Caregivers’ Coping and Self-Forgiveness After the Death of a Care-Receiver

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ABSTRACT. This study explores the relationship of self-forgiveness with adaptive coping and non-adaptive coping. This study addresses self-forgiveness as part of the grieving process of Alzheimer’s disease caregivers. One hundred and thirty-three caregivers who had recently lost a loved one were surveyed. The bivariate analysis revealed a significant relationship between self-forgiveness and adaptive coping and non-adaptive coping. Furthermore, stepwise regression models computed for the study variables revealed that adaptive coping and non-adaptive coping were statistically significant in explaining the variation in self-forgiveness. Based on these findings, future directions in research are explored.

KEYWORDS. Caregivers, self-forgiveness, adaptive coping, non-adaptive coping, Alzheimer’s disease

INTRODUCTION

Coping strategies of caregivers whose family members died from complications of Alzheimer’s disease (AD) and other chronic illnesses can significantly affect the caregivers during the grief process. Many caregivers are challenged with increasing responsibility that comes about due to the dual roles of family member and caregiver (Jacinto, 2007). The increased responsibility for the caregiver in relationship to the care-receiver places stress on the caregiver’s coping resources. As it progresses, AD affects the care-receiver’s functioning on many levels. One of the most disconcerting areas is the care-receiver’s inability to recognize loved ones and to communicate with them, both of which are most prevalent in the final stages of the disease. Because it is difficult to communicate with the care-receiver, caregivers are often unable to understand the needs and desires of the care-receiver. This difficulty in communication has the potential to significantly increase the stress of caregiving and can tax the caregiver’s coping resources. The care-receiver most likely will not be able to say good-bye to the caregiver, and this lack of closure can contribute to the caregiver experiencing an increase in feelings of guilt and regret (Jacinto, 2007). An important part of the process of resolving unfinished business with the care-receiver is self-forgiveness. This article is part of a larger study that considered a number of variables related to caregiver self-forgiveness (Jacinto, 2010). The purpose of this article is to explore the effects of adaptive coping and non-adaptive coping behaviors on
caregiver self-forgiveness after the death of the care-receiver.

According to Jacinto (2007, p. 8), self-forgiveness is the result of a process in which persons work through negative feelings toward the self that result from her or his behavior. Drawing from this definition for this study, self-forgiveness is defined as a conscious choice to let go of self-blame, resentment, anger, hurt, and other negative feelings toward oneself related to events in the caretaking period related to the care-receiver (Jacinto, 2007).

DEFINITION OF VARIABLES

In reference to self-forgiveness, several variables have been shown to influence the post-death grief process related to the care-receiver (Luskin, 2002; Wuest et al., 2000). The variables, cited by Jacinto (2007), included in this study are adaptive coping and non-adaptive coping. The variables will be defined here for the purpose of this study.

Adaptive Coping

Adaptive coping is defined as caregivers’ behaviors that express the following positive emotions: seeking emotional and instrumental support, engaging in active coping behaviors, planning for the future, suppressing non-adaptive activities, maintaining optimism, accepting self and positively reframing experiences (Zuckerman & Gagne, 2003, p. 177).

Non-Adaptive Coping

Non-adaptive coping is defined as caregivers’ behaviors that express the following negative behaviors: denial, blaming others, mental and emotional disengagement, self-blame, and self-centered rumination (Zuckerman & Gagne, 2003, p. 177).

LITERATURE REVIEW

To provide a literary base for this study, scholarly work from various disciplines including social work, psychology, sociology, and religion was critically reviewed. The literature about caregivers negotiating self-forgiveness after the death of a care-receiver is limited; however, there is increasing research around the topic of forgiveness and self-forgiveness with other populations (Enright & the Human Development Study Group, 1996; Ingersoll-Dayton & Krause, 2005; Ross, Kendall, Matters, Wrobel, & Rye, 2004). A review of the self-forgiveness literature included approximately 47 peer-reviewed articles on the topic, although one (Jacinto, 2010) focused on caregivers working through self-forgiveness after the death of a care-receiver diagnosed with AD (e.g., Bauer et al., 1992; Halling, 1994; Macaskill, Maltby, & Day, 2002). Self-forgiveness is an important experience for many caregivers.

Self-Forgiveness

Although the study of forgiveness has a history dating back to the 1970s, the focus on studying self-forgiveness increased in the 1990s (Axelrod, 1980; Brown, 1968; Darby & Schlenker, 1982; Worthington, 1998; Zillman, Bryant, Cantor, & Day, 1975). Various religious teachings have focused on forgiveness throughout the years (Ali, 2000; Coates, 1996; Hallisey, 2000; Koenig 1999, 2000; Koenig et al., 1988; Kurtz & Ketchum, 1992; Narayan, 2000; Pargament et al., 2000; Williams, 2000); and the focus on the study of forgiveness by mental health professionals, a recent trend, had its origin in the 1970s (Roakeach, 1973; Shoemaker & Bolt, 1977). Self-forgiveness emerged from the forgiveness research and led to an understanding of how individuals work through their issues related to forgiving themselves (Flanagan, 1996; Luskin, 2002; Rutledge, 1997; Whol et al., 2008). According to Worthington, prior to 1985, there were five studies published that explored forgiveness: Brown, 1968; Zillman et al., 1975; Zillman and Cantor, 1976; Axelrod, 1980; and Darby and Schlenker, 1982. In 1984, Smedes wrote a book on forgiveness that captivated the general public and gained the attention of mental health professionals (Worthington). Smedes’s work explored how individuals were able to transition from unforgiving attitudes toward forgiveness of others and self-forgiveness.
Like Smedes (1984), other authors have postulated that caregivers who provide long-term care for a care-receiver may experience many events, some of which may include: losing patience with the care-receiver and saying something they regret; dropping and injuring the care-receiver when attempting to help transfer them; and failing to remember to take the care-receiver to an important medical appointment during the caregiving period.

**Coping Theory**

Coping theory has developed along two distinct pathways: *trait* and *cognitive*. The early literature focused on *trait* approaches that were based on defense processes. This pathway found its genesis in the psychoanalytic movement that posited defense mechanisms, which were the result of internal conflicts (Freud, 1966; Vaillant, 1977). The *cognitive* approach was applied to research that included mostly adults who did not have a diagnosis indicating psychopathology (Lazarus & Folkman, 1984). This pathway included the work of Lazarus and Folkman, who discussed coping as a cognitive process that involved the person’s perception of events that are negatively affecting well-being. This *cognitive* approach provides a sound theoretical model and effective techniques to work with grieving caregivers.

**Adaptive Coping**

There are several studies that have explored *adaptive coping* strategies in response to anticipatory future stressors and stress-producing situations (Aspinwall & Taylor, 1997; Schwarzer & Knoll, 2003; Willis, Blechman, & McNamara, 1996). Because of this contribution to understanding caregiver stress, these studies provide insight to practitioners who work with caregivers of long-term care-receivers. Although these studies are very helpful in understanding *adaptive coping*, missing is the relationship between *adaptive coping* and *self-forgiveness* in the caregiver grieving process.

**Non-Adaptive Coping**

Non-adaptive coping strategies of caregivers may keep them in the bereavement-grief process (McClendon, Smyth, & Neundorfer, 2004). It has been reported that non-adaptive emotion-focused coping strategies, including feelings of shame, guilt, self-blame, and self-focused rumination, impede the individual in the development of *adaptive coping* strategies (Tangney, Boone, & Dearing, 2005; Zuckerman & Gagne, 2003). Rumination and seeking an understanding about causality are among non-adaptive coping behaviors that keep individuals stuck in the grief process (Lyubomirsky & Nolen-Hoeksema, 1993). Non-adaptive coping strategies also include feelings of despair, anger, loneliness, anxiety, sadness, crying, agitation, withdrawal, anxiousness, irritability, depression, numbness, shock, dissociation, sleep disturbance, decreased appetite, immune suppression leading to illness, decreased energy, somatic complaints, and exhaustion (American Psychological Association, 2000; Rando, 2000; Rosenzweig, Prigerson, Miller, & Reynolds, 1997; Silverberg, 2007; Stroebe, Hansson, Stroebe, & Schut, 2001; Waldrop, 2001).

As a result of reviewing the current literature about caregivers after the death of care-receivers, several gaps in services emerged. Although *self-forgiveness* provides an umbrella from which to conceptualize this study, the variables including *adaptive coping* and *non-adaptive coping* are an integral part of the bereavement-grief continuum (Jacinto, 2007). While not all caregivers need to work through the *self-forgiveness* process, Rutledge’s (1997) framework supports caregivers in working through *self-forgiveness* to move beyond the caregiving role. Based on the literature review, there appears to be a relationship between *self-forgiveness* and *adaptive coping*. It appears that as *adaptive coping* increases, *self-forgiveness* would increase. The use of *self-forgiveness* at the end of the grief process was explored by Jacinto (2010). For many caregivers, an important part of resolving unfinished business via the grief process is *self-forgiveness*, which is described as “fostering compassion, generosity, and love toward oneself” (Enright & the Human Development Study Group, 1996,
p. 116). The lingering effects of unfinished business become important problems to be faced during the grief process. As a caregiver significantly experiences decreased grief symptoms, the person will then be able to enter into self-forgiveness work if there are lingering feelings of guilt, anger, depression, anxiety, and shame related to the caregiving experience.

**HYPOTHESES**

There are two hypotheses developed for this study.

**Hypothesis One**

There is a positive relationship between self-reports of caregiver adaptive coping and reported levels of caregiver self-forgiveness. The independent variable is the reported level of the caregivers’ adaptive coping, and the dependent variable is the reported level of caregivers’ self-forgiveness.

**Hypothesis Two**

There is an inverse relationship between self-reports of non-adaptive coping practices and reported levels of caregiver self-forgiveness. The independent variable is the reported level of the caregivers’ non-adaptive coping practices, and the dependent variable is the reported level of caregivers’ self-forgiveness.

**METHODOLOGY**

**Procedure**

After receiving approval for the study through the Human Subjects Review Board at the University of Central Florida, participants were recruited for the study through two hospices, one retirement community, two community centers, and two social organizations that provide services for AD care-receivers and their caregivers.

Each hospice, retirement community, and social service organization mailed out the survey packet with a cover letter from a social worker in the organization, explaining the purpose of the study and inviting caregivers to participate in the study. Participants were asked to complete the survey and return it to the researcher in a pre-stamped return envelope. Of the 426 survey packets mailed out, 133 were completed and returned. No names were gathered, and it was explained that by returning the completed survey, participants understood that this would indicate informed consent. In addition to the five survey instruments, a demographic information sheet gathered age and race.

**Measures**

**Self-Forgiveness**

Although there are several self-forgiveness instruments, results from a six-member pilot study revealed that these instruments were not appropriate for this study’s population because of their length or formatting of questions. As a result of the pilot study participants’ suggestions, the researcher developed questions specifically related to self-forgiveness focused on the needs of this population. A 10-item self-forgiveness measure using a 5-point Likert-type scale was developed by the researcher for use in this study. The author developed a brief self-forgiveness instrument. Five of the items on the scale were reverse scored. The measure includes questions about whether the caregiver is able to forgive self and the caregiver’s perception of her or his affective state after forgiving self. The following is an example of one of the items: “It is easier for me to forgive myself than to forgive others.” Because this measure was designed by the researcher, reliability information was computed. The scores ranged from 10 to 50, with higher scores indicating higher levels of self-forgiveness. The Cronbach’s alpha for this measure was .75.

**R-COPE**

Developed by Zuckerman and Gagne (2003), the Revised-COPE (R-COPE) was selected to measure adaptive coping and non-adaptive coping in this study. Zuckerman and Gagne developed the 40-item self-report instrument containing five subscales: Self-Help, Approach, Accommodation, Avoidance, and Self-Punishment. The R-COPE uses a 7-point Likert-type scale ranging from Strongly Agree to Strongly
Disagree. The three subscales Self-Help, Approach, and Accommodation address adaptive coping. The three scales were summed together to produce the Adaptive Coping scores of participants. The two subscales summed together to produce the Non-Adaptive Coping score were Avoidance and Self-Punishment. The total scores for the three adaptive coping subscales of the R-COPE ranged from 24 to 168. The following is an example of one of the items: “I work on staying positive even when things look bad.” The total scores for the two non-adaptive coping subscales of the R-COPE ranged from 16 to 112. The following is an example of one of the items: “I think about my problem constantly.” The Cronbach’s alpha scores reported by Zuckerman and Gagne and this study are reported in Table 1.

**FINDINGS**

**Participants**

The study sample consisted of 133 participants. The majority of the participants were female (75.9%), White (97.7%), and Protestant (58.6%). With regard to marital status, 56 (42.1%) reported they were widowed, 54 (40.6%) reported they were married, and 2 (1.5%) reported they were remarried. The caregiver’s relationship to the care-receiver included child (43.6%) or spouse (42.1%). The age of study participants ranged from 41 to 91 years. Participants were asked to indicate the number of people in their social support network. The list included family members, friends, pets, health care professionals, clergy persons, coworkers, and church acquaintances. The largest group of people reported by caregivers who offered social support was family (27%), followed by health care professionals and service providers (21%). Of the 133 study participants, 5 (3.8%) reported that they had no social support network, and 12 (9%) indicated that they had more than 41 people in their social support network. The range for caregivers’ social support networks was from 0 to 41 people. The length of time caregivers provided care ranged from 6 months to 21 years.

**Tests of Hypotheses**

Before each of the major hypotheses was tested for possible explanatory power using regression analysis, the relationships were examined at the bivariate level with the following results.

**Hypothesis 1**

Hypothesis 1 revealed a positive relationship between self-reports of caregiver adaptive coping incidents and reported levels of caregiver self-forgiveness. To test the hypothesis, a Pearson correlation analysis was completed. The results indicated a moderate positive correlation \( r = .536, p < .001 \) between the two variables. It appears that for this group of participants, an increase in caregiver adaptive coping is associated with increased levels of caregiver self-forgiveness, which supported Hypothesis 1 (see Table 2).

**TABLE 1. Cronbach’s Alpha for R-COPE Subscales**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Zuckerman &amp; Gagne (2003)</th>
<th>This study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sample 1</td>
<td>Sample 2</td>
</tr>
<tr>
<td>Self-Help</td>
<td>.92</td>
<td>.91</td>
</tr>
<tr>
<td>Approach</td>
<td>.87</td>
<td>.88</td>
</tr>
<tr>
<td>Accommodation</td>
<td>.82</td>
<td>.88</td>
</tr>
<tr>
<td>Avoidance</td>
<td>.74</td>
<td>.84</td>
</tr>
<tr>
<td>Self-Punishment</td>
<td>.81</td>
<td>.88</td>
</tr>
</tbody>
</table>

**TABLE 2. Pearson Correlation Analysis Between Self-Forgiveness and the Study Variables**

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-Forgiveness</td>
<td>1</td>
<td>.536**</td>
<td>-.485**</td>
</tr>
<tr>
<td>2. Adaptive Coping</td>
<td>1</td>
<td>1</td>
<td>-.404**</td>
</tr>
<tr>
<td>3. Non-Adaptive Coping</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Correlation is significant at the .01 level (two-tailed).**
Hypothesis 2

Hypothesis 2 revealed an inverse relationship between non-adaptive coping of the caregiver and caregiver self-forgiveness. The Pearson correlation analysis was completed to determine whether these variables were inversely correlated. The results from testing this hypothesis found a moderate inverse correlation ($r = -.485$, $p < .001$) between non-adaptive coping and self-forgiveness. It appears that for this group, an increase in caregiver non-adaptive coping is associated with a decrease in self-forgiveness. Hypothesis 2 is supported (see Table 2).

Bivariate and Stepwise Regression Analysis

After testing for the bivariate relationships postulated in the two hypotheses, stepwise regression analysis was computed to explore relationships and to determine which variables might be significant predictors of self-forgiveness. The reason for examining the relationships in the regression models was based on the correlational values found between adaptive coping and self-forgiveness ($r = .536$, $p < .01$) and non-adaptive coping and self-forgiveness ($r = -.485$, $p < .01$).

The proposed self-forgiveness framework that was presented in Figure 1 was supported by the stepwise regression models of this study. The original hypothesized relationships in Figure 1 postulated associations between the variables adaptive coping and non-adaptive coping and their impact upon caregiver self-forgiveness. The researcher reasoned that caregivers who engaged regularly in adaptive coping strategies were most likely able to work through issues resulting in self-forgiveness. It was postulated that when self-forgiveness increases, non-adaptive coping decreases (Jacinto, 2007; Figure 1).

Figure 2 presents the Revised Self-Forgiveness Framework. Data from the stepwise regression were used to examine relationships in the Self-Forgiveness Framework. In the Revised Self-Forgiveness Framework, the independent variables adaptive coping and non-adaptive coping were found to be significantly associated with self-forgiveness.

Stepwise regression models were computed for the variables in the study hypotheses. Self-forgiveness (dependent variable) and the independent variables from the two study hypotheses were entered into the equation (Table 3). In Model 1 when adaptive coping was entered into the model, a moderate association ($\beta = .536$, $p < .01$) was found. When non-adaptive coping was entered into the model, a low association was found ($\beta = -.321$, $p < .05$).
that people who report the use of adaptive coping strategies in dealing with the stress of caregiving would more likely report being able to forgive themselves. These findings are similar to those of Willis et al. (1996), who reported on coping strategies in response to stress-producing situations. In addition, the findings of this study are consistent with the findings of Aspinwall and Taylor (1997) and Schwarzer and Knoll (2003) who examined anticipatory coping responses to figure stressors. In this study, those who used adaptive coping strategies while caregiving appeared to have been able to work through the grief process and arrive at self-forgiveness within a normal post-death bereavement period.

The second hypothesis, which explored the effects of non-adaptive coping on self-forgiveness, was supported. Non-adaptive coping was inversely associated with self-forgiveness in the Pearson correlation analysis, and Model 4 of the stepwise analysis suggested that as non-adaptive coping increases, self-forgiveness decreases (Table 3). These findings are consistent with Tangney et al. (2005) who reported that non-adaptive coping strategies included feelings of shame and guilt. The feelings of shame and guilt complicate the self-forgiveness process. The findings of this study are also consistent with the findings of Zuckerman and Gagné (2003) who reported that emotion-focused strategies including self-blame and self-focused rumination impede individuals in the development of adaptive coping strategies. In addition, Lyubomirsky and Nolen-Hoeksema (1993) reported that for some caregivers, rumination is among non-adaptive coping behaviors that keep individuals stuck in the grief process.

**DISCUSSION**

The study found support for the two research hypotheses. The first hypothesis that examined the relationship between adaptive coping and self-forgiveness was supported. In the Pearson correlation analysis, adaptive coping had a strong association with self-forgiveness. In Model 1 of the stepwise regression analysis, with self-forgiveness the dependent variable, adaptive coping accounted for 29% of the variance in self-forgiveness (Table 3). This suggests
coping variables were supported. Therefore, these findings provide support to the assertion that the grief process, with its associated adaptive coping and non-adaptive coping behaviors, is complicated, and individuals would more readily work through self-forgiveness if they use adaptive coping strategies.

**Limitations of the Study**

The study sample consisted of a nonrandom convenience sample of caregiver participants, and the majority of respondents were predominantly European-American, Christian, and female. With regard to the demographic information, the wording of the demographic question regarding racial/ethnic group membership may have confused respondents. The study is also limited in its generalizability to other groups.

**CONCLUSION**

This study suggests that there are a number of implications with regard to how caregivers cope during the time they are caregiving. Assessing caregivers to determine how adaptive coping strategies may assist them in work on self-forgiveness is an important intervention when addressing bereavement issues. Adaptive coping and non-adaptive coping behaviors were important variables impacting self-forgiveness among caregivers in this study. Asking if the caregiver wants to work on self-forgiveness is an important part of the caregiver assessment for practitioners working with bereavement and grief. Self-forgiveness is affected by a number of variables, two of which are adaptive coping and non-adaptive coping behaviors (Jacinto, 2007). Exploring ways in which the caregiver coped with stressful situations that arise during the period of caregiving will help the practitioner understand the caregiver’s coping patterns; for instance, answering the question: “Does the caregiver engage in adaptive coping behaviors, or does the caregiver engage in non-adaptive coping behaviors?” The answer to this question can assist the practitioners in understanding the caregiver’s way of coping, and will allow for effective interventions to be developed by the practitioner. Adaptive coping is strongly associated with self-forgiveness, and working with clients to develop adaptive coping strategies will assist them in working through the post-death bereavement period. This study suggests that working with caregivers can be complicated by non-adaptive coping strategies, including shame and guilt, and other behaviors such as the ways one perceives life events. Working with caregivers to recognize their coping styles can assist them in choosing more adaptive coping behaviors such as expanding their social support network or looking at life events differently than they have in the past. Providing caregivers with choices will help them embrace adaptive coping behaviors that will move them beyond grief.

Based on the results of this study, it appears beneficial to caregivers if service providers would offer an assessment of the coping skills of caregivers. When the assessment is completed, the intervention process could focus on assisting individuals in recognizing non-adaptive coping thoughts and behaviors and in further developing adaptive coping strategies. While self-forgiveness can be understood as a coping strategy, it is also associated with the grief process. Development of efficacious adaptive coping behaviors may lead to increased self-forgiveness. Therefore, interventions that address non-adaptive coping behaviors and the development of adaptive coping behaviors to replace old ways of dealing with stress would benefit the caregiver as the person works through self-forgiveness activities. Offering support groups for caregivers allows members to share their stories about coping with circumstances they encountered with the care-receiver. Sharing stories about how the caregiver coped with stress will allow those who used adaptive coping behaviors to share with those who used non-adaptive coping behaviors. The interaction between caregivers can serve as a teachable moment where peers offer strategies about adaptive coping choices they have made and discuss the psychological and emotional resolution of stress. These shared experiences can be helpful to caregivers who are having difficulty transitioning from non-adaptive coping patterns of behavior.
Further research that addresses self-forgiveness among caregivers may include exploration of additional variables such as personality type, resilience, and religious beliefs. It would be helpful to investigate the relationships between adaptive coping and self-forgiveness, reduction of grief symptoms and adaptive coping, reduction of grief symptoms and self-forgiveness, adaptive coping and resilience, non-adaptive coping and resilience, resilience and self-forgiveness, to name a few exploratory possibilities. In addition, research that focuses on pre-death coping strategies of caregivers may provide some suggestions as to the types of services that can help caregivers prior to the death of the care-receiver.

REFERENCES


