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# Service Utilization among Bereaved Spouses and Family Caregivers

Elizabeth J. Bergman  
*University of South Florida*

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Service Utilization among Bereaved Spouses and Family Caregivers

by

Elizabeth J. Bergman

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
School of Aging Studies  
College of Arts and Sciences  
University of South Florida

Major Professor: William E. Haley, Ph.D.  
Tamara A. Baker, Ph.D.  
Yuri Jang, Ph.D.  
Victor Molinari, Ph.D.  
Brent J. Small, Ph.D.

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resources

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## Dedication

This dissertation is dedicated to the people in my life who encouraged me to follow my passion and who supported and encouraged me along the way:

To my parents, Walter and Carol Johnson, remarkable people whose values and example I will always hold up as ideals to be emulated. Thank you for giving me a solid foundation and a love of learning and for always believing in me, even when I didn't believe in myself.

To my brother, Pete Johnson, who teaches me through his example that gentle tenacity is the best way to effect change and that I can do whatever I set my mind to.

To my friends and family, for your support, mentorship, understanding, and love.

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## Service Utilization among Bereaved Spouses and Family Caregivers

Elizabeth J. Bergman

### ABSTRACT

For family caregivers, response to the death of the care recipient is marked by a high degree of variability. In recognition of this variability, a range of services and interventions is available to assist individuals in the adjustment to bereavement. The present dissertation, consisting of three related studies, was conducted to examine the utilization of bereavement services by family caregivers.

The first study examined the role of psychological distress in the utilization of bereavement services by spousal caregivers in the Changing Lives of Older Couples (CLOC) study. The second study examined bereavement service utilization among dementia caregiver participants in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. Both employed Andersen's Behavioral Model of Health Services Use. The third study examined bereavement service utilization, barriers, and preferences among bereaved spousal caregivers of patients of three hospices in Tampa Bay.

Taken together, results of the current studies point to the importance of family physicians and members of the clergy in the provision of services to bereaved family caregivers and to the prominent role of bereavement outcomes (e.g., depressive symptoms, grief) as need factors in the utilization of bereavement services.

## Chapter One: Introduction

Accompanying growth in the size of the older adult population (U.S. Census Bureau, 2005) is an increase in the number of older adults experiencing physical limitations, frailty, and chronic and terminal illness. These conditions frequently necessitate reliance upon spouses, family members, and other sources of informal care. The long duration and intense level of care frequently required has led researchers to describe caregiving as a “career” (Pearlin & Aneshensel, 1994) accompanied by transitions such as institutionalization and bereavement (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). The U.S. Administration on Aging estimates that more than 22.4 million Americans act as informal caregivers to an older or disabled person and this number is projected to rise dramatically in the coming decades (U.S. Department of Health and Human Services, 2003).

For family caregivers, response to the death of the care recipient is marked by a high degree of variability (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Bonanno et al., 2002; Bonanno, Moskowitz, Papa, & Folkman, 2005; Christakis & Iwashyna, 2003; Goodkin et al., 2001; Schulz, Mendelsohn, et al., 2003). Some respond to the transition with resilience, while for others it is a disruptive and painful life experience marked by years of intense physical, psychological, and existential suffering (Bonanno et al.). Most exhibit a bereavement response that falls somewhere between these extremes (Bonanno & Kaltman, 2001). Bereavement outcomes reported in the literature include

mental health decrements (e.g., depression, anxiety, complicated grief) (Bonanno et al.; Schulz et al., 2001), physical health decrements (Kaprio, Koskenvuo, & Rita, 1987), and heightened risk of mortality (Christakis & Iwashyna; Goldman, Korenman, & Weinstein, 1995; Goodkin et al.).

Given the stressful nature of family caregiving and bereavement, a wide array of interventions and services has been developed to assist individuals with the emotional, practical, and social adjustments that accompany the death of the care recipient. These services are provided by a range of professionals and organizations. Examples include grief therapy, cognitive behavioral therapy, support groups, pastoral counseling, widow-to-widow programs, psychoeducational programs, and pharmacotherapy.

While a detailed discussion is beyond the scope of this dissertation, recent research has produced some interesting and important results regarding the efficacy of bereavement interventions (e.g., Allumbaugh & Hoyt, 1999; Kato & Mann, 1999; Schut, Stroebe, van den Bout, & Terheggen, 2001; Schut & Stroebe, 2005). The general conclusion that can be drawn from this work is that the efficacy of bereavement interventions increases in direct proportion to the level of complication or distress in bereavement (Schut et al., 2001). However, we do not know whether the individuals most in need of intervention are receiving services in bereavement nor is there any widespread, systematic effort in place to target those in the greatest need.

Some of the most commonly identified mental health outcomes associated with bereavement and experienced at higher rates than non-bereaved controls include depression (Bodnar & Kiecolt-Glaser, 1994; McHorney & Morr, 1988; Schulz, Mendelsohn, et al., 2003; Zisook, Paulus, Shuchter, & Judd, 1997), anxiety (Beem,

Maes, Cleiren, Schut, & Garssen, 2000; Byrne & Raphael, 1997; Zisook & Shuchter, 1985), and complicated grief (Barry, Kasl, & Prigerson, 2002; Prigerson et al., 1995; Prigerson et al., 1997 ; Zhang, El-Jawahri, & Prigerson, 2006). Some researchers have found an association between elevated distress and service use. For example, Cherlin and colleagues (2007) reported that family caregivers who used bereavement services were more likely to have met criteria for Major Depressive Disorder at the time of study enrollment than were those who did not. Caserta and Lund (1992) found an association between service utilization and elevated depression in the first three months after spousal bereavement. Similarly, Levy and Derby (1992) found an association between bereavement support group use and higher levels of anxiety and depressive symptoms at 6 months after the death of a spouse. However, Prigerson and colleagues (1997) found that heightened distress in bereavement, in the form of severe depression and complicated grief, was associated with a decreased likelihood of physical and mental health service use in bereavement.

In light of these contradictory findings, there exists a need to more closely examine whether those with the greatest opportunity for benefit are indeed aware of and utilizing bereavement interventions available in the community. In learning about factors associated with the utilization of bereavement services, we can better tailor interventions and services to the needs and preferences of those experiencing or belonging to groups at high risk for distress. Further, we can work to achieve more equitable access to services for individuals and groups who are currently underserved.

One category of factors which may be associated with bereavement service utilization may be viewed collectively as resources, including social resources,

religiosity, perceived control, and participation in a caregiver intervention prior to the death of the care recipient. These resources may serve to strengthen ties to the community or formal service delivery system (McIntosh, Silver, & Wortman, 1993; Stroebe & Stroebe, 1987; Coulton & Frost, 1982; Pearlin, Menaghan, Lieberman, & Mullan, 1981), change self-perceptions of health and well-being and resulting motivation to seek care (Berkman, 1979), or improve access to resources necessary for participation (e.g., transportation) (Toseland, McCallion, Gerber, & Banks, 2002).

Sociodemographic characteristics, including age, gender, race/ethnicity, and education, may also be associated with bereavement service utilization. For example, the subset of older individuals who experience mental health decrements in response to bereavement may be less likely to utilize intervention due to an age bias in referral for psychological services (Ginsberg & Goldstein, 1974) or to stigma associated with mental health service use (Gallagher-Thompson et al., 2003). In general, it is believed that women are more likely to recognize a mental health problem (Kessler, Brown, & Broman, 1981) and utilize mental health services (Coulton & Frost, 1982), suggesting that female gender may predict bereavement service utilization.

While the role of education in predicting bereavement service utilization is not known, health and human service use research suggests that higher educational level is a predictor of service use among the elderly (Mutran & Ferraro, 1988; Snider, 1980), dementia caregivers (Toseland et al., 2002), and Black caregivers (Williams & Dilworth-Anderson, 2002). It may be the case that lower educational level diminishes the likelihood of service use through its impact on knowledge of the service delivery system

and community resources (Snider; Wallace, Levy-Storms, Kingston, & Andersen, 1998) or on socioeconomic status and income (Wallace et al., 1998).

Ethnic and racial minorities are drastically underrepresented among those seeking psychological and supportive services (American Psychological Association, 2002; Coulton & Frost, 1982; Mui & Burnette, 1994). In response to the historical pattern of denial of access to formal sources of support, many racial/ethnic minorities rely on extensive informal support networks, including extended family and church, in coping with the demands of providing care for disabled relatives (Dilworth-Anderson, Williams, & Gibson, 2002), a practice which may extend into bereavement. Research suggests that religious leaders in the Black community play an important role both in delivering and referring to services with the potential to improve the mental health and quality of life of bereaved individuals (Kart, 1991; Williams & Dilworth-Anderson, 2002).

The Andersen model of health services utilization, first proposed by Andersen (1968) and subsequently revised and expanded (Andersen & Newman, 1973; Aday & Andersen, 1974) to aid in the identification and description of determinants of health care use, is a major perspective used in health service utilization research. It has been used extensively to examine health care utilization and equity in the health care system (e.g., Andersen, Kravits, & Anderson, 1975), to make cross-national comparisons in health service utilization (Andersen, 1976), and in many studies of the use of nursing homes, in-home nursing, formal and informal helpers, social services, adult day care, and dental services by older adults (e.g., Arling, 1985; Conrad, Hughes, & Wang, 1992; Coulton & Frost, 1982; Counte & Glandon, 1991; Evashwick, Rowe, Diehr, & Branch, 1984; Eve, 1988; Freedman, 1993; Miller & McFall, 1991; Mutran & Ferraro, 1988; Rabiner, 1992;

Rosner, Namazi, & Wykle, 1988, Wan, 1989). Thus, the Andersen model is a useful conceptual tool in the investigation of the determinants of bereavement intervention utilization.

The Andersen model encompasses three categories of individual determinants of health service utilization, including predisposing characteristics, enabling resources, and need factors (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973). Need factors include the level of illness or the need for health care, both as perceived by the individual and as evaluated by health personnel. Enabling resources are those which allow for the use of services, and include personal resources (e.g., insurance coverage), family resources (e.g., social support), and community resources (e.g., geographic characteristics of the community). Predisposing characteristics are those which, present prior to the onset of need (Aday & Andersen), would deter or predispose the individual from using health care services. Examples include demographic characteristics (e.g., age, gender), aspects of social structure (e.g., race/ethnicity, education), and health beliefs (e.g., attitudes, perceptions, and knowledge of disease and medical care).

Need factors are believed to be the most immediate predictor of health services use (Aday & Andersen, 1974; Andersen, 1995; Coulton & Frost, 1982; Kart, 1991; Wallace et al., 1998), accounting for the most variance in the use of physician visits, mental health services, personal care, and recreational services (Coulton & Frost), informal and formal home care and community services (Kart), and in-home and community-based services (Mui & Burnette, 1994). However, the roles of predisposing characteristics and enabling resources may become more prominent relative to need factors when greater discretion can be exercised by the potential consumer in the decision

whether or not to utilize health services and in the type of service pursued (Aday & Awe, 1997), as may be the case with bereavement services.

The present doctoral dissertation examines bereavement in the context of family caregiving, with specific emphasis on service utilization and preferences among bereaved caregivers. A series of three studies was conducted. In the first two, bereavement service utilization rates and the types of services used were examined using two publicly available datasets. The first is the Changing Lives of Older Couples (CLOC) study, a longitudinal, multi-wave, prospective study of spousal bereavement. The second is the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study, a multi-site study evaluating the longitudinal impact of family caregiver interventions. In both studies, guided conceptually and analytically by Andersen's behavioral model of health services use, predictors of bereavement service utilization were examined. In the third study, bereavement service utilization rates, patterns, preferences, barriers to use, and the roles of depressive symptoms and social network were examined in a sample of bereaved caregivers whose spouses died while under hospice care in the Tampa Bay area.

Chapter Two:  
The Role of Grief and Depressive Symptoms  
in the Utilization of Bereavement Services

## Abstract

This study examined the role of psychological distress in the utilization of bereavement services by caregivers in the Changing Lives of Older Couples study. Approximately 57% of caregivers utilized services, most commonly provided by family physicians and clergy members. Elevated grief was associated with higher likelihood of using any service and of talking with a physician. Higher depressive symptoms were associated with decreased likelihood of talking with a physician. Findings suggest the need for outreach and education with family physicians and clergy. Individuals experiencing elevated grief may be utilizing bereavement services, while those experiencing elevated depressive symptoms may be underserved.

## Introduction

Recent demographic trends and projections point to dramatic growth in the size and proportion of the older adult population in the United States (U.S. Census Bureau, 2005). Coupled with the finding that approximately 80 percent of care for older adults is provided by family members (National Alliance for Caregiving & AARP, 1997), the critical role of family caregivers is in increasing demand. At the same time, technological and medical advances are delaying death, prolonging the end-of-life stage frequently characterized by high levels of impairment and a need for intense levels of care.

Caregiving has been described in the literature as a “career” (Aneshensel et al., 1995; Pearlin & Aneshensel, 1994) with the potential to be a long-term experience (Hurley & Volicer, 2002; Schulz, Mendelsohn, et al., 2003) punctuated by transitions, such as institutionalization and bereavement (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Gaugler, Anderson, Zarit, & Pearlin, 2004). The transition to bereavement, which occurs when the care recipient dies and the caregiving role ceases, is marked by great variability (Bonanno & Kaltman, 1999). For some, bereavement results in years of intense physical, psychological, and existential suffering, while others respond with remarkable resilience (Bonanno et al., 2002). Most exhibit a bereavement response that falls somewhere between these extremes. Bereavement outcomes of family caregivers reported in the literature include grief, depression, anxiety, diminished quality of life, increased health care utilization, and increased risk of physical illness and mortality (Christakis & Iwashyna, 2003; Goodkin et al., 2001; Stroebe, Schut, & Stroebe, 2007).

An array of interventions and services has been developed to assist individuals with the emotional, practical, and social problems that can accompany the loss of a loved one. These services are provided by a range of professionals and organizations and examples include grief therapy, cognitive behavioral therapy, support groups, pastoral counseling, widow-to-widow programs, psychoeducational programs, and pharmacotherapy. Reviews of the efficacy of these interventions have been mixed, with some evidence to suggest that highly-structured interventions targeting those who are most vulnerable to or currently experiencing negative bereavement outcomes have the greatest impact (Allumbaugh & Hoyt, 1999; Forte, Hill, Pazder, & Feudtner, 2004; Larson & Hoyt, 2007b; Schut & Stroebe, 2005; Schut et al., 2001).

In previous studies, bereavement service utilization rates have ranged from approximately 10% to 35% (Billings & Kolton, 1999; Caserta & Lund, 1992; Cherlin et al., 2007; Levy & Derby, 1992; Provini, Everett, & Pfeffer, 2000; Schulz, Mendelsohn, et al, 2003). Cherlin and colleagues identified factors associated with service use by bereaved hospice caregivers, including spousal relationship, younger age, more complicated caregiving context, presence of major depressive disorder, and adequate instrumental support. They found, however, that even among participants identified as experiencing clinically significant levels of depressive symptoms, less than half utilized bereavement services despite the fact that all had received information about available hospice bereavement services. These findings suggest that many spousal caregivers at risk for or experiencing negative bereavement outcomes are unlikely to utilize bereavement services. Additionally, we know of no widespread, systematic effort in place to target those in greatest need. Therefore, questions remain as to whether those

individuals most in need of intervention are seeking out or receiving services in bereavement.

The purpose of this study was to examine predictors of bereavement service utilization among bereaved spousal caregivers. We were conceptually and analytically guided by Andersen's health services utilization model (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973) to examine the contributions of predisposing characteristics (i.e., sociodemographics), enabling factors (i.e., resources), and need factors (i.e., bereavement outcomes). Need variables are believed to be the most immediate predictor of health services utilization (Aday & Andersen; Coulton & Frost, 1982; Kart, 1991; Wallace et al., 1998). However, predisposing characteristics and enabling resources may take on greater importance when more discretion may be exercised in the decision to utilize health services and in the type of service pursued (Aday & Awe, 1997), as may be the case with bereavement services.

Age is hypothesized to serve as a predisposing characteristic, with older age associated with greater utilization of services provided by a family physician and younger age associated with the utilization of other bereavement services, such as counseling and support groups. In a survey of older and younger adults (Robb, Haley, Becker, Polivka, & Chwa, 2003), older adults reported that they were significantly less likely to utilize mental health services for depression, anxiety, bereavement, or stress. They were also less likely to have had prior experience with mental health providers and were less confident about their knowledge of mental health care and treatment. Older adults were more likely to view their primary physician as the appropriate source of referral to a mental health professional.

Female gender is hypothesized to serve as a predisposing characteristic predictive of greater bereavement service utilization. Studies indicate that, in general, women are more likely to recognize mental health problems (Kessler et al., 1981) and to utilize mental health services (Coulton & Frost, 1982).

Racial or ethnic minority status is hypothesized to serve as a predisposing characteristic in greater utilization of services provided by a member of the clergy, whereas non-minority status is expected to predict for greater use of other types of bereavement services. Ethnic and racial minorities are drastically underrepresented among those seeking psychological and supportive services (APA, 2002; Coulton & Frost, 1982; Mui & Burnette, 1994). In addition, examinations of racial differences in sources of caregiving support and assistance reveal that White individuals demonstrate the highest levels of formal home health care and nursing home use, whereas Black individuals demonstrate the highest levels of reliance on informal helpers (Dilworth-Anderson et al., 2002; Mui & Burnette). In a study of Black older adults, Kart (1991) found that assistance overwhelmingly came from informal, unpaid sources and that participants looked to respected leaders to act as brokers between community members and the formal social service system. This suggests that some individuals in the Black community, particularly religious leaders, may play an important role in delivering and referring to services with the potential to improve the mental health and quality of life of bereaved individuals.

Education is expected to serve as a predisposing characteristic, with higher levels of education leading to greater use of services. Health and human service use research suggests that educational level is a predictor of service use among the elderly (Mutran &

Ferraro, 1988; Snider, 1980), dementia caregivers (Toseland et al., 2002), and Black caregivers (Williams & Dilworth-Anderson, 2002). It has been hypothesized that lower educational level serves to decrease service use through its impact on knowledge of the service delivery system and available community resources (Snider; Wallace et al., 1998) and on socioeconomic status and income (Wallace et al.).

Internal control, social resources, and religious involvement are hypothesized to serve as enabling resources, or resources which allow for service use, with higher levels of each leading to greater bereavement service utilization. This may occur through strengthening ties to the community (Coulton & Frost, 1982; Pearlin et al., 1981), changing self-perceptions of health and well-being and resulting motivation to seek care (Berkman, 1979), or improving access to resources necessary for participation (e.g., transportation) (Toseland et al., 2002).

Bereavement outcomes including depressive symptoms, anxiety, and grief are expected to serve as need factors, with higher levels of distress predictive of greater bereavement service utilization.

## Methods

These analyses used data from the Changing Lives of Older Couples (CLOC) study, which was conducted to examine spousal bereavement as a life stressor and to elucidate the mechanisms through which bereavement affects mental and physical health (Bonanno, Wortman, & Nesse, 2004). The CLOC study is a longitudinal, multi-wave, prospective study of spousal bereavement conducted in the Detroit Standardized Metropolitan Statistical Area by the Institute for Social Research at the University of Michigan and funded by the National Institute on Aging. Baseline interviews were

conducted in 1987 and 1988 with both members of each couple. Follow-up interviews were then conducted with survivors in three waves at 6, 18, and 48 months after the death of their spouse, concluding in 1994.

### *Participants*

CLOC participants were community-dwelling, English-speaking, and capable of participating in a 2-hour face-to-face interview and they were members of a married couple in which the husband was at least 65 years of age at the time of enrollment. During the study, 319 CLOC participants lost a spouse and 86% of those (n=276) participated in at least one follow-up interview. The current analyses include 126 participants who provided care to their spouse in the last six months of life and who completed at least one post-loss wave of follow-up.

### *Measures*

#### *Predisposing Characteristics*

The sociodemographic characteristics of interest include age, gender, race, and education. Due to the small number of minorities in the sample, race was categorized as White or non-White.

#### *Enabling Resources*

*Internal control.* The internal control index ( $\alpha = .71$ ) contained the following 4 items: 1) My life is determined by my own actions, 2) When I make plans, I am almost certain to make them work, 3) When I get what I want, it's usually because I worked hard for it, and 4) I am usually able to protect my own interests. Each item was scored on a 4-point Likert scale ranging from "not true at all" to "very true." Higher scores indicate higher levels of internal control.

*Religious involvement.* The religious involvement index ( $\alpha = .83$ ) is a composite of 4 items including: 1) In general, how important are religious and spiritual beliefs in your day-to-day life, 2) How often do you usually attend religious services, 3) When you have problems or difficulties in your family, work, or personal life, how often do you seek spiritual comfort and support, and 4) When you have decisions to make in your everyday life, how often do ask what God would want you to do? Higher scores indicate higher levels of religious involvement.

*Emotional support.* This variable is a composite index ( $\alpha = .71$ ) of two items measuring the degree to which friends and relatives made the respondent feel loved and cared for and how willing they were to listen to the respondent talk about their worries or problems. Higher scores indicate higher levels of positive emotional support.

*Instrumental support.* This variable is a composite index ( $\alpha = .68$ ) of three items measuring the degree to which the respondent felt they could rely on friends or relatives for help if they needed extra help with general housework or home maintenance, needed extra money, or were ill. Higher scores indicate higher levels of instrumental support.

#### *Need Factors*

*Depressive Symptoms.* An 11-item subscale of the CES-D (Radloff, 1977) ( $\alpha = .84$ ) was used to measure depressive symptoms with responses ranging on a 3-point Likert scale from “hardly ever” to “most of the time.” Converted into z-scores with a mean of 0 and a standard deviation of 1, higher scores indicate higher levels of depressive symptomatology.

*Anxiety.* Anxiety was measured using a 10-item index ( $\alpha = .87$ ) with responses ranging on a 5-point Likert scale from “not at all” to “extremely.” This variable was also converted to centered z-scores and higher scores indicate higher anxiety.

*Grief.* Overall grief was measured using a 19-item scale ( $\alpha = .88$ ) developed by the CLOC researchers. The scale utilized a 5-point Likert scale ranging from 0 to 4 with higher scores indicating higher levels of grief.

#### *Bereavement Service Utilization*

Bereavement service utilization was determined based on participants’ answers to the following questions: To help handle feelings of grief, loneliness or missing your husband/wife, have you...

- a. gone to a self-help group or support group for people who have lost a spouse?
- b. seen a minister, priest or other clergy for help?
- c. talked to your family doctor?
- d. gone to a mental health professional for help – someone like a social worker or psychologist?

A composite bereavement service utilization variable was also created, representing the use of any one or more of the above bereavement services.

#### *Statistical Analysis*

Correlation analyses were performed in order to examine the bivariate associations among study variables. Predictors of bereavement service utilization were examined using Cox proportional hazards models, chosen for their ability to accommodate censored cases, or those for which the event of interest did not occur (i.e., individuals did not utilize bereavement interventions) or for whom occurrence status was

not known due to discontinuation of the study (Cantor, 2003; Tabachnick & Fidell, 2001). Predictors were categorized as predisposing characteristics, enabling resources, or need factors. Predisposing characteristics included baseline age, gender, race, and education. Enabling resources included internal control, religiosity, and instrumental and emotional support as reported at the first post-loss follow-up. Need factors included bereavement outcomes, including depressive symptoms, anxiety, and grief as reported at the first post-loss follow-up. For those individuals lacking 6 month follow-up data, data from the first available follow-up wave were used for enabling resources and need factors.

Time, measured in days, from the date of the care recipient's death to the date of the post-loss interview at which service use was reported, was used to account for differences in the interval until first service use. For these analyses, use of bereavement service was coded as "1" and non-use (i.e., "survival") as "0." Separate analyses were conducted for the use of any bereavement service, talking with the family doctor, and talking with a minister, priest, or other member of the clergy. We were unable to individually examine predictors of support group attendance and use of a mental health professional due to the small number of participants who utilized these bereavement services. For those who never utilized bereavement services, the date of the 48 month post-loss follow-up interview was used as a right-censoring event. For those who dropped out of the study before 48 month follow-up, the date of the last available post-loss follow-up interview was used as the censoring event. In the model examining use of any service, event occurrence was coded at the date of the first wave at which use of any one of the four services under investigation was reported.

In the Cox proportional hazards models, we entered predisposing characteristics, enabling resources, and need factors in sequential blocks in order to examine the importance of each block to the prediction of time to service use after statistical adjustment for the effects of the preceding block or blocks of covariates.

## Results

### *Sociodemographics and Descriptive Analyses*

The sample consisted primarily of White (84.1%) females (84.9%) with a median of 12 years of education and an average age of 69. Table 2.1 shows sociodemographic and background characteristics of the sample. While the sample consisted primarily of females, this is similar to other studies of older bereaved spouses (e.g., Schulz, Mendelsohn, et al., 2003) and generally representative of the gender distribution of older bereaved spouses. The sample is not, however, representative of the population of older bereaved spouses with regard to race and the generalizability of these findings are thus limited.

The mean baseline depressive symptom and anxiety scores of all 1,532 CLOC participants were centered with a mean of zero and SD of 1. Thus, depressive symptom and anxiety scores above zero indicate that they were higher than the baseline mean of the broader sample. As displayed in Table 2.1, caregiver depressive symptoms were approximately one quarter of a standard deviation above the total group at baseline, peaked by 6 months post-loss at nearly one half of a standard deviation above the baseline mean, and declined thereafter. Caregiver anxiety scores were highest prior to the death of the care recipient and fell at each successive wave, ultimately reaching a

level below the baseline mean of the broader sample. Grief scores were highest at 6 months post-loss and declined at each successive wave.

Table 2.1. Sample Background Characteristics and Descriptives

	%	Mean	SD	Range
<b>Predisposing Characteristics</b>				
Age		68.8	7.0	48 -86
Gender (Female)	84.9			
Race (White)	84.1			
Education (Median in years)		12		3 - 17
<b>Enabling Resources</b>				
Internal Control <sup>a b</sup>		-.10	1.0	-2.8 – 1.2
Religious Involvement <sup>a c</sup>		.15	.94	-2.4 – 1.3
Instrumental Support <sup>a c</sup>		-.05	1.0	-2.6 – 1.2
Emotional Support <sup>a c</sup>		.34	1.1	-2.7 – 1.4
<b>Need Factors</b>				
<i>Depression</i> <sup>a</sup>				
Baseline		.24	1.1	-1.1 – 4.2
6 Months		.43	1.3	-1.1 – 6.1
18 Months		.15	1.2	-1.1 – 5.2
48 Months		-.28	1.1	-1.1 – 3.9
<i>Anxiety</i> <sup>a</sup>				
Baseline		.22	1.3	-.59 – 7.0
6 Months		.12	1.0	-.59 – 4.5
18 Months		-.01	.84	-.59 – 3.5
48 Months		-.09	.92	-.59 – 3.5
<i>Grief</i>				
6 Months		2.1	.62	1.1 – 3.9
18 Months		1.9	.52	1.0 – 3.2
48 Months		1.6	.54	1.0 – 3.2
<b>Service Utilization (%)</b>				
Use of Any Service	57.1			
Family Doctor	42.1			
Clergy	29.4			
Support Group	15.1			
Mental Health Professional	5.6			

<sup>a</sup> z-scores

<sup>b</sup> Baseline

<sup>c</sup> Wave 1 (6 months post-loss)

Seventy two (57.1%) bereaved spouses utilized at least one of the four bereavement services of interest (i.e., family physician; clergy; bereavement support group; mental health professional). Fifty three (42.1%) participants talked with their family physician about feelings of grief, loneliness, or missing their spouse and thirty seven (29.4%) participants met with their minister, priest, or clergy member. Nineteen (15.1%) participants attended a bereavement self-help or support group. Only seven (5.6%) saw a mental health professional such as a social worker or psychologist.

#### *Bivariate Analyses*

The results of the bivariate correlation analyses are shown in Table 2.2. The results indicate that female participants were more likely to be younger ( $r = -.25, p < .01$ ). Participants with higher levels of education were also more likely to be younger ( $r = -.25, p < .01$ ) and to report higher levels of emotional support ( $r = .19, p < .05$ ). Non-Whites reported significantly higher levels of religious involvement ( $r = .20, p < .05$ ), but lower levels of instrumental support ( $r = -.19, p < .05$ ). Participants who reported higher levels of religious involvement had significantly higher levels of emotional support ( $r = .25, p < .01$ ). Social resources were inversely correlated with bereavement outcome, with higher levels of instrumental and emotional support associated with lower levels of depressive symptoms ( $r = -.31$  and  $-.28$  respectively,  $p < .01$ ), anxiety ( $r = -.31$  and  $-.32$  respectively,  $p < .01$ ), and grief ( $r = -.24, p < .05$  and  $r = -.26, p < .01$ ).

#### *Multivariate Analysis*

Complete data were available for one hundred and thirteen bereaved spouses who participated in at least 1 post-loss interview. In the first proportional hazards model, a composite variable indicating time to use of any one or more of the four bereavement

Table 2.2. Correlation Matrix for Study Variables

	1	2	3	4	5	6	7	8	9	10	11
<b>Predisposing Characteristics</b>											
1. Age		-.25**	-.25**	-.04	.03	-.05	.09	-.09	.06	-.08	-.10
2. Gender			.11	.00	-.14	.15	.11	.11	.02	.12	-.02
3. Education				.02	-.11	.05	-.04	.19*	-.10	-.09	.11
4. Race					.12	.20*	-.19*	.07	-.16	-.01	-.17
<b>Enabling Resources</b>											
5. Internal Control						-.02	.18	-.01	-.15	-.16	-.17
6. Religious Involvement							.05	.25**	-.18	-.17	-.12
7. Instrumental Support								.25**	-.31**	-.31**	-.24*
8. Emotional Support									-.28**	-.32**	-.26**
<b>Need Factors</b>											
9. Depression										.70***	.74***
10. Anxiety											.53***
11. Grief											

\*p<.05, \*\*p<.01, \*\*\*p<.001

services under examination (family doctor, clergy/pastor, support group, mental health professional) served as the dependent variable. Regarding the use of any bereavement service (see Table 2.3), the proportional hazards model indicated that grief successfully predicted time to service use after adjusting for the other covariates ( $\chi^2(1) = 8.152, p = .004$ ). As shown in Table 2.3, for each one-point difference in grief at the first post-loss follow-up, the probability of using any bereavement service increased by approximately 92%.

The proportional hazards model for talking with the family doctor about feelings of grief, loneliness, or missing one's spouse indicated that the need factor block containing depressive symptoms and grief successfully predicted time to service use after adjusting for predisposing characteristics and enabling resources ( $\chi^2(2) = 14.250, p = .001$ ). As shown in Table 2.4, for each one-point difference in grief, the probability of

Table 2.3. Cox Regression Model of Bereavement Service Utilization (Any Service)

	B	Odds Ratio	95% Confidence Interval	
			Lower	Upper
<b>Predisposing Factors</b>				
Age	.016	1.02	.98	1.06
Gender	-.162	.85	.41	1.75
Race	-.424	.65	.36	1.19
Education	.039	1.04	.95	1.14
<b>Enabling Resources</b>				
Internal Control	-.114	.89	.67	1.19
Religious Involvement	.111	1.12	.82	1.53
Instrumental Support	-.054	.95	.72	1.24
Emotional Support	-.071	.93	.71	1.22
<b>Need Factors<sup>a</sup></b>				
Grief	.650	1.92**	1.23	2.99

\*\*p<.01

<sup>a</sup> Anxiety and depressive symptoms were excluded from the model.

talking with the family doctor increased nearly four and a half times. The effect of depressive symptoms was in the opposite direction, however, with each standard deviation difference resulting in a nearly 33% decrease in the probability of talking with the family doctor.

Table 2.4. Cox Regression Model of Bereavement Service Utilization (Family Doctor)

	95% Confidence Interval			
	B	Odds Ratio	Lower	Upper
<b>Predisposing Factors</b>				
Age	.043	1.04	.99	1.09
Gender	-.084	.92	.40	2.10
Race	-.543	.58	.29	1.15
Education	.025	1.03	.92	1.14
<b>Enabling Resources</b>				
Internal Control	.188	1.21	.86	1.69
Religious Involvement	.176	1.19	.83	1.72
Instrumental Support	-.185	.83	.61	1.14
Emotional Support	-.221	.80	.59	1.08
<b>Need Factors<sup>a</sup></b>				
Depressive Symptoms	-.397	.67*	.46	.98
Grief	1.522	4.58**	1.93	10.91

\*p<.05, \*\*p<.01

<sup>a</sup> Anxiety was excluded from the model.

The proportional hazards model for talking with a minister, priest, or other member of the clergy about feelings of grief, loneliness, or missing one's spouse indicated that the predisposing characteristics block successfully predicted time to service use ( $\chi^2(4) = 11.451, p = .022$ ) and the probability of talking with a clergy member was 67% less for Whites than for non-Whites (see Table 2.5). The enabling resources block also predicted time to service use ( $\chi^2(4) = 12.765, p = .012$ ) after adjusting for

predisposing characteristics, and with each unit difference in religious involvement the probability of talking with a clergy member increased by more than two times.

Table 2.5. Cox Regression Model of Bereavement Service Utilization (Clergy)

	B	Odds Ratio	95% Confidence Interval	
			Lower	Upper
<b>Predisposing Factors</b>				
Age	-.023	.98	.93	1.03
Gender	-.573	.56	.17	1.90
Race	-1.116	.33**	.16	.67
Education	-.024	.98	.84	1.13
<b>Enabling Resources</b>				
Internal Control	-.267	.77	.50	1.16
Religious Involvement	.751	2.12**	1.21	3.72
Instrumental Support	.092	1.10	.76	1.59
Emotional Support	.132	1.14	.75	1.74
<b>Need Factors</b>				
Depressive Symptoms	.328	1.39	.83	2.33
Anxiety	-.281	.76	.41	1.38
Grief	-.068	.94	.33	2.63

\*p<.05, \*\*p<.01

## Discussion

In the current study, approximately 57% of caregivers utilized bereavement services after the death of their spouse. This fairly high proportion may indicate that bereaved spousal caregivers who are experiencing distress recognize their need for and seek out bereavement services consistent with their preferences. However, nearly half of bereaved spousal caregivers did not utilize bereavement services from which they may have benefited. While we found a bereavement service utilization rate higher than previous studies (Billings & Kolton, 1999; Caserta & Lund, 1992; Cherlin et al., 2007; Levy & Derby, 1992; Provini et al., 2000; Schulz, Mendelsohn, et al., 2003), this may be

accounted for by the fact that the current study focused on spousal caregivers, a group who may have been more closely linked to or accustomed to the use of formal supportive services. It could also be attributed to the liberal definition of bereavement services employed in the current study, including the characterization of talking with a clergy member and the family doctor as use of a bereavement service.

The most commonly used services included talking with the family physician (42.1%) and seeing a minister, priest, or other clergy for help (29.4%). These findings indicate the need for outreach and education with family doctors and members of the clergy, as they are likely to have regular contact with older adults and to be viewed by older adults as important gatekeepers to other mental health services (Robb et al., 2003). In many cases, they may be the only professionals with the opportunity to identify an individual who is suffering in bereavement. Ideally, family physicians and members of the clergy should receive information and training regarding risk factors for negative bereavement outcomes, the identification of negative outcomes and distress, and resources available in the community to provide specialized bereavement services which are beyond their scope of resources or training.

A comprehensive review of the efficacy of bereavement interventions (Schut et al., 2001) and a more recent update to this review (Schut & Stroebe, 2005) concluded that interventions were more effective when targeted to individuals in high-risk groups or individuals already suffering from complicated grief, as opposed to primary preventive interventions offered routinely to bereaved individuals. The authors advocated for inreaching interventions, or those provided to bereaved individuals who seek out and ask for help, as they are likely to be in the greatest need. The current study suggests that

individuals experiencing a high level of grief may indeed perceive a need for and seek out bereavement intervention. However, individuals suffering from higher levels of anxiety were not more likely to utilize bereavement services than those exhibiting low anxiety. Furthermore, individuals experiencing higher levels of depressive symptoms were actually less likely to talk with their family doctor about feelings of grief, loneliness, or missing their spouse. Those experiencing elevated levels of depression or anxiety in bereavement may well be in a high risk group for complicated bereavement and yet they may not seek out or receive intervention. This is an important consideration in the planning of screening and outreach efforts with bereaved spousal caregivers.

This research has some limitations which should be noted. First, the dataset does not contain information about whether or not the spouse died while under hospice care. The provision of hospice care is likely to impact knowledge of available bereavement services, the lack of which may be a significant barrier to bereavement service utilization as it was in the use of long term care (Bradley et al., 2002). Future research should address this in an effort to understand the roles played by knowledge of available services and by hospice use in general. Second, information about the utilization of bereavement services was collected retrospectively and was self-reported by participants. This is a common approach to the study of health behavior and the only option for the collection of data pertaining to utilization of bereavement services which are not reimbursable under Medicare, Medicaid, or other insurance plans (e.g., bereavement support group, clergy/pastoral counseling). However, studies indicate that when compared with information about actual utilization as obtained from administrative records, self-reported health services utilization is frequently underestimated (Dunlop, Manheim, Song, &

Chang, 2002). Finally, the available data offers little insight into the specifics of the bereavement services of interest. For example, information was not available about the credentials of service providers, the duration of the services, or the theoretical foundations of the services under examination. Attention to these and other details in future studies will help us to better understand preferences, motivations, and choices regarding bereavement service utilization as well as the specific features of services which lead to positive outcomes for diverse groups of bereaved individuals.

Chapter Three:

Who Uses Bereavement Services?

An Examination of Service Use by Bereaved Dementia Caregivers

## Abstract

Despite the availability of a wide range of services and interventions for bereaved family caregivers, little is known about the characteristics of those who use them. The current study employed Andersen's Behavioral Model of Health Services Use in an examination of bereavement service utilization among dementia caregiver participants in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. Approximately one in three participants utilized bereavement services, primarily during the first 9 months after the death of the care recipient. Support groups, counseling, and psychotropic medications were used in similar proportions. Depressive symptomatology and complicated grief served as need factors, with higher levels resulting in higher probability of service utilization. Race/ethnicity served as a predisposing characteristic, with Black caregivers less likely and Hispanic caregivers more likely than White caregivers to utilize support groups. Future research should focus on interventions designed to assure timely access to those bereaved family caregivers who are most in need.

## Introduction

It has been well established that caring for a loved one with Alzheimer's disease or dementia can be difficult and stressful, potentially leading to a range of negative outcomes for family caregivers (Pinquart & Sörensen, 2003). With bereavement (i.e., the death of the care recipient) increasingly recognized as an experience not separate from the caregiving "career" (Pearlin & Aneshensel, 1994), many studies of the bereavement transition among family caregivers (see Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997 for a review) have focused on mental health outcomes. Recent studies suggest wide individual variation in both the initial response and the long-term trajectory of adjustment to bereavement (Aneshensel et al., 2004; Bonanno et al., 2002; Zhang, Mitchell, Bambauer, Jones, & Prigerson, 2008). While some family caregivers respond to bereavement with remarkable resilience, others experience varying degrees of depressive symptomatology, anxiety, complicated grief, and other mental health problems.

While the range of available services varies by community, bereaved family caregivers who are experiencing negative mental health outcomes have a variety of choices regarding services designed to facilitate their adjustment. Some consult a psychologist, psychiatrist, or mental health professional; others may prefer the services of their family physician; while still others look to a trusted spiritual or religious advisor. Hospice, hospitals, and other community organizations offer self-help and support groups, bereavement counseling, and widow-to-widow programs. Despite the availability of these and other services for bereaved family caregivers, we know little about the characteristics of those who do, and those who do not, utilize bereavement services.

A review of the literature reveals mixed findings regarding variables associated with formal bereavement service utilization. In a study of bereaved hospice caregivers, Cherlin and colleagues (2007) found a bereavement service utilization rate of approximately 30%. Spousal relationship, younger age, presence of Major Depressive Disorder, having discussed the care recipient's prognosis with a doctor, having assisted the care recipient with Instrumental Activities of Daily Living (IADLs), and the presence of adequate instrumental support were associated with bereavement service utilization. Levy and Derby (1992) found that social support was not associated with service use, while the experience of stressful events after the death and higher levels of depressive symptomatology and anxiety were associated with bereavement support group use among bereaved spouses, of whom approximately 30% utilized the service. Caserta and Lund (1992) found a formal service utilization rate of nearly 12% in the first two to three months after the death of a spouse. Demographic characteristics, social network, and social support were not associated with the use of formal services. Those who utilized formal services reported higher depression scores, lower coping ability, poorer perceived health, and lower levels of instrumental and resource-identification personal competency skills than non-users.

The small number of studies of bereavement service utilization conducted to date have not used a theoretical framework to guide the selection of measures and have methodological limitations which highlight the need for more research in this area. Andersen's Behavioral Model of Health Services Use (Aday & Andersen, 1974; Andersen, 1968; Andersen, 1995; Andersen & Newman, 1973), developed to aid in the identification and description of determinants of health care use, is a widely used

perspective in health service utilization research and is therefore a useful theoretical and conceptual tool in the investigation of the determinants of bereavement services utilization.

Within Andersen's model, predisposing characteristics are those which, present prior to the onset of need, deter or predispose individuals from using health care services. Examples include demographic characteristics (e.g., age), aspects of social structure (e.g., race/ethnicity), and health beliefs (e.g., perceptions and knowledge of disease and medical care). Enabling resources are those which allow for the use of services, which include personal resources (e.g., income), family resources (e.g., social network characteristics), and community resources (e.g., geographic characteristics of the community). Need variables include the level of illness (e.g., depression) or the need for health care, both as perceived by the individual and as evaluated by health personnel (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973).

Some researchers have argued that need variables are the most immediate predictor of health services utilization (Aday & Andersen, 1974; Coulton & Frost, 1982; Kart, 1991; Wallace et al., 1998). However, the roles of predisposing characteristics and enabling resources may take on greater importance relative to need factors when greater discretion can be exercised by the potential consumer in the decision to utilize health services and in the type of service pursued (Aday and Awe, 1997), as may be the case with bereavement services.

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) study provides a valuable means to examine determinants of bereavement service utilization for a number of reasons. First, the study includes a comprehensive range of caregiver and

care recipient characteristics, resources, and bereavement outcomes. The multi-site sample represents a broad geographic sample of diverse family caregivers who were followed over a period of more than 18 months. Finally, the sample is of sufficient size to employ a range of multivariate statistical techniques.

The current study was conducted to examine the determinants of bereavement service utilization in a diverse sample of bereaved dementia family caregivers. Guided by the literature reviewed above and the literature on general mental health services utilization, we hypothesized that caregivers who were younger (Cherlin et al., 2007), female (Rhodes, Goering, To, & Williams, 2002), non-minority (Harris, Edlund, & Larson, 2005), and more highly educated (Crabb & Hunsley, 2006) would be more highly predisposed to the utilization of bereavement services. We also hypothesized that prior participation in a caregiver intervention, higher religiosity, and higher levels of social resources (Cherlin et al., 2007) would serve to strengthen an individual's community and formal service network ties and enable the utilization of bereavement services. Finally, we expected that greater distress in bereavement, as indicated by higher levels of depressive symptoms (Caserta & Lund, 1992; Cherlin et al.; Levy & Derby, 1992), anxiety (Levy & Derby), and complicated grief, would influence need and result in a higher probability of bereavement service use.

## Methods

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) Study is a longitudinal, multisite, prospective study funded by the National Institute for Nursing Research and the National Institute on Aging and conducted with Alzheimer's disease caregivers and patients beginning in 1995. A primary goal was to evaluate the

effectiveness of interventions with family caregivers of individuals with Alzheimer's disease and related disorders (Schulz, Burgio et al., 2003). Baseline and 6, 12, and 18-month post-baseline follow-up data used in this study, as well as introductory information and codebook, were downloaded from the Inter-university Consortium for Political and Social Research (ICPSR), part of the Institute for Social Research of the University of Michigan.

### *Participants*

In order to be eligible for REACH, participants had to be a family caregiver living with a person with dementia for at least 6 months and providing care for a minimum of four hours each day. Participants were randomly assigned to the intervention or control conditions. Interventions varied by study site, including Birmingham, Memphis, Boston, Philadelphia, Miami, and Palo Alto. A total of 1,222 caregiver-care recipient dyads were recruited for participation (Wisniewski et al., 2003). During the course of the study, 265 participants experienced the death of the care recipient. Bereavement outcome and service utilization data were obtained from 224 of these bereaved caregivers.

For the purposes of our study, waves of data were reconceptualized as either pre- or post-loss according to the timing of the death of the care recipient. Therefore, participants varied in the number of post-loss waves of data available. Specifically, some participants contributed three waves of post-loss data (N=60), as the death of their care recipient occurred between the baseline and 6-month follow-up interviews. For others, we had 2 or 1 waves of post-loss data (N=64 and N=100 respectively), depending on whether the care recipient died between 6 and 12-months follow-up or between 12 and 18-months follow-up. Twelve bereaved caregivers did not participate in the first wave of

bereavement follow-up, but were available for subsequent waves of post-loss data collection.

### *Measures*

#### *Predisposing Characteristics*

The predisposing characteristics on which we focused were baseline sociodemographic characteristics including caregiver age, gender, education (measured in years), and race/ethnicity (White, Black, Hispanic).

#### *Enabling Resources*

Enabling resources included caregiver intervention status (treatment vs. control) and religiosity. Religiosity was measured at baseline with a single item in which caregivers reported the importance of religion in their lives using a 4-point Likert scale ranging from “not important” to “very important.” Also included were two measures of social resources - social network and satisfaction with support – obtained at the first available post-loss interview. Social network was measured with 6 items from Lubben’s Social Network Scale (LSNS; Lubben, 1988). Measures included the number of relatives or friends seen at least once a month (0 to 9 or more), frequency of contact (less than monthly to daily), and the number of relatives or friends the subject felt close to (0 to 9 or more). Satisfaction with support was measured with 3 items measuring satisfaction with tangible, emotional, and informational support received (Krause, 1995; Krause & Markides, 1990), with modified response options ranging from “not at all” to “very” on a 4-point Likert scale. Mean imputation was used to avoid losing observations due to missing data. Social network (LSNS) had 9 missing values (4%) and satisfaction with support had 10 missing values (4.5%).

### *Need Factors*

Need factors included three outcomes frequently examined in studies of bereavement—depressive symptoms, anxiety, and complicated grief, as measured at the first available post-loss follow-up interview. Depressive symptoms were measured using the Center for Epidemiological Studies-Depression (CES-D) scale (Radloff, 1977), a 20-item measure of the frequency with which respondents experienced depressive symptoms within the past week. Anxiety was measured with the 10-item “state” anxiety subscale of the State-Trait Personality Inventory (Spielberger, 1979; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Participants were asked to report their experience of symptoms of anxiety during the past week using a 4-point scale of intensity ranging from “not at all” to “very much.” Complicated grief was measured using Prigerson and colleagues’ (1995) well-validated 19-item Inventory of Complicated Grief designed to measure the frequency of grieving thoughts and behaviors considered to be maladaptive (e.g., anger, disbelief, hallucinations). Responses ranged on a 5-point scale from “never” to “always.”

### *Bereavement Service Utilization*

At each post-loss follow-up, REACH participants were asked whether they were currently receiving any type of counseling or other support services to help in coping with the death of the care recipient. If so, they were then prompted with further questions to describe the nature of the services being utilized. For these analyses, participants were coded as using a support group if they confirmed the use of a support group for family members of bereaved dementia caregivers or other support group. They were coded as using counseling if they confirmed the use of individual counseling, family counseling, or clergy/pastoral counseling.

At each wave, participants were asked to report all prescription and non-prescription medications they were currently taking. Participants were coded as using psychotropic medication if they confirmed the use of any medication identified as a psychiatric medication using the Systems Key of the Instant Drug Index (Aloisi, 2001). Participants were further coded as using any bereavement service if they confirmed the use of any one or more of the above bereavement services.

### *Statistical Analysis*

Descriptive statistics were calculated to examine the sample's demographic and background characteristics and correlational analyses were used to examine bivariate associations among study variables. Multivariate analyses were conducted using Cox proportional hazards modeling (Allison, 1995; Tabachnick & Fidell, 2001). This method was chosen for its utility in examining the likelihood of occurrence of a given outcome as well as covariates associated with risk of event occurrence. In addition, Cox proportional hazards models can accommodate censored cases, or those in which the event is not experienced during the observational period. The dependent variable for the present study was defined as time to bereavement service utilization following the death of the care recipient. For those cases in which bereavement services were utilized, time was calculated as the number of days between the date of the care recipient's death and the date of the interview at which use was first reported. For censored cases in which bereavement service utilization did not occur, time was calculated as the number of days between the date of the care recipient's death and the date of participation in the final follow-up interview.

Four Cox proportional hazard models were constructed to examine the relationship of hypothesized predisposing characteristics, enabling resources, and need factors with the likelihood of (a) any bereavement service utilization, (b) support group use, (c) counseling use, and (d) psychotropic medication use. The hierarchical method was chosen to control the order of entrance of blocks of covariates in accordance with the Andersen model of health services use. Cox proportional hazards models provide estimates of the effect of a covariate on the likelihood of the occurrence of the outcome.

### Results

Table 3.1 displays the descriptive and background characteristics of the 224 study participants. The sample consisted primarily of White females with a mean of 12 years of education and an average age of 63 years. On average, the amount of time between the care recipient's death and the first bereavement follow-up interview was 99 days ( $N = 212$ ;  $SD = 52.8$ ), or 3.3 months. Average time until the second bereavement follow-up interview was 261 days ( $N = 124$ ;  $SD = 63.7$ ), or 8.5 months, and until the third bereavement follow-up was 445 days ( $N = 66$ ;  $SD = 65.0$ ), or 14.6 months.

The results of the univariate correlation analyses revealed that the three need factors - depressive symptoms, anxiety, and complicated grief – were significantly and positively correlated. Those with higher depressive symptom scores were also more likely to have higher anxiety scores ( $r=.80$ ,  $p<.000$ ) and higher complicated grief scores ( $r=.59$ ,  $p<.000$ ). Similarly, those with higher anxiety scores were also more likely to have higher complicated grief scores ( $r=.48$ ,  $p<.000$ ).

Table 3.1. Sample Background Characteristics and Descriptives

	N (%)	Mean	SD	Range
<b>Predisposing Characteristics</b>				
Age (years) <sup>a</sup>		63.2	13.3	28 - 89
Gender				
Female	189 (84.4)			
Male	35 (15.6)			
Race/Ethnicity				
White/Caucasian	148 (66.1)			
Black/African American	45 (20.1)			
Hispanic/Latino	31 (13.8)			
Education (years)		12.3	3.0	0 - 17
<b>Enabling Resources</b>				
Religiosity <sup>a</sup>		3.5	.85	1 - 4
Caregiver Intervention Status				
Intervention Group	143 (63.8)			
Control Group	81 (36.2)			
Social Network (LSNS) <sup>b c</sup>		18.8	5.0	5 - 30
Satisfaction with Support <sup>b</sup>		6.4	2.3	0 - 9
<b>Need Factors</b>				
Depressive Symptoms (CES-D) <sup>b</sup>		16.2	12.3	0 - 60
Anxiety (STPI anxiety subscale) <sup>b</sup>		20.0	6.7	10 - 40
Grief (ICG) <sup>b</sup>		37.3	12.8	19 - 86

SD = Standard Deviation

LSNS = Lubben's Social Network Scale

CES-D = Center for Epidemiological Studies-Depression scale

STPI = State-Trait Personality Inventory

ICG = Inventory of Complicated Grief

<sup>a</sup> baseline

<sup>b</sup> first bereavement follow-up

The support group utilization rate reported in the current study was 17% (N = 38), reflecting participation in a support group for family members of bereaved dementia caregivers or other support group at any bereavement follow-up interview. First use of a support group was reported by participants who used them an average of 154 days (SD = 92.1), or 5.1 months, after the death of the care recipient. Ninety percent (N = 34) utilized a support group during the first 9 months after the care recipient's death.

The Cox proportional hazards model for support group use is displayed in Table 3.2. The model indicated that the predisposing characteristics block successfully predicted time to support group use ( $\chi^2(5) = 12.75, p = .026$ ). Black caregivers were 77% less likely to participate in a support group than White caregivers, while Hispanic caregivers were more than two times more likely than White caregivers to participate. In addition, the needs factor block containing complicated grief successfully predicted time to support group use after adjusting for predisposing characteristics and enabling resources ( $\chi^2(1) = 6.72, p = .010$ ), with each one-unit difference in complicated grief score resulting in a 4% increase in the probability of support group participation.

Table 3.2. Cox Proportional Hazards Model of Support Group Use

	B	Odds Ratio	95% Confidence Interval	
			Lower	Upper
<b>Predisposing Factors</b>				
Age	.001	1.001	.975	1.028
Gender <sup>a</sup>	-.232	.793	.268	2.345
Race/ethnicity				
White/Caucasian <sup>b</sup>	-	-	-	-
Black/African American	-1.468	.230*	.054	.982
Hispanic/Latino	.837	2.310*	1.028	5.193
Education	.027	1.028	.927	1.139
<b>Enabling Resources</b>				
Caregiver Intervention <sup>c</sup>	.136	1.145	.571	2.296
Religiosity	.351	1.421	.894	2.260
Social Network	-.028	.972	.908	1.042
Satisfaction with Support	.005	1.005	.865	1.169
<b>Need Factors<sup>d</sup></b>				
Complicated Grief	.036	1.037**	1.009	1.065

\*p<.05, \*\*p<.01

<sup>a</sup> Reference category: females

<sup>b</sup> Reference category

<sup>c</sup> Reference category: control group

<sup>d</sup> Depressive symptoms and anxiety were excluded from the model

The counseling utilization rate, or use of individual, family, or clergy/pastoral counseling at any wave of bereavement follow-up, was 16% (N = 36). On average, participants who used the service reported first use of counseling 126 days (SD = 69.6), or 4.1 months, after the death of the care recipient. All but one (i.e., N = 35; 97%) used counseling services within the first 9 months of the death.

As shown in Table 3.3, the Cox proportional hazards model indicated that age served as a significant predisposing characteristic, with increasing age resulting in a lower probability of counseling use. Further, the needs factor block containing depressive symptoms successfully predicted time to counseling use after adjusting for

Table 3.3. Cox Proportional Hazards Model of Counseling Use

	B	Odds Ratio	95% Confidence Interval	
			Lower	Upper
<b>Predisposing Factors</b>				
Age	-.026	.974*	.949	.999
Gender <sup>a</sup>	.357	1.429	.577	3.538
Race/ethnicity				
White/Caucasian <sup>b</sup>	-	-	-	-
Black/African American	-.482	.618	.248	1.536
Hispanic/Latino	-.110	.895	.291	2.754
Education	.066	1.068	.938	1.216
<b>Enabling Resources</b>				
Caregiver Intervention <sup>c</sup>	.153	1.165	.588	2.310
Religiosity	.007	1.007	.691	1.468
Social Network	-.022	.978	.911	1.051
Satisfaction with Support	.012	1.012	.868	1.179
<b>Need Factors<sup>d</sup></b>				
Depressive Symptoms	.050	1.051**	1.021	1.082

\*p<.05, \*\*p<.01

<sup>a</sup> Reference category: females

<sup>b</sup> Reference category

<sup>c</sup> Reference category: control group

<sup>d</sup> Anxiety and complicated grief were excluded from the model

other covariates ( $\chi^2(1) = 11.55, p = .001$ ), with each one-unit difference in depressive symptoms resulting in a 5% increase in the probability of counseling use.

During bereavement follow-up, 19% of study participants (N = 42) reported the utilization of psychotropic medication, all within the first 9 months after the death of the care recipient. First medication use was reported an average of 122 days (SD = 69), or 4 months after the death.

The Cox proportional hazards model for psychotropic medication use (displayed in Table 3.4) indicated that the needs factor block containing depressive symptoms

Table 3.4. Cox Proportional Hazards Model of Psychotropic Medication Use

	95% Confidence Interval			
	B	Odds Ratio	Lower	Upper
<b>Predisposing Factors</b>				
Age	-.003	.997	.972	1.022
Gender <sup>a</sup>	-.225	.798	.303	2.104
Race/ethnicity				
White/Caucasian <sup>b</sup>				
Black/African American	-.724	.485	.185	1.271
Hispanic/Latino	.012	1.012	.386	2.652
Education	.000	1.000	.902	1.109
<b>Enabling Resources</b>				
Caregiver Intervention <sup>c</sup>	.457	1.579	.839	2.971
Religiosity	-.292	.747	.532	1.048
Social Network	.027	1.027	.961	1.097
Satisfaction with Support	-.016	.984	.851	1.137
<b>Need Factors<sup>d</sup></b>				
Depressive Symptoms	.054	1.055***	1.027	1.085

\*p<.05, \*\*p<.01

<sup>a</sup> Reference category: females

<sup>b</sup> Reference category

<sup>c</sup> Reference category: control group

<sup>d</sup> Anxiety and complicated grief were excluded from the model

successfully predicted time to psychotropic medication use after adjusting for other covariates ( $\chi^2(1) = 14.77, p = .000$ ), with each one-point difference in depressive symptoms resulting in a 6% increase in the probability of psychotropic medication use.

Table 3.5. Cox Proportional Hazards Model of Overall Bereavement Service Utilization

	B	Odds Ratio	95% Confidence Interval	
			Lower	Upper
<b>Predisposing Factors</b>				
Age	-.007	.993	.975	1.012
Gender <sup>a</sup>	.034	1.035	.516	2.074
Race/ethnicity				
White/Caucasian <sup>b</sup>				
Black/African American	-.497	.608	.306	1.210
Hispanic/Latino	.531	1.700	.889	3.254
Education	.018	1.018	.945	1.098
<b>Enabling Resources</b>				
Caregiver Intervention <sup>c</sup>	.070	1.073	.660	1.745
Religiosity	-.044	.957	.727	1.261
Social Network	-.006	.994	.946	1.045
Satisfaction with Support	.033	1.033	.926	1.153
<b>Need Factors<sup>d</sup></b>				
Depressive Symptoms	.035	1.035**	1.015	1.056

\*\*p<.01

<sup>a</sup> Reference category: females

<sup>b</sup> Reference category

<sup>c</sup> Reference category: control group

<sup>d</sup> Anxiety and complicated grief were excluded from the model

The overall bereavement service utilization rate, reflecting use of any one or more of the above bereavement services during the course of the study, was 33.9% (N = 76).

The first use of any bereavement service was reported an average of 137 days (SD = 83.8), or 4.5 months, after the care recipient's death and 93% (N = 70) reported use within the first 9 months.

In the overall Cox proportional hazards model of bereavement service use (displayed in Table 3.5), only the needs factor block containing depressive symptoms successfully predicted time to service use ( $\chi^2(1) = 11.36, p = .001$ ). After adjusting for other covariates, each one-point difference in depressive symptoms resulted in a 4% increase in the probability of bereavement service utilization.

### Discussion

Overall, approximately one-third of bereaved family caregivers utilized services, almost entirely during the first 9 months after the death of the care recipient. Participants utilized support groups, counseling, and psychotropic medications in similar proportions. Slightly less than one fifth of participants utilized each of these bereavement services to facilitate their adjustment to bereavement after providing care to a loved one with Alzheimer's disease or dementia. These rates of bereavement service utilization are consistent with rates found in other studies (Billings & Kolton, 1999; Caserta & Lund, 1992; Cherlin et al., 2007; Levy & Derby, 1992; Provini et al., 2000; Schulz, Mendelsohn, et al, 2003).

The most striking finding in the present analyses is the prominent role of need factors in the utilization of bereavement services by family caregivers. Consistent with studies of other types of health services utilization employing the Andersen model (Aday & Andersen, 1974; Coulton & Frost, 1982; Kart, 1991; Wallace et al., 1998) need factors, including depressive symptoms and complicated grief, appear to be important in driving service use. In another recent study of bereavement service utilization grounded in Andersen's model (Bergman, Haley, & Small, 2008), grief served as a need factor in the use of any bereavement service and in talking with a physician for help in coping with the

death of the care recipient. Bergman and Haley (2008) also found no relationship between depressive symptoms and bereavement service utilization in a study of bereaved hospice caregivers. Taken together, these findings suggest that while bereavement outcomes are an important consideration in the planning and design of bereavement services, more research is needed to understand the contributions of a broad range of potential need factors.

We are encouraged by our findings in the current study which indicate that those who are most distressed in bereavement are seeking out and utilizing bereavement services. This suggests the need for continued and increased outreach and other efforts to assure timely access to those bereaved family caregivers who are most in need. This could be achieved through the standardization of regular screenings by family physicians of bereaved family caregivers and referral to bereavement services for those identified as experiencing mental health decrements. Also of potential benefit are educational efforts designed to inform family caregivers and the general public that, while some emotional distress is to be expected, excessive psychological distress is not a normal part of bereavement and services are available to aid in the adjustment to this transition. Furthermore, efforts to assure the availability of a wide range of carefully-evaluated services which appeal to the needs and preferences of diverse family caregivers are important.

Also of interest in the current study is the finding that race/ethnicity served as a predisposing characteristic for support group utilization, with Black caregivers being the least likely and Hispanic caregivers the most likely to utilize a support group. Research suggests that Black individuals possess unique strengths in coping with family caregiving

(for a review see Dilworth-Anderson et al., 2002), strengths which may be carried into bereavement (Schulz et al., 2001) resulting in decreased need for bereavement services. In a study using REACH data of racial differences between Caucasian and African-American caregivers (Haley et al., 2004), Caucasian caregivers reported significantly higher levels of anxiety but no difference emerged in the experience of depressive symptoms. No ethnic difference on either of these measures was found when comparing the experiences of Latina and White caregivers in the REACH study (Coon et al., 2004). Similarly, post hoc analyses in the current study revealed no differences in depressive symptoms, anxiety, or complicated grief between White, Black, and Hispanic bereaved caregivers. Given that Black caregivers in the present study were not suffering less in bereavement than their White or Hispanic peers, Black caregivers may have lacked knowledge of or access to support group services (Bradley et al., 2002), held stronger preferences against support group use, or relied more heavily instead on their informal support network as has been found in studies comparing the formal service utilization rates of different racial and ethnic groups (Dilworth-Anderson et al., 2002; Mui & Burnette, 1994; Williams & Dilworth-Anderson, 2002).

In general, Hispanic adults in the U.S. report fewer mental health problems and less mental health service use than White adults (Harris et al., 2005). A recent meta-analysis (Pinquart & Sörensen, 2005) reveals, however, that Hispanic caregivers experience worse physical and mental health than White caregivers. Thus, for many Hispanic caregivers, bereavement may represent an end to the role captivity experienced during caregiving and the opportunity to address long-standing mental health issues and grief. An alternative potential explanation for our finding that bereaved Hispanic family

caregivers utilized support groups at a rate more than twice that of their White peers may be that Spanish-speaking support groups were more accessible or highly preferred by Hispanic caregivers than other types of bereavement services.

To date, the REACH dataset represents the largest and most diverse sample of family caregivers with which to examine bereavement service utilization. However, further research with larger sample sizes and more specific measures is necessary in order to better understand the reasons behind and implications of our findings regarding race/ethnicity and bereavement service utilization.

Contrary to our expectations, few other variables in the current study served as predisposing characteristics or enabling resources in the utilization of bereavement services in the current study. More research is needed in this area to examine the roles of demographic characteristics, religiosity, social resources, and other potential covariates affecting bereavement service utilization among diverse samples of bereaved family caregivers. One such potential addition to the model is health beliefs, described by Andersen (1995) as a predisposing characteristic including “attitudes, values, and knowledge that people have about health and health services that might influence their subsequent perceptions of need and use of health services” (p. 2). Related to the current study, health beliefs may include individual attitudes about “normal” and “pathological” grief. For example, an individual who believes that a certain degree of psychological suffering is a normal part of bereavement may be less inclined to utilize services than someone who does not hold this health belief.

The Andersen model has been used extensively to examine health care utilization (e.g., Andersen, 1968) and equity in the health care system (e.g., Andersen et al., 1975),

to make cross-national comparisons in health service utilization (Andersen, 1976), and in many studies of the use of nursing homes (e.g., Freedman, 1993), in-home nursing (e.g., Rabiner, 1992), adult day care (e.g., Conrad et al., 1992), and other formal and informal services by older adults. The primary strength of the current study is the extension of the application of the Andersen model to the examination of bereavement service utilization.

As with any research conducted using secondary data, the current research has some limitations which should be noted. Specifically, in the current study need was conceptualized as the self-report of symptoms of depression, anxiety, and complicated grief at the first interview after the death of the care recipient. We were not able to examine the role, if any, of need as evaluated by a healthcare professional.

Communication with a physician or other healthcare provider in the early stages of bereavement may result in the identification of the need for intervention, referral to bereavement services, or increased knowledge of available services and these factors may in turn increase the probability of bereavement service utilization (Cherlin et al., 2007). Hospice enrollment of the care recipient may also lead to increased bereavement service utilization through increased access to health personnel trained in end-of-life issues and the provision of bereavement follow-up mandated by Medicare regulations. Future study is needed regarding the influence of communication with a physician or other healthcare provider, such as hospice bereavement personnel, on perceived and evaluated need for bereavement services.

## Chapter Four:

Depressive symptoms, social network, and bereavement service utilization and preferences among spouses of former hospice patients

## Abstract

**Background:** Bereavement services are an important part of comprehensive end-of-life care with potential to ameliorate physical, psychological, and spiritual distress. We studied bereaved spouses of hospice patients to examine bereavement service utilization, barriers, and preferences regarding content, structure, and delivery of potential bereavement services. We also examined the impact of depressive symptoms and social network. **Methods:** Retrospective cohort study of bereaved spousal caregivers of patients of three hospices in Tampa Bay. Descriptive and univariate analyses assessed demographics, depressive symptoms, social network, service utilization, barriers, and preferences. **Results:** Nearly half utilized at least one type of specialized professional bereavement intervention to aid in coping with their loss. The most frequently used services were provided by clergy members and physicians. Primarily attitudinal in nature, barriers included the finding that more than one third felt available services did not fit their needs or interests. Individual and spiritually-based services were highly endorsed, as were services designed to provide tools to reframe the loss and cope with accompanying changes and emotions. Lower social network was associated with higher content preferences for services consistent primarily with restoration-oriented coping. **Conclusion:** Clinicians and service providers may facilitate coping by routinely screening for depressive symptoms and social network and tailoring interventions to those identified as experiencing elevated distress or lacking social resources. Attitudinal barriers and preferences suggest that even in the service-rich environment of hospice some modification of bereavement services might reach more bereaved spouses. Future

studies might address whether preferences lead individuals to services of the greatest benefit.

## Introduction

Nearly one million individuals in the United States each year experience the death of their spouse (Kung, Hoyert, Xu, & Murphy, 2008). This can be a difficult and stressful transition, leading to considerable physical and psychological distress for some individuals (Bonanno et al., 2002; Genevro, 2004). Bereavement outcomes which have been reported in the literature include grief, depression, anxiety, diminished quality of life, increased health care utilization, and increased risk of physical illness and mortality (Christakis & Iwashyna, 2003; Goodkin et al., 2001; Stroebe et al., 2007).

An array of services and interventions has been developed in an effort to assist widows and widowers in their adjustment to bereavement (Forte et al., 2004; Schut et al., 2001). Although most studies have focused on a particular service or services of interest rather than examining use of a comprehensive range of services, previous estimates of bereavement service utilization rates range from 10% to 35% (Billings & Kolton, 1999; Caserta & Lund, 1992; Cherlin et al., 2007; Levy & Derby, 1992; Provini et al., 2000; Schulz, Mendelsohn, et al., 2003). However, little is known about the types of services individuals choose or about whether they face challenges or barriers to the utilization of these services. Further, it is important to consider the preferences of bereaved individuals regarding the content and structure of bereavement services, as they are likely to impact whether or not an individual initiates use, follows through upon referral, or maintains their participation in a service from which they could potentially benefit.

In a study of attitudes towards mental health care (Robb et al., 2003), older adults reported favorable attitudes, but lacked experience and knowledge of mental health care as compared to younger adults. Many viewed their family doctors and clergy as

important sources for help with mental health issues and for referral to other mental health services. Because most individuals experience widowhood in later life, these findings are likely to have bearing in the utilization of services for bereaved spouses. Other services frequently available to survivors of hospice patients include bereavement support groups and bereavement counseling.

Research indicates that bereavement interventions can be of benefit in mitigating the potential negative outcomes associated with spousal loss (Larson & Hoyt, 2007a; Zisook & Shuchter, 2001). However, while claims of treatment induced deterioration effects of bereavement counseling (Fortner, 1999; Neimeyer, 2000) have largely been dismissed (Larson & Hoyt, 2007b), reviewers of the efficacy of bereavement services (Raphael, Middleton, Martinek, & Misso, 1993; Schut & Stroebe, 2005) argue against routine intervention for bereaved individuals, citing a lack of justification for their need by those who respond to bereavement with resilience (Chentsova Dutton & Zisook, 2005). Instead, experts advocate for the targeting of resources and interventions to those suffering in bereavement, those in a high-risk group, and to those lacking access to supportive persons and resources (Parkes, 1998). Thus, interventions and services which are not tailored to fit the needs of these individuals and which they do not find appealing are not likely to be utilized (Mittelman, 2008; Robb et al., 2003; Zhang et al., 2006), and represent an inefficient use of resources. It is important to study the preferences and motivations of bereaved individuals and to incorporate these into the design of services which will appeal to and facilitate adjustment among those most in need.

Two risk factors which may simultaneously serve as a reason bereaved spouses may benefit from services and why they do not seek services are high levels of depressive

symptoms (Jordan & Neimeyer, 2003) and low levels of social resources. Depression is a frequently studied bereavement outcome (Stroebe et al., 2007), and it is estimated that between 25% and 45% of bereaved individuals experience mild levels and between 10% and 20% experience clinically significant levels of depressive symptoms (Hansson & Stroebe, 2003). In the general mental health services literature, elevated distress is associated with increased likelihood of utilizing mental health services (Mojtabai & Olfson, 2006; Rhodes, Jaakkimainen, Bondy, & Fung, 2006). However, Prigerson and colleagues (2001) found that those suffering the most in bereavement tended to be the least likely to seek out formal services. Older bereaved spouses experiencing elevated levels of depressive symptoms may favor services viewed as psychoeducational or supportive (e.g., support groups) rather than services viewed as treatment for a mental health diagnosis (e.g., psychologist/psychiatrist), due to concerns about stigma (Gallagher-Thompson et al., 2003) and perceptions of their need for professional help as indication of their inability to live independently (Bambauer & Prigerson, 2006).

Research indicates that social network members are an important factor in the decision to utilize mental health services in general (Vogel, Wade, Wester, Larson, & Hackler, 2007) and that those with larger social networks are less likely to use formal, outpatient mental health services (Kang et al., 2007; Pescosolido, Wright, Alegría, & Vera, 1998), whereas those with greater perceived deficits in the amount of support available from social network members are more likely to use formal mental health services (Phillips & Murrell, 1994). In bereavement, those with larger social networks characterized by more frequent contact and greater perceived closeness with network members may be less likely to need services as they receive support informally from

network members. Alternatively, larger social networks characterized by closer relationships and more frequent contact may facilitate service use as network members observe suffering and encourage the use of formal resources or make their use possible through the provision of instrumental support, such as transportation.

The present study was conducted in an effort to examine the bereavement service utilization rates and perceived barriers to service use reported by former spousal hospice caregivers and to examine their preferences regarding the content, structure, and delivery of potential bereavement services. An additional goal was to examine group differences in bereavement service utilization rates, barriers, and preferences based on levels of depressive symptoms and social network. We hypothesized that those with higher levels of depressive symptoms and smaller social networks would report higher bereavement service utilization rates and ratings reflecting stronger preferences regarding potential bereavement services.

## Methods

### *Procedure*

This study was conducted in collaboration with three hospice organizations serving the Tampa Bay community, including LifePath Hospice and Palliative Care, Hernando Pasco Hospice, and Hospice of Southwest Florida (now TideWell Hospice and Palliative Care). The spouses of patients who died under the care of these hospices between 6 and 20 months prior received a letter from the hospice bereavement department inviting them to participate in the study. Data were collected during in-home interviews conducted by the lead author.

### *Participants*

The final sample included 61 bereaved spousal caregivers of former hospice patients. The mean age of participants was 72 years (SD=10).

### *Measures*

#### *Demographics & Sample Characteristics*

Basic demographic and sample characteristics included age, gender, race/ethnicity, education, religious affiliation, the number of years married, and the amount of time elapsed since the death.

#### *Depressive Symptoms*

We utilized the 20-item version of the Center for Epidemiologic Studies-Depression Scale (CES-D), a self-rated measure of depressive symptoms (Radloff, 1977). Participants were asked to provide information as to the frequency of behaviors and feelings during the past week. Responses ranged from “rarely or none of the time” to “most of the time” on a 4-point Likert scale. The CES-D has been used in a broad range of studies, including those of caregiving and bereavement, and validated cutpoints for clinical significance have been established. Specifically, a score of 16 or higher on the 20-item version of the CES-D is indicative of clinically relevant depressive symptomatology (Lewinsohn, Seeley, Roberts, & Allen, 1997).

#### *Social Network*

Lubben’s Social Network Scale (LSNS) is a composite scale for measuring social network in adult populations (Lubben, 1988). The first six items of the LSNS, which assess social network size, frequency of contact, and closeness with family and friends, were selected for use in this study. Possible scores range from 0-30, with higher scores

indicating greater size, more frequent contact, and more closeness with members of the social network.

#### *Bereavement Service Utilization and Barriers*

Participants were asked a series of questions designed to learn about their use of bereavement services. Specifically, they were asked whether or not they received help from a list of professionals (see Table 4.2) to aid in dealing with their loss and about support group attendance and use of bereavement counseling. They were also presented with a range of potential barriers (see Table 4.3) to bereavement service utilization and asked to retrospectively report whether or not they experienced any of these barriers.

#### *Bereavement Service Preferences*

In the first part of this measure, using a 7-point Likert scale ranging from “least appealing” to “most appealing,” participants were asked to rate 19 items (see Table 4.4) pertaining to the content of potential bereavement services. Items included in this measure were intended to reflect a variety of perspectives on bereavement intervention, including grief work (Bonanno, 2001), cognitive-behavioral therapy and cognitive restructuring (Boelen, de Keijser, van den Hout, & van den Bout, 2007), and psychoeducational, interpersonal resource and practical skill building perspectives (Caserta & Lund, 1993). The measure was also designed to reflect the dual process model of grief (Stroebe & Schut, 1999), including features of interventions which emphasized loss-oriented and restoration-oriented coping among the bereaved. The second part of this measure asked participants to rate 11 items (see Table 4.5) pertaining to the structure and delivery of bereavement services.

### *Statistical Analysis*

Basic descriptive analyses were used to assess participants' demographic characteristics, depressive symptoms, and social network as well as bereavement services utilization, barriers, and preferences. Independent samples t-tests and chi-square analyses were used to examine group differences in service utilization, barriers, and preferences based on level of depressive symptoms and social network. The sample was divided into low and high social network groups using a median split. Those with scores of 21 or higher on the LSNS were categorized as high social network and those with scores below 21 were categorized as low social network. The sample was divided into low and high depressive symptoms groups using a cutoff score of 16 or higher on the CES-D, a score suggestive of clinically relevant depressive symptomatology. Since bereavement service utilization and perceived barriers were measured dichotomously, chi-square tests were used to examine associations. Group differences in preferences were examined using independent samples t-tests. Preference scores for each of the 30 items were centered using z-transformation in order to standardize the interpretation of mean comparisons, but for simplicity of presentation raw means are shown in the tables.

### Results

#### *Sample Characteristics*

Table 4.1 displays the characteristics of the sample, which consisted primarily of Caucasian females. Participants ranged in age from 46 to 87 years and most reported at least some education beyond high school. The length of time participants had been married to their spouse ranged from 2 to 65 years, with a median of 40 years. Bereavement occurred between 7 and 18 months prior to taking part in the study. The

median length of time since the death was 11 months. The mean CES-D depressive symptoms score for participants was 15.7 (SD = 10.2; range 0-39). The mean LSNS score was 20.2 (SD = 5.6; range 2-29).

Table 4.1. Sample Characteristics (N = 61)

<i>Variable</i>	<i>N</i>	<i>(%)</i>
<b>Gender</b>		
Female	45	(73.8%)
Male	16	(26.2%)
<b>Race/Ethnicity</b>		
Caucasian	60	(98.4%)
Hispanic	1	(1.6%)
<b>Education</b>		
8 <sup>th</sup> Grade or Less	6	(9.8%)
High School/GED	14	(23%)
Some College	17	(27.9%)
College Graduate	16	(26.2%)
Post-Graduate Study	8	(13.1%)
<b>Religious Affiliation</b>		
Protestant	34	(55.7%)
Roman Catholic	17	(27.9%)
Jewish	2	(3.3%)
Other	8	(13.1%)

#### *Bereavement Service Utilization*

We found that nearly half (45.9%) of the bereaved caregivers who participated in this study utilized at least one type of specialized professional bereavement intervention, including either a support group, bereavement counseling, or a psychologist or psychiatrist to aid in coping with the death of their spouse. Nearly all participants

(88.5%) reported some bereavement service utilization when we employed a more liberal definition of some kind of formal professional service utilization, which also included receiving help from a physician, member of the clergy, social worker, or nurse.

The most frequently used bereavement services were provided by members of the clergy and by physicians, followed by bereavement support groups and individual bereavement counseling. Smaller proportions of participants reported talking with a social worker, volunteer, or a psychologist or psychiatrist about their loss.

Table 4.2. Bereavement Service Utilization Rates

Service	N (%) Reporting Use (N = 61)
Talked with Clergy	34 (55.7%)
Talked with Physician	30 (49.2%)
Support Group	24 (39.3%)
Bereavement Counseling	19 (31.1%)
Talked with Nurse	18 (29.5%)
Talked with Social Worker	13 (21.3%)
Talked with Volunteer	11 (18%)
Talked with Psychologist or Psychiatrist	6 (9.8%)

#### *Barriers to Service Use*

The most commonly reported barriers to service utilization were attitudinal, in that participants did not recognize the utility of bereavement services, they did not feel they needed assistance in coping with bereavement beyond that provided by their informal social network, or they perceived that the available services did not match their

needs or interests. It is of particular note that 41% of bereaved spouses reported that available services did not fit their needs or interests, suggesting that even in the relatively service-rich environment of hospice some modification of bereavement services might reach more bereaved spouses. A small minority of participants reported experiencing practical barriers to bereavement service utilization, such as a lack of transportation or the inability to pay for services.

Table 4.3. Perceived Barriers to Bereavement Service Utilization

Perceived Barrier	Yes N (%)
Didn't see the use in participating	32 (54.2%)
Didn't think I needed any help beyond family and friends	27 (44.3%)
Services available didn't fit my needs or interests	25 (41%)
Too depressed	4 (6.8%)
Lack of transportation/Required traveling too far	2 (3.3%)
Couldn't afford a service I was interested in	1 (1.6%)
My family did not want me to participate	0 (0%)

#### *Bereavement Service Preferences*

The mean preference ratings of all 19 items regarding the content of potential bereavement services are shown in rank order in Table 4.4. Results reflect preferences for services designed to give participants tools to reframe their loss and to cope with the changes and feelings that accompanied the loss. They also favored services focused on engagement with community and a broadened social network and on distraction, relaxation, and stress management.

Table 4.4. Mean Preferences Regarding Content of Bereavement Services

Preference	M	SD
Find things to laugh about	4.22	2.23
Starts before your spouse dies and help you know better what to expect	4.18	2.30
Talk about your feelings related to the loss	4.13	1.95
Help you make new friends	4.08	2.07
Provide information about community resources	4.00	2.15
Teach you how to relax	3.95	2.28
Rethink or work through challenging situations	3.95	2.27
Focus on growth and things you've learned	3.83	1.99
Give you tools to help with loneliness or depression	3.79	2.09
Stress management	3.75	2.22
Give you confidence to know you can make it through the loss	3.64	2.23
Express your grief over the loss	3.59	2.20
Make meaning of your loss	3.33	2.38
Teach you how to do things your spouse used to do	3.33	2.26
Explore your continued relationship with your spouse	3.22	2.22
Get involved in your community and with your friends again	3.17	2.01
Help you stop thinking about your loss all the time	2.87	2.18
Work through "unfinished business" with your spouse	2.62	2.29
Relate better or participate more in lives of family members	2.49	1.86

Regarding structure and delivery, participants favored individual, spiritually based interventions delivered in their homes. Their preferences also reflected a desire for diversity with regard to gender and age among participants, and very low ratings for online and instructional formats. The mean preference ratings for all 11 items regarding the structure of potential bereavement services are shown in rank order in Table 4.5.

#### *Impact of Depressive Symptoms*

Using a cutoff score of 16 on the CES-D, 29 (47.5%) participants were included in the high depressive symptoms category and 32 (52.5%) were included in the low depressive symptoms category. Fisher's exact and Pearson's chi-square tests were then used to compare the bereavement service utilization rates and reports of barriers to service use among high and low depressive symptoms groups. Contrary to our expectations, depressive symptoms had little relationship with service utilization or perceived barriers. No significant differences between low and high depressive symptoms groups were found in utilization rates of support groups, bereavement counseling, or in talking with a physician, clergy member, nurse, social worker, volunteer, psychologist or psychiatrist. The only significant difference in barriers to service use was in the proportion of participants in the low and high depressive symptoms groups who felt too depressed to participate (0% and 13.8% respectively; Fisher's exact test  $p = .045$ )

Table 4.5. Mean Preferences Regarding Structure of Bereavement Services

Preference	M	SD
Individual	5.19	1.91
Spiritually-based	4.42	2.31
Provided in your home	4.27	2.02
Group	3.73	2.27
Widow-to-widow	3.70	2.32
Limited by age group	3.37	2.15
Therapy	3.30	2.38
Self-administered	3.03	2.05
Instructional or lecture format	3.02	2.18
Limited by gender	3.02	2.09
Computer-based or online	2.24	1.93

The mean preference score for services designed to help participants find things to laugh about for the low depressive symptoms group was 3.61 (N=31; SD=2.33) and for the high depressive symptoms group it was 4.86 (N=29; SD=1.94). A statistically significant difference was found between the two scores,  $t(58) = 2.25, p=.029$ . There were no significant differences in preferences regarding the other 18 items related to content (see Table 4.4) or the 11 items related to the structure and delivery (see Table 4.5) of potential services based on level of depressive symptoms.

### *Impact of Social Network*

Group differences based on social network were then examined for each item on the bereavement service utilization measure and the measure of perceived barriers to service use. Of those in the low social network group, 44.8% (n=13) utilized bereavement counseling, compared to 16.1% (n=5) of those in the high social network group,  $\chi^2(1, N=60) = 5.88, p=.015$ . No significant differences emerged in the proportion of participants in the low and high social network groups who utilized the other seven bereavement services (see Table 4.2).

For those in the high social network group, 71.0% (n=22) reported that they did not see the use in participating in bereavement services, compared with 35.7% (n=10) of those in the low social network group,  $\chi^2(1, N=59) = 7.37, p=.007$ . There were no significant differences based on social network in the proportion of participants who reported experiencing the other six perceived barriers to bereavement service utilization (see Table 4.3).

As shown in Table 4.6, the mean preference ratings for ten of the items pertaining to the content of potential services were rated significantly higher for the low social network group when compared with the high social network group. Services that were more highly favored by those in the low social network group included those intended to help participants reframe or distract from the loss, to help them express or cope with their grief, or to promote self-efficacy, skill building, or social engagement. There were no significant differences in preference ratings for the 11 items related to the structure and delivery of potential services based on social network group.

Table 4.6. Differences in Content Preferences Based on Level of Social Network

Preference	Low Social Network		High Social Network		df	t
	M	SD	M	SD		
Find things to laugh about	5.10	1.80	3.39	2.29	57	-3.55**
Help you stop thinking about your loss all the time	3.59	2.32	2.13	1.83	56	-2.83**
Express your grief over the loss	4.34	2.11	2.87	2.11	57	-2.68*
Give you tools to help with loneliness or depression	4.48	1.82	3.23	2.14	57	-2.60*
Give you confidence to know you can make it through the loss	4.31	2.27	3.00	2.07	57	-2.56*
Teach you how to do things your spouse used to do	4.00	2.39	2.71	1.97	57	-2.48*
Relate better or participate more in lives of family members	3.11	2.10	1.97	1.45	55	-2.39*
Teach you how to relax	4.66	1.97	3.29	2.42	57	-2.38*
Rethink or work through challenging situations	4.62	2.11	3.33	2.31	56	-2.17*
Focus on growth and things you've learned	4.34	1.78	3.35	2.09	57	-2.04*

\*  $p < .05$ , \*\*  $p < .01$

## Discussion

In the current study, 45.9% of bereaved spouses used specialized professional bereavement services (i.e., support group, bereavement counseling, or

psychologist/psychiatrist) and 88.5% reported any formal service use (also including physician, clergy, social worker, nurse) to aid in the adjustment to bereavement. This is a higher rate of bereavement service utilization than has been found in previous studies (Billings & Kolton, 1999; Caserta & Lund, 1992; Cherlin et al., 2007; Levy & Derby, 1992; Provini et al., 2000; Schulz, Mendelsohn, et al., 2003). This is likely due to the fact that all spouses died while enrolled in hospice, a system of care which includes the availability of bereavement follow-up and services for surviving family members and other loved ones. These caregivers likely had access to information and services which are not routinely available to non-hospice caregivers.

The most frequently used services were provided by members of the clergy (55.7%) and by physicians (49.2%). These results are consistent with previous studies of mental health service utilization by older adults in highlighting the importance of these professionals as sources of support (Caserta & Lund, 1992; Phillips & Murrell, 1994; Robb et al., 2003). Despite their importance as sources of support to the bereaved, fewer than 25% of physicians take a course in death in dying while in medical school (Wass, 2004) and many express lack of confidence and training in the provision of bereavement care (Genevro, 2004; Joanna Briggs Collaborating Center for Evidence-based Multi-professional Practice, 2006). Wide variation also exists in the level of bereavement care training of clergy and other religious service providers (Joanna Briggs Collaborating Center for Evidence-based Multi-professional Practice, 2006). Our findings suggest the merit of the inclusion of bereavement training in the professional and continuing education curricula of these professionals. At a minimum, such training might consist of effective methods of communication with bereaved individuals, risk factors for and

identification of distress both before and after the loss, the assessment of bereavement service needs, and professional collaborations and referral sources available in the effort to ensure that patients and parishioners receive comprehensive end-of-life care, including bereavement services for survivors (Genevro, 2004).

We are encouraged by our finding that few participants experienced practical barriers to bereavement service utilization. The higher rate of reported attitudinal barriers to service use, however, suggests the need for education and outreach with bereaved individuals in an effort to dispel these attitudes. The finding that the majority of participants did not see the use in participating in bereavement services may reflect many participants' resilience and ability to effectively utilize support provided by the informal network in coping with and adjusting to the loss of a spouse. However, similar proportions of individuals experiencing low and high depressive symptomatology failed to see the utility in service use. Thus, screening for depressive symptoms as well as outreach and education with bereaved individuals who are experiencing high levels of depressive symptoms are important considerations for bereavement service providers.

Nearly half of participants reported that the available services did not match their needs or interests. This attitudinal barrier, reported in similar proportions by low and high depressive symptoms and social network groups, suggests a need for careful attention to the preferences of potential participants in planning and delivering bereavement services, as they are likely to impact initiation and ongoing participation.

In the current study, preferences regarding the content, structure and delivery of bereavement services reflected a wide variety of perspectives and participants' desire to be actively engaged in their adjustment to widowhood as well as in other aspects of their

lives. Preferences also reflected a desire for services designed to enhance both types of coping, loss-oriented and restoration-oriented, included in the dual process model of grief (Stroebe & Schut, 1999). Of note, the low social network group expressed significantly higher preferences than the high social network group for services consistent primarily with restoration-oriented coping. Previous research has suggested that those lacking in social resources may be especially vulnerable in bereavement given their diminished opportunities for the expression of grief, an activity consistent with loss-oriented coping (Raphael, Minkov, & Dobson, 2001). Our findings suggest that social resources are also vital in providing an environment which allows for activities consistent with restoration-oriented coping, including attending to life changes, establishing new roles and relationships, and distractions from grief.

Future studies should examine whether the provision of services viewed as more appealing and applicable to the needs and preferences of bereaved individuals lead to more favorable adjustment in bereavement. For example, participants highly favored services designed to give them the opportunity to talk about their feelings related to the loss. However, research (Stroebe, Schut, & Stroebe, 2005) suggests that talking about the loss or one's feelings about the loss may not facilitate adjustment to bereavement. On the other hand, the highest preference rating in this study was given to services designed to help participants find things to laugh about. Genuine laughter by bereaved individuals has been associated with an increase in positive emotions, as well as a reduction in the experience of negative emotions (Keltner & Bonanno, 1997). Therefore, it will be important to understand whether or not preferences lead individuals to services which will be of greatest benefit.

We found little relationship between social network and depressive symptoms and bereavement service utilization rates. For example, only 41.4% of bereaved spouses with high depressive symptoms used support groups, and only 37.9% used bereavement counseling, despite these services being readily available in the hospices. This suggests that many with the potential to benefit may not be accessing bereavement services. Bereaved older adults may view negative experiences in bereavement as a normative part of growing older and may benefit from expanded outreach and educational efforts, as well as improved access to bereavement services.

While limited by sample size and cross-sectional design, this study was intended to set the stage for more in-depth examinations of the needs and characteristics of distressed bereaved individuals as well as individual motivations and preferences for bereavement service utilization. We view this study as an important step in the development and evaluation of appealing bereavement interventions that are accessible to and widely utilized by those most in need.

## Chapter Five

### Conclusions

In recognition of the wide variability in the experiences of bereaved family caregivers and the potential for distress, the present series of three studies examined bereavement services utilization among bereaved family caregivers. Current service utilization as well as preferences regarding the content, structure, and delivery of potential bereavement services were examined. Collectively, these studies were undertaken in an effort to better understand current predictors of service utilization and to determine whether those experiencing the highest levels of distress were accessing bereavement services designed to help ameliorate this distress. It is also hoped that the current studies will contribute to the effort to develop and deliver bereavement services which appeal to the preferences and are utilized by those most in need.

Guided conceptually and analytically by Andersen's behavioral model of health services use (Aday & Andersen, 1974; Andersen, 1968; Andersen & Newman, 1973), the first study examined bereavement service utilization rates, the types of services used, and predictors of service utilization among bereaved spousal caregivers using data from the Changing Lives of Older Couples (CLOC) study. Results indicated that a large proportion utilized some type of bereavement service, including talking with their family doctor or a member of the clergy, attending a support group, or seeing a mental health professional. The most commonly utilized services were provided by members of the

clergy and by family physicians. Grief was found to be a need factor, with higher levels of grief playing a prominent role in talking with the family doctor and in the use of services in general. Higher levels of depressive symptoms resulted in a decreased likelihood of talking with the family doctor. While need factors were not associated with use of clergy for bereavement care, racial minority status served as a predisposing characteristic and higher religious involvement served as an enabling resource in the utilization of services provided by members of the clergy.

Similar to the first, the second study examined service utilization rates, the types of services used, and predictors of service utilization. This study included bereaved family caregivers, regardless of relationship, who had provided care to a loved one who suffered from Alzheimer's disease or dementia. Data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) were utilized in the second study. One-third of study participants utilized bereavement services after the death of the care recipient. Similar rates – nearly one in five – were found for the use of support groups, bereavement counseling, and psychotropic medication. Depressive symptoms, a need factor, played a prominent role in the use of counseling (individual, family, and pastoral) and psychiatric medication, and in service use in general. Complicated grief served as a need factor in the use of a support group, with higher complicated grief associated with greater likelihood of using this service. Black caregivers were less likely and Hispanic caregivers were more likely than White caregivers to use a support group.

The third study examined service utilization rates, the types of services used, barriers to service use, and preferences regarding the content, structure, and delivery of bereavement services in a sample of bereaved caregivers whose spouses died while under

the care of one of three local hospice organizations. Hospice is a relatively service rich environment in which programs are mandated to offer bereavement services for family members for one year after the death of the hospice patient. Thus in hospice services lack of service use is not due to lack of availability. The majority of participants utilized bereavement services, including support groups and counseling, as well as talking with a psychologist or psychiatrist, a physician, member of the clergy, social worker, or nurse for help in coping with the death of their spouse. The most commonly used services were provided by members of the clergy and physicians. Barriers were primarily attitudinal, rather than practical, in nature. Participants preferred services designed to give them tools to reframe their loss and adjust to accompanying changes, to help them engage with the community, and to manage stress. They favored interactive services over those offering little opportunity to engage with other bereaved individuals or with service providers. A significantly higher proportion of participants in the low social network group utilized bereavement counseling than did those in the high social network group, a group more likely to report that they did not recognize the utility of bereavement services. Services that were more highly favored by those in the low social network group and by those with higher levels of depressive symptomatology were those intended to help participants reframe or distract from the loss. Those in the low social network group also favored services designed to help them express or cope with their grief or to promote self-efficacy, skill-building, or social engagement.

Collectively, the studies in this dissertation suggest that need factors play a prominent role in driving the utilization of bereavement services and that the experience of grief and depressive symptoms is associated with seeking out and accessing supportive

services in bereavement. However, there is still a significant gap, with many highly depressed bereaved caregivers not using services. More research is necessary in order to more clearly describe the full range of need factors and to understand how need is determined and ultimately results in service utilization. While social resources did not play an enabling role in the use of services, they were associated with preferences regarding the content of bereavement services. These findings, combined with recommendations that bereavement services target those at highest risk for and experiencing distress in bereavement (Genevro, 2004; Schut & Stroebe, 2005; Schut et al., 2001), have some important implications. First, outreach with and routine screening to identify individuals with elevated depressive symptoms, complicated grief, and other need factors and for decrements in social resources are needed. Findings regarding the importance of physicians and members of the clergy in the lives of bereaved family caregivers suggest that these professionals are critical partners in these outreach and screening efforts. In addition, services should be designed and delivered in a manner consistent with preferences and should take level of social resources into consideration. Tailoring interventions to the needs and preferences of those in greatest need will maximize the likelihood of their utilization in facilitating adjustment to the bereavement transition and will contribute to ensuring the highest possible quality of life for bereaved family caregivers.

### Limitations

The research described in this dissertation suffers from some limitations which should be noted. While the datasets used in the secondary data analysis portions of the current project were chosen specifically because they best allowed for examination of the

research questions, they nonetheless omitted some data which would likely strengthen the explanatory power of the model. First, the CLOC and REACH datasets did not contain information about whether or not the care recipient died while under hospice care. The provision of hospice care is likely to impact knowledge of available bereavement services, the lack of which may be a significant barrier to bereavement service utilization as it was in the use of long term care (Bradley et al., 2002). Future research should address this in an effort to understand the roles played by knowledge of available services and by hospice use in general.

In both the CLOC and REACH studies, information about the utilization of bereavement services was collected retrospectively and was self-reported by participants. This is a common approach to the study of health behavior and the only option for the collection of data pertaining to utilization of bereavement services which are not reimbursable under Medicare, Medicaid, or other insurance plans (e.g., bereavement support group, clergy/pastoral counseling). However, studies indicate that when compared with information about actual utilization as obtained from administrative records, self-reported health services utilization is frequently underestimated (Dunlop et al., 2002).

The available data offered little insight into the specifics of the bereavement services of interest. For example, information was not available about the credentials of service providers, the duration of the services, or the theoretical foundations of the services under examination. In addition, limitations in the available data meant that we could only focus on the first reported use of bereavement services, rather than on patterns of use over time. Attention to these and other details in future studies will help us to

better understand preferences, motivations, and choices regarding bereavement service utilization as well as the specific features of services which lead to positive outcomes for diverse groups of bereaved individuals.

Finally, the small sample size and study design in study three of the present dissertation restricted the types of statistical analyses we could employ to examine service use, preferences, and barriers. While practical considerations drove the choices in study design, future research should include larger, more diverse samples as well as multiple waves of data collection in an effort to understand patterns of use and changes in preferences over time.

#### Future Directions

This dissertation highlights some important next steps in the study of bereavement interventions and services. First, more research is needed in an effort to more fully identify and describe factors associated with bereavement service utilization. While current study findings pointed primarily to need factors, future efforts should aim to determine the roles played by factors which may predispose individuals to or enable bereavement service utilization. In studying factors associated with bereavement service use, careful consideration should be given to their mutability, or the degree to which these factors are subject to change or alteration through policy changes or other intervention (Andersen, 1995). This may enable better targeting of services to those in greatest need or increase access or the likelihood of service use among bereaved individuals who were previously underserved.

Researchers face a remarkable challenge in identifying and developing culturally-relevant bereavement interventions. Perhaps the most promising approach is to develop

highly targeted bereavement services available both prior to and after the death (Schulz, Burgio, et al., 2003). It is also important not to use race or ethnicity as proxies for cultural values (Dilworth-Anderson et al., 2002), but rather to carefully consider the many cultural and individual characteristics and circumstances which impact the bereavement experience and to make modifications to interventions in order to maximize their relevance to the particular individual or group targeted (Burgio, Stevens, Guy, Roth, & Haley, 2003). More research with diverse samples of bereaved individuals is thus called for.

This research was conducted in an effort to learn about the characteristics of those who utilize bereavement services and to aid in refining policy and interventions with the goal of helping those most in need. Future work is needed to understand the mechanisms behind predictors of bereavement service utilization and to contribute to the development of bereavement interventions which are appropriately targeted, lend themselves to methodologically sound evaluation of their efficacy, and are appealing to individuals who are distressed in bereavement. Changes to policy and practice should be informed by preferences regarding the content, structure, and delivery of bereavement services as well as by their demonstrated efficacy. We must first determine whether or not preferences lead bereaved individuals to select the most efficacious services.

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## Appendices

CURRICULUM VITAE

**Elizabeth J. Bergman, M.A., Ph.D. Candidate**

School of Aging Studies  
University of South Florida  
4202 E. Fowler Avenue, MHC 1308  
Tampa, FL 33620  
Tel: (813) 974-1337  
Fax: (813) 974-9754  
ebergman@mail.usf.edu

**Education**

- 2003-present      Doctoral Candidate, Ph.D. in Aging Studies  
University of South Florida  
Advisor: William E. Haley, Ph.D.  
Dissertation: *Service Utilization among Bereaved Spouses and Family Caregivers*
- 1996-1998      M.A., Gerontology, University of South Florida, Tampa, FL
- 1991-1996      B.A., Psychology, Auburn University, Auburn, AL

**Research Interests**

Family caregiver and bereavement interventions and service utilization; end-of-life issues; hospice and palliative care; stress and coping in the context of the aging family; gender and multicultural aspects of aging

**Research Experience**

- 2007-present      Project Manager  
Understanding Disparities in Service Use among White, African American, and Hispanic Caregivers  
PI: William E. Haley, Ph.D.  
Florida Alzheimer's Disease Research Center
- 2005-2006      Graduate Research Assistant  
Brent Small, Ph.D.  
School of Aging Studies, University of South Florida
- 2004-2005      Principal Investigator  
Hospice Bereavement Service Utilization and Preferences among Spouses in Three Hospices

Appendix A (continued)

	Center for Hospice, Palliative Care, and End-of-Life Studies, University of South Florida
2004-2005	Graduate Research Assistant Center for Hospice, Palliative Care, and End-of-Life Studies, University of South Florida
2004	Project Manager Physical and Mental Well-Being of Older Adults in Assisted Living Facilities PI: Yuri Jang, Ph.D. Department of Aging and Mental Health, Florida Mental Health Institute, University of South Florida
2003-2004	Graduate Research Assistant Quality of Life in Older Breast Cancer Survivors (NIA #1R03AG21210-01) PI: William E. Haley, Ph.D. School of Aging Studies, University of South Florida

**Teaching Experience (University of South Florida)**

Spring 2008	Instructor, Directed Readings in Family Caregiving (GEY 4900)
Fall 2007	Instructor, Introduction to Gerontology (GEY 2000)
Summer 2007; Summer 2006; Spring 2006; Fall 2004	Instructor, Death and Dying (GEY 4641)
Spring 2007; Fall 2005; of Aging Spring 2005	Graduate Teaching Assistant, Sociocultural Aspects (GEY 3625)
Fall 2006	Instructor, Sociocultural Aspects of Aging (GEY 3625)
	Instructor, Directed Readings in Family Caregiving (GEY 4900)
2003-2007	Guest Lecturer, The Life Cycle (DEP 2004), Psychology of Aging (GEY 4612), Women and Aging (GEY 4935)

## **Professional Experience**

- 2002-2003** Foster Grandparent Program Director  
Seniors in Service of Tampa Bay, Inc., Tampa, FL  
*Supervised employees and stipended volunteers; wrote grants (resulting in \$300,000 in grant awards); managed contracts; conducted ongoing program evaluation; reported program outcomes; conducted trainings and orientation sessions; oversaw monthly payroll of \$45,000.*
- 2000-2002** Program Coordinator  
Seniors in Service of Tampa Bay, Inc., Tampa, FL  
*Supervised, trained, and placed Bill Payer Program and Senior Companion Program volunteers; conducted in-home client assessments; reported program outcomes.*
- 1998-2000** Information and Referral Specialist  
West Central Florida Area Agency on Aging, Inc., Tampa, FL  
*Provided information and referral service to seniors and their caregivers; maintained I&R database; managed Gatekeeper Program; coordinated activities in celebration of Older Americans Month; coordinated "My Favorite Older Person" essay contest in Polk and Hillsborough County public schools; Ceridian Employee Assistance Program counselor.*
- 1997-1998** Director of Activities  
Palm Terrace Resident Care, Inc. (assisted living facility)  
*Trained and supervised activities department staff and volunteers; implemented and maintained activities programs in assisted living and specialized memory support units.*

## **Grants and Fellowships**

Principal Investigator, "Hospice Bereavement Service Utilization and Preferences among Spouses in Three Hospices," Center for Hospice, Palliative Care, and End-of-Life Studies, University of South Florida, 2004-2005 (\$12,000).

Graduate Fellowship, Institute on Aging, University of South Florida, 2003-2004 (\$15,000 & Graduate Tuition Waiver).

## **Peer Reviewed Journal Publications**

Haley, W. E., Bergman, E. J., Roth, D. L., McVie, T., Gaugler, J. E., & Mittelman, M. S. (in press). Long-term effects of bereavement and caregiver intervention on caregiver depressive symptoms. *The Gerontologist*.

## Appendix A (continued)

Jang, Y., Bergman, E., Schonfeld, L., & Molinari, V. (2007). The mediating role of health perceptions in the relation between physical and mental health: A study of older residents in assisted living facilities. *Journal of Aging and Health, 19*, 439-452.

Jang, Y., Bergman, E., Schonfeld, L., & Molinari, V. (2006). Depressive symptoms among older residents in assisted living facilities. *International Journal of Aging & Human Development, 63*, 299-315.

## Book Chapters

Allen, R. S., Haley, W. E., Roff, L. L., Schmid, B., & Bergman, E. J. (2006). Responding to the needs of caregivers near the end of life: Enhancing benefits and minimizing burdens. In J. L. Werth & D. Blevins (Eds.), *Psychosocial issues near the end of life: A resource for professional care providers*. Washington, DC: American Psychological Association.

## Papers Under Review or In Preparation

Bergman, E. J., Haley, W. E., & Small, B. J. (under review). The role of grief and depressive symptoms in the utilization of bereavement services.

Bergman, E. J., & Haley, W. E. (under review). Depressive symptoms, social network, and bereavement service utilization and preferences among spouses of former hospice patients.

Bergman, E. J., & Perkins, E. A. (in preparation). Older women's experience of surviving breast cancer.

Bergman, E. J., Haley, W. E., & Small, B. J. (in preparation). Outcomes and Service Utilization among Bereaved Dementia Caregivers: Findings from the REACH Study.

Bergman, E. J., & Polubinski, J. (in preparation). Access to the hospice care option at the end of life: A review of reported barriers.

Bergman, E. J. (in preparation). Grief and spousal loss: A qualitative study of former hospice caregivers.

## Invited Presentations

Bergman, E. J. (2007, July). Coping. Invited workshop for the Alzheimer's Association Florida Gulf Coast Chapter's Early Alzheimer's Support and Education Program.

## Appendix A (continued)

Bergman, E. J., & Haley, W. E. (2005, November). Hospice bereavement service utilization and preferences among spouses in hospice. Invited presentation at the Center for Hospice, Palliative Care, and End-of-Life Studies, University of South Florida, Tampa, FL.

## Conference Presentations

Bergman, E. J., Perkins, E. A., & Haley, W. E. (2007, November). Patient perspectives on breast cancer: The qualitative experience of older breast cancer survivors. Poster presentation at the 60<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America, San Francisco, CA.

Bergman, E. J., & Haley, W. E. (2006, November). Bereavement service utilization and preferences of bereaved spousal caregivers. Poster presentation at the 59<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America, Dallas, TX.

Kuchta, L., Bergman, E. J., & Davis, B. (2006, April) W.O.M.E.N. working for women. Panel presentation at the Many Floridas: Women Envisioning Change Conference, Tampa, FL.

Bergman, E. J. (2006, April). Breaking down barriers to the hospice care option: Opportunities for education & advocacy. Poster presentation at the 28<sup>th</sup> Annual Scientific Meeting of the Association for Death Education and Counseling, Tampa, FL.

Bergman, E. J. (2006, February). The journey through grief following the loss of a spouse and the qualitative experiences of hospice caregivers. Paper presentation at the 32<sup>nd</sup> Annual Scientific Meeting of the Association for Gerontology in Higher Education, Indianapolis, IN.

Bergman, E. J., & Mills, W. L. (2006, February). Student perspectives of teaching and professional development best practices within an interdisciplinary aging studies program. Resource exchange at the 32<sup>nd</sup> Annual Scientific Meeting of the Association for Gerontology in Higher Education, Indianapolis, IN.

Bergman, E. J., Small, B. J., & Haley, W. E. (2005, November). Depression, social support, and utilization of formal bereavement services. Poster presentation at the 58<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America, Orlando, FL.

## Appendix A (continued)

Bergman, E. J., Jang, Y., Schonfeld, L., & Molinari, V. (2005, May). The role of psychosocial resources in physical and mental health among older residents in assisted living facilities. Paper presentation at the 16<sup>th</sup> Annual Scientific Meeting of the Southeastern Regional Student Mentoring Convention in Gerontology and Geriatrics, Savannah, GA.

Jang, Y., Bergman, E. J., Schonfeld, L., & Molinari, V. (2005, March). Depressive symptoms among older residents in assisted living facilities. Paper presentation at the 26<sup>th</sup> Annual Scientific Meeting of the Southern Gerontological Society, Orlando, FL.

Bergman, E. J., Jang, Y., Schonfeld, L., & Molinari, V. (2005, March). Health perceptions and depressive symptoms among older residents in assisted living facilities. Poster presentation at the 26<sup>th</sup> Annual Scientific Meeting of the Southern Gerontological Society, Orlando, FL.

Bergman, E. J., & Polubinski, J. (2005, March). Both sides of the coin: Factors in the decision to choose or not choose hospice care. Poster presentation at the Center for Hospice, Palliative Care, & End-of-Life Studies Annual Scientific Meeting, Tampa, FL.

Robb, C., Haley, W. E., Balducci, L., Extermann, M., Perkins, E. A., Small, B. J., Bergman, E. J., Jang, Y., & Mortimer, J. (2004, November). Examining quality of life in older breast cancer survivors. Paper presentation at the 57<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America, Washington, DC.

Haley, W. E., Robb, C., Balducci, L., Extermann, M., Perkins, E. A., Bergman, E. J., Small, B. J., Mortimer, J., & Jang, Y. (2004, July). Psychological, social, and health impact of breast cancer survivorship in older women. Poster presentation at the National Cancer Institute and the American Cancer Society Annual Co-sponsored Scientific Meeting, Washington, DC.

## Awards and Honors

2007	Provost's Commendation for Outstanding Teaching by a Graduate Teaching Assistant University of South Florida
2006, 2005	Travel Grant Award Graduate and Professional Student Council, University of South Florida
2006	Graduate Student Paper Award Association for Death Education & Counseling

## Appendix A (continued)

- 1998 Dr. Tom Rich Scholarship  
University of South Florida and West Central Florida Area Agency  
on Aging
- 1997 – Present Sigma Phi Omega  
National Gerontology Honor and Professional Society

### **Committees and Service**

Ad hoc abstract reviewer for the Thirty-fourth Annual Meeting of the Association for Gerontology in Higher Education (2007)

Research Committee Member, Pilot Research Grant Program reviewer, Center for Hospice, Palliative Care, & End-of-Life Studies (2007)

Conference Planning Committee Member, Program Committee Member, & Film Committee Member, Florida without Borders: Women at the Intersections of the Local and Global, Conference sponsored by the Florida Consortium for Women's Studies, February 2007.

Ad hoc abstract reviewer for the Annual Meeting of the Gerontological Society of America Conference (2005-2008)

Ad hoc abstract reviewer for the Gerontological Health Section, American Public Health Association Annual Meeting (2005-2008)

Student Association for Aging Studies, University of South Florida  
President, 2004-2005  
Member, 2003-present

School of Aging Studies Ph.D. Governance Committee, University of South Florida  
Student Association for Aging Studies representative, 2004-2005

### **Professional Affiliations**

Gerontological Society of America, 1996-1998, 2003-present

Center for Hospice, Palliative Care, and End-of-Life Studies, USF, 2003-present

Southern Gerontological Society, 1998-present

Florida Council on Aging, 1998-present

### **Volunteer Experience**

Memory Walk Team Captain, The Alzheimer's Association Florida Gulf Coast Chapter, 2006, 2007

Appendix A (continued)

Volunteer Driver, Meals on Wheels of Tampa, 2006-present

Women's Organization for Medical Emergency Needs, Inc.

Board Chair, 2004-2007

Board Secretary, 2000-2004

Board Member, 1999-present

Patient Care/Respite Volunteer, LifePath Hospice & Palliative Care, Inc.

1996-1999

### About the Author

Elizabeth J. Bergman received a Bachelor's Degree in Psychology from Auburn University in 1996 and a Master's Degree in Gerontology from the University of South Florida in 1998. She worked as a gerontologist for five years in service delivery and program administrative roles before entering the Ph.D. in Aging Studies program at the University of South Florida in 2003.

While in the Ph.D. program at the University of South Florida, Ms. Bergman was employed as a Graduate Teaching Associate, teaching undergraduate Introduction to Gerontology, Sociocultural Aspects of Aging, and Death and Dying courses. She also served as Project Manager for two grant-funded research projects, co-authored three peer-reviewed journal articles and one book chapter, and presented her work at several national and regional conferences including the Gerontological Society of America, the Southern Gerontological Society, the Association for Gerontology in Higher Education, and the Association for Death Education and Counseling.