden. Older respondents discussed burden in relation to not wanting to complicate the busy lives of adult children, guilt about health problems, and concern that children were overly worried about the care of their older family member. The expression and meaning of burden differed according to ethnicity. This study has implications for practice and policies to meet the needs of families and promote the independence of older persons.

Keywords

family caregivers; chronic illness; family; primary health care; ethnicity

Demographic aging, defined as an increase in the percentage of a population aged 65 years old or more, is now an established trend in most world regions (Lloyd-Sherlock, 2000). In the United States, the percentage of persons aged 65 years and older has grown from 10% to 13% during the period 1970 to 1997, and by 2050, 20% of all adults are expected to be 65 years old and older (U.S. Census Bureau, 1996). From 2000 to 2050, projections indicate that the White elderly population will double, and the Black elderly population will quadruple (U.S. Census Bureau, 2000). Current trends in health care reform focus on cutting costs in acute care settings resulting in a shift from the hospital to the home. Research in the United States and internationally has found that families have become critical in providing financial, physical, and emotional support to ill patients (Armstrong & Armstrong, 2004; Australian Institute of Health and Welfare, 2007; Barg, Pasacreta, Nuamah, & McCorkle, 1998; Varley & Blasco, 2000). Because of the increasingly complex needs of care receivers, the family will be required to perform more care and for longer periods of time.

A vast amount of research has examined caregiving from the caregiver perspective with a focus on the burden and psychological distress of care-givers. Similarly, ethnic differences in the role the family plays in health care and illness have been studied from the perspective of caregivers (Ayalong, 2004; Dilworth-Anderson, Williams, & Gibson, 2002; Haley et al., 2004; Pinquart & Sorensen, 2005). But caregiving by its very nature is a process consisting of

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at least two people and thus research must examine both people in the caregiving dyad (Pruchno, Burant, & Peters, 1997). Caregiving is generally perceived to be beneficial to the care receiver; however problems associated with care receiving have been identified, including depression and relational quality (Clark & Stephens, 1996; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007; Wolff & Agree, 2004). The perspectives of older adults on family involvement in their care should account for histories, beliefs, and value systems as well as how these factors are associated with ethnicity. Although caregiving has been studied from the point of view of the care receiver (Chappell & Kuehne, 1998; Lyons, Zarit, Sayer, & Whitlatch, 2002; Tetz et al., 2006; Ward-Griffin, Bol, & Oudshoorn, 2006; Whitlatch & Feinberg, 2003), little work has used an open-ended, qualitative format to explore ethnic differences from the perspectives of older adults who may or may not be care receivers. We sought to explore the views of older adults in order to place a focus on how the care process affects their health and well-being. Our study goal was to describe how older adults interact with their families around care, of particular interest to nursing, and the concept of burden emerged. Our sample was stratified by ethnicity thus giving us the opportunity to examine ethnic differences.

Ethnicity refers to a common heritage shared by a particular group (Zenner, 1996). We recognize that designations of ethnic status imply a homogeneity within groups, which is a simplification (Cooper & David, 1986; Osborne & Feit, 1992). Any differences we observe across ethnic groups are likely to represent measured and unmeasured differences in social class, exposures, health beliefs and practices, and other characteristics (Kaplan & Bennett, 2003). We also recognize that ethnic categories, even when self-identified, are crude indicators of shared experiences and course markers of common attitudes and beliefs. At the same time, recognition of distinct experiences with the health care system across ethnic groups has drawn national attention (Smedley, Stith, & Nelson, 2003). In our work, we acknowledge the importance of individual differences by employing methods that allow respondents to tell us, in their own words, how they view health and health care (Barg et al., 2006; Bogner, Cahill, Fraunhoffer, & Barg, 2009; Gallo, Bogner, Morales, & Ford, 2005; Wittink, Barg, & Gallo, 2006). Consistent with current publications of the National Institutes of Health, (Office of Research on Women's Health, 2000), we use the term *Black* to include individuals of African, African American, and African Caribbean descent and *White* to include individuals of European descent.

Background on Family Caregiving

Ethnicity and Caregiving

Caregiving research has focused on how ethnic differences affect the health and mental health of family caregivers. Black caregivers are less likely to be married, more likely to care for more than one individual, more likely to care for non-family members, and more likely to experience financial hardship than White caregivers (National Alliance for Caregiving and the American Association of Retired Persons, 1997). These factors have been shown to be predictive of negative caregiving experiences among samples of other caregivers (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Yet Black caregivers report less depression (Farran, Miller, Kaufman, & Davis, 1997; Haley et al., 1995; Haley et al., 1996; Lawton, Rajagopal, Brody, & Kleban, 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995), less burden (Fredman, Daly, & Lazur, 1995; Hinrichsen & Ramirez, 1992; Knight, Silverstein, McCallum, & Fox, 2000; Lawton et al., 1992), lower levels of emotional distress and appraised their caregiving situation more favorably than White caregivers (Farran et al., 1997). Black caregivers tend to have a more positive outlook than White caregivers when dealing with the difficulty of caring for a dependent elder (Farran et al., 1997; Haley et al., 1995; Knight et al., 2000; Wood & Parham, 1990). There are indications that the use of informal supports is more diverse for Black caregivers than for White caregivers (Cox, 1993; Lawton et al., 1992; Wood & Parham, 1990). Furthermore, Black caregivers may be far more likely than White caregivers

to identify with traditional values that focus on the importance of providing care to elder family members. Traditional care-giving ideology has been cited as the wish to repay the debt of being cared for as a child, continuing a family tradition of mutual concern, fulfilling personal values, and setting an example for one's children (Dilworth-Anderson, Goodwin, & Williams, 2004; Lawton et al., 1992).

Caregiver and Care Recipient Experiences

Recent studies have begun to look at the caregiving experience from both the perspective of the caregiver and the care recipient. One Canadian study examined the perspectives of women with dementia who received care from their adult daughters. All the mothers spoke of feeling grateful for the care received but at the same time they felt guilty for being a burden to their daughters. Overall, the mothers wished they could be less of a burden to their families (Ward-Griffin et al., 2006). Elderly parents are more interested in affection, thoughtfulness, and open communication from their adult children, rather than involvement in health care issues (Blieszner & Mancini, 1987; van der Pas, van Tilburg, & Knipscheer, 2005). A link has been identified between reciprocity in family relations and well-being and concluded that inability to reciprocate can undermine the morale of older persons (Davey & Eggebeen, 1998; Stoller, 1985; Wolff & Agree, 2004). A study by Lyons et al. (2002) examined caregiving dyads to determine how the responses of each member had an impact on the well-being of the other member of the dyad. These authors found that when caregivers perceived less support and cooperation than care recipients, the level of caregiving difficulties, both instrumental and emotional support, increased (Lyons et al., 2002). Another study which examined the experiences of caregivers and care receivers found ethnic differences in rating whether the caregiver or care receiver's best interests were more important. Compared with White, Asian, and Latino care receivers, the Black care receivers who were predominantly mothers cared for by their daughters, felt their daughters' best interests were most important to consider (Whitlatch & Feinberg, 2003).

An in-depth understanding of ethnic differences in older adults regarding care from family members is important if we are to develop person-centered strategies and interventions. New treatments, if they are to be sustainable and acceptable to older patients and their family members must account for the role of families in care. In an effort to meet the needs of families and advance nursing knowledge, we employed semistructured interviews to better understand the perspective of older adults on involving family in their care. Because the discussion of family involvement in care often occurs within families, older adults and family members were interviewed together. To improve our understanding of the range of older adults' experiences, we included both older adults and their spouse and older adults' and their adult children. In this article, we describe the concept of burden that emerged. A second goal for the study was to explore both similarities and differences for the concept of burden among older Black and White adults.

Method

The Spectrum Study

The goal of the Spectrum Study (the parent study from which our sample was derived) was to characterize how depression presents in older primary care patients. The Spectrum Study involved in-home interviews of 355 respondents aged 65 years and older recruited from nonacademic primary-care practices in the Baltimore, Maryland area and is described in detail elsewhere (Bogner et al., 2004; Gallo, Bogner, Straton, et al., 2005). The self-identified ethnic groups of the 355 respondents consisted of 121 (34%) Black, 231 (65%) White, and 3 (0.8%) Other.

Sampling Strategy

Respondents and their family members were selected for semistructured interviews from the pool of 352 older adults who participated in the Spectrum Study and who self-identified as White or Black (Barg et al., 2006; Wittink, Barg, & Gallo, 2006). Previous Spectrum respondents were excluded when family members were too seriously ill or too cognitively impaired to answer questions. A purposive sampling strategy was used to select respondents and family members. We purposively sampled to achieve approximately an equal number of Black and White older respondents in order to explore ethnic differences in older adults' notions of family involvement in care. Additionally, respondents were chosen so that half of interviews would be with older respondents and their spouses, and half would be with older respondents and their adult children. In all, 50 older respondents and their spouse or adult child were interviewed. Based on our prior work, and on published guidelines (Bernard, 2002), we estimated that interviewing approximately 50 persons would be sufficient. The study protocols were approved by the Institutional Review Board of the University of Pennsylvania.

Semistructured Interviews

Some research addressing ethnic differences in the caregiving experience from the point of view of the older adult uses a quantitative study design. Quantitative research is important to determine the frequency and distribution of specific attributes but, in this format, older adults are unable to talk about their experiences. Structured interviews or fixed choice questionnaires are limited in surveying patients' attitudes because they are based on investigator-defined, not person-derived attitudes and beliefs. Preferences expressed in quantitative research constrain responses to a given response format. However, qualitative research provides an inductive approach to uncover experiences and perceptions from a person-centered perspective. Therefore, we decided to carry out semistructured interviews to explore how families interact around care from the perspective of the older person.

Interviews were conducted in the respondents' homes between March 2005 and June 2005. Each semistructured interview consisted of open-ended questions and lasted approximately 2 hours. Interviews were conducted by one of four trained lay interviewers who were instructed in interviewing by the study investigators working with Battelle Memorial Institute's Center for Public Health Research and Evaluation in Baltimore. The training took place over a 2-day period with role-play until the interviewers could competently carry out the interview. All interviews were audiotaped and transcribed. During monthly telephone conferences interviewers were given additional training and feedback based on the multidisciplinary research teams' review of transcripts.

Assessment of Older Respondents

At the end of the interview, older respondents completed a brief standardized assessment. We obtained information from older respondents on age, gender, ethnicity, marital status, and living arrangements. The Medical Outcomes Study Short Form (SF-36) has been employed in studies of outcomes of patient care (Gallo, Bogner, Straton, et al., 2005; McHorney, 1996; Stewart et al., 1989; Stewart, Hays, & Ware, 1988; Stewart & Ware, 1993; Wells et al., 1989) and appears to be reliable and valid in older adults (Stadnyk, Calder, & Rockwood, 1998). The SF-36 represents eight health concepts: physical functioning, role disability due to physical health problems, bodily pain, general health perceptions, vitality, social functioning, role disability due to emotional problems, and general mental health. We employed the scales representing physical functioning and role disability due to physical health problems (Stewart & Ware, 1993). The scale for each theme ranges from 0 to 100, with higher scores representing better health. In addition, we obtained information from the family members on the number of hours the family member helped the older respondent per week.

Data Management and Analysis

After the semistructured interviews were transcribed and inspected for accuracy, we entered the transcripts into QSR N6 software for coding and analysis (DiGregorio, 2001, 2003; Richards, 2002). A multidisciplinary team including medical anthropologists, geriatricians, family physicians, and older persons from the community reviewed and discussed transcripts weekly (details are provided elsewhere; Barg et al., 2006; Wittink et al., 2006). Before the weekly meetings, team members defined and applied codes to the transcripts. During the meetings team members used the constant comparative method, moving iteratively between codes and text to derive themes in older adults' views about involving family members in their care (Boeije, 2002). The constant comparative method involves taking themes that emerge from the data and rechecking themes against other transcripts to explore similarities and differences in themes across cases.

In the 50 interviews, older adults spontaneously raised the concept of burden when asked about family involvement in care. Because our focus was on the concept of burden that emerged from the data, we performed a text search to find all instances where respondents used the terms *burden*, *bother*, and *worry*. The text around mention of these words was examined for relevance to the concept of burden. First, we analyzed these sections of transcripts to hear individual voices and stories to more fully understand older adults' perceptions. Second, we compared the characteristics of respondents who mentioned burden with the characteristics of respondents who did not mention burden. Because our focus was on the concept of burden, we felt it would be helpful to readers to describe the sample along dimensions that might have a relationship to burden, including sociodemographic characteristics, functional status, and the number of hours the family member helped the older respondent per week. Third, we examined themes of burden according to ethnicity. The third phase allowed us to examine the relationship between ethnicity and the values and experiences expressed through the notion of burden. A similar strategy been used in previous investigations exploring the views of older adults (Bogner et al., 2009; Wittink et al., 2006).

Results

Sample Characteristics

Fifty older adults and family members participated in semistructured interviews. In all, 29 older respondents aged 65 years and older were interviewed with an adult child (58%) and the remaining 21 respondents aged 65 years and older were interviewed with their spouse (42%). Of the 50 older adults, 22 self-identified as Black (44%), and 28 self-identified as White (56%). Of the 22 Black older adults, 17 were interviewed with an adult child (77%), whereas only 12 of the 29 White older adults were interviewed with an adult child (41%).

The mean age of the older respondents was 77.9 years with a standard deviation of 6.0 years. The age range was 69 to 90 years. Thirty-one (62%) of the respondents were women, and 28 (56%) self-identified as White. Twenty-seven (58%) of older respondents were married and 9 (18%) lived alone. Of the 9 older respondents living alone, 7 self-identified as Black (78%), and 2 self-identified as White (22%). The mean number of hours the family member reported helping the older respondent per week was 9.3 with a standard deviation of 30.0.

Characteristics of Respondents Who Mentioned "Burden"

Twenty-three older adults (46%) spontaneously mentioned the word burden or a statement relating to burden when discussing family involvement in their care. White older adults were more likely to mention burden than Black adults. Eight of the 23 older respondents (35%) who spontaneously mentioned burden were Black, and 15 out of the 23 older respondents (65%) were White. Older adults who mentioned burden did not differ from older adults who did not

mention burden in terms of age, gender, marital status, living alone, whether the family member was an adult child, physical functioning score or role physical score (Table 1).

Themes of Burden From Semistructured Interviews

Through talk about burden, older adults indicated an aversion to encumbering family with information about poor health or asking for involvement in daily routines, medication adherence, and doctor's appointments. Three major themes emerged in relation to burden: not wanting to complicate the busy lives of adult children, guilt about health problems, and concern that children were overly worried about the health care of their older family member. Here we describe these themes and how they differ according to ethnicity.

They have families of their own—Ten of the 23 older respondents (43%) thought their children were busy with their own lives and should not be burdened with their parents' health problems. These respondents gave priority to their children's own families and jobs and did not want to ask their children to be involved in their health care. Yet some of the respondents indicated that they felt lonely and wished their family could visit more. The 10 older adults expressing the theme, "They have children of their own" had low levels of functioning as indicated by scores on the physical function (45.0) and role physical (43.1) scales of the SF-36 and received 4.8 hours of help per week from family members.

Seven respondents expressing this theme self-identified as White (70%), whereas only three self-identified as Black (30%). Although Black and White respondents discussed the theme "They have families of their own" in a similar way, their perspectives about the meaning of caretaking and family involvement differed slightly. The Black respondents acknowledged the importance of the older adults' role as the primary caregiver within the family.

One older Black woman said,

I have five sons . . . but now he's the only one here with me and he'll explain to me . . . "Mother you ought to tell them—they should know what your medicines and things you take" and just like he does. I said, They have families of their own and they work and they don't have as much time. But he thinks, well they should take the time and find these things out.

After her son talked about the recovery from his renal transplant, he recalled,

The only one that really was there for me was my mother.

Another older Black woman stated that she did not want to involve her daughter beyond what she already does.

I drive myself. Cause one thing, sometimes you might have to sit and wait and I don't want to have people doing that.

The White respondents discussing the theme "They have families of their own" did not have children living with them and may be less enmeshed with their children. The White respondents were mindful of their children's lives and made an effort to restrict care to a minimum. The following quotes illustrate this perspective:

My one daughter has all these responsibilities with her job and she has her children. I don't feel that they should have to take care of us.

They should see us more because we are getting older. But like I said, they got big houses to take care of. They got yards to keep clean and they're workaholics.

I cannot do the things I used to do—Five of the 23 older respondents (21%) expressed frustration over losing the capacity to do the things they used to do. These five older adults expressing the “I cannot do the things I used to do” theme had low levels of functioning as indicated by scores on the physical function (36.0) and role physical (35.0) scales of the SF-36 and received, on average, 10.8 hours of help per week from family members. This represents twice as many hours of care than the average respondent who mentioned burden received from their family member.

Three of the older adults discussing this theme self-identified as White (60%) and two self-identified as Black (40%). Although these were small numbers and all expressed frustration, the Black respondents emphasized their desire to remain independent and have a sense of control in their lives. They described frustration and defeat at their inability to function as they had previously and seemed to have unrealistic expectations concerning their physical capabilities. One older Black woman continued to care for herself and her husband despite physical pain, and rejected any form of help. She stated,

I cannot do the things I used to do . . . with your kids or your grand kids, knowing you can't because you got to have somebody to push you in a wheelchair. That's the way you got to get around, you don't want to bother them. To me it's like being a burden on somebody and I never want to be a burden to no one . . . I'm just not ready to just give up even though I'm hurting most of the time.

White respondents appeared to express this theme in the context of feeling guilty, rather than in relation to remaining independent or in control. These respondents referred to situations in which they caused family to worry, instances when family was limited by their illness, or an aversion to having family take care of them when they could no longer take care of themselves. The feeling of guilt was caused by having children involved in health care or inconvenienced by problems with health. For example,

Well, living with my dialysis I can't really do . . . what I would like to do. We would like to go on vacation or something. I don't think that I'd really be able to. It kind of makes me feel bad for (my husband) and for the rest of the family that would go with us because we all used to go to Myrtle Beach and North Penn and Nags Head and we just don't do it any more and I feel like it's because of me.

I hate to be—have to have somebody catering to me all the time. You know what I mean, especially if you can't control your bowels or something like that. I don't know. I think I'd rather be in a nursing home.

I feel very guilty that I cause so much worry to my husband and my family.

I just wish I could erase that. And I'm sorry that I can't get around. I used to be the world's greatest volunteer . . . and did a lot now I don't have anything. I don't do anything.

They get a little overly worried—Eight of the 23 older respondents (35%) preferred to not tell their children about health care issues because their children would worry too much. The respondents who expressed the theme “They get a little overly worried” stated that they preferred not to be parented by their children. Some older respondents held the belief that children should not know about a parent's illness because the children could not do anything to change the situation:

They know how sick he is but there is no reason to depress them.

The 8 older adults expressing this theme had high levels of functioning as indicated by scores on the physical function (76.0) and role physical (75.0) scales of the SF-36 and received, on average, 1.9 hours of help per week from family members.

Five of the older adults expressing this theme self-identified as White (62.5%) and three self-identified as Black (37.5%). Consistent with the “I cannot do the things I used to do” theme, the Black respondents expressing the theme, “They get a little overly worried” appeared to be primarily concerned with a loss of independence. These respondents thought that if they talked with their children about health problems or depression their children would make the older women move out of their homes and move in with them. The older Black women were not ready to have their children take care of them. The concerns of these older women are reflected in the following quotes:

Sometime I have to tell her I'm ok but I'm not. Cause she want me to move out of my house and come live with her and her husband.

The five White respondents discussing the theme, “They get a little overly worried” seemed to acknowledge that their children were interested in their well-being, but the concerns of their children were unnecessary.

They're constantly bugging me about something. I mean they're saying did you do this or that . . . how are you feeling, where are you going, are you going to try to do this or that?

It's just certain times that we think they get a little overly worried. So we don't always want to tell them that we're feeling . . . because they get overly worried about us. And then say, “Oh Mom are you sure you're alright, are you sure you're well enough to drive, are you sure—you shouldn't go out this time of day.” You know they just get a little overly worried.

Discussion

In our study about family involvement in care, older adults raised concerns about burdening their families with their care. Burden implied disruption in daily routines, social relationships, and other activities of family members. We found that White older adults were more likely than Black older adults to mention burden in their discussion of the role of family members in providing care. On further exploration we discovered that burden was conceptualized in three ways: (a) a desire not to complicate the busy lives of their adult children, (b) guilt about health problems, and (c) concern that children were overly worried about their health. Black and White respondents discussed the same underlying themes, yet the nuances of their responses demonstrate subtle differences. Previous studies investigating the role of burden in caregiving generally did not take the point of view of the older adults; therefore the idea that burden might have different meanings to older adults has not been thoroughly investigated.

It is important to note that more than half of the sample did not express the concept of burden. Older adults who did not express the concept of burden were more likely to be Black. The concept of burden raised by respondents may represent a concern about who will provide care in the future. Respondents who did not discuss burden may already be receiving care or have made arrangements for care. These older adults may also consider family involvement in care as a natural part of aging. Black caregivers have reported a traditional caregiving ideology (Dilworth-Anderson et al., 2005) and less sense of intrusion on their lives from caregiving responsibilities (Lawton et al., 1992).

Before discussing our results, we acknowledge several limitations. We did not include any question about burden in our semistructured interview. Instead, the concept of burden was raised by older adults during interviews. We focus on respondents who brought up burden spontaneously and cannot know if other respondents also felt the perception of burden when involving family in their care. Although our approach does not allow us to generalize about the prevalence of burden, it does provide a more in-depth understanding of burden because we

were able to observe the ways respondents naturally used the concept burden while discussing family involvement in care. The fact that these older respondents brought up burden spontaneously suggests it may be a salient concept for them. Second, the sample consists of persons who were willing to be screened in a primary-care practice, and participate in an in-home assessment and follow-up study. These individuals might have particular characteristics, such as independence, that made it more likely to express a desire not to burden their families than others who did not participate. Third, our results were obtained from patients who receive care at a limited number of primary-care sites that might not be representative of most primary-care practices. However, these primary-care practices were not academically affiliated and were probably similar to other primary-care practices in the region. Fourth, the expression of burden may be related to other factors such as family-structure differences between the Blacks and Whites in our sample. We acknowledge that ethnicity is a coarse marker of complex social and behavioral patterns. Culture is broadly defined as a common heritage or set of beliefs, norms, and values (U.S. Department of Health and Human Services, 2001). Finally, our decision to conduct conjoint interviews with the older adult and family member was based on the belief that involvement in care often occurs in the context of families. The possibility exists that the responses of older adults may have been influenced by the presence of a family member. However, the decisions that are made about receiving care are often difficult discussions, and we attempted to tap into a more natural dialogue and environment to elucidate what happens during these discussions.

They have families of their own was expressed by older adults who thought their adult children had enough responsibilities with jobs and families, and therefore should not play a role in older adults' care. Among the respondents who expressed the concept of burden, this theme was discussed by the largest number of older adults. Respondents who expressed this theme of burden had low physical functioning and received on average 4.8 hours of help per week. A similar concept, referred to as social burdens was discussed by cancer patients in a study exploring self-perceived burden at the end-of-life. Participants in this study talked about the imposition of caregiving on busy family members who already had family and work commitments (McPherson, Wilson, & Murray, 2007). A study of caregiving relationships in Denmark found that older adults were hesitant to make demands on their caregivers, because the caregivers were very busy with their own jobs and problems (Lewinter, 2003). Investigators found that employment was a reason for women not to become involved in parent care (Dautzenberg et al., 2000). A considerable amount of literature has noted the importance of family and friends in the caregiving experience; however, this theme of burden underscores the challenges that older adults may face when considering enlisting family members in their care. As older adults confront medical issues, they often have few options for receiving instrumental, emotional, or physical care. Furthermore, family members may not be aware that older adults want them to participate in making decisions for them. A study by Whitlatch and Feinberg (2003) found that 30% of caregivers were unaware that their families wanted their assistance. Families are asked to assume roles for which they are unprepared and older adults may be reluctant to place them in that position.

Although Black and White respondents discussed the theme, "They have families of their own" in a similar way, their perspectives about the meaning of caretaking and family involvement differed slightly. These slightly different perspectives could represent different cultural expectations and family roles among Blacks and Whites. The three older Black women expressing this theme asserted their role as caregivers and preferred to not include children in care. Gaugler, Kane, and Kane (2002) suggest that families have experiences providing assistance to members and develop patterns that are not easily changed. For example, family members may see themselves as primarily parents or caretakers and do not want to accept a different role. The White respondents discussing this theme mentioned that they would like to see their children more, but felt their children's other responsibilities took precedence. Older

adults have reported that they expect their children to visit them more often when they need care for a short-term period; however they do not want children to adjust their work and family situations to help parents (van der Pas et al., 2005). Older adults may be reluctant to include adult children in care because they viewed parenting as more difficult because of factors such as both parents working, single-parent families, teen suicide, and substance abuse (Blieszner & Mancini, 1987).

I cannot do the things I used to do suggests that older respondents felt guilty about the limitations caused by their illness. Often older adults were unable to care for themselves or participate in family activities because of limited physical functioning. The older adults did not want their children to provide assistance or be restricted by illness. The respondents who expressed this theme of burden had low physical functioning and received extensive care from family members. Respondents discussing this theme and respondents discussing the theme, "They have families of their own" had similar physical functioning scores; however, the average number of hours of help from family members differed. Older adults expressing the "I cannot do the things I used to do" theme received on average 10.8 hours per week, whereas the respondents expressing the theme "They have families of their own" received on average 4.8 hours per week. The guilt expressed by respondents in the "I cannot do the things I used to do" theme may stem from the amount of assistance they need, whereas the comments of respondents in the theme, "They have families of their own" may represent a coping mechanism for lack of assistance. The respondents expressing the theme "They have families of their own" might need more help, but their families are unavailable to provide it.

Equity theory posits that individuals seek to maintain symmetry in interpersonal relations; unequal exchanges, such as receiving help with activities of daily living may cause distress (Fisher, Nadler, & DePaulo, 1983). Researchers have found the inability to reciprocate when receiving assistance predicted depression in older adults (Davey & Eggebeen, 1998; Wolff & Agree, 2004). In a study of filial responsibility, Blieszner and Mancini (1987) found that parents hope that they will never need to ask their children for long-term assistance, and if they become debilitated they hope to find affordable, suitable care. Furthermore, older adults who are able to give support to family members had better mental health outcomes (Davey & Eggebeen, 1998; Liang, Krause, & Bennett, 2001; Newsom & Schulz, 1998; Pruchno, Burant, & Peters, 1997; Wolff & Agree, 2004).

Black respondents seemed to frame their feelings of guilt in the context of losing independence and their own ability to contribute to their social networks. These respondents struggled to continue to care for themselves even with great difficulty. In contrast, White respondents seemed to discuss feelings of guilt in relation to burdening families. In a study by Aberg, Sidenvall, Hepworth, O'reilly, and Lithell (2004), informal caregivers recognized that older adults tried to avoid becoming a burden to caregivers in an attempt to remain independent, but did not examine ethnic differences. Blacks may not have expressed guilt in terms of burdening family because providing support is viewed as part of the normative experience (Lawton et al., 1992). Blacks also generally score lower than Whites on measures indicating psychological distress while taking care of an elderly person (Dilworth-Anderson et al., 2002; Haley et al., 2004). Considering the White older adults were all married, the couples may feel more responsibility to take care of each other, regardless of their level of physical functioning. This notion is consistent with studies that have shown that in White families, the role of caregiving is generally assumed by the spouse, and the spouse is the first choice in terms of caregiving selection (Haley et al., 2004; Lawton et al., 1992). Awareness of ethnic differences is important for understanding how divergent points of view can lead to family disappointment and conflict.

They get a little overly worried was mentioned by older adults who thought that giving adult children information about their health would cause unnecessary worry. These older adults felt

they were still capable of taking care of themselves and did not need assistance or input from their children. The respondents expressing this theme had the highest physical functioning among the three groups and received the least amount of help during the week from family members. Studies have shown that care receivers are dissatisfied with a dependent role and with overly protective and patronizing communication (Edwards & Noller, 1998; Pruchno, Burant, & Peters, 1997). A study by Franks, Pierce, and Dwyer (2003) found that adult children have expectations for what their level of involvement would be prior to the parent's need for assistance. Adult children report feeling responsible for the needs of aging parents and hold higher expectations for themselves than their parents do (Blieszner & Hamon, 1992; Hamon & Blieszner, 1990). The adult children of older respondents who expressed this theme of burden may have expectations for their roles in their parents' care, which are not shared by their parents. The decision of these respondents to withhold information to avoid worrying their children, underscores the need for better communication of the expectations for care within families. Adult children must acknowledge that aging parents, especially those with higher physical functioning, deserve to have their preferences concerning health and housing respected.

The differences between the responses of White and Black respondents expressing this theme of burden echo the disparity seen in the "I cannot do the things I used to do" theme. Again, the Black respondents expressing this theme seemed to assert a preference to remain independent and not be parented by their children. The White respondents mentioning this theme were all married and seemed to feel as though they still can take care of themselves. As the Black respondents in our study indicated, some older adults may prefer to remain in their own homes (McAuley & Blieszner, 1985). Moving older adults out of their homes in an effort to address a physical, cognitive, or emotional problem may result in stress in the new environment, create unnecessary dependencies, and take away control and choices for older adults. Personal control is an important psychological component of well-being, and loss of such control is related to poorer health, psychological distress, and even higher mortality in older adults (Zarit & Zarit, 1998).

It is impossible to determine with our current data whether these findings reflect differences in culture, age, or cohort. However, burden is expressed in different ways and meanings that sometimes correspond to the experiences of particular ethnic groups. The findings highlight a number of areas that need to be addressed by practitioners, policymakers, and researchers in order to promote the health and well-being of older adults. In this sample of older respondents, role-definitions and attitudes about care appeared to vary by ethnicity. The Black older adults seemed to value independence, retaining their role as caregiver, and having a sense of control in their lives. The Black respondents often needed care, based on their physical functioning scores, but their remarks seemed to indicate an unwillingness to receive care from a family member. The White older adults seemed to not want family to be inconvenienced or limited by their illness. The White respondents appeared to express preference for emotional support rather than physical assistance from family.

Our findings suggest that nurses and other health care providers need to explore how older adults conceive burden and how the role concerns about being a burden play in family involvement in care, and the physical and mental health of older adults. Older adults may experience guilt related to their concerns about being a burden on family members. Depending on family members for care may also result in feelings of inequality or loss of independence. As a result, nurses providing care for these older adults should assess for feelings of burden. Treatment decisions should only be made when nurses and practitioners understand older adults' expectations for care in the context of their social and cultural beliefs. Policymakers and researchers should consider the expectations and needs of both care-givers and care recipients. By understanding differences in the views of older adults regarding accepting care

from family members, we can modify social and family interventions to be more acceptable to older patients and their families and therefore sustainable. Nursing interventions also need to assess the availability of formal care. As noted by the older adults in this study, younger generations may not have the time to be involved in care. Additionally, family involvement in care may lead to feelings of inequality in relationships or unnecessary loss of independence. Genuine partnerships among caregivers and care receivers will only be possible when all voices are heard. Further research from the perspective of older adults can complement the extensive caregiving literature and can help inform policy.

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Table 1

Characteristics of Older Adults According to Mention of Burden in Semistructured Interviews ($n = 50$). Data from the Spectrum Study (2001-2005). Percents are column percents.

	Burden ($n = 23$)	No Burden ($n = 27$)	Total Sample ($n = 50$)
Sociodemographic characteristics			
Age, mean (<i>SD</i>)	76.70 (6.1)	78.96 (5.8)	77.92 (6.0)
Female, n (%)	13 (57)	18 (66)	31 (62)
African American, n , (%)	8 (35)	14 (52)	22 (44)
Married, n (%)	13 (57)	14 (52)	27 (54)
Lives alone, n (%)	4 (17)	5 (19)	9 (18)
Family member was an adult child, n (%)	12 (52)	17 (63)	29 (58)
Hours helping older respondent in a week, 12-months mean (<i>SD</i>)	5.09 (8.6)	13.30 (40.0)	9.25 (30.0)
Functional status			
Physical function score, mean (<i>SD</i>)	47.83 (31.5)	46.59 (26.7)	47.16 (28.7)
Role physical score, mean (<i>SD</i>)	41.30 (38.9)	40.74 (38.7)	41.00 (38.4)