

2-1-2018

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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 and Spencer, 1986](#), [Loos and 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 and 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 and Spencer, 1986](#), [Loos and 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 et al., 2001](#), [Chan et al., 2010](#), [Hayes et al., 2009](#), [Navab et al., 2012](#), [Persson and Zingmark, 2006](#), [Sanders et al., 2008](#), [Siriopoulos et al., 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 et al., 2010](#), [Loos and Bowd, 1997](#), [Papastavrou et al., 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 and Zingmark, 2006](#), [Sanders and 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 et al., 2009](#), [Navab et al., 2012](#), [Netto et al., 2009](#), [Shim et al., 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 et al., 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 et al., 2012](#), [Greene et al., 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 et al., 2012](#), [Bekhet et al., 2012](#), [Greene, 2008](#), [Rutter, 1987](#), [Zauszniewski et al., 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 and Greeff, 2015](#), [Petriwskyj et al., 2016](#)), and resourcefulness ([Petriwskyj et al., 2016](#), [Zauszniewski et al., 2016](#), [Zauszniewski et al., 2016](#)).

More recently, there has been an increased interest in resilience in adults and families ([McCubbin and 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 and Matel-Anderson, 2016](#), [Graneheim and 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 and Matel-Anderson, 2016](#), [Graneheim and Lundman, 2004](#)).

The credibility of the data was achieved through independent coding by the two authors until consensus was reached ([Glaser, 1992](#), [Struebert and 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*."

Table 1. Summary of categories expressed by caregivers of persons with dementia.

Category	Subcategory	Quotes
<b>1. Risk factors</b>	a. Stressful	"I am sure the normal caregiver would say ' <i>stressful</i> ' and I can honestly say it is <i>well beyond stressful</i> . 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"
		"I find it very <i>stressful</i> and I am more tired than I used to be"
		"Dad will get up in the middle of the night repeatedly and that interferes with me and my husband's sleep-which is <i>stressful</i> "
	b. Difficult and challenging	" <i>Difficult</i> and challenging.... <i>Difficult</i> to see them going down and can't stop it"
		"Being caregiver for a parent is a role reversal that is <i>difficult</i> 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"
		"It is <i>difficult</i> to adjust to the changes in her personality and abilities"
	c. Demanding	"The <i>hardest part</i> is having sleep interrupted at night when he needs to go to the bathroom or has wet clothes that need changing"
		" <i>Very demanding</i> "
		" <i>Demanding</i> , and can get to be pressure if not operating with a plan"
	d. Frustration	"For me ...the hardest thing when my dad is with us is the stress of <i>multiple demands</i> "
		" <i>Frustrating!!</i> '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"
		"... The anger, denial and lack of rational thinking is (are) <i>frustrating</i> "
	e. Lack of social support	" <i>I need help</i> (time) from all three sons. But only one son helps with details. One lives 90 miles away and one lives in Pasadena, CA. Neither of them are helpful"
		"My sister <i>doesn't help</i> or understand what mom is going through"
		"Hard to get other family members <i>involved</i> "

Category	Subcategory	Quotes
		<p>"I'm <i>Tense</i> (and) <i>stressed</i> and <i>nervous</i> all the time...<i>worried</i> that something may go wrong"</p> <p>"<i>Draining, confusing, sad...scary</i>"</p> <p>"<i>Restrictive, anxious, sad, angry... terribly angry</i> at the world"</p> <p>"I also find it <i>very sad</i> to see someone mentally deteriorate, that was so active"</p> <p>"One <i>grieves</i> constantly for the losses that occur in functioning in the 'patient.' It is <i>very sad</i>"</p> <p>"<i>Sad</i> to be losing the grandfather I have so many amazing memories of.... I <i>fear</i> he will not know me soon"</p>
	f. Negative feelings	<p>"It makes me <i>very sad</i> to see my 82 year old mom suffering"</p> <p>"It is also <i>sad</i>, obviously, to feel a parent to your parent"</p> <p>"I am <i>angry</i> that my sister doesn't help or understand what mom is going through"</p> <p>"It is also hard to feel <i>angry/irritated</i> a lot; which I think is also kind of unavoidable"</p> <p>"Sometimes I <i>feel guilty</i> about not doing enough"</p> <p>"I am dealing with <i>extreme guilt</i>"</p> <p>"I sometimes feel like <i>I am not doing my best</i> and want to quit"</p>
2. Protective factors	Rewarding	<p>"It is very rewarding"</p> <p>"It is rewarding and I feel like I'm serving a purpose"</p> <p>"Difficult but rewarding"</p>
3. Overlapping factors	Challenging (frustrating) and rewarding	<p>"Tiring and busy... but rewarding"</p> <p>"Hard... yet rewarding"</p> <p>"It's very rewarding, sometimes it's hard"</p>

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 “... The anger, denial and lack of rational thinking is (are) *frustrating*.”

The fifth subcategory to emerge from the data was “lack of social support”. Some of these caregivers expressed a need for help from their family members. One caregiver said, “*I need help* (time) from all three sons. But only one son helps with details. One lives 90 miles away and one lives in Pasadena, CA. Neither of them are helpful.” Another caregiver said, “My sister *doesn't help* or understand what mom is going through.” A third caregiver mentioned that “Hard to get other family members *involved*.”

The sixth subcategory to emerge from the data was “negative feelings.” Many caregivers expressed strong negative emotions related to caregiving. One described her caregiving experience as “I'm *Tense* (and) *stressed* and *nervous* all the time...*worried* that something may go wrong.” Another described the caregiving experience as “*Draining, confusing, sad...scary*.” Yet a third caregiver pointed out that she felt “*Restrictive, anxious, sad, angry... terribly angry* at the world.”

Sadness and anger were the most negative emotions expressed by caregivers. Examples included: “I also find it *very sad* to see someone mentally deteriorate, that was so active” and “One *grieves* constantly for the losses that occur in functioning in the ‘patient.’ It is *very sad*.” Another caregiver expressed her sadness and fear about the future as follows: “*Sad* to be losing the grandfather I have so many amazing memories of... I *fear* he will not know me soon.” Two other caregivers expressed their sadness as “It makes me *very sad* to see my 82 year old mom suffering,” and “It is also *sad*, obviously, to feel a parent to your parent.”

Anger was also expressed by caregivers. Some pointed out that their anger was related to the fact that they needed more support from their family members. One caregiver said, “I am *angry* that my sister doesn't help or understand what mom is going through.” Another caregiver expressed her feelings thus: “It is also hard to feel *angry/irritated* a lot; which I think is also kind of unavoidable.”

Guilty feelings were expressed by only a few caregivers. Three said that “Sometimes I *feel guilty* about not doing enough,” “I am dealing with *extreme guilt*,” and “I sometimes feel like *I am not doing my best* and want to quit.”

## PROTECTIVE FACTORS

The only protective factor that emerged from the data was “rewarding” ([Table 1](#)). When caregivers were asked about their experiences of being a caregiver for a person with dementia, a few stated that the caregiving experience was rewarding and served a purpose in their lives. For examples, they said, “It is very rewarding” and “It is rewarding and I feel like I'm serving a purpose.”

## OVERLAPPING FACTORS

The following examples show an “overlap” risk and protective factors ([Table 1](#)). When caregivers were asked about their experiences, four addressed caregiving as both stressful and difficult (a risk factor) and rewarding (a protective factor), as follows: “Difficult but rewarding,” “Tiring and busy... but rewarding,” “Hard... yet rewarding,” and “It's very rewarding, sometimes it's hard.”

## DISCUSSION

This study is the first to investigate the risk and [protective factors](#) of being a caregiver of a person with dementia using a resilience framework. Consistent with resilience theory, the findings suggest that the experience of dementia caregivers involves risk factors, protective factors, and a combination of the two. Risk factors can lead to physical and psychological health problems if not well managed, but protective factors can minimize the impact of these risk factors, and enhance health outcomes ([Bekhet et al., 2012](#), [Bekhet et al., 2012](#), [Greene, 2008](#), [Greene et al., 2003](#), [Smith-Osborne, 2007](#), [Zauszniewski et al., 2010](#)). Interestingly, some of these caregivers described both risk and protective factors as part of their experience caring for a person with dementia. This may reflect their feeling torn or conflicted. That is, their words may reflect a sense of tension between the risk and protective forces, uniquely describing their experience with caregiving. If protective factors are predominant, then caregivers become more resilient over time and experience positive outcomes. However, if risk factors are more apparent and are not well-managed, then caregivers can be at risk for health and psychological problems.

Understanding caregivers' risk factors is essential in planning for tailored interventions. This study showed that the risk factors experienced by dementia caregivers included stress, difficulty and challenging caregiving, demanding, frustration, lack of [social support](#), and negative feelings (mainly sadness and anger). These data suggest that there are stages that can lead finally to negative emotions. In other words, perceiving the situation as “stressful and difficult,” “demanding,” and “frustrating” with a “lack of support” from family and friends can lead to “draining/exhaustion” and can generate “negative feelings.” Indeed, previous research has shown that family caregivers who appraise their situation as threatening are at greater risk for health and psychological problems ([Fortune et al., 2005](#), [Zauszniewski et al., 2010](#)). Therefore, interventions should be directed toward

caregivers' perception/appraisal of their situation. Equipping caregivers with [psycho-education](#), and social support, and increasing their use of internal resources (positive thinking) and external resources (seeking help from others and from professional members), will help them to gain control over their destiny. Previous research has shown that resourcefulness training interventions helped caregivers to deal with the stress of caregiving ([Zauszniewski, Lekhak, Burant, et al., 2016](#)). [Primary prevention](#) is essential to preserve the well-being of caregiver and aimed at preventing the problems from occurrence. Therefore, reaching out caregivers whom their loved ones have been recently diagnosed with dementia and provide them with resourcefulness training interventions is essential in preventing the physical and psychological health problems. Reaching caregivers early will help preventing many health problems and save the US money associated with loss of productivity.

The study also draws attention to protective factors that may be important foci for future intervention. According to resilience theory, protective factors improve caregivers' coping and adjustment ([Bekhet et al., 2012](#), [Bekhet et al., 2012](#), [Rutter, 1987](#), [Zauszniewski et al., 2010](#)). The only protective factors in this study included "rewarding and serving a purpose." The lack of other protective factors in this analysis may be related to the non-directional interview prompt of "What is it like to be a caregiver of a person with dementia?" Wherein the only protective factors identified were those that participants directly associated with being inherent to their lived experience. Other studies of caregivers of persons with dementia within systems of care have indicated additional potential protective factors such as increased [health literacy](#) and knowledge, receipt of caregiver training, assistive technology, formal caregiver support, consistent informal caregiver assistance, and high level of external resources ([Smith-Osborne & Felderhoff, 2016](#)).

Previous research has suggested that caregivers' ability to view caregiving as rewarding and providing a sense of meaning and joy in life has been linked to caregivers' adjustment and led to more positive experiences ([Ayres, 2000a](#), [Ayres, 2000b](#), [Norman et al., 2004](#), [Shim et al., 2012](#)). Indeed, a positive appraisal of one's situation and positive cognitions have both been linked to greater resilience and better health outcomes ([Fortune et al., 2005](#), [Zauszniewski et al., 2009](#)). Therefore, interventions can be directed toward enhancing protective factors by helping caregivers to develop positive thinking. In fact, caregivers of persons with dementia might benefit from [cognitive-behavioral interventions](#) to strengthen their positive cognitions/thinking. Such interventions including relaxation techniques and distraction might help caregivers transform their negative thoughts into positive ones and helping them to interrupt pessimistic thoughts by using relaxation techniques and distraction. Other strategies might include providing caregivers with activities to practice positive thinking and helping them to break a problem into smaller chunks so they can manage it ([Bekhet & Zauszniewski, 2013](#)). Further, many caregivers are distracted by fears about the future and thus they fail to live in the present moment. Helping caregivers to plan for the future but also to live in the present is essential to adjustment.

Some caregivers in this study expressed a need for family members' support. "Support from family" can be viewed as a protective factor but only if caregivers get it. In fact, social support and psycho-education programs for caregivers and families have been found to have positive effects on resilience and health for individuals and the family unit ([Pipatananond et al., 2002](#), [Zauszniewski et al., 2010](#)). Support groups for dementia caregivers can help them to develop relationships with other caregivers

who might have positive experiences. Caregivers also need psycho-educational programs to educate them about [Alzheimer's disease](#) and related dementia, its progression, current medications and their role, and way to manage the patients' care at home ([Vellone, Sansoni, & Cohen, 2002](#)).

The majority of the themes experienced by these caregivers focused on risk factors; however, sometimes risk and protective factors occurred together. Some caregivers expressed feelings of ambivalence about the caregiving experience. Future studies should therefore examine the co-occurrence of risk and protective factors in dementia caregivers, and interventions should address the possibility that caregivers may experience both risk and protective factors associated with caregiving.

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