# RELATIONSHIPS BETWEEN RESILIENCE AND WELL-BEING IN FAMILY CAREGIVERS TO HOLOCAUST SURVIVORS

#### **Abstract**

The caregiver role can be challenging as family members address the often complex needs of aging relatives. Resilience, the process or trait related to addressing and rebounding from adversity, may play a role in determining how well family caregivers fare. In this study, the authors explored the relationships between resilience and well-being in a uniquely resilient group – family caregivers to Holocaust survivors. Surveys were completed by a convenience sample of family caregivers (N = 89) living in the United States. One-way between subjects ANOVA with Scheffé post-hoc tests were run to compare low-, moderate-, and high-resilience caregivers. Depression was significantly lower for each progressively higher resilience group. Physical well-being was significantly lower in the low-resilience group. Caregiver burden was not significantly different between groups. Resilience may have a prophylactic role in preserving physical and emotional well-being in family caregivers; however, resilience and burden may have a more nuanced relationship. Burden may have been underreported due to (a) comparisons with the stress experienced by the Holocaust survivors and/or (b) a heightened sense of filial piety. Health care practitioners should be aware of the complex role that resilience can potentially play both in protecting well-being and in masking burden in family caregivers.

Key words: caregiving; resilience; well-being; burden; depression; Holocaust

Family caregivers play an integral role in the care of older adults and provide a wide range of services, from assistance with activities of daily living to providing full physical and psychosocial care. These services do not come without a cost, however. Family caregivers have been found to experience a number of problematic outcomes due to the stress associated with caregiving. This stress can negatively affect caregivers' physical, social, and emotional well-being (Aneshensel et al. 1995; Pearlin, Mullan, Semple, Skaff 1990; Pinquart, Sorensen 2003; Son et al. 2007; Vitaliano, Zhang, Scanlon 2003). Caregivers often rely upon their coping skills, adaptive behaviors, and inner strength to address these stressors, typically referred to as "caregiver resilience." While research has begun to find positive associations between caregiver resilience and health outcomes (Harmell, Chattillion, Roepke, Mausbach 2011), questions remain as to whether resilience moderates caregiver burden or if the relationship is more complex (Gaugler,

Kane, Newcomer 2007; Scott 2013). There is also little understanding of the relationship between perceived resilience and the reluctance to seek assistance with caregiving duties. In the present study, the researchers focused on a uniquely resilient group, family caregivers to Holocaust survivors, to examine relationships between resilience and well-being. The findings shed light on the complex and nuanced role of resilience in the face of caregiving demands.

Resilience has been defined both as an adaptive, dynamic process and as an individual characteristic or trait. Viewed as a process, resilience can be operationalized as "being mindful of and prioritizing those behaviors, thoughts, and feelings that facilitate contentment with a specific developmental, physical, emotional, and spiritual context" (Allen et al. 2011: 2). This process is a cyclical interplay of personal characteristics, environmental resources, daily stressors, and adverse events that result in competencies that are applied and ever adapted to future challenging situations. Applying this process view to caregiving, the evolving demands of caring for an older adult require caregivers to both draw upon and to develop resilience in a dynamic fashion, particularly in the face of progressive conditions (e.g., Alzheimer's disease). Others have defined resilience as a trait of "personality characteristic that moderates the negative effects of stress and promotes adaptation" (Wagnild, Young 1993: 165). In this view, resilience has been conceptualized as consisting of five cores: meaning and purpose in life; perseverance; self-reliance; equanimity (balance in life); and coming home to yourself (existential aloneness; Wagnild 2010). Applying this trait view of resilience to caregiving, these characteristics may protect caregivers, allow them to remain emotionally and spiritually grounded, and persevere in the face of challenges.

Reflective of the strengths perspective, resilience in caregivers to older adults has been the focus of a growing body of research over the past few decades. Several approaches have been taken by researchers to evaluate resilience in caregivers. Rather than using a resilience scale, some researchers used an inferred approach where resilience was viewed as stress resistance through a combination of problem-solving abilities, social support, and spirituality. Several studies have examined caregiver resilience using established resilience scales and subscales capturing elements of resilience, such as personal mastery and self-efficacy. Other researchers have conceptualized caregiver resilience as the presence of low subjective burden in the face of high care demands. Some have viewed resilience as having a mediating role in caregiver outcomes, while others have speculated that it played a moderating role. Finally, researchers have viewed resilience as both a predictor of caregiving outcomes (e.g., burden) and an outcome of the caregiving process.

These varied approaches have provided some clarity in terms of the impact of resilience in caregiving, but have not yielded a consensus on the role played by resilience. In terms of physical and emotional well-being, high resilience has consistently been found to be related to better outcomes for caregivers, particularly for dementia caregivers (for a review, see Harmell et al. 2011). For example, a recent longitudinal study of caregivers to spouses with dementia found that a positive relationship between resilience and depression (O'Rourke et al., 2010). Another study linked low levels of resilience in

spousal caregivers with higher levels of stress and higher production of antigens related to cardiovascular disease (Mausbach et al. 2007). The relationship between caregiver resilience is less clear. A recent systematic review found that ineffective coping behaviors, such as avoidance coping, were related to higher levels of caregiver burden and, therefore, less caregiver resilience (Del-Pino-Casado et al. 2011). In looking at resilience as a moderator, Gaugler and colleagues found that high resilience was linked with less frequent nursing home placement, which is at times viewed as the end result of caregiver burden and burnout (Gaugler, Kane, Newcomer 2007). On the other hand, a recent study of family caregivers did not find this moderating effect, but did find an inverse relationship between resilience and burden (Scott 2013). Synthesizing this body of research is challenging; however, one could conclude that resilience is beneficial, yet functions within a complex constellation of personal, interpersonal, and environmental factors.

In the current study, we attempt to add to and advance this body of research by examining a unique group – family caregivers to Holocaust survivors. The characteristics and experiences of this group tends to differ from the general body of caregivers in several ways. First, caregiving for survivors of early life trauma can present extraordinary challenges. Compared with the general population of older adults, aging Holocaust survivors have been found to have higher levels of mental health issues, diminished physical health, and lower functional status (Stessman et al. 2008; Trappler, Cohen, Tulloo 2007). These factors can translate into higher care demands and greater burden for family members. Memories of the Holocaust may complicate caregiving interactions with survivors, as well. For example, survivors may react negatively to assistance with activities of daily living, such as bathing and dressing, or being left alone or being in the dark. Other more invasive activities, such as medical exams or procedures, may trigger even stronger reactions and present even greater challenges for family caregivers (David, Pelly 2003).

Holocaust survivors have also been found to be incredibly resilient and there is some evidence that this strength can be transmitted to family members and inherited by subsequent generations (Braga, Mello, Fiks 2012; Shmotkin, Shrira, Goldberg, Palgi 2011; Greene 2010; Shrira, Palgi, Ben-Ezra, Shmotkin, 2011). Such resilience may serve as a protective factor as family members of survivors assume caregiving roles. On the other hand, there is emerging evidence that resilience, combined with high levels of filial piety (as is typical in caregiving for Holocaust survivors, see Kellerman 2008), may be linked with a reluctance to seek assistance. A recent qualitative study of family caregivers to Holocaust survivors found this to be the case and the results suggest that being "too strong to ask for help" may be a problematic byproduct of high perceived resilience (Anderson, Fields, Dobb 2013). In the current study, the researchers examine quantitative data from the same study to see whether evidence of this paradox exists. The following hypotheses were tested:

1. Resilience in family caregivers to Holocaust survivors would have significant, positive relationships with emotional and physical well-being. This hypothesis was based upon the relatively consistent findings linking caregiver resilience with general well-being.

2. Resilience in family caregivers to Holocaust survivors would not have a significant relationship with caregiver burden. The researchers anticipate that the relationship between resilience and burden is a zero-sum proposition. Caregivers with low-resilience would be at greatest risk of burden, but would be more likely to seek assistance. Caregivers with high-resilience would be able to better cope with the stressors of caregiving, but would be resistant to seeking assistance.

#### **Methods**

# Sample

Prior to beginning data collection, the study was reviewed and approved by the university institutional review board. Family caregivers in this study were defined as family members who provide assistance with personal care, transportation, emotional and psychological support, financial management, and/or care management both in community and institutional settings (e.g., nursing homes, assisted living facilities). Targeted convenience sampling was conducted through several channels. In collaboration with Jewish Family Services providers, family caregivers to Holocaust survivors were contacted via mail and through letters, community newspapers, and postings on websites of support groups and other networks. Interested individuals then contacted the researchers directly and were, in turn, sent printed surveys to complete and return via mail. Recruitment was incentivized by providing participants the option of receiving \$20 or donating the funds to a cause of their choice.

#### Measures

In addition to basic demographic information on family caregivers and care recipients, the following data were collected:

- Resilience –The 14-item Resilience Scale (RS-14) was used to measure caregivers' self-perceived resilience. This scale has been found to have very high reliability ( $\alpha = 0.88$ ; Wagnild, Young 1993).
- Burden The 12-item Zarit Burden Interview (ZBI) Short Version was used to measure how family caregivers subjectively appraise the care demands and care challenges. This scale has been found to be highly correlated with the 22-item version of the ZBI (Zarit, Orr, Zarit 1985) and has been found to have very good reliability ( $\alpha = 0.88$ ; Bedard et al. 2001).
- **Depression** The 20-item Center for Epidemiology Studies-Depression Scale (CES-D) was used to measure the presence and frequency of depressive symptoms in caregivers. Reliability has been reported to range from moderate to very good ( $\alpha = 0.85$  to 0.90; Radloff 1977).

• Overall Well-Being – The 8-item Physical Well-Being subscale of the Perceived Well-Being Scale-Revised (PWB-R) was used to measure physical well-being. Reliability has been reported to be high for the PWB-R across age groups ( $\alpha = 0.85$ ; Reker, 1995; Reker, Wong 1984).

# **Data Analysis**

Following data collection, the data were entered into SPSS 19.0. Several quality control measures were taken prior to analyzing the data. Descriptive statistics were computed to ensure the accuracy of data entry and computation. A missing values analysis (MVA) indicated that missing values constituted less than five percent on each item in the survey and that patterns did not exist in the missing data. Missing values were subsequently imputed using maximum likelihood estimation (Tabachnick, Fidell 2012). Participants were divided into the following three groups based upon their level of resilience: "low-resilience;" "moderate-resilience;" and "high-resilience." Cut-off scores specified in the user guide for the RS-14 were used to determine these groupings (Wagnild 2009). One-way between subjects analyses of variance (ANOVA) with Scheffé post-hoc tests were then run to examine whether there were significant relationships between level of resilience and differences

# **Results**

A total of 89 family caregivers (N = 89) completed surveys. As reported in Table 1, caregivers were generally in their early 60's (M = 62.1), female (68.5%), married (78.7%), adult children (61.8%) and spouses (25.8%) of the care recipients. Participants reported to have been in the caregiving role for an average of 18.1 years. Care recipients were generally in their mid-80's (M = 84.9), female (59.6%), and either widowed (50.6%) or married (34.8%). Most care recipients lived with a spouse (29.2%), alone (28.1%), or in a long-term care setting (25.8%).

Following cut-off scoring guidelines, family caregivers were grouped as having low-resilience (n = 14), moderate-resilience (n = 46), and high-resilience (n = 26). One-way ANOVA analyses revealed that caregiver resilience was not significantly related to burden (F(2,86) = 0.72, ns). As indicated in Table 2, post-hoc comparisons revealed that there were no significant differences in mean levels of burden between the low, moderate, and high resilience groups. Caregiver resilience was significantly related to symptoms of depression (F(2,86) = 12.98, p = .000). Post-hoc comparisons indicated that mean levels of depression were significantly lower for each progressively higher resilience group. Caregiver resilience was also significantly related to physical well-being (F(2,86) = 7.05, p = .001). Post-hoc comparisons indicated that mean levels of physical well-being were significantly lower in the low-resilience group compared to the moderate- and high-resilience groups.

Table 1. Family Caregiver and Care Recipient Characteristics (N = 89)

		Mean	Range	SD	%
Family Caregivers					
Age		62.1	33-90	13.0	
Years in Caregiver Role		18.1	1-64	19.7	
Gender (Female)					68.5
Relationship to Care Recipient					
Adult Child		1.00			61.8
Spouse					25.8
Other					9.0
Marital Status					
Married/Partnered	1	CAPI			78.7
Divorced/Separated				7-1	10.1
Single				7	9.0
Widowed			,		1.1
Care Recipients					
Age		84.9	68-102	6.6	
Gender (Female)	- 64		At	4	59.6
Marital Status					
Married/Partnered					34.8
Divorced/Separated	1				7.9
Single					1.1
Widowed					50.6
Living Arrangement					
With Spouse			A		29.2
Alone					28.1
Assisted Living Facility					15.7
Nursing Home					10.1
With Adult Child					5.6
With Other Family	1				5.6

Table 2. Mean Scores of Caregiver Well-Being as a Function of Resilience Level (N = 89)

	Caregiver Resilience Groups							
	Low (n = 14)		Moderate $(n = 46)$		High (n = 29)			
Well-Being Measure	M	SD	М	SD	М	SD		
Caregiver Burden	15.2	11.3	12.8	8.1	11.8	9.0		
Depression	21.5 <sub>a</sub>	8.6	13.1 <sub>a</sub>	9.2	7.5 <sub>a</sub>	7.1		
Physical Well-Being	25.3 <sub>a,b</sub>	11.5	36.7 <sub>a</sub>	11.1	39.6 <sub>b</sub>	13.4		

Note: Means in a row sharing subscripts are significantly different at the p < .05 level. For burden and depression, higher scores denote lower well-being. For physical well-being, higher scores denote higher well-being.

### Discussion

The results from this study further illustrate the complexity of resilience in concept and in-situ, particularly in complicated caregiving situations. In this discussion, we will locate the findings in the literature, explore practical implications for social workers and other healthcare professionals, and outline the limitations of this study. As hypothesized, higher resilience was associated with higher levels of physical and emotional well-being. This is reflective of the literature on resilience in caregiving, including research on dementia caregiving (Harmell et al. 2011; Mausbach et al. 2007; O'Rourke, Beattie 2010). The link between resilience and physical well-being has also been found in family members to Holocaust survivors, most notably their adult children; however, perceived physical well-being did not equate to fewer health problems in this group. Shrira and colleagues (2011) found that children of Holocaust survivors reported higher perceived health but more physical health problems than a comparison sample of the same age. High levels of resilience may influence the way that individuals report their perceived physical health despite health problems. In terms of emotional well-being, researchers have found high levels of resilience in family members of Holocaust survivors along with specific vulnerabilities, including emotional distress and compromised psychosocial well-being (Wiseman, Barber, 2008). In the current study, caregivers with high-resilience appeared to cope with these vulnerabilities more effectively than caregivers with low-resilience. These findings are indicative of the resilience-vulnerability paradox that exists in Holocaust survivors and that can and often does get transmitted to family members and future generations (Shmotkin et al. 2011).

In the second hypothesis, the researchers postulated that caregiver resilience and burden was a zero-sum proposition. Analysis of the data revealed that there was not a significant relationship between caregiver resilience and burden in this sample. This hypothesis was largely derived from a qualitative study of 17 family caregivers drawn from the same study (Authors 2013). A key finding was that caregivers seemed to be reluctant to seek assistance. Three factors appeared to play a role in this reluctance by family caregivers: (a) a high perceived level of resilience and ability to cope with adversity, possibly inherited from the Holocaust survivors; (b) high levels of filial piety and a sense of "duty to care;" and (c) a tendency to downplay their burden in comparison with the trauma experienced by the Holocaust survivors. The findings from the present study suggest that resilience may play a more complex role for this group of caregivers. Resilience may serve in both a protective role and an inhibiting role. This raises the question of whether an "optimal" level of resilience exists where caregivers are able to cope with care demands, but also know their limits and are able to ask for help. Future research should consider this as we learn more about the complex, dynamic interplay between resilience, coping, burden, and well-being.

It is also important to recognize culture in interpreting these findings. The majority of the participants in this study were Jewish and caregiving in this community is shaped by religious doctrine, tradition, and culture. Within the Jewish community, there is

strong sense of filial piety and caring for aging family members is often viewed as an honor and an expectation (Friedman 2008). Complaining about caregiver stress and relinquishing care responsibilities to others can induce feelings of guilt (Kestenbaum 2009). These feelings may be especially strong in caregivers to Holocaust survivors. Survivors are typically revered within the Jewish community and serving and protecting this group is viewed as an honor and an obligation. These cultural characteristics add another layer of complexity to understanding the relationship between resilience, burden, and well-being. Resilience and filial piety tend to be viewed as strengths; however, there may be limits where these strengths become deficits for family caregivers. Additional research is needed to examine whether and where these tipping points exist.

## **Practical Implications**

The findings from the current study provide insight for healthcare professionals (e.g. physicians, nurses, social workers, therapists) into the complex relationship between resilience and caregiver well-being. In light of the reluctance that some highly resilient caregivers might feel toward seeking help from others, it is critical that healthcare providers have an understanding of resilience and its significance in the family caregiving of trauma survivors. Resiliency plays an important role in the well-being of family caregivers, yet as a result of high resiliency caregivers may be more vulnerable in terms of their own psychological and physical health. Caregivers may overlook the difficulties of caregiving and instead try and manage beyond their capabilities, both physically and emotionally. Denial about caregiver stress and burden may lead caregivers to overestimate their ability to handle stress and in turn may lead to a false sense of resilience.

The assessment of resilience is an important aspect of clinical practice and practitioners should consider using a reliable and valid measure such as the Resilience Scale (Wagnild, Young, 1993). However, the findings from this study suggest that the results of a resilience assessment should be interpreted with caution when working with family caregivers of Holocaust survivors. For example, characteristics measured in the Resilience Scale such as *perseverance* and *self-reliance* may on one hand point toward high resilience, yet at the same time may connote that caregivers are strong enough to cope without the help of others, even when help is truly needed. Healthcare professionals should be cognizant that high resilience may be both a strength and a limitation, especially when caregivers may be less inclined to recognize the strain of caregiving in comparison to the trauma experienced by survivors.

Health care professional who serve family member of survivors may find that the needs of caregivers are not being expressed and therefore may go unmet. As suggested by David and Pelly (2003), practitioners should consider that family caregivers of aging survivors of trauma might not share their feelings and experiences of caregiver burden and stress. Clinicians and practitioners may need to more intentionally explore

the reasons why a caregiver may not be seeking help and offer suggestions as to the benefits of services such as respite, adult day care, and other caregiver support programs. Taking a proactive and anticipatory approach to working with caregivers of Holocaust survivors may be effective for health care providers in terms of recommending additional support services for caregivers (Anderson, Fields, Dobb 2013).

Several research studies have demonstrated significant effects in reducing caregiver burden through targeted interventions that include counseling, case management and support programs via telephone (Holland, Currier, Gallagher-Thompson 2009; Schulz, Martire, Klinger 2005). The Resources for Enhancing Alzheimer's Caregiver Health (REACH) study provided caregivers with education, skills training, social support, cognitive reframing techniques, and stress management strategies to improve caregiver quality of life and to reduce caregiver depression (Belle et al. 2006). The REACH II study focused on racial and ethnic differences in caregiving through an intervention that included education on caregiver self-care and health behaviors (Elliott, Burgio, DeCoster 2010). Both the REACH and REACH II studies provide strong examples of evidence-based interventions that may be useful for healthcare providers working with family caregivers of trauma survivors.

The findings from this study may also have applications to other family caregivers impacted by past early life trauma. Researchers have found similarities with other groups of older adults who experienced genocide in early life such as survivors of the Cambodian genocide in the 1970s who faced challenges not unlike those of Holocaust survivors (Teshuva 2010). Aging combat veterans may also hold some parallels to Holocaust survivors as both groups have elevated levels of PTSD and are viewed as cultural icons or heroes (Wilmoth, London, 2011). The stress and burden of family caregivers of veterans may also be influenced by a sense of filial piety, and in turn guilt, if veterans are placed in long-term care settings such as a nursing home. It is important to note that great care and caution should be used when comparing the experiences of caregivers to Holocaust survivors with other groups such as aging combat veterans, as the Holocaust is an extreme and horrific example of early life trauma with unique historical significance. However, the findings of this study provide a starting point for better understanding the challenges related to caring for aging survivors of other early life traumas.

#### Limitations

There are several limitations to this study that should be considered in interpreting and generalizing these findings. First, this study focused on a unique caregiving dyad and the experiences of caregivers to Holocaust survivors may differ to a degree from caregivers in general. While we intentionally chose to focus on this group due to their high resilience, additional research is needed to explore whether this phenomenon exists in the general population of family caregivers. Second, the sample for this study was rela-

tively small and this prevented the use of more sophisticated statistical analyses. Larger samples and more advanced methods (e.g., structural equation modeling) are needed to disentangle the complex function of resilience. Finally, it is difficult to compare the Holocaust to other forms of trauma, particularly given the extreme nature of the Holocaust and the variability of the experiences of survivors and caregivers. Much has been learned from Holocaust survivors and their families and, unfortunately, this knowledge must be carried forth and applied to more recent and future human atrocities.

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