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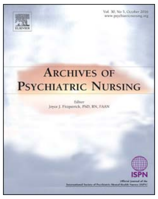

Resilience from the Perspectives of Caregivers of Persons with Dementia☆

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INTRODUCTION

The incidence and prevalence of dementia are on the rise. More than 5 million Americans are presently afflicted with Alzheimer's disease (Alzheimer's Association, 2016).

Adults with dementia often rely on caregivers to assist them with daily functions; most of them are unpaid family members such as spouses or adult children. In 2015, it was estimated that 18.1 billion h of unpaid care had been provided by > 15 million caregivers (Alzheimer's Association, 2016). Early studies of the experiences of family caregivers of persons with dementia focused primarily on the negative aspects of caregiving (Chenoweth & Spencer, 1986; Loos & Bowd, 1997; Parsons, 1997). Caregivers described confusion and uncertainty prior to and after their loved ones were diagnosed with dementia, resulting in a sense of loss, fear, anger, and disbelief (Chenoweth & Spencer, 1986; Parsons, 1997). They also identified a sense of isolation or loss created by advancing dementia and having to give up social interactions, jobs, and leisure activities for caregiving (Chenoweth & Spencer, 1986; Loos & Bowd, 1997; Parsons, 1997). Despite advances in the care of persons with dementia, these negative aspects of caregiving remain common themes in studies of the experiences of people caring for those with dementia (Adams, 2006; Butcher, Holkup, & Buckwalter, 2001; Chan et al., 2010; Hayes, Boylstein, & Zimmerman, 2009; Navab, Negarandeh, & Peyrovi, 2012; Persson & Zingmark, 2006; Sanders, Ott, Kelber, & Noonan, 2008; Siriopoulos, Brown, & Wright, 1999).

Another negative theme in studies of the experience of caregivers is caregiving burden (Adams, 2006; Butcher et al., 2001; Chan et al., 2010; Conde-Sala, Garre-Olmo, Turró-Garriga, ta-Franch, & López-Pousa, 2010; Loos & Bowd, 1997; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Parsons, 1997; Sanders et al., 2008; Siriopoulos et al., 1999). A related negative theme is the need for caregivers to adjust their roles and their expectations of their loved one and what they are able to do for the loved one (Chan et al., 2010; Persson & Zingmark, 2006; Sanders & Power, 2009).

Yet despite these negative themes, the experience of caring for a loved one with dementia is not entirely negative. There are many positive experiences from caregiving, such as a closer relationship with the care recipient (Duggleby, Williams, Wright, & Bollinger, 2009; Navab et al., 2012; Netto, Jenny, & Philip, 2009; Shim, Barroso, & Davis, 2012). One study found that 78% (n = 80) of the caregivers interviewed identified positive aspects of caregiving such as finding meaning and joy in the experience (Butcher et al., 2001). Another study found that caregivers who reported more positive aspects of caregiving tended to demonstrate greater empathy and compassion than those who reported largely negative or apathetic views of caregiving (Shim et al., 2012). The experience of caring for a loved one is broad and dynamic; thus it is not entirely negative or entirely positive (Butcher et al., 2001; Duggleby et al., 2009; Gates, 2000; Netto et al., 2009; Shim et al., 2012).

Although previous qualitative studies addressed the experience of caregiving, they did not directly identify the components of resilience theory from dementia caregivers' perspectives as proposed in this study.

RESILIENCE THEORY AS A THEORETICAL FRAMEWORK

The current study used resilience theory as a guiding framework. This theory proposes that resilience manifests the interplay between risk factors and protective factors in the face of hardship (Luthar, Cicchetti, & Becker, 2000). According to the resilience theory, an adverse event disrupts the homeostasis and thus balancing risk and protective factors determines the resulting adaptation, which can have a positive or a negative outcome (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski, & O'Flaherty, 2013; Richardson, 2002; Rutter, 1985). Resilience occurs when homeostasis is restored after adversity which includes new insight and growth from a disruptive experience (Richardson, 2002). Risk factors predispose persons to stress and can result in physical and psychological health problems if not well managed (Bekhet, Johnson, & Zauszniewski, 2012; Greene, Galambos, & Lee, 2003; Smith-Osborne, 2007). Protective factors are elements that modify an individual's risk in an adverse situation by eliminating or reducing the effects of these risk factors (Rutter, 1985). Protective factors can reduce the impacts of risk factors, minimize its influence, and lead to positive physical and psychological health outcomes (Bekhet, Johnson, and Zauszniewski, 2012; Bekhet, Zauszniewski, and Matel-Anderson, 2012; Greene, 2008; Rutter, 1987;

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Zauszniewski, Bekhet, & Suresky, 2010). Protective factors are individualized and contextual. Thereby, it is difficult to generalize that protective factors are causal or predictive in their nature as they are individualized to person and situation (Rutter, 1987). Even though these protective factors may operate differently and benefit individuals to different degrees, the literature indicates that there are common protective factors for caregivers of persons with dementia. Some of these protective factors include spirituality (Deist & Greeff, 2015), positive outlook (Deist & Greeff, 2015; Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016), and resourcefulness (Petriwskyj et al., 2016; Zauszniewski, Lekhak, Burant, Variath, & Morris, 2016; Zauszniewski, Lekhak, Napoleon, & Morris, 2016).

More recently, there has been an increased interest in resilience in adults and families (McCubbin & McCubbin, 1996; Smith-Osborne, 2007). Given the fact that caregivers of persons with dementia are struggling over many losses and facing much adversity, it became apparent that it is necessary to look at the interplay between risk factors and protective factors and how protective factors can offset the impacts of risk factors by mitigating its effects. Richardson defined resilience as “the process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors” (Richardson, 2002; p. 308). Definitions of resilience in caregivers vary, but the common theme for resilience is to overcome adverse situations to not only endure the day-to-day burden associated with caring for a family member of a person with dementia, but to prosper; that is, to grow into a stronger, more flexible, and healthier person (Gillespie, Chaboyer, & Wallis, 2007). If we are able to identify even one common protective factor for caregivers; we can build our intervention around this factor to help them to thrive.

The purpose of this descriptive qualitative study is to identify components of resilience theory; namely risk factors, protective factors, and overlapping factors from the perspectives of caregivers of persons with dementia. Identification of these factors can help health care providers to tailor their interventions to target specific areas so that risk factors can be reduced and protective factors can be enhanced. This, in turn, will help caregivers to maintain their well-being so that they can continue providing quality care to their care recipients.

METHOD

The qualitative data for this analysis were collected as a part of a larger study of 80 caregivers of persons with dementia (Bekhet, 2013). The parent study looked at whether positive cognitions mediated and/or moderated the relationship between dementia caregiver burden and their level of resourcefulness (Bekhet, 2013). Qualitative data in the current study answered two research questions: “What is it like to be a caregiver of a person with dementia?” and “Is there anything else that you want us to know?”

Eighty caregivers of persons with dementia completed the two open-ended questions. The two questions were part of larger written questionnaires. In the parent study, IRB approval was obtained and the administrators at the Alzheimer's Association early stage programs in Southeastern Wisconsin helped to distribute recruitment flyers. Caregivers who were interested contacted the research assistant and caregivers completed the consent form at an agreed upon date and time. Then, questionnaires were distributed to caregivers and the research assistant double checked completion of each questionnaire in order to minimize missing data. Caregivers were given a $15 gift card to thank them for their time and participation (Bekhet, 2013).

The two authors used content analysis to study the categories across dementia caregivers. Forming categories is the crucial feature of qualitative content analysis. A category is.

a group of content that shares a commonality (Bekhet & Matel-Anderson, 2016; Graneheim & Lundman, 2004; Krippendorff, 2013). Content analysis consists of the process of reading the transcripts repeatedly to get a sense of the whole, coding the data, and identifying the categories in each caregiver's response and then re-reading the responses to come up with similar categories across caregivers (Bekhet & Matel-Anderson, 2016; Graneheim & Lundman, 2004).

The credibility of the data was achieved through independent coding by the two authors until consensus was reached (Glaser, 1992; Struebert & Carpenter, 1999). Credibility and truthfulness of the data were also enhanced by the use of quotations reflecting caregivers' experiences; caregivers who have had the experiences immediately recognized them from the descriptions (Guba & Lincoln, 1989). Also, the study findings are meaningful in contexts outside the current study situation; thus, “fittingness,” was achieved. Saturation was also achieved as there was redundancy and as no new themes arising from the caregivers' experiences (Guba & Lincoln, 1989).

RESULTS

The mean age of the 80 caregivers was 57 years (SD = 15.6). The great majority were female (90%; *n* = 72). Fifty-six percent were Caucasian, 35% were African American, and the remaining caregivers represented other races/ethnicities. More than half of the caregivers were married (55%). Three distinct categories were identified; risk factors, protective factors and overlapping factors. Risk factors included: stressful and difficult, demanding, frustration, lack of social support, draining/exhaustion, and negative feelings (sadness, anger). Protective factors included “rewarding and serving a purpose”. Overlapping factors reflected the caregivers' descriptions of both risk and protective factors. The section below provides examples for each of the three categories.

CATEGORY 1: RISK FACTORS

Six subcategories were identified as risk factors for caregivers of persons with dementia (Table 1). The first subcategory that emerged from the data as a risk factor was “stressful.” Many caregivers expressed the feeling that caring for a person with dementia can be stressful. One caregiver said, “I am sure the normal caregiver would say *‘stressful’* and I can honestly say it is *well beyond stressful*. It is all time consuming, seems fruitless and unyielding in the fact that the patient understands and knowledge is gone and the normal response is not there.” Another two caregivers stated: “I find it very *stressful* and I am more tired than I used to be,” and “Dad will get up in the middle of the night repeatedly and that interferes with me and my husband's sleep-which is *stressful.*”

The second subcategory that emerged from the data was “difficult and challenging”. A caregiver described the experience as “*Difficult* and challenging…. *Difficult* to see them going down and can't stop it.” Yet, another caregiver described their experience as follows: “Being caregiver for a parent is a role reversal that is *difficult* for both of us to accept. It's hard to go back to taking care of a “child-like” person again when my children are grown.” Other caregivers described the experience thus: “It is *difficult* to adjust to the changes in her personality and abilities” and “The *hardest part* is having sleep interrupted at night when he needs to go to the bathroom or has wet clothes that need changing.”

The third subcategory was “demanding.” Caregivers' description captured their feelings of the experience as “Very *demanding*,” “*Demanding*, and can get to be pressure if not operating with a plan,” and “For me …the hardest thing when my dad is with us is the stress of *multiple demands*.”

The fourth subcategory to emerge was “frustration.” Many caregivers expressed frustration at being a caregiver of a person with dementia. One caregiver described her experience as follows: “*Frustrating*!! ‘I’ need to toughen up and not let hurtful comments bother me. My mom accuses me of stealing her money and jewelry-tells untrue stories about me-why?-Do I let this ‘get’ to me!?! I know better-…” Another caregiver described her caregiving experience as follow “…