Caregiver Grief in Terminal Illness and Bereavement: A Mixed-Methods Study
Deborah P. Waldrop

Caregivers experience multiple losses during the downhill trajectory of a loved one’s terminal illness. Using mixed methods, this two-stage study explored caregiver grief during a terminal illness and after the care recipient’s death. Caregiver grief was a state of heightened responsiveness during end-stage care: anxiety, hostility, depression, and trouble concentrating, remembering, and getting things done. Following the death, caregiver grief became a state of sustained reactivity: Overall distress was diminished and anxiety and hostility decreased significantly, but loneliness, sadness, and tears increased. Overwhelming responses were triggered by unforeseen visual or auditory reminders of the person. Sleep disturbances began during end-stage care and continued after the death. At both times, caregiver grief was highly influenced by the social context; relationships with family and friends (more cohesive versus conflicted) shaped responses. Social work practitioners can help caregivers who may be unaware they are experiencing grief to identify and integrate these normal responses to loss.

KEY WORDS: bereavement; caregiver grief; end-stage caregiving

Chronic illnesses that become terminal bring losses for both ill people and their caregivers. Less attention has been focused on the losses entailed while caring for a chronically ill person than on those that occur after death. Advancing illness encompasses both physical loss, which occurs when something tangible becomes unavailable (for example, functional decline or dependence) and psychosocial loss, which results from changed social interactions (for example, the need for assistance with activities of daily living) (Rando, 2000). Losses begin with the onset of symptoms, such as decreased function and increased fatigue, continue as the symptoms of a progressive illness become more pronounced and intensify during the active dying process (Loscalzo & Brintzenhofeszoc, 1998). Losses continue to emerge long after the person dies.

There is growing recognition that caregivers experience normal anticipatory grief while engaged in the caregiving process (Sanders & Saltz Corley, 2003). “Caregiver grief” has been described as the intellectual, affective, and existential elements of changing care demands and expectations (Meuser & Marwit, 2001). Because individuals’ grief varies in intensity, duration, and form of expression, caregiver grief accompanying different illnesses is likely to involve distinct features and dynamics (Carr, House, Wortman, Neese, & Kessler, 2001). For example, the caregivers of people with dementia experience anticipatory grief and a long goodbye (Walker & Pomeroy, 1996).

This article focuses on the situation-specific responses of caregivers of terminally ill people who died while receiving hospice care and aims to expand the knowledge base about caregiver grief in different illnesses. Hospice programs typically require that a person be diagnosed with an incurable illness that is expected to result in death within six months; many, although not all, have cancer (National Hospice and Palliative Care Organization, 2005).

CONCEPTUALIZING RESPONSES TO ILLNESS, CAREGIVING, AND LOSS
The concepts of distress, grief, bereavement, and mourning are often used interchangeably in relation to psychosocial responses to a terminal illness. Distress has been used to distinguish and measure specific indicators such as depression and anxiety (psychological distress) and pain or nausea (physical distress) (Cameron, Franche, Cheung, & Stewart, 2002). The National Comprehensive Cancer Network (2003) has defined distress as "a multifactorial..."
The multifaceted nature of distress, grief, bereavement, and mourning underscores the importance of viewing the response to loss from a biopsychosocial perspective.

unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment (p. 6).

Grief is the multifaceted response to death and losses of all kinds, including emotional (affective), psychological (cognitive and behavioral), social, and physical reactions (Stroebe, Hansson, Stroebe, & Schut, 2001). Death brings the loss of social and family roles and shared activities. Affective manifestations of grief involve despair, anxiety, anger, and loneliness. Behavioral symptoms include agitation, fatigue, crying, and withdrawal. Cognitive manifestations can consist of preoccupation with thoughts of the person who is dying or has died, lowered self-esteem, helplessness and hopelessness, a sense of unreality, and problems with memory and concentration. Physiological symptoms can manifest as diminished appetite, sleep disturbance, energy loss and exhaustion, somatic or physical complaints, changes in drug intake, and susceptibility to illness and disease (Rando, 2000; Stroebe et al.). Grief has also been associated with increased mortality (Schulz & Beach, 1999).

Bereavement is the state of having lost a significant person to death. Mourning is the process of adapting to the loss and involves restructuring or renegotiating the psychosocial ties with the person who died (Klass & Walter, 2001). Thus, the person develops an identity without the lost loved one and adapts to living without his or her physical presence (Rando, 2000). The multifaceted nature of distress, grief, bereavement, and mourning underscores the importance of viewing the response to loss from a biopsychosocial perspective. For conceptual clarity, caregiver grief is used here as a construct that encompasses the symptoms of distress.

CONTEXT OF TERMINAL ILLNESS
AND BEREAVEMENT

The concept of an illness context has been described by Stroebe and colleagues (2001) as a merger of the distinct features of a disease with the patient’s and caregiver’s social context. The illness context has been described in multiple sources and includes the following eight features: (1) the diagnosis and presence of coexisting conditions (Vigano et al., 2000); (2) the amount, type, and duration of symptoms (Barry & Prigerson, 2002); (3) the need for caregiving and whether care is partial or total and provided informally or through formal providers, including a nursing home (Carr et al., 2001); (4) the age and life stage of the ill person (Sörensen, Pinquart, & Duberstein, 2002); (5) the type of relationship between the ill person and caregiver (Pinquart & Sörensen, 2003); (6) the nature and quality of the social support network (Marwit & Meuser, 2002); (7) how quickly the illness moves from the onset of symptoms through diagnosis and treatment and enters the terminal decline (Schulz et al., 2001); and (8) how the ill person and close family members communicate about death (Chen et al., 1999). Features of the illness context subsequently influence the caregiver’s response to bereavement (Chentsova-Dutton et al., 2002).

How a family functions during the course of a terminal illness can influence the caregiver’s health and well-being long after the death (Schulz & Beach, 1999). Bereaved caregivers express intense feelings (both positive and negative) about end-stage caregiving. Recent caregiving studies have emphasized that gains and losses coexist in the caregiving relationship (Kramer, 1997). Negative feelings are expressed as the wish to have done more, perceptions of mistakes, or regrets about unresolved issues (Bernard & Guarnaccia, 2003; Mullan, 1992). Positive feelings about caregiving have also been identified as satisfaction and meaning making; those emerge from viewing the importance of final, shared times. Two perspectives on bereavement responses are the relief and the complicated models.

The relief model portrays the resolution of distress after the ill person dies and caregiving ends. The relief of responsibilities frees the individual to re-establish employment, social contacts, or leisure time and to use psychological resources to adapt to the loss (Bernard & Guarnaccia, 2003). In some situations, a longer trajectory allows for preparation before the death (Bass & Bowman, 1990). Bereaved caregivers who experience relief find decreased feelings of overload and an increased sense of mastery in their lives (Mullan, 1992).

The complicated model portrays how distress can become exacerbated after the death. Heightened
role strain from caregiving may lead to greater difficulty in subsequent bereavement (Bernard & Guarnaccia, 2003). Role strain emerges from the overlapping responsibilities that accompany the simultaneous family roles (Mullan, 1992). The lack of an opportunity for closure and unresolved relationship issues between caregiver and care recipient can complicate the bereavement process; multiple responsibilities can interfere with resolution of the relationship before death. Perceptions are paramount; family members who perceive caregiving as difficult are at greater risk of troubled bereavement (Bass & Bowman, 1990; Schulz & Beach, 1999).

Knowledge about the relationship between caregiver grief and well-being is important for health and mental health professionals who work with caregivers at the turning points of a terminal illness and after the death. This study explored caregiver grief during terminal illness and one year after the care recipient's death. The study aimed to answer two research questions: (1) What is the nature of caregiver grief in terminal illness and (2) how do the features of caregiver grief change after the death?

METHOD

Study Design and Procedures
This exploratory descriptive phenomenological study was conducted at a hospice in western New York state from 2001 to 2002 in two stages and used a mixed-methods approach. Qualitative and quantitative methods were used in parallel and equal status (Tashakkori & Teddlie, 1998) to facilitate triangulation and to illuminate overlapping components of grief in end-of-life care (Padgett, 1998). Standardized instruments provided a means for measuring distress. An interview schedule was used to guide discussions and gather descriptions of participants' experiences in their own words.

Sample
Purposeful sampling was used to identify people who were caring for a terminally ill family member or friend. Following university Institutional Review Board approval, recruitment was conducted through the participating hospice by using inclusion criteria that were developed collaboratively by myself and an advisory board. Participants had to be caregivers of adults who had received hospice care at home for at least two weeks and had a Palliative Performance Scale score of 40 to 50 or higher. A Palliative Performance Scale score of 40 to 50 indicates that a person requires considerable assistance with self-care but is able to converse (Anderson, Downing, & Hill, 1996). Because the final stages of a terminal illness can bring rapid change, procedures were developed to ensure that contact about or participation in the study did not intrude into the family's shared time during the final stage of life. Contact was made only with families who were still caring for the terminally ill person at home after the first two weeks of hospice, for two reasons: (1) Many people enter hospice only during the terminal decline and die within two weeks (National Hospice and Palliative Care Organization, 2005) and (2) all of the interdisciplinary team members make initial visits to the patient within the first two weeks.

Participants ranged in age from 28 to 75 (M = 61 years) and included 23 women (77 percent) (daughters, daughters-in-law, wives, granddaughter, and a friend) and seven men (23 percent) (husbands and sons). Patients ranged in age from 61 to 85 (M = 77 years), and a majority (87 percent) were admitted with cancer.

Time 1 interviews were conducted after the care recipient had received hospice care for at least two weeks. Participants received an informational letter that explained that the project aimed to explore how caregivers' experiences change over time and that they would be contacted about a future follow-up interview. Time 2 interviews were conducted approximately one year after the care recipient's death.

Time 1 and 2 interviews were conducted by myself or one of three second-year MSW student research assistants. All interviews were scheduled at a time and place of the participants' choice. The dates of care recipients' deaths were provided by the hospice, and letters about time 2 interviews were sent one year after the death. Willing participants returned a response form, and telephone contact was made to schedule an appointment. This time period was selected because it corresponds with the end of hospice bereavement services.

Instrumentation and Measures
Open-ended questions and the Brief Symptom Inventory (BSI, Derogatis, 1993) were used in time 1 and time 2 interviews. The Texas Revised Instrument on Grief (TRIG, Faschingbauer, DeVaul, & Zisook, 1987) was also used during time 2 interviews. The sequence for both time 1 and time 2 interviews was
similar: open-ended questions, embedded scaled questions, and open-ended questions. The open-ended questions encouraged participants to describe their experiences of a loved one's terminal illness at their own pace.

The BSI is a 53-item self-report instrument that asks participants how they have been feeling during the past 14 days. Each item is rated on a five-point scale of distress: 0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, and 4 = extremely. In addition to measuring distress symptoms, the BSI is designed to measure distress on dimensional and global levels.

The nine dimensions of distress and their documented internal reliability coefficients are as follows: somatization or perceptions of bodily dysfunction (.80); obsessive-compulsive thoughts and impulses that are both unremitting and unwanted (.83); phobic anxiety or a persistent fear response that is disproportionate (.77); anxiety or feelings of nervousness, tension, and apprehension (.81); clinical indicators of depression (.85); interpersonal sensitivity or feelings of personal inadequacy, inferiority, self-deprecation, and self-doubt in interpersonal interactions (.74); hostility or thoughts, feelings, and actions that characterize anger (.78); psychoticism as withdrawal and isolation (.71); and paranoid ideation or thoughts that are projective, hostile, suspicious, and grandiose and related to a loss of autonomy (.77). The three measures of overall distress and their internal reliabilities are the Global Severity Index (.90), which is determined by combining the numbers of symptoms and intensity of distress; the Positive Symptom Inventory Total (.80), or the number of reported symptoms; and the Positive Symptom Distress Inventory (.87), which measures the intensity level of distress.

The TRIG was designed to assess grief responses. The Past Disruption subscale has eight items and an internal reliability of .77 to .87. Past Disruption questions begin with “After the person died....” and are followed by the eight items. The Present Feelings subscale consists of 13 items and has an internal reliability of .69 to .89. Present Emotion questions begin with “How do you presently feel about the person’s death?” Each response is followed by five choices: 1 = completely false, 2 = mostly false, 3 = true and false, 4 = mostly true, and 5 = completely true. One question, “No one can take the place of the person who died,” was removed because the advisory board’s review of the instrument generated concern that the suggestion of replacing the person could be upsetting for participants.

Open-ended questions during the time 1 interview focused on the participants’ caregiving experiences. Questions about the person’s illness and decline were followed by probing questions to encourage participants to fully describe their experiences. During the time 2 interview, participants were asked to describe the final stage of the illness, the death, and their responses.

Quantitative Data Analysis
Demographic and diagnostic information was entered in SPSS; frequencies and descriptive statistics were calculated. Time 1 and 2 responses to the BSI and the TRIG were entered in SPSS. Global distress indices and dimensional scores were calculated. BSI subscale scores and individual items were ranked by descending means. The differences between time 1 and time 2 scores were calculated by using paired t tests.

Qualitative Data Analysis
Interviews were tape recorded and transcribed. Analysis began with open coding, or identification of meaning units through line-by-line examination, to generate naturally occurring themes from within the participants’ descriptions at times 1 and 2 (Padgett, 1998). Next, axial coding, or the systematic use of concepts for data exploration around one category, was accomplished by using a start list of codes that were concepts from the biopsychosocial perspective (Miles & Huberman, 1994). Concept codes were physical health, psychological well-being, and social functioning and were used to explore participants’ narrative descriptions of their experiences at both times. Coding was conducted by partitioning sections of textual data and copying them under headings that corresponded to the concept. To ensure rigor and trustworthiness of the data, transcripts were explored by two coders (myself and an MSW clinician), and the iterative process of constant comparative analysis or recoding by using newly emergent themes was used. A text file of quotes was created for illustration.

A cross-case matrix was constructed to reduce the substantial amount of text and to organize coded data so that the salient features would emerge. A matrix is a visual display that presents qualitative data systematically by using a 2 x 3 grid with defined
rows and columns in which quotes and phrases are placed (Miles & Huberman, 1994). This analysis used a variable × time format. Columns in the matrix were set up for time 1 and time 2 responses. Rows in the matrix were divided and labeled as three main sections: physical health, psychological/emotional well-being, and social functioning. Subcells of the grid were created for each participant’s responses. The text from both Time 1 and 2 interview responses were coded for the biopsychosocial dimensions of distress for each participant. Themes were developed from the summary matrix.

RESULTS
Findings are drawn from a comparison of the responses of only those people who completed both time 1 and time 2 interviews (N = 30).

Time 1: Providing End-Stage Care
Table 1 presents the nine BSI dimension scores and individual item scores that were either greater than one at both times or significantly different between Times 1 and 2. Table 2 presents a matrix of the themes that illustrate biopsychosocial dimensions of distress during caregiving and bereavement. The symptoms of distress that characterize caregiver grief during the end stage of care and after a year of bereavement are illustrated in participants’ words.

Physical Health. Three distinct physical health-related features of distress occurred during end-stage care: sleep disruption, exacerbation of chronic illness symptoms, and physical strain. Participants described frequent sleep interruptions while they were providing around-the-clock care because they became accustomed to either sleeping lightly or getting up frequently to help the person during the night. The exacerbation of illnesses such as hypertension and cardiac conditions was attributed to caregiving stress. Participants also described fatigue and physical strain from providing 24-hour care. One participant’s description illustrates the physical nature of her caregiving distress: “He couldn’t breathe without his oxygen and was afraid to be alone so I couldn’t leave him. I needed help but couldn’t find anyone good to stay with him. We had some really bad experiences. My blood pressure went sky-high; my doctor said it was stress/anxiety.” Descriptions of the physical demands of caring for someone with increasing needs and functional decline influenced participants’ outlook on life and perspectives on caregiving.

<table>
<thead>
<tr>
<th>Grief Response</th>
<th>Time 1: Caregiving</th>
<th>Time 2: Bereavement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Obsessive-compulsive(a)</td>
<td>1.35</td>
<td>1.12</td>
</tr>
<tr>
<td>Remembering things(b)</td>
<td>1.56</td>
<td>1.40</td>
</tr>
<tr>
<td>Trouble concentrating(b)</td>
<td>1.46</td>
<td>1.21</td>
</tr>
<tr>
<td>Mind goes blank(b)</td>
<td>1.44</td>
<td>1.40</td>
</tr>
<tr>
<td>Blocked get things done(b)</td>
<td>1.33</td>
<td>1.36</td>
</tr>
<tr>
<td>Anxiety(a)</td>
<td>1.14</td>
<td>0.90</td>
</tr>
<tr>
<td>Tense/keyed up(b)</td>
<td>1.93</td>
<td>1.17</td>
</tr>
<tr>
<td>Nervous/shaky(b)</td>
<td>1.41</td>
<td>1.25</td>
</tr>
<tr>
<td>Restless(b)</td>
<td>1.19</td>
<td>1.11</td>
</tr>
<tr>
<td>Fearful(b)</td>
<td>1.11</td>
<td>1.09</td>
</tr>
<tr>
<td>Terror/panic(b)</td>
<td>0.74</td>
<td>1.10</td>
</tr>
<tr>
<td>Depression(a)</td>
<td>0.93</td>
<td>0.83</td>
</tr>
<tr>
<td>Feeling blue(b)</td>
<td>1.93</td>
<td>1.14</td>
</tr>
<tr>
<td>Feeling lonely(b)</td>
<td>1.15</td>
<td>1.20</td>
</tr>
<tr>
<td>Hostility(a)</td>
<td>0.73</td>
<td>0.82</td>
</tr>
<tr>
<td>Annoyed/irritated(b)</td>
<td>1.56</td>
<td>1.28</td>
</tr>
<tr>
<td>Temper outbursts(b)</td>
<td>0.85</td>
<td>1.13</td>
</tr>
<tr>
<td>Interpersonal sensitivity(b)</td>
<td>0.64</td>
<td>0.75</td>
</tr>
<tr>
<td>Psychoticism(a)</td>
<td>0.61</td>
<td>0.78</td>
</tr>
<tr>
<td>Lonely with people(b)</td>
<td>1.26</td>
<td>1.26</td>
</tr>
<tr>
<td>Somatization(a)</td>
<td>0.60</td>
<td>0.66</td>
</tr>
<tr>
<td>Paranoid ideation(a)</td>
<td>0.63</td>
<td>0.64</td>
</tr>
<tr>
<td>Phobic anxiety(a)</td>
<td>0.44</td>
<td>0.69</td>
</tr>
<tr>
<td>Additional items(b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble falling asleep(b)</td>
<td>1.37</td>
<td>1.62</td>
</tr>
<tr>
<td>Trigger: past disruption</td>
<td>18.89</td>
<td>6.65</td>
</tr>
<tr>
<td>Hard to sleep</td>
<td>3.0</td>
<td>1.60</td>
</tr>
<tr>
<td>Do things person wanted</td>
<td>2.9</td>
<td>1.50</td>
</tr>
<tr>
<td>Not normal activities</td>
<td>2.6</td>
<td>1.60</td>
</tr>
<tr>
<td>Trigger: present emotions</td>
<td>34.0</td>
<td>7.01</td>
</tr>
<tr>
<td>Miss very much</td>
<td>4.6</td>
<td>0.92</td>
</tr>
<tr>
<td>Things remind me</td>
<td>3.9</td>
<td>1.00</td>
</tr>
<tr>
<td>Still cry</td>
<td>3.8</td>
<td>0.92</td>
</tr>
</tbody>
</table>

*Dimension-level scores. **Symptom-level scores remaining more than one at both times or demonstrating significant change.

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

Psychological and Emotional Well-Being. Psychological and emotional responses were intense and had the predominant features of sadness and anger. Caregivers’ emotional responses paralleled the ill person’s decline. Participants described their responses to the person’s advancing illness with the following words: “sobbing,” “crying,” “not able to

WALDROP / Caregiver Grief in Terminal Illness and Bereavement: A Mixed-Methods Study
Table 2: Elements of Distress from Caregivers’ Narratives

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Time 1: Caregiving</th>
<th>Time 2: Bereavement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>• Sleep disruption: Caregiver is up frequently responding to needs.</td>
<td>• Sleep disturbance: Caregiver is “programmed” to awaken through the night, or distress permeates sleep, causes awakening.</td>
</tr>
<tr>
<td></td>
<td>• Exacerbation of symptoms of chronic conditions: blood pressure, back problems, stress-related conditions.</td>
<td>• Chronic conditions: Most prior exacerbations of symptoms diminish; some had new onset.</td>
</tr>
<tr>
<td></td>
<td>• Physically burdensome tasks: lifting, managing household tasks.</td>
<td></td>
</tr>
<tr>
<td>Psychological and emotional well-being</td>
<td>• Sadness—tears: observing the person’s decline.</td>
<td>• Overwhelming sadness—tears.</td>
</tr>
<tr>
<td>Social functioning</td>
<td>• Increased family cohesion: Family members share caregiving responsibilities and problem solving.</td>
<td>• Triggers (sights, sounds, smells, geographic locations, family events) bring on intense déjà-vu experiences and overwhelming responses.</td>
</tr>
<tr>
<td></td>
<td>• Decreased family cohesion: conflict about caregiving responsibilities</td>
<td>• Increased family cohesion: shared grief and memories.</td>
</tr>
<tr>
<td></td>
<td>• Increased social support: Increased contact for hands-on assistance, informational and emotional support.</td>
<td>• Decreased family cohesion: Pejorative expectations of grief reactions cause distance.</td>
</tr>
<tr>
<td></td>
<td>• Decreased social support: Friends become uncomfortable or fatigued with caregiver’s needs; withdrawal from interaction.</td>
<td>• Increased social support: Bereaved caregiver is enveloped by friends, neighbors who make invitations, call, and send cards.</td>
</tr>
</tbody>
</table>

stop the tears,” and “wailing,” as well as “screaming,” “hollering,” “rage,” and “[being] angrier than ever before.” One participant illustrated this by saying, “I’m so angry that he refuses to talk about his illness—he needs ‘hope’ but I need to know what to do about the septic tank!” Another participant said, “I’m an emotional mess. I don’t feel like anyone understands what I’m going through.”

Participants sometimes submerged intense responses while they were dealing with the ill person’s needs. One participant’s words illustrated how she buried her responses: “It is like pushing everything down where you can’t get at it.” Managing these responses was a way of maintaining control in an otherwise overwhelming situation.

Finally, participants described the need to periodically avoid discussion about the illness and dying process. Emotional responses to change and loss are an integral part of end-stage caregiving, but the intensity of feelings that accompany an advancing disease process manifests itself in distinctly individual ways.

Social Functioning. End-stage caregiving changed the interpersonal dynamics within families and social support networks. For some, changes included intensified conflict, whereas for others there was greater cohesiveness. Some social networks enveloped the ill person and caregivers; friends, extended family, church members, or coworkers prepared meals and provided transportation, respite, and emotional support through visits, phone calls, and cards. One participant said, “My whole office knew [about her father] and they were devastated for me.”

Others felt limited support from those in their social network. In these situations, participants were overwhelmed and believed that those around them were uncertain how to respond. One man explained that whenever he would talk with friends, caregiving for his mother was discussed. Feeling that he was monopolizing the conversation and making his friends uncomfortable, he said, “I began to realize that this was all I talked about with them and it was too much. I dropped out of social interaction.” Other participants described how caregiving changed the way that they related to family members. One participant described how caregiving had influenced her relationship with her family:

I’m so moody at times. I mean my husband does one thing and I wanna punch him in the face. I’m not kidding you! I’m very edgy. And to the kids too. Last night they said, “Something’s wrong with you, Mom.” I hate that. And their grandmother is dying. OK but that’s not what this is about. They left this big fat mess in the
house when I came home after sitting with my mother all day, you know?

Caregiving for someone who is dying becomes a primary focus and changes the nature of all social relationships. These accompanying social losses ripple through the network of family members, friends, neighbors, acquaintances, and coworkers.

**How Distress Changed at Time 2: Bereavement**

The Global Severity Index results indicate that overall distress decreased between caregiving and bereavement (GSI₁, M = 0.83, SD = 0.69, and GSI₂, M = 0.60, SD = 1.0) and was significantly different (p ≤ .044). Positive Symptom Inventory results indicate that the number of symptoms decreased (PSI₁, M = 20.59, SD = 12.20, and PSI₂, M = 18.86, SD = 12.72), but the difference was not significant (p < .557). The Positive Symptom Distress Inventory results indicate that the intensity of the distress decreased (PSDI₁, M = 2.02, SD = 0.96, and PSID₂, M = 1.57, SD = 0.63) and was significantly different (p ≤ .014). See Table 2 for time 2 BSI and TRIG scores.

**Physical Health.** Bereaved caregivers described sleep disruptions and fatigue during the first year of bereavement. Most participants reported experiencing relief from previously exacerbated symptoms (for example, hypertension), and a small number discussed the onset of new physical symptoms. Two participants’ words illustrate how bereavement affected their health with regard to sleep disturbance and other symptoms:

I have trouble sleeping. I hadn’t been sleeping when he was dying and then for many months I would wake up on schedule at 2 a.m., 4 a.m., and 6 a.m. the way I did when he was sick and I had to give him some kind of care. I still didn’t sleep even last night really. I slept until 4-ish and I’ve been up ever since.

* * * *

This is my way of being stressed: I lost my hair in huge amounts after he died. And, I can’t really walk well because I have a terrible pain in my left leg. There is nothing wrong with my leg and I’ve had it off and on for the whole year now.

Overall, participants reported relief from the physical burden of providing total care for a physically dependent person and improvement in symptom exacerbations, but the loss affected some caregivers’ sleep patterns for a long time after the death.

**Psychological and Emotional Well-Being.** A variety of occurrences triggered overwhelming emotional responses. These trigger events occurred without warning, stimulating vivid memories and overpowering reactions. Trigger events included sights (for example, photos, clothing), sounds (for example, alarm, “his” music), and smells (for example, a favorite food), geographic locations (for example, church, the grocery store), and family events at which the person’s presence was deeply missed (for example, birth of a baby, graduation). Responses included feeling flooded with emotions and a sense of déjà vu or of being back in the situation. Shopping became a trigger event for one daughter:

I was walking through the grocery store and I couldn’t believe it. I glanced over at baby food and my heart just went down in my stomach. I wonder if it is ever going to stop; I associate things that I see in the store that I would buy for Mom and I automatically think about her. For the longest time everywhere I looked, I was reminded of Mom.

Participants also referred to intense emotional responses that accompanied thoughts of or conversations about the person. These responses most often included tears, feelings of despair, sobbing, and being simultaneously happy and sad. It is important to note that all participants became tearful during the second interview. Many reported that they cried whenever they talked about the person who died. Some expressed feeling regret about something they were unable to do for the person. The following quote illustrates caregiver grief in bereavement: “This incredible sadness comes over me at times. I just stay with it. I say ‘Good, I’m sad, I need to be sad.’ I just let it just hurt me inside for awhile and then I’m over it.” Caregivers’ emotional responses to grief were overpowering at different times during the first year after the person’s death. For many participants, the emotion did not subside and re-emerged as they talked about the person, but they had grown to expect this and over time were less surprised by their feelings and reactions.

**Social Functioning.** Some families became closer, whereas in others conflict was exacerbated. Likewise,
Normal anticipatory mourning has been found to accompany an impending loss as an emotional attachment is being relinquished.

for some participants relationships with friends, neighbors, and coworkers provided intensified social support, whereas for others, the social support network offered minimal support. Two participants illustrate these social dynamics. One explained, “After Mom’s death we got much closer. For a whole year on Sunday afternoon, we would get together at Mom’s house to clean closets, cupboards, and the basement. We’d have dinner and share memories. It was wonderful.” Another described the experience this way: “People would invite me for dinner but I would feel overwhelmed because they were places where she would have been with me. I’d have to excuse myself and go outside to cry. I stopped accepting invitations because I couldn’t stand it.” After the death, participants’ relationships with others influenced their grief. Feelings of acceptance and support or distance and intolerance shaped the nature of their responses.

DISCUSSION
The results of this study add to knowledge of normal anticipatory grief and mourning responses by providing a longitudinal view of caregivers’ grief through the experiences of being in a close relationship with someone who is terminally ill, watching the person lose function, and providing hands-on care while simultaneously preparing emotionally for an approaching death. Normal anticipatory mourning has been found to accompany an impending loss as an emotional attachment is being relinquished (Rando, 2000). This distinct type of grief occurs over time and in parallel with the terminally ill person’s illness and continues after the death.

In this study, caregiver grief during end-stage care was a state of heightened responsiveness: anxiety, depression, and feeling nervous, restless, fearful, and tense while also having trouble remembering, concentrating, and getting things done. Caregivers felt intense emotions, primarily a merger of sadness and anger. These findings suggest that the features of caregiver grief are directly linked to the nature of an advancing illness (for example, increasing physical needs) and the sometimes dramatic exacerbation of symptoms such as pain, restlessness, and confusion, which contribute to an intense and overwhelming situation that can make the caregiver feel on edge and responsible while simultaneously facing an approaching death.

Following the death, caregiver grief became a state of sustained reactivity: Overall distress was diminished, but the number of positive symptoms was not significantly different. Anxiety and hostility decreased significantly, but loneliness, sadness, and tears increased; overwhelming responses were triggered by unforeseen visual or auditory reminders of the person. Having trouble concentrating, remembering things, and getting things done continued. At both times, caregiver grief was highly influenced by the social context. Relationships with family and friends (whether more cohesive or conflicted) and heightened interpersonal sensitivity shaped caregivers’ responses. Sleep disturbances were also present throughout the process. Beginning during end-stage care when around-the-clock care was often needed, sleep patterns continued to be changed, later being affected by psychological factors that prevented sleep or caused awakening.

Building on the existing caregiving literature, these findings can be used to extend both the relief and complicated models of caregiver grief (Bass & Bowman, 1990; Bernard & Guarinaccia, 2003). Portraying caregivers’ responses to the death as relief from or exacerbation of distress, these models conceptualize adaptation as overall functioning. The findings of this study illustrate that although the physical strain ceased when the care recipient died and overall distress, anxiety, and hostility were significantly diminished, some symptoms remained the same and others became intensified. The sustained presence of sadness and tears, together with ongoing sleep disturbance and reactivity, can be viewed as symptoms of grief.

In addition, these results add to knowledge about how caregiver grief begins early and continues long after the death, underscoring the importance of both accurately assessing and effectively intervening with caregiver grief (Meuser & Marwit, 2001; Sanders & Saltz Corley, 2003).

This study had several limitations. The sample was small and lacked racial or ethnic diversity. Responses to illness and loss are strongly influenced by cultural factors; thus, a larger and more diverse sample would have provided a deeper view of caregiver grief. Although concepts from the biopsychosocial model guided this study, grief is most
commonly understood as an emotional response to death. Study participants were asked about their grief in general, but they were not specifically questioned about changes in their physical health. Exploring caregivers’ perspectives about how their health was affected would have provided important additional information, especially as earlier studies have established a connection between caregiving and mortality (Schulz & Beach, 1999).

**IMPLICATIONS FOR PRACTICE**

These results underscore the importance of assessment beyond overall function, with clinical attention to symptom clusters in caregivers. Identifying and assessing the distinct features of caregiver grief is an important component of social work practice with people who are caring for a terminally ill person. Caregivers may not identify their distress as grief, especially while they are still engaged in caregiving responsibilities, but they may wonder what is happening and why they feel so sad and as though they are going crazy. Practitioners can help normalize these responses by educating caregivers about how their responses parallel end-stage care, death, and adaptation to loss. In addition, social workers can attend to and help caregivers understand that their experiences providing end-stage care may have long-term effects (for example, sensory experiences can trigger a flood of memories). Social workers in nursing homes, hospice, home health agencies, community-based oncology or primary care clinics, and hospitals can use these findings to support the importance of making regular supportive and therapeutic contact with caregivers during the course of a terminal illness and after the person’s death. Recently developed standards for social work in end-of-life care provide additional guidance for practitioners who encounter caregiving families in health care as well as other settings (National Association of Social Workers, 2003).

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