

Facing the Losses: Gender Differences in Anticipatory Grief in Caregivers of Alzheimer's Victims

Sara Lassig

Faculty Sponsor: Elizabeth Seebach, Department of Psychology

Introduction

Alzheimer's is a disease of the brain that causes a steady decline in memory and results in dementia. This dementia, which is the loss of intellectual function, is severe enough to interfere with an individual's everyday life, and will eventually incapacitate the individual. Providing care to an individual with Alzheimer's disease or a related dementia is a difficult endeavor and carries with it many challenges for the families of the over four million individuals afflicted with Alzheimer's disease. Numerous studies have found that caregivers of individuals with Alzheimer's disease are at an increased risk for poor mental and physical health outcomes in comparison to well-matched non-caregiving controls (e.g., Anthony-Bergstone, Zarit, & Gatz, 1998; Haley, Levine, Brown, Berry, & Hughs, 1987).

Depression and Caregiving

In the past, depression has been the most frequently studied effect of caregiving for an individual with dementia. Studies have repeatedly found that when compared with non-caregiving populations normed on age or gender, caregivers have elevated depression rates (e.g., Cohen & Eisdorfer, 1998; Gallagher, Rose, Rivera, Levett, & Thompson, 1989; Pruchno & Resch, 1989). However, questions have been raised about the appropriateness of depression being used as the primary diagnosis of emotional distress found in caregivers. Schultz, Visintainer, and Williamson (1990) suggested caution after reviewing many of these findings. They noted that questions were raised as to the clinical significance of the reported psychiatric symptoms. Becker and Morissey (1998) argued that among caregivers, major depressive disorders were more likely to occur only in the smaller numbers of caregivers already predisposed to depression. Thus, although increased levels of depression have often been displayed, concern has been expressed by some researchers in regards to the distinguishing of clinical depression versus grief over the changes in the care recipient and the seemingly hopeless situation (Walker & Pomeroy, 1996).

Anticipatory Grief

The grief associated with the situation may be more specifically defined as "anticipatory grief" – a term most often used when discussing the family members of those who have a terminal illness (Rando, 1984). Anticipatory grief allows for the absorbing of the reality of the loss to occur gradually over time (Rando, 1984). The literature on anticipatory grief of caregivers of dementia-afflicted individuals is quite minimal and largely suggestive. Rando (1986) proposed that the controversies concerning the effects and existence of anticipatory grief were based upon the thought of death as a singular loss and the failure to consider the multiple losses that are grieved before death in situations such as Alzheimer's disease. Family members do not simply anticipate a loss when caring for a loved one with dementia. They

may also be grieving for the losses that have already occurred, such as dreams for the future that will never be realized, security, companionship, economic certainty, and a relationship and lifestyle that have changed dramatically (Rando, 1986).

Gender

Furthering the investigation of the presence and intensity of anticipatory grief among caregivers is the question of gender differences. Gender has been found to affect responses to caregiving, and thus, the study of gender differences in caregiving is gaining increasing recognition (Monahan & Hooker, 1995). Gender differences reveal women's more frequent, intensive, and affective involvement in the caregiving role and also the associated psychological costs (Parks & Pilisuk, 1991). Rose-Rego, Strauss, & Smyth (1998) have associated these differences with the emotional attentiveness theory. This theory implies that it is not solely the caregiving experience that accounts for differences in psychological well-being, but rather the females' recognition of the distress producing more psychological effects.

Although several studies have found higher levels of depression in female caregivers than in male caregivers, the examination of gender differences in anticipatory grief remains incomplete. Despite the fact that anticipatory grief may be particularly well suited to Alzheimer's caregivers, there are no known studies examining the gender differences in anticipatory grief in Alzheimer's caregivers. Given the many losses that occur during a dementing illness such as Alzheimer's disease, it is proposed that gender differences might best be examined in the context of husband and wife caregivers. As the dementia progresses and more physical and mental abilities are lost, the spouse would be very aware of these changes. As physical and mental functioning of the dementia-afflicted spouse occur, it would seem that a greater sense of loss would occur, and anticipation of the final loss would become greater. Similar to the findings involving depression, it is possible that these loss anticipations may also be stronger among female caregivers than male caregivers.

Understanding the presence and levels of anticipatory grief among spousal caregivers of Alzheimer's afflicted spouses has several very important implications. First, this previously under-researched area may add to the understanding of the general effects of caregiving. Additionally, the findings may be helpful in planning and implementing future clinical and social interventions for spouses serving as caregivers. Such interventions, if delivered in a timely manner, may prevent caregivers who are experiencing normal grief from developing a clinical depression. Furthermore, the findings may point to the need for differently tailored interventions for female versus male caregivers. Clinical interventions, social support groups, and educational programs could all be tailored to better suit the gender specific need.

The purpose of the present research is to test the following three hypotheses: Hypothesis 1. - Wives caring for a dementia-afflicted spouse will report higher levels of anticipatory grief than will husbands caring for a dementia afflicted spouse. Hypothesis 2. – In both husband and wife caregivers, the level of reported anticipatory grief will correlate positively with the progression of the dementia. Hypothesis 3. – Both male and female non-caregiving spouses will report lower levels of anticipatory grief than will caregiving spouses.

Method

Participants

Participants consisted of 40 spouses of individuals who have been given an Alzheimer's disease or a related dementia diagnosis. Data from five of the participants were not used because their spouses died during the time of the study. After the elimination of the data from

these participants, there were 22 female spouses and 13 male spouses in the study. Fifteen of the females were serving as the primary caregiver for their husbands, and 7 had husbands who resided in some type of care facility. Seven of the males were serving as the primary caregiver for their wives, and 6 male participants had a wife that resided in a type of care facility. Participants were from the states of Minnesota, Wisconsin, Iowa, Arizona, California, Florida, Nebraska, Michigan, North Dakota, and South Dakota. Participants ranged in age from 59 to 89 years of age. Each participant received ten dollars for participating in the research. Several of the participants chose to have this money instead donated to their area Alzheimer's Association or support group. This level of inducement is necessary, as indicated in previous similar research samples (e.g., Monahan & Hooker, 1995), because caregivers have very little free time and additional motivation is needed in order to gain enough participants.

Procedure

The researcher sent out informational packets to various Alzheimer's Associations throughout the country. Included in these packets was a letter describing the study, 25 flyers to hand out to prospective participants, and 25 self-addressed and pre-postage postcards. At the support group meetings, the Alzheimer's Association support group meeting facilitators handed out these flyers out to the group members. If the support group members met the qualifications described in the flyer (have a spouse dementia) they could then write their name and address on the postcard and send it back to the researcher. Upon receiving the postcard, the researcher then sent out a packet of information to the participant. This packet included the informed consent, the ten dollar check, the three measures to fill out, directions, postage and a sheet that explained the study and how to contact the researcher. After completing the measures, the participants then sent the materials back to the researcher in the same envelope, using the included postage.

Measures

The Grief Experience Inventory (GEI) (Sanders, Mauger, & Strong, 1985), consisting of 135 true-false items designed to assess the feelings, experiences and symptoms of individuals during the grief process, was used to measure the intensity of the anticipatory grief of the caregiver. The alpha coefficient for internal validity ranged from .52 to .84 and evidence of criterion and internal validity has been demonstrated (Sanders, Mauger, & Strong, 1985). The Grief Experience Inventory consists of twelve including anger, atypical responses, death anxiety, denial, despair, depersonalization, guilt, loss of control, rumination, social desirability, social isolation, and somatization. Examples of the questions include, "life has lost its meaning for me" and "I have dreamed of times that took place before the loss." All questions are stated in a true and false format.

The Record of Independent Living (Weintraub & Baratz, 1990) was used to measure the caregivers' interpretation of the Alzheimer's afflicted spouses' level of independence with activities of daily life. This scale is an informant completed (completed by the caregiver) measure of activities of daily living and behavior in elderly patients with cognitive impairment. The informant ranks the care recipient's levels of independence on activities such as eating, getting dressed, and using the toilet.

The participants also completed a personal data sheet that included information such as age of participant, number of years married to current spouse, whether or not they attend a support group, how many years ago the spouse was diagnosed, and age of spouse.

Control Variables

Several variables may influence the relationship between gender and grief and will be statistically controlled for. These measures include: length of time that the caregiver has been serving as primary caregiver for the care recipient, whether or not he or she attends a support group, age of caregiver, and length of marriage in years.

RESULTS

Data were analyzed on SPSS using a MANOVA design in order to detect differences in anticipatory grief between the four groups (male caregivers, male non-caregivers, female caregivers, and female non-caregivers). Gender was shown to be a main effect with females scoring significantly higher than males on their total anticipatory grief scores (see Table 1.). This value was significant with the F-value, at one degree of freedom being 5.923, $p < .025$. This result supported hypothesis number one.

Contrary to what the researcher hypothesized in hypothesis number 3, the results indicated (not at a significant level) that non-caregiving spouses scored higher on anticipatory grief than did caregiving spouses (see Table 1.).

As suggested by hypothesis number two, the results did indeed indicate a positive correlation between total anticipatory grief scores and the Record of Independent Living Scores, but this correlation of .102 was not a strong correlation.

The MANOVA of total anticipatory grief scores indicated an interaction relationship of gender (husbands versus wives) by caregiver status (caregiver versus non-caregiver), but this interaction was not statistically significant. With a larger sample, this could be shown to be a significant interaction. Caregiving wives scored the highest of the four groups.

DISCUSSION

Even with a sample size this small, it was clear that differences in levels of anticipatory grief do exist between males and females and also between caregivers and non-caregivers. Females scoring higher in measure of grief are consistent with the idea that women are more likely to share their feelings and emotions than are men. This idea of men being less open with their emotions was well exemplified by a comment made by one of the participants. He stated, "I do not show emotion but I DO feel emotion."

Contrary to the researchers hypothesis, non-caregivers scored higher in anticipatory grief than did caregivers. This could have been because non-caregivers may not see their spouses everyday and thus when they do, the gradual changes in condition may seem more abrupt. Caregivers, on the other hand, may see the decline happening slowly each day or week, and thus may not be affected in the same way by anticipate grief relating to the losses.

Certainly, the information resulting from this study could be helpful for practitioners and community support workers. These individuals could use this information to help them in providing clinical interventions, educational programs, cognitive therapy, coping strategies, and support groups that are all designed to suit gender specific and situational specific needs. For example, a support group designed specifically for caregivers may be of more help to spouses serving as caregivers than would a group with both caregiving and non-caregiving members.

Non-afflicted spouses may be able to better understand their emotions and feelings if they are made aware of the concept of anticipatory grief, and not simply diagnosed with depres-

sion right away (Walker & Pomeroy, 1996). Though anticipatory grief is a relatively new concept in the area of coping with dementia, it is certainly an emotion that calls for more research and study. Studies with larger sample sizes would certainly be able to give more accurate results, and may even be able to offer more expanded areas of study within the topic of anticipatory grief.

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Table 1. Scores on the Grief Experience Inventory

Group	n	Possible Range	Actual Range	Mean	Standard Deviation
Male	13	0-135	21-64	37.488	4.735
Female	22	0-135	32-85	52.410	3.896
Caregiver	22	0-135	21-85	43.838	3.896
Non-caregiver	13	0-135	23-83	46.060	4.735