

Marquette University

e-Publications@Marquette

Nursing Faculty Research and Publications/College of Nursing

This paper is NOT THE PUBLISHED VERSION; but the author's final, peer-reviewed manuscript. The published version may be accessed by following the link in the citation below.

Journal of Holistic Nursing, Vol. 32, No. 2 (2014): 127-135. [DOI](#). This article is © SAGE Publications and permission has been granted for this version to appear in [e-Publications@Marquette](#). SAGE Publications does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from SAGE Publications.

Strategies for Sustaining Self Used by Family Caregivers for Older Adults With Dementia

Margaret J. Bull

College of Nursing, Marquette University, Milwaukee, WI

Abstract

The negative health consequences of caring for an older adult family member with dementia are well documented. However, not all family caregivers experience these negative health consequences. The purposes of this study were to describe strategies family caregivers use to help them continue to provide care for an older family member with dementia despite challenges and describe these family caregivers' resilience and psychological distress. A mixed methods design was used with a narrative approach dominant and standardized scales for resilience and psychological distress used to enhance the description of the sample. Data were collected through telephone interviews with 18 family caregivers residing in an urban area. The findings indicate that family caregivers used four strategies to sustain the self: drawing on past life experiences, nourishing the self, relying on spirituality, and seeking information about dementia. Understanding strategies used by family caregivers to sustain themselves is essential for providing holistic nursing care and developing effective interventions.

Keywords: caregivers, dementia, older adults, group/population, mixed methods

Approximately 35.6 million people in the world have dementia, and this number is expected to increase to 65.7 million by 2030. Dementia is a major cause of disability and functional decline in older adults ([World Health Organization, 2012](#)). Family members provide care for more than 75% of these older adults ([Alzheimer's Association, 2010](#)). The negative health consequences of caring for an older family member with dementia, particularly the effect on mental health, are well documented ([Clark & Diamond, 2010](#); [Ornstein & Gaugler, 2012](#); [Schoenmakers, Buntinx, & Delepeieire, 2010](#)). However, these negative health consequences are not experienced by all family caregivers.

Purpose

The purposes of this study were to (a) describe strategies that family caregivers use to continue in their caregiving role despite the challenges encountered in caring for an older family member with dementia and (b) describe these family caregivers' resilience and psychological distress. Understanding strategies that family caregivers find helpful and that might protect them from negative health consequences can aid nurses in providing holistic care and developing interventions that support family caregivers in their caregiving role. An awareness of these family caregivers' resilience and psychological distress enhance the understanding of the caregiving context.

Literature Review

The findings of previous studies indicate that family caregivers for older adults with dementia spend more time providing care and experience more depression than those caring for older adults without cognitive impairments ([Chappell & Dujela, 2008](#); [Ornstein & Gaugler, 2012](#); [Schoenmakers et al., 2010](#)). It is estimated that these family caregivers provide an average of 21.9 hours of care per week ([Alzheimer's Association, 2010](#)). Psychological distress, specifically depression, is one of the most common negative health consequences found across studies of family caregivers ([Clark & Diamond, 2010](#); [Clay, Roth, Wadley, & Haley, 2008](#); [Schoenmakers et al., 2010](#)). Family members caring for older adults with dementia reported depressive symptoms more often than those caring for cognitively intact older adults and more often than noncaregivers ([Clark & Diamond, 2010](#); [MacNeil et al., 2010](#); [Schulz & Sherwood, 2008](#); [Schoenmakers et al., 2010](#)). Anxiety and anger also have a negative impact on health; however, these health consequences have received less attention in studies of family caregivers ([Garcia-Alberca, Lara, & Berthier, 2011](#); [Lewis et al., 2009](#); [MacNeil et al., 2010](#)). However, not all family caregivers become depressed, angry, or anxious.

Factors such as resilience, coping, social support, and a strong sense of spirituality have been posited as protective factors that mediate negative health outcomes ([Garrity, 2006](#); [Hodge & Sun, 2012](#); [Li, Cooper, Bradley, Shulman, & Livingston, 2012](#); [Roscoe, Corsentino, Watkins, McCall, & Sanchez-Ramos, 2009](#); [Wilks & Coom, 2008](#)). Resilience is a dynamic process that fluctuates across time and situations and enables individuals to adjust or cope successfully despite stress or adversity ([Tusaie & Dyer, 2004](#); [Wilks & Coom, 2008](#)). Previous studies of family caregivers have given little attention to resilience ([O'Rourke et al., 2010](#)). Only one study, to date, examined resilience in family caregivers for older adults with Alzheimer's disease ([O'Rourke et al., 2010](#)). The findings of this study indicated that family caregivers who had higher scores on resilience reported fewer depressive symptoms ([O'Rourke et al., 2010](#)). Resilience also was associated with positive psychological well-being for family members of adults with mental illness; family members who scored higher on resilience not only reported better psychological well-being but were also less hostile toward the person with mental illness ([Zauszniewski, Bekhet, & Suresky, 2010](#)). Similarly coping, those actions that family caregivers engage in to deal with stressful situations, has been associated with fewer depressive symptoms ([Li et al., 2012](#)). The results of a systematic review of 35 studies found that family caregivers who use more acceptance-based coping and have more emotional support were less likely to experience negative health consequences of anxiety and depression ([Li et al., 2012](#)). The findings of previous quantitative studies also suggest that social support and a strong sense

of spirituality protect family caregivers against negative health consequences ([Garrity, 2006](#); [Lewis et al., 2009](#); [Wilks & Coom, 2008](#); [Yeh & Bull, 2009](#)). Social support and a strong sense of spirituality were associated with family caregiver sense of well-being ([Hodge & Sun, 2012](#); [Kim, Reed, Hayward, Kang, & Koenig, 2011](#)). However, the findings from these quantitative studies do not provide an understanding of the actions family caregivers for older adults with dementia engage in that enable them to provide care despite challenges encountered. Understanding those actions that family caregivers take and the context of their caregiving situation might help nurses identify family caregivers who might be at risk for negative consequences and design interventions that help sustain them in their caregiving role.

Method

A descriptive, mixed methods design was used with a narrative approach dominant and standardized scales for depression and resilience used concurrently to enhance the description of the sample ([Polit & Beck, 2012](#)). Data were collected through telephone interviews with 18 family members providing care for older adults with dementia. A narrative approach was used to allow family caregivers to tell their story; stories that are shaped by their values and experiences ([Riessman, 2008](#)). In telling their stories, family caregivers make meaning of the experience for themselves and for the researcher ([Riessman, 2008](#)). The narrative approach also was consistent with the researcher's perspective that family caregivers are holistic beings (bio-psycho-social-spiritual) and the design provided them with an opportunity to share a comprehensive portrait of their experience with providing care for a loved one with dementia. The narrative approach encourages reflection, and as [Johns \(2012\)](#) noted, reflection contributes to holistic engagement and this holistic approach is consistent with narrative methods.

Digitally recorded telephone interviews were chosen to accommodate needs of family caregivers. The telephone interviews provided an opportunity to include family caregivers who were reluctant to be away from the older adult with dementia, those who did not want to upset the older adult with dementia by introducing a stranger into their home, and those who did not want to use their limited respite time to meet the researcher at a different location. Telephone interviews were also convenient for family caregivers who were advanced in age and sometimes needed to reschedule the interview because of changes in their own health or changing needs of the older adult with dementia. A limitation of using telephone interviews was that it was not possible to observe facial expressions of participants or their physical appearance.

All the family caregivers described the current context of caregiving, their relationship with the older adult, and the older adult's current level of functioning. Family caregivers noted that in the early years of caregiving they experienced more frustration than in more recent years. Family caregivers were asked to talk about their experience with providing care for the older adult family member with dementia and to describe what helped them continue in the caregiving role. Family caregivers were asked to describe their experiences and specifically three open-ended questions were asked of each family caregiver: (a) What helps you in caring for your family member? (b) What helps you continue helping, despite the challenges or problems that you encounter? (c) Is there anything that we have not talked about that you consider important. Interviews lasted 50 to 90 minutes. Given the volume of literature on prevalence of depression in family caregivers for older adults with dementia, descriptive data on psychological distress (depression, anxiety, anger, and somatic illness) and resilience were collected following the narrative interview to enhance the description of the sample.

Sample and Setting

Five adult day centers (ADCs) located in a Midwestern city in the United States were selected as sites for identifying family caregivers who met the study criteria. The ADC administrators recommended using telephone interviews with the family caregivers based on their knowledge of their clients' situations. ADCs located in different geographic areas of the city were selected to recruit participants of varied ethnic and socioeconomic background. Two of the ADCs had a religious affiliation; all were nonprofit. ADC administrators were asked to

identify family caregivers who met the following criteria: (a) 18 years of age or older, (b) able to speak and understand English, (c) identified by the older adult attending the ADC as a primary caregiver, and (d) having access to a telephone. None of the family caregivers were excluded for lack of telephone access; four Spanish speaking individuals were excluded because of limited English comprehension. Eighteen family caregivers who met these criteria were recruited for the study.

Procedures

Ethical approvals were obtained from the university's and from the participating adult day center's institutional review boards for the Protection of Human Subjects in Research before initiating recruitment of participants. The ADC administrators informed family caregivers that the investigator was conducting a study about family caregiving and obtained the family caregivers' permission to give the investigator their name and telephone number. After this permission was obtained, the investigator telephoned the potential participants to introduce the study. Potential participants were informed that they were not required to participate in the study, that they could stop the study at any time, and that their decision whether or not to take part in the study would not influence their older adult family members' day care services. Participants were assured that the information they shared would remain confidential and that individuals would not be identified by name or have identifying information appear in any reports. Consent forms, which requested permission to audio record the telephone interviews, were mailed to the family caregivers interested in participating in the study and arrangements made for the interview. After the interview was completed, participants received a \$10 gift certificate for a grocery store in appreciation for their time.

Structured Instruments

Resilience was measured using the 25-item resilience scale developed by [Wagnild and Young \(1990\)](#). Items are scored on a Likert-type scale ranging from 1 to 7 (*disagree* to *agree*). Reliability coefficients of .91 and .94 have been reported ([Wagnild, 2003](#)). Examples of items are the following: "I usually take things in stride," "I usually manage one way or another," and "I feel I can handle many things at a time." It required 5 to 10 minutes to complete.

Symptom Distress Questionnaire, developed by [Kellner \(1987\)](#), was used to measure psychological distress. The Symptom Distress Questionnaire consists of 92 yes/no items that describe feelings (e.g., anxious, tired, sad) that can be summed for a total score or summed for each of the four subscales (anxiety, depression, anger, and somatic ills). Reports on its reliability and validity are extensive and it has been used to discriminate between persons who are clinically depressed and those who are not depressed. Test-retest reliability has been reported as .71 for anxiety, .95 for depression, .77 for somatic ills, and .82 for anger. Cronbach's alphas with samples of family caregivers have ranged from .86 to .92 ([Bull, Maruyama, & Luo, 1995](#); [Yeh & Bull, 2009](#)). It required approximately 10 minutes to complete.

Demographic information included age, race, religion, and education. In addition, information was obtained from family caregivers on the length of time they had been in the caregiving role, length of the time older adult could be left alone, whether family caregivers were employed outside the home, and the frequency of the older adult attending the ADC.

Data Analysis

The audio-recorded narrative data were transcribed verbatim and transcripts checked for accuracy by the investigator. Data were entered in N-Vivo software. Data were coded independently by the investigator and a graduate research assistant for the types of activities that enabled the family caregivers to continue caregiving and for contextual information about the caregiving situation. Initially substantive categories were developed that used the words of the participants. These substantive categories were then collapsed to form four broader

conceptual categories. The investigator and research assistant each noted the defining characteristics for the category labels and met to discuss them. Agreement was arrived at by reviewing the transcripts and words of the participant to assure that the categories reflected the participant's meaning and the defining characteristics of the category. For instance, the category "cognitive breakthrough" was used to describe family caregivers' descriptions of brief periods when the care recipient was alert, oriented to the people around them, and aware of the environment. The principal investigator and research assistant also examined the data for both positive and negative perspectives on the caregiving experience and to assure attention to understanding the holistic dimensions (biological, psychosocial, and spiritual) of the family caregivers' stories in an effort to assure further rigor in the analyses. Evidence of repetitive themes in the stories (data saturation) contributed further to rigor in the data analysis. Descriptive statistics were used to identify family caregivers' level of psychological distress and resilience.

Rigor

In summary, rigor was maintained in several ways. First, audio recording the telephone interviews and checking transcriptions assured accuracy. Second, the use of intercoder checks between the principal investigator and research assistant led to development of a codebook that listed defining characteristics for each category. Third, triangulation of investigators provided rigor in the analysis. Fourth, data saturation or evidence of repetitive story themes suggested that the narrative data provided a comprehensive picture of the caregiving experience and self-sustaining strategies used by family caregivers (Polit & Beck, 2012).

Results

The 18 family caregivers ranged in age from 37 to 86 years, with an average age of 64 years ($SD = 14.1$). The education level of the family caregivers ranged from 9th grade through completion of graduate school with a mean of 13.5 years ($SD = 2.6$). About 39% of the family caregivers were caring for spouses; the others were children of the older adult. Monthly income ranged from less than \$1,000 per month to more than \$5,000 per month. Most of the family caregivers were female (67%); 60% were White and 40% were African American. The majority (89%) identified themselves as Christian. Family caregivers had been providing care for the older adult with dementia for an average of 10 years ($SD = 7.3$). Many of the older adults were no longer able to express their needs verbally and most required assistance with bathing and dressing. Nearly 65% of the family caregivers stated they could not leave the older adult alone at any time. Approximately 71% of the older adults were attending an ADC 5 days per week.

In examining the narrative data, it is important to keep in mind that the majority (approximately 94%) of these family caregivers scored high on resilience and that their mean scores on the measure of psychological distress were within the normal range. This was surprising considering the amount of care family caregivers were providing. The mean scores on the subscales for anxiety, depression, anger/hostility, and somatic illness were all within the normal range. Examination of the frequency distribution indicated that all of the family caregivers scored in the normal range on anxiety and anger/hostility; only one family caregiver scored in the moderate range on depression. As noted in [Table 1](#), the average resilience score for these family caregivers was 154.29 ($SD = 15.76$). This score falls in the high range according to the norms established by [Wagnild and Young \(1990\)](#). Only one family caregiver, with a score of 119, fell in the low range on the resilience scale; this same family caregiver scored in the moderate range on depression.

Table 1. Family Caregiver Scores on Resilience and Psychological Distress (N = 18).

Scales	Mean	SD	Range
Resilience	154.29	15.76	119-172
Psychological Distress	14.94	6.55	4-25
Anxiety	2.76	1.56	0-5
Depression	2.47	1.87	0-7
Anger/Hostility	3.53	2.27	1-8
Somatic	6.06	3.21	2-12

Table 1. Family Caregiver Scores on Resilience and Psychological Distress (N = 18).

The narrative data suggest that these family caregivers had found strategies to sustain the self and cope effectively with the challenges of providing care for the older adult with dementia. Family caregivers described four types of self-sustaining strategies that helped them continue in their caregiving role: drawing on past life experiences, nourishing the self, relying on spirituality, and seeking information about the older adult’s dementia.

Drawing on past life experiences referred to the reflective practice of recognizing how earlier life experiences prepared them for the caregiving role. It included previous experiences caring for other family members, experience with problem-solving, and with knowing the older adult with dementia. The latter was particularly important when the older adult with dementia was no longer able to verbally express needs and wants as the family caregivers’ experience in knowing the older adult provided a basis for their caregiving actions. Family caregivers described this as “using their intuition” to decide what the older adult wanted or needed. Other family caregivers described how experiences with problem solving earlier in their life, either in previous caregiving or in life experiences, made caring for the older adult with dementia easier. The following spousal caregiver’s comment illustrates use of problem-solving:

My wife went through a stage where I would go into her bedroom in the morning and find she had taken off her pajama bottoms and Depends and things would be in a mess. Then I thought of putting suspenders on the pajama bottoms and I put a T-shirt over the suspenders. That solved the problem. She can’t remove the suspenders and her pajamas are intact in the morning. Taking time to figure out how to deal with problems helps a lot. . . . My military experience helped me become a problem solver.

This husband described his long-standing, loving relationship with his wife from the time of their courtship through more than 60 years of marriage. He could not imagine life without her and spent time each week reflecting on ways in which he could make her comfortable and make his caregiving easier.

A daughter indicated that caring for older adult family members was part of her family culture from the time she was a child. She stated, “Seeing my parents care for their parents. This is a part of my culture; it’s a part of me.” This daughter expected to be caring for her mother because it was part of her family culture and this perspective helped her to deal with the challenges of caregiving. Caregiving occurred within a family structure that included supportive siblings.

Nourishing the self referred to practices the family caregiver used to restore their energy. It included physical activities such as golfing or taking a walk, engaging in hobbies or leisure activities such as playing cards or listening to music, and reminiscing about good times. One husband stated that although his wife could not

remember his name, she liked to cuddle next to him on the sofa and listen to their favorite songs. A daughter caregiver reported experiencing joy in her mother's moments of cognitive clarity or "breakthroughs." This daughter described how her mother's moments of cognitive clarity affected her by stating, "If mother has a good day, I feel rejuvenated." This daughter caregiver further clarified that on good days her mother recognized the daughter and was lucid in conversing. These exchanges made the daughter feel good about keeping her mother at home. If the mother was in a nursing home the daughter felt she would have missed the moments of cognitive clarity. For spousal caregivers reminiscing and listening to music were often activities that they did with the older adult with dementia. These shared experiences restored their energy as they felt there were still some pleasant activities that could be shared with the older adult with dementia.

Other family caregivers described hobbies such as raising lilies, taking a vacation (sometimes with the older adult), and conversations with other people as activities that reenergized them. The following husband's comment illustrates this view: "Doing something for someone else gives me a positive outlook. We have an older adult neighbor and I pick her up and take her to church. We have a nice conversation on the way to and from church." This caregiver further noted that this was an uplifting experience because the neighbor provided conversation now that his wife was unable to hold a conversation.

Relying on spirituality referred to religious and spiritual beliefs and practices. Faith was viewed as a source of strength. Spirituality also included existential dimensions such as finding meaning in life and in caregiving. In fact, caregiving itself was viewed as an activity that gave meaning and purpose to life, particularly for family caregivers who had provided care over the years for various family members. The following caregiver statement illustrates this perspective: "God has brought me through this for a reason." Other family caregivers noted the importance of both private and intercessory prayer. Prayer was used by both spousal caregivers and children caring for parents. The following comments illustrate this strategy: "Prayer helps. I can't tell you how much it helps to know I am supported in prayer. I have been a member of a prayer group for more than 30 years and know that the group supports me in prayer." Another family caregiver stated, "I put my hand in the hand of Jesus and keep going. I listen to a religious station on TV and it helps me a lot."

Seeking information referred to active efforts to learn about Alzheimer's disease, find out what to expect as the disease progressed, and locate resources to provide assistance. Family caregivers noted that these types of information helped because they were able to anticipate progression of the disease and plan for ways of dealing with it. The following daughter's comment illustrates this type of strategy: "When mother was diagnosed with Alzheimer's disease four years ago, I started reading up on it. It helped to find out about the disease, what to expect, and how to deal with it." Family caregivers noted that the ADC was a source of information as some held support groups and ADC staff provided suggestions on how to cope with specific challenges in caring for an older adult with dementia. In addition to the information that the ADC staff provided, family caregivers noted that it was important to have someone to talk to about decisions that had to be made related to the older adult's care, to have someone that they could trust for advice, and to have someone to listen to their concerns. A daughter caregiver described how her own daughter would come to visit and that they would discuss the information about dementia and "grandma's needs and what to do about her care." The importance of having another person to talk to about care decisions became increasingly important as the older adult's dementia progressed.

In summary, previous life experiences in dealing with difficult situations, engaging in activities that nourished the self, seeking information about what to expect as the dementia progressed, and relying on spirituality enabled these family caregivers to continue caregiving and thrive despite challenging caregiving situations. The data suggest that these self-sustaining strategies might explain the family caregivers' high scores on resilience and low levels of psychological distress, particularly the lack of depression.

Discussion

The family caregivers in this study might be viewed as role models of resilience since the majority scored high on resilience and low on psychological distress. The fact that these family members had been providing care to the older adult with dementia for an average of 10 years further attests to their resilience and ability to thrive despite adversity. All the family caregivers in this study were receiving support from the ADC and had some respite from caregiving when the older adult attended the ADC. The use of the ADC allowed family caregivers to have some time for self, to go to work without worrying about the older adult, to participate in social activities, and to take care of household tasks and errands. Use of these supportive services coupled with the family caregivers' resourcefulness in developing strategies that helped them continue in the caregiving role might have contributed to the low scores on psychological distress.

All the family caregivers reported using strategies to nourish the self and seek information. In nourishing the self, most of the family caregivers engaged in activities with other people to renew their spirit and their energy. For some, especially spouse caregivers, strategies to nourish the self included engaging in activities with the older adult who had dementia. The stories of adult children providing care tended to reflect nourishing the self in activities with other family members or friends. These family caregivers engaged in self-reflection and evidenced self-awareness about their feelings about providing care and recognized the importance of taking time for themselves. All the family caregivers actively sought information about dementia, specifically Alzheimer's disease, and available resources. Knowing what to expect as the Alzheimer's disease progressed and learning about resources that were available helped family caregivers prepare for future needs.

The narrative data suggest that faith and belief in God were important dimensions in the lives of more than half of these family caregivers. Relying on spiritual practices helped them continue in their caregiving role. Family caregivers described diverse spiritual activities contributing to well-being. Spending time in individual prayer, attending Bible study, knowing that members of their church were praying for them, and listening to religious programs on television helped family caregivers to cope with the challenges of caregiving. Listening to religious programs on television was described as helpful to family caregivers who were unable to leave the older adult alone to attend activities at their church. This finding concurs with those from quantitative studies ([Kim et al., 2011](#); [Yeh & Bull, 2009](#)) that noted that religious practices helped family members cope with the demands of caregiving.

The majority of these family caregivers' stories reflected long-standing, loving relationships with the older adult who had dementia. Spouse caregivers in particular noted that they could not imagine life without their partner and described years of doing activities as couple. Although respite care was offered for the spouse to "get away" these family caregivers said they would not enjoy being away from their spouse and preferred to focus on what they could still do together. In contrast, the story of one son who scored low on resilience and moderate on depression indicated that he felt obligated to care for his mother. Although he engaged in strategies to nourish the self and sought information about Alzheimer's disease, he did not report using spiritual resources or relying on past experiences. He also described a limited support network.

The use of these self-sustaining strategies might explain the high scores on resilience and low levels of psychological distress in this sample of family caregivers. It was clear from their stories that the demands of caregiving were extensive given the progression of dementia in their loved ones. Yet despite the demands, these family caregivers continued to provide care for the older adult with dementia in their home. In fact, these family caregivers expressed a preference for keeping their loved one at home rather than placing them in a nursing home.

The findings of this study also have implications for practice. It is important for nurses providing holistic care to remember to focus on the interrelationship of physical, psychological, social, and spiritual health in conducting

an assessment ([Potter & Frisch, 2013](#)). In addition to asking about current health status, nurses might want to ask family caregivers what sorts of things or activities are life giving or help to sustain or nurture them. For some, it might be gardening or having time alone to meditate; for others it might be spending meaningful time with the older adult with dementia; still others might thrive on having time with other family members or friends. For family caregivers who might not find anything in their present life nurturing, nurses might want to explore what sorts of things helped sustain them during other difficult times. By encouraging family caregivers to reflect on past experience and identify life giving activities, the nurse helps family caregivers to draw on their own strengths and thus incorporates the holistic caring process in the nursing assessment and therapeutic interventions ([Anselmo, 2013](#); [Potter & Frisch, 2013](#)). Assessing the family caregiver's strengths by identifying things they do to maintain their health and well-being might necessitate a shift from a problem focused approach that is often taken to a strengths-based holistic nursing assessment ([Potter & Frisch, 2013](#)). It is also important for nurses to assess the extent to which family caregivers are comfortable taking time to nourish the self because some family caregivers might need encouragement to take time for self. For some family caregivers, this might mean making time to use relaxation therapies at home ([Anselmo, 2013](#)), for others it might mean going out to lunch with friends. Family caregivers might also need assistance in locating resources that would allow them to take time to nourish the self. Knowing the self-sustaining strategies that helped family caregivers deal with the challenges of caring for an older adult with dementia also might help nurses develop effective interventions for other family caregivers.

Strengths and Limitations

Triangulation of the qualitative narrative approach with the use of quantitative standardized scales was a strength in this study. The quantitative data on resilience and the low level of psychological distress enhanced the description of the sample. This detailed description of the sample enabled greater depth in the narrative analysis in that the researcher could examine negative cases (those situations that were different from the overall homogenous findings) such as the son who scored low on resilience. These negative cases can provide direction for future quantitative research with larger samples.

This study also had limitations. Although the sample size was adequate for a qualitative narrative approach, it was insufficient to conduct statistical analysis on the correlations between resilience and psychological distress. In addition, it is important to note that this sample was limited to family caregivers who lived in a large metropolitan area in which adult day services were available for older adults with dementia. Family caregivers residing in rural areas might not have the same resources available. Also family caregivers who were resilient might have been more willing to participate in the study and share their stories. This might partially account for the relatively homogeneous findings.

Implications for Future Research

Future quantitative studies with larger samples are needed to examine associations between resilience and psychological distress and compare resilience in urban and rural dwelling family caregivers. In addition, studies that describe strategies used by family caregivers who reside in rural areas to sustain themselves in the caregiving role would provide vital information for nurses who work with those populations.

Future research also might explore whether incorporating holistic care practices, such as encouraging family caregivers to reflect on life giving activities, influences family caregivers' psychological distress and satisfaction with nursing care. Longitudinal studies are also needed to test an intervention based on self-sustaining strategies for family caregivers of older adults newly diagnosed with dementia. The latter approach would be particularly appropriate for a community nursing focus on prevention. Knowledge on the effectiveness of self-sustaining strategies in reducing psychological distress is particularly important for nurses who embrace holistic nursing practice with the goal of promoting health and healing.

Author's Note:

Appreciation is extended to Heather Feltzer, master's student, who assisted with coding narrative data.

References

Alzheimer's Association . (2010). Alzheimer's disease facts and figures. Chicago, IL: Author.
Anselmo, J. (2103). Relaxation. In Dossey, B. M., Keegan, L. (Eds.), <i>Holistic nursing practice: A handbook for practice</i> (pp. 327-361). Burlington, MA: Jones & Bartlett.
Bull, M. J., Maruyama, G., Luo, D. (1995). Testing a model of posthospital transition of family caregivers for older adults. <i>Nursing Research</i> , 44, 132-138.
Chappell, N., Dujela, C. (2008). Caregiving: Predicting at risk states. <i>Canadian Journal on Aging</i> , 27, 169-179.
Clark, M. C., Diamond, P. M. (2010). Depression in family caregivers of older adults: A theoretical model of caregiver burden, sociotropy, and autonomy. <i>Research in Nursing and Health</i> , 33(1), 20-34.
Clay, O., Roth, D. L., Wadley, V., Haley, W. (2008). Changes in social support and their impact on psychosocial outcomes over a 5-year period for African-American and White dementia caregivers. <i>International Journal of Geriatric Psychiatry</i> , 23, 857-862.
Garcia-Alberca, J. M., Lara, J., Berthier, M. (2011). Anxiety and depression in caregivers are associated with patient and caregiver characteristics in Alzheimer's disease. <i>International Journal of Psychiatry in Medicine</i> , 41(1), 57-69.
Garrity, J. (2006). Caring for a family member with Alzheimer's disease. <i>Journal of Gerontological Nursing</i> , 32, 39-48.
Hodge, D., Sun, F. (2012). Positive feelings of caregiving among Latino Alzheimer's family caregivers: Understanding the role of spirituality. <i>Aging and Mental Health</i> , 16, 689-698.
Johns, C. (2012). How holistic are we: The role of narrative, storytelling and reflection in the development of holistic practice. <i>European Journal of Cancer Care</i> , 21, 561-564.
Kellner, R. (1987). A symptom questionnaire. <i>Journal of Clinical Psychiatry</i> , 48, 268-274.
Kim, S., Reed, P. G., Hayward, R. D., Kang, Y., Koenig, H. G. (2011). Spirituality and psychological well-being: Testing a theory of family interdependence among family caregivers and their elders. <i>Research in Nursing & Health</i> , 34, 103-115.
Lewis, S., Miner-Williams, D., Novian, A., Escamilla, M., Blackwell, P., Kretzschmar, J., . . . Bonner, P. (2009). A stress-busting program for family caregivers. <i>Rehabilitation Nursing</i> , 34, 151-159.
Li, R., Cooper, C., Bradley, J., Shulman, A., Livingston, G. (2012). Coping strategies and psychological morbidity in family careers of people with dementia: A systematic review and meta-analysis. <i>Journal of Affective Disorders</i> , 139(1), 1-11.
MacNeil, G., Kosberg, J., Durkin, D. W., Dooley, W. K., DeCoster, J., Williamson, G. (2010). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. <i>Gerontologist</i> , 50(1), 76-86.
Ornstein, K., Gaugler, J. E. (2012). The problem with "problem behaviors" a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. <i>International Psychogeriatrics</i> , 24, 1536-1552.
O'Rourke, N., Kupferschmidt, A. L., Claxton, A., Smith, J., Chappell, N., Beattie, B. L. (2010). Psychological resilience predicts depressive symptoms among spouses of persons with Alzheimer's disease over time. <i>Aging and Mental Health</i> , 14, 984-993.
Polit, D., Beck, C. (2012). <i>Nursing research</i> . Philadelphia, PA: Lippincott Williams & Wilkin.

Potter, P. J., Frisch, N. C. (2013). The holistic caring process. In Dossey, B. M., Keegan, L. (Eds.), <i>Holistic nursing practice: A handbook for practice</i> (pp. 145-160). Burlington, MA: Jones & Bartlett.
Riessman, C. (2008). <i>Narrative methods for the human sciences</i> . Thousand Oaks, CA: Sage.
Roscoe, L. A., Corsentino, E., Watkins, S., McCall, M., Sanchez-Ramos, J. (2009). Well-being of family caregivers of persons with late-stage Huntington's disease: Lessons in stress and coping. <i>Health Communications</i> , 24, 239-248.
Schoenmakers, B., Buntinx, F., Delepeire, J. (2010). Factors determining the impact of caregiving on caregivers of older adult patients with dementia. A systematic literature review. <i>Maturitas</i> , 66, 191-200.
Schulz, R., Sherwood, P. (2008). Physical and mental health effects of family caregiving. <i>American Journal of Nursing</i> , 108(9), 23-27.
Tusaie, K., Dyer, J. (2004). Resilience: A historical review of the construct. <i>Holistic Nursing Practice</i> , 18(1), 3-8.
Wagnild, G. (2003). Resilience and successful aging. <i>Journal of Gerontological Nursing</i> , 29(12), 42-48.
Wagnild, G., Young, H. M. (1990). Resilience among older women. <i>IMAGE: Journal of Nursing Scholarship</i> , 22, 252-255.
Wilks, S., Croom, B. (2008). Perceived stress and resilience in AD caregivers. <i>Aging and Mental Health</i> , 12, 357-365.
World Health Organization . (2012). <i>Dementia: A public health priority</i> . Geneva, Switzerland: Author.
Yeh, P. M., Bull, M. J. (2009). Influences of spiritual well-being and coping on mental health of family caregivers for older adults. <i>Research in Gerontological Nursing</i> , 2, 173-181.
Zauszniewski, J., Bekhet, A., Suresky, M. J. (2010). Resilience in family members of persons with serious mental illness. <i>Nursing Clinics of North America</i> , 45, 613-626.