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Depressive Symptoms, Grief, and Complicated Grief Among Family Caregivers of Patients With Advanced Cancer Three Months Into Bereavement

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Bereaved family caregivers remain a neglected and marginalized group in clinical practice and research, and very little is known about how best to identify caregivers most at risk during bereavement (Holtslander, 2008). Family caregivers of patients with cancer are known to have high levels of burden, including physical strain and emotional distress (Kim & Schulz, 2008). Often older themselves, caregivers of patients with advanced cancer commonly experience an intense trajectory of events, including an increased need for symptom management and steep declines in functional status at the end of the patient's life (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). The caregiving experience is known to have consequences that will affect bereavement outcomes (Brazil, Bedard, & Willison, 2003). Bereavement itself has a significant negative effect on mortality and morbidity, particularly for older spousal caregivers (Kowalski & Bondmass, 2008; Stroebe, Schut, & Stroebe, 2007), including increased risk of suicide, distress, loneliness, substance abuse, physical and emotional disability, pain, gastrointestinal issues, and sleep disturbance.

International guidelines for palliative care emphasize the importance of supporting families through the illness and into bereavement (World Health Organization, 2010). The National Comprehensive Cancer Network ([NCCN], 2009) clinical practice guidelines for palliative care include bereavement support for family and caregivers as an essential aspect of a continuum of care and services. Exploring key indicators of grief and depression surrounding the unique situation of bereaved caregivers of patients with advanced cancer is an important step in determining their needs and developing effective interventions, policies, and programs of support that would promote positive outcomes for this at-risk population.

Purpose/Objectives: To describe depressive symptoms, grief, and complicated grief for bereaved family caregivers of patients who died from cancer-related causes and to explore relationships among these variables.

Design: A nonexperimental, secondary analysis of cross-sectional descriptive data from a longitudinal intervention study evaluating the effect of providing feedback from standardized assessment tools.

Setting: Two large, private, not-for-profit hospices in Florida.

Sample: Convenience sample of 280 family caregivers, bereaved three months.

Methods: Secondary analysis of self-report, survey data three months following death.

Main Research Variables: Depressive symptoms, grief, and complicated grief.

Findings: Three months after the loss of a loved one, 34% of the caregivers had clinically meaningful scores for depressive symptoms. A significant number of bereaved caregivers were experiencing grief and depression.

Conclusions: Bereaved caregivers were experiencing significant levels of depressive symptoms and complicated grief. Caregivers with higher levels of grief had more depressive symptoms.

Implications for Nursing: Tools are available to identify bereaved caregivers most in need of intervention.

Background

Although being able to provide care for a dying family member is considered by family caregivers to be a valuable and meaningful opportunity, many will face intense and difficult emotions during bereavement (Grbich, Parker, & Maddocks, 2001), higher than average depressive symptoms (Wyatt, Friedman, Given, & Given, 1999), and difficulty finding adequate support (Ingleton et al., 2004; Jansma, Schure, & de Jong, 2005;

Kristjanson, Cousins, Smith, & Lewin, 2005). Family caregivers of hospice patients reported high levels of depression and grief, particularly during the first few months of bereavement, but many symptoms were prominent at the study's 13-month time point (Chentsova-Dutton et al., 2002). Severe sleep problems also have been reported in research with bereaved caregivers of patients with cancer receiving palliative care (Carter, 2005).

Difficulties adjusting to bereavement often have been related to the challenges of recovering from caregiving exhaustion (Addington-Hall & Karlsen, 2000; Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004). A caregiving experience characterized by aggressive care and worse patient quality of life was associated with bereavement maladjustment and a greater risk of a major depressive disorder in a study of 332 dyads followed for six months after the death of the patient (Wright et al., 2008). A highly stressful caregiving experience was even more difficult for older adults losing a spouse and was related to more issues adapting to bereavement, particularly if they were experiencing social isolation (Burton, Haley, & Small, 2006).

Support during the caregiving experience may affect bereavement because a very short enrollment in hospice services has been correlated with significantly higher levels of depression (Bradley et al., 2004). In a study of 50 spouses of hospice patients, adequate social support while caregiving was the only variable significantly correlated with higher levels of life satisfaction after a loss (Burton et al., 2008). Hospice support was a predictor of lower mortality rates in a study of almost 200,000 older adult couples in the United States (Christakis & Iwashyna, 2003). The role of adequate care and support for patients and the families providing care cannot be underestimated; however, providing support to caregivers after the death of a patient remains a neglected aspect of most hospice services (Demmer, 2003), and very little is known about the needs and experiences of family caregivers during bereavement (Holtslander, 2008). Specific outcomes of caregiving that emerge during bereavement should be determined to identify those most at risk of complications during grief and to focus scarce resources for those most in need. Assessment tools, developed and tested in research with bereaved family caregivers, would provide the information needed so that effective and compassionate care can be offered to this population.

Bereavement is defined as the objective loss of someone significant, and grief is a reaction to bereavement (Stroebe, Hansson, Stroebe, & Schut, 2001). Complicated grief usually involves grief that deviates from a cultural norm and may involve symptoms of depression (Stroebe et al., 2001). In previous studies, reactions to grief among caregivers showed a significant decline over the first year (Carlsson & Nilsson, 2007); however, what is not known is how best to assess for adverse effects that

may arise and which validated assessment tools would be most effective (Grande et al., 2009). Caregivers who experience complicated grief may require closer monitoring, targeted interventions, and support.

Depression is a frequently reported symptom and a widely used gauge of a person's response to bereavement (Neimeyer, Hogan, & Laurie, 2008). Depression has been a focus of many bereavement studies, and newer scales measuring grief and complicated grief are emerging, but very little research has examined the correlations and relationships among these measures. The purpose of this secondary analysis of data obtained from family caregivers, bereaved three months after providing care to a patient with advanced cancer, was to describe their levels of depressive symptoms, grief, and complicated grief and to explore the relationships among these variables.

Methods

This secondary analysis is a cross-sectional, descriptive analysis of data from the three-month bereavement assessment of the family caregivers with treatment and control groups combined (McMillan, Small, & Haley, 2010). Cross-sectional data from a longitudinal intervention study were collected from 2005–2008 to determine the effect on patients and caregivers of providing systematic feedback from standardized assessment tools for improving hospice outcomes. This feedback was given to hospice staff at interdisciplinary team conferences, held within one week of admission to the program and at two weeks following admission. The difference between the treatment and control group was the feedback of the results of the assessment tools to hospice staff.

Sample and Setting

The convenience sample included in this analysis was comprised of 280 family caregivers of patients with advanced cancer, three months after loss of the family member, from two large private, not-for-profit hospice programs in West Central Florida. Each hospice offers comprehensive services from an interdisciplinary team that included bereavement counselors. For inclusion, caregivers had to be 18 years or older and identified as the primary caregiver. If two or more individuals shared caregiving responsibilities, the research team was trained to identify the individual who was the decision maker and also provided at least four hours of care each day. If this could not be determined, the patient/caregiver dyads were excluded from the study. Caregivers were excluded if they were in active treatment for cancer themselves.

Instruments

Depressive symptoms: The short-form 10-item version of the Center for Epidemiological Studies–Depression

(CES-D) Scale was used because of its excellent reliability (Cronbach alpha 0.92 and test-retest reliability of 0.83) (Irwin, Artin, & Oxman, 1999). Correlation of the short form and the full CES-D was 0.88. The items are scored as either present or absent, rather than rated for frequency. A score of 4 or higher indicates clinical depression.

Grief experiences: The **Texas Revised Inventory of Grief (TRIG) Present Feelings subscale** (Faschingbauer, DeVaul, & Zisook, 1977; Zisook, DeVaul, & Click, 1982) is one of the most commonly used instruments to assess the intensity of the grief experience. The inventory includes 13 self-report items assessing common grief symptoms and has been used to track grief symptoms over time. Items are rated on a five-point Likert scale ranging from completely true (1) to completely false (5). The scale does not have a cutoff point to demonstrate a clinically meaningful score, but rather it measures the grief experience at a point in time. High scores in this measure represent low grief, ranging from high grief (13) to low grief (65). High internal consistency of the Present Feelings subscale has been demonstrated, having a Cronbach alpha coefficient of 0.86 and a split-half reliability of 0.88 (Faschingbauer, Zisook, & DeVaul, 1987).

Complicated grief: The **Inventory of Complicated Grief (ICG)** was employed to measure this phenomenon. Complicated grief has been defined as symptoms associated with loss that are unresolved over time and are associated with impairment in the performance of daily activities (Prigerson et al., 1995). In Prigerson et al.'s (1995) study of 97 widowed participants, Cronbach alpha was high at 0.94, six-month test-retest reliability was 0.8, and concurrent and criterion validity were supported. This 19-item scale was developed to assess grief symptoms and has a possible range of 0–76. A score greater than 25 indicates complicated grief.

Procedures

Approval was obtained in writing from the two involved hospice programs and from the institutional review board at the University of South Florida. Patient and caregiver dyads were interviewed in their homes, the study was explained, and any questions were answered. Patients and caregivers signed the informed consent form prior to participation. Three months after the death of a patient, the research assistant submitted a packet of questionnaires to the caregiver for follow-up data collection. Demographic data were collected from each participant at baseline.

Data Analysis

The data were entered into computer software (SPSS®, version 17.0) in preparation for the analysis. Participants with missing data were removed from the data set. From the original sample of 302 participants who completed the study, 22 had one or more missing items of data

from the questionnaires and were not included in the analysis. Means, standard deviations, frequencies, and percentages were used to analyze demographic data; scores on depression, grief, and complicated grief; and other descriptive data. Pearson correlations were calculated to evaluate relationships among variables. Cronbach alpha also was calculated for each measure.

Results

A majority of the bereaved caregivers were older adult Caucasian women who were caring for a spouse (see Table 1).

Mean scores with ranges for depressive symptoms (CES-D), grief experiences (TRIG Present Feelings subscale), and complicated grief (ICG), and the percentage of the sample with clinically meaningful scores on the CES-D and ICG can be found in Table 2. The CES-D focuses on evaluation of mood, thoughts, quality of sleep, and ability to reach out to others; more than a third were experiencing clinically significant levels of these depressive symptoms at three months of bereavement.

The mean grief experiences score from the TRIG Present Feelings subscale indicated that most participants were experiencing feelings of grief at three months. For the measure, high scores represent low levels of grief. About 24% of the sample had clinically meaningful scores (25 or higher) on the ICG, indicating they were experiencing significant impairment with social, general, mental, and physical functioning. A significant negative

Table 1. Demographic Characteristics of Hospice Caregivers Three Months After the Patient's Death

Characteristic	\bar{X}	SD	Range
Caregiver age (years)	66.1	12.5	29–91
Characteristic	n	%	
Gender			
Female	212	76	
Male	68	24	
Caregiver's relationship to patient			
Spouse	173	62	
Child	57	20	
Significant other	17	6	
Sibling	8	3	
Parent	7	3	
Other (grandchildren, neighbors, friends, etc.)	18	6	
Race or ethnicity			
Caucasian	273	97	
African American	5	3	
Other	2	1	

N = 280

Note. Because of rounding, not all percentages total 100.

Table 2. Total Scores of Hospice Caregivers Three Months Following the Death of the Patient

Instrument	\bar{X}	SD	Clinically Meaningful Scores		Range of Patient Scores
			n	%	
Center for Epidemiological Studies–Depression ^a	3.33	2.55	94	34	0–10
Texas Revised Inventory of Grief ^b Present Feelings subscale	38.77	9.45	–	–	13–65
Inventory of Complicated Grief ^c	18.01	11.6	68	24	0–59
N = 280					
^a Indication of clinically meaningful score is more than 4.					
^b No cutoff score exists; however, a low score indicates high grief.					
^c Indication of clinically meaningful score is more than 25.					

correlation was found between the TRIG Present Feelings subscale and CES-D ($p < 0.0001$) (see Table 3).

As part of this analysis, reliability of the instruments was assessed. Among the caregivers, the computed Cronbach alphas were high for each of the variables (CES-D = 0.8, TRIG Present Feelings subscale = 0.86, and ICG = 0.88).

Discussion

This secondary analysis sought to examine grief and depression among a sample of bereaved caregivers in West Central Florida. Although very little research has been conducted to compare findings of depressive symptoms, grief, and complicated grief for bereaved family caregivers, the results of this study are similar to previous findings. The sample of bereaved caregivers is typical of caregivers of patients with advanced cancer in terms of age and gender (Bradley et al., 2004). Women in Western society are more likely to serve as caregivers. In a study of bereaved caregivers of hospice patients, 72% were women and 72% of the total sample were older than 65 years of age (Bradley et al., 2004). In addition, the researchers interviewed 174 bereaved caregivers six months into bereavement and found depression rates up to 24%, similar to the findings of this analysis.

Grief is a normal process and may be expected three months following the death of a loved one, especially after a difficult caregiving experience (Brazil et al., 2003). Three months into bereavement, family caregivers may continue to experience persistent effects of caregiving. For example, exhaustion (Addington-Hall & Karlsen, 2000) and emotional distress related to caregiving may

play a role in their depression or grief (Ferrario et al., 2004). Specific elements of the caregiving experience such as uncontrolled pain, difficult memories (Koop & Strang, 2003), and a stressful family context during caregiving (Dumont, Dumont, & Mongeau, 2008) are known to affect the grieving process and must be addressed to promote positive outcomes for caregivers. However, the concern of healthcare providers should be whether normal grief has evolved into clinical depression or whether complicated grief is being obscured by normal grieving. Approximately a third of the caregivers in the current study had levels of depressive symptoms that were indicative of clinical depression. Because of the negative impact on the individual's overall quality of life and the health risks associated with depression, healthcare providers must be alert for depressive symptoms. Results of this study suggest that bereaved caregivers may be experiencing clinical depression. A simple assessment by providers might help to differentiate between depression and grief symptoms.

The correlations among depression, grief, and complicated grief are strong, which shows that bereaved caregivers experiencing depressive symptoms also are experiencing many symptoms of grief and complicated grief. Because comprehensive palliative care continues after the death of the patient, including identifying risk factors for complicated grief and providing intervention (NCCN, 2009), a careful and appropriate assessment is important and can provide a valuable opportunity to identify those most at risk for difficulties so that interventions can be targeted where they are most needed.

Limitations

This study is limited by geographic location; two hospice programs were included, but both were in the West Central portion of one state. In addition, the data are cross-sectional and were taken at a single point of

Table 3. Pearson's Correlation of Variables of Hospice Caregivers of Patients With Cancer Three Months Following the Death of the Patient

Instrument	TRIG Present Feelings Subscale		
	CES-D	ICG	
CES-D	1	–0.52*	0.6*
TRIG Present Feelings subscale	–0.52*	1	–0.79*
ICG	0.6*	–0.79*	1

N = 280

* $p < 0.001$

CES-D—Center for Epidemiological Studies–Depression; ICG—Inventory of Complicated Grief; TRIG—Texas Revised Inventory of Grief

time; thus, patterns that may have occurred over time could not be determined.

Although all caregivers in the hospice programs were eligible for inclusion in the study, 97% were Caucasian. This very homogenous convenience sample limits the generalizability of the study results. However, given that the results support earlier research (Bradley et al., 2004), they may serve as a useful basis for ongoing dialogue and enhanced awareness of the needs of bereaved caregivers.

Implications for Nursing

The results of the current study cannot be generalized to other populations, but the findings suggest that nursing practice should include routine assessment of bereaved caregivers for symptoms of complicated grief and depression. The measurement tools used in this study are brief, clinically useful, and available to target scarce resources to those most in need of intervention. Schools of nursing need to include caregiving stresses in their curricula and emphasize the risk for complicated grief during bereavement. In addition, continuing education programs on the effects of caregiving are important for practicing nurses in all oncology settings, as well as in primary care settings where caregivers are likely to receive care. Future studies should attempt to include more diverse samples and should report symptoms over time. Inclusion of a comprehensive framework to guide research and practice, such as the NCCN (2009) guidelines, would provide the needed rationale to focus on complex variables such as exhaustion, emotional distress, and the implications of a difficult caregiving experience in future research.

Conclusion

Assessment of family caregivers three months after the patient's death revealed a considerable portion of the sample had clinically significant levels of depressive symptoms and scores suggesting complicated grief. The strong correlations between the depression and grief scores indicate the difficulty in fully understanding the grief experience without careful assessment with valid tools. Assessment may reveal that complicated grief and depression may be hidden by normal grieving. This issue deserves greater attention in practice and in ongoing studies. Cancer is currently the second most common cause of death in the United States (American Cancer Society, 2010). Oncology nurses have an obligation to provide care and support that promote positive outcomes for family caregivers of patients. Ongoing research focused on meeting the needs of family caregivers during bereavement is critical to advance the health promotion strategy for a population at risk.

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