Informal Caregiving of Hospice Patients

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Abstract

Background: Informal caregivers play a critical role in the provision of care to hospice patients. The care they provide often impacts their physical and psychological well-being.

Objective: This study synthesized 58 articles pertaining to informal hospice caregiving, focusing on caregivers' satisfaction with hospice services, the physical and psychological well-being of caregivers, the predictors of caregivers' well-being, the direct impact of hospice services on caregivers, and the effectiveness of targeted interventions for hospice caregivers.

Method: A systematic literature review of journal articles published between 1985 and 2012 was conducted.

Results: The studies reviewed found hospice caregivers to experience clinically significant levels of anxiety, depression, and stress; however, results for caregiver burden and quality of life were mixed. Caregivers' perceptions regarding the meaningfulness of care as well as their levels of social support were associated with enhanced psychological outcomes.

Conclusions: Beyond satisfaction with hospice services, the direct impact of standard hospice care on caregivers remains uncertain. Caregiver intervention studies have demonstrated promising outcomes signifying a need for additional investigations into hospice-specific interventions that improve caregiver outcomes. Additional research and resources are needed to assist hospice caregivers, with the ultimate goal of minimizing their psychiatric and physical morbidity and enhancing their caregiving and subsequent bereavement processes.

Introduction

PATIENTS WITH LIFE-LIMITING ILLNESS often wish to remain at home versus being admitted to a hospital, shifting caregiving responsibilities from formal or institutional caregivers to informal caregivers.^{1–3} Family and friends as informal or unpaid caregivers provide an average of 66 hours per week of physical, emotional, and practical care during the last year of a loved one's life.^{4,5} In the United States over 70% of patients with life-limiting illness receive care from an informal caregiver at the time of their death, and an estimated three million informal caregivers accompany hospice patients through the dying process annually.⁶ The care provided by family and friends represents considerable economic value to the health care system.^{2,3,5} However, providing care to a loved one during the dying process involves significant personal, professional, and financial sacrifices,^{6,7} and consequently should also be viewed in terms of its personal and societal costs.

Unfortunately, providing care to a family member or loved one at the end of life has also been associated with detrimental effects on caregivers' physical and psychological well-being^{8–14} and increased risk of mortality.^{12,15–17} Furthermore, the well-being of caregivers and patients are intimately linked. For example, caregivers' well-being often deteriorates as the burden and stress of caregiving increases, putting the patient at increased risk of hospitalization.^{11,18,19} Also, psychological distress within a caregiver-patient dyad is correlated, suggesting that the caregiver and patient are interdependent and respond to distress as a unit.^{9,20} As caregivers typically survive beyond the patient, reducing psychological and physical morbidity in these individuals has a long-term impact both on their well-being and their bereavement process after the death of the patient.^{11,12,21} For hospice care to be most effective and speak to this public health issue, hospice services must address the needs and stressors associated with informal caregiving.

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Objectives

The aim of this study was to review the published research on informal hospice caregivers that evaluated the psychological and physical effect of providing care, the impact of hospice care on caregivers, and the effectiveness of hospice-based interventions for improving caregivers' well-being. Since hospice care is defined differently throughout the world, this review focuses exclusively on caregivers of hospice patients within a U.S. context. The objective of this review is to address the following questions:

- 1) What is the psychological and/or physical well-being of informal caregivers who provide care to a dying family member or friend enrolled in a U.S. hospice program?
- 2) Do hospice services have an effect on caregivers' well-being?
- 3) Do hospice-based caregiver interventions enhance informal caregivers' well-being?

Methods

Design

This study systematically identified and evaluated quantitative and qualitative research on informal hospice caregivers and employed a narrative approach to data synthesis. This approach was selected because of the broad research questions and the diversity of study designs.²² A narrative synthesis was used to assimilate the evidence from the identified studies. This synthesis involved comparing and contrasting the individual studies to identify relevant themes as well as factors that may account for the variability in the results.²³

Data sources

Studies from peer-reviewed medical and psychological journals were extracted by searching three electronic databases: PubMed, PsycINFO, and CINAHL. Searches were conducted by the first author and were limited to studies in English published between January 1985 and December 2012. The following keywords/MeSH search terms were utilized: hospice, caregivers, satisfaction (personal), stress (psychological), caregiver burden, dependency (psychological), well-being, quality of life, health (status), and mental health.

Inclusion and exclusion criteria

Studies were evaluated by two independent reviewers (first and fourth authors) based on an a priori set of criteria; discrepancies in study ratings were settled by a third independent rater (second author). These were the criteria:

- (1) The articles defined an informal caregiver as an individual who provided physical and/or supportive care to a hospice patient, and that care was not provided as part of employment.
- (2) The articles provided a clear description of the methods and results.
- (3) The articles measured outcomes of caregivers' emotional and/or psychological/psychiatric well-being, physical health, or satisfaction.

Because hospice care in the United States involves unique admission criteria and prescribes a core set of services, only caregivers involved in a U.S. hospice program were included. Self-reports, case studies, editorials, as well as studies not published in English were excluded.

Results

Database searches generated 402 articles (see Fig. 1). Abstracts of these articles were reviewed and 292 articles were rejected based on the a priori criteria. The primary reasons for rejection included inadequate caregiver outcomes, a lack of hospice involvement, and participants not receiving

FIG. 1. Decision process for inclusion of informal hospice caregiver articles in the review.

TABLE 1. KEY METHODOLOGICAL FEATURES OF THE STUDIES INCLUDED IN THIS REVIEW OF INFORMAL CAREGIVING FOR HOSPICE PATIENTS

<i>Study (reference)</i>	<i>Sample size^a</i>	<i>Percent female; race</i>	<i>Primary disease type; data collection points pre/post patient death</i>	<i>Research design</i>	<i>Response rate (%)</i>	<i>Outcomes</i>
Archer & Boyle, 1999 (24)	44	59% Caucasian, 82% African American	NR Post death	Quantitative descriptive, retrospective	80	Caregiver satisfaction on Primary Caregiver Satisfaction Survey
Bernard & Guarnaccia, 2002 (43)	213	29% Caucasian, 92% African American, 8% Other	Breast cancer Pre & post death	Quasi-experimental, prospective	NR	Grief Experience Inventory and Despair Subscale
Bernard & Guarnaccia, 2003 (30)	213	29% NR	Breast cancer Pre & post death	Quasi-experimental, prospective	NR	Grief Experience Inventory and Despair Subscale
Bialon & Coke, 2012 (10)	9	78% Caucasian, 67% African American, 22% Other	Mixed Post death	Qualitative	NR	Caregiver interviews
Cagle & Kovacs, 2011 (37)	69	72% Caucasian, 84% African American, 4% African American, 11% Other	Cancer Pre & post death	Qualitative, prospective	26	Survey responses
Casarett, Hirschman, Crowley, Galbraith, & Leo, 2003 (52)	112	77% Caucasian, 69% African American, 27% African American, 4% Other	Mixed (predominantly cancer) Post death	Quantitative descriptive, retrospective	54	Satisfaction with services
Chentsova-Dutton, et al., 2000 (32)	181/112	79% Caucasian, 96% African American, 1% Hispanic	NR Pre death	Quasi-experimental, retrospective	NR	Depression (BDI, Hamilton Psychiatric Rating Scale for Depression); Psychological symptomatology (BSI); Health (self-rating estimates, medical visits); Social functioning (Social Support Questionnaire)
Chentsova-Dutton, et al., 2002 (49)	84/48	83% Caucasian, 96% African American, 2% Hispanic	NR Pre & post death	Quasi-experimental, prospective	44	Depression (Hamilton Rating Scale for Depression); Psychological symptomatology (BSI); Grief (Texas Revised Instrument of Grief)
Christakis & Iwashyna, 2003 (44)	61,676	80% Caucasian, 93% others, NR	Mixed Post death	Quasi-experimental, retrospective, matched control group	100	Duration of survival of bereaved widows/widowers
Dawson, 1991 (54)	100	66% Caucasian, 95% others, NR	NR Post death	Quantitative descriptive, retrospective	58	Three satisfaction measures
Demiris, Oliver, Courtney, & Day, 2007 (74)	12	75% NR	Mixed (predominantly cancer) Pre death	Quasi-experimental, prospective	NR	Anxiety (State Trait Anxiety Inventory)

(continued)

TABLE 1. (CONTINUED)

Study (reference)	Sample size ^a	Primary disease type; data collection points pre/post patient death		Research design	Response rate (%)	Outcomes
		Percent female; race				
Demiris et al., 2010 (33)	23	76% Caucasian, 86% African American, 1% Other	NR	Quasi-experimental, prospective	89	Quality of life (CQLI-R); Anxiety (State Trait Anxiety Inventory)
Demiris, Oliver, Wittenberg-Lyles, & Washington, 2011 (31)	33	81% Caucasian, 98% African American, 2% Other	NR	Quasi-experimental	79	CQLI-R; State-Trait Anxiety Inventory; Problem-Solving Inventory
Demiris, et al., 2012 (41)	89	79% Caucasian, 87% African American	Pre death	Experimental, prospective	71	CQOLI-R; State-Trait Anxiety Inventory; Problem-Solving Inventory
Empeño, Raming, Irwin, Nelesen, & Lloyd, 2011 (77)	123	82% Caucasian, NR	NR	Quasi-experimental, prospective	43	Pearlin Role Overload Measure
Evans, Cutson, Steinhauser, & Tulskey, 2006 (55)	18	50% Caucasian, 61% African American	NR	Qualitative, retrospective	22	Caregivers' experiences extracted from semi-structured interviews
Fenix et al., 2006 (68)	175	75% Caucasian, NR	Most (63%) post death	Quasi-experimental, prospective	53	Major Depressive Disorder (SCID)
Ganzini, Johnston, & Silveira, 2002 (25)	50	NR	ALS	Quantitative descriptive, retrospective	NR	Satisfaction with care (FAMCARE)
Gill, Kaur, Rummans, Novotny, & Sloan, 2003 (59)	57	68% Caucasian, NR	NR	Quasi-experimental, prospective	NR	CQOL (multidimensional measurement)
Goldstein, et al., 2004 (26)	206	71% Caucasian, 96% African American, 3% Other	Cancer	Quantitative descriptive, retrospective	53	Caregiver burden (Zarit Burden Inventory)
Goy, Carter, & Ganzini, 2008 (27)	47	77% Caucasian, 92% African American, 8% Other	Parkinson's	Quantitative descriptive, retrospective	39	Caregiver mood (CES-D); Caregiver satisfaction with care
Haley, LaMonde, Han, Burton, & Schonwetter, 2003 (34)	80	79% Caucasian, NR	Lung cancer & dementia	Quasi-experimental, retrospective	NR	Caregiver depression (CES-D); Life Satisfaction Index
Haley, LaMonde, Han, Narramore, & Schonwetter, 2001 (57)	120	83% Caucasian, 82% African American, 18% Other	Lung cancer & dementia	Quasi-experimental, retrospective	NR	Caregiver depression (CES-D); Life Satisfaction Index; Caregiver physical health (Health Perception Scale & Medical Outcomes Study Short Form Health Survey)

(continued)

TABLE 1. (CONTINUED)

<i>Study (reference)</i>	<i>Sample size^a</i>	<i>Percent female; race</i>	<i>Primary disease type; data collection points pre/post patient death</i>	<i>Research design</i>	<i>Response rate (%)</i>	<i>Outcomes</i>
Herth, 1993 (38)	25	76% NR	Mixed (cancer most common) Pre death	Qualitative and quantitative; descriptive, prospective	NR	Hope (Herth Hope Index and semi-structured interview)
Holtzlander & McMillan, 2011 (28)	280	76% Caucasian, 3% African American, 1% Other	Cancer Post death	Quantitative descriptive, retrospective	NR	Depressive symptoms (CES-D); grief (Texas Revised Inventory of Grief); (Inventory of Complicated Grief)
Hull, 1990 (79)	14	79% NR	NR Pre & post death	Qualitative descriptive, prospective	NR	Caregiver stressors (interviews)
Jones, 2010 (64)	388	NR NR	Mixed (predominantly cancer) Post death	Quantitative descriptive, retrospective	NR	Utilization of bereavement services
Kilbourn, et al., 2011 (73)	19	91% NR	NR Pre death	Quantitative descriptive, prospective	NR	CES-D; PSS; MOS SF-36; ENRICH Social Support Inventory Benefit Finding Scale
Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010 (71)	152	80% Caucasian, 3% African American	Lung cancer Post death	Quantitative descriptive, retrospective	47	Complicated grief (Inventory of Complicated Grief)
Kreling, et al., 2010 (39)	30	NR 50% Caucasian, 50% Hispanic	NR Post death	Qualitative design, retrospective	NR	Caregivers' experience of hospice (interviews)
Kris, et al., 2006 (50)	175	75% NR	Cancer Pre and post death	Quasi-experimental, prospective	53	Major Depressive Disorder (SCID)
Kutner, et al., 2009 (61)	36	86% Caucasian	NR Post death	Qualitative design, retrospective	NR	Hospice caregivers' needs (interviews)
Kwak, Salmon, Acquaviva, Brandt, & Egan, 2007 (76)	926	81% Caucasian, 88% African American, 7% African American	NR Pre death	Quasi-experimental, prospective	46	Comfort with caregiving tasks; Completion and closure; Caregiving gain (Comfort with Caregiving Scale, Caregiver Closure Scale, CSS)
McMillan, 1996 (46)	118	64% NR	Cancer Pre death	Quasi-experimental, prospective	NR	Caregiver quality of life (CQOLI)
McMillan, et al., 2006 (40)	354	85% NR	Cancer Pre death	Experimental	31 (completed all measures)	Quality of life (CQOL-C); Caregiver burden due to patient symptoms (MSAS); Caregiver burden due to tasks (CDS); Caregiver mastery (6-item scale)
McMillan & Mahon, 1994 (66)	130	85% NR	Cancer Pre death	Quasi-experimental, prospective	NR	Caregiver quality of life (CQLI)

(continued)

TABLE 1. (CONTINUED)

Study (reference)	Sample size ^a	Percent female; race	Primary disease type; data collection points		Research design	Response rate (%)	Outcomes
			pre/post	patient death			
McMillan, Small, & Haley, 2011 (42)	716	74% NR	Cancer	Pre death	Experimental, prospective	48%	CES-D; Spiritual Needs Inventory; Mental Status Questionnaire
Meyers & Gray, 2001 (53)	44	75% 91% Caucasian, 1% African American, 8% Other	Mixed (66% cancer)	Pre death	Quantitative descriptive, retrospective	94	Satisfaction with hospice care (FAMCARE Scale); Quality of life CQOLC; Burden (Caregiver Strain Index)
Mickley, Pargament, Brant, & Hipp, 1998 (69)	92	78% NR	NR	Pre death	Quantitative descriptive, retrospective	37	Depression (CES-D); Anxiety (BAD); Meaning (Purpose in Life Test); Situational Outcomes (General and Religious Outcome Scales)
Moody & McMillan, 2003 (65)	162	78% 85% Caucasian, 11% African American, 6% Hispanic, 1% Other	Cancer (mixed cancer types)	Pre death	Quantitative descriptive, retrospective	54	Caregiver quality of life
Newton, Bell, Lambert, & Fearing, 2002 (62)	33	73% NR	Mixed (predominantly cancer)	Pre death	Quantitative descriptive, retrospective	33	Needs and concerns of caregivers (interview)
Parker, et al., 2010 (75)	24	77% 97% Caucasian	Mixed (predominantly cancer)	Pre death	Quasi-experimental, prospective	39	Caregiver quality of life (CQLI-R)
Prigerson et al., 2003 (58)	205	71% NR	Pre death	Cancer	Quantitative descriptive, retrospective	61	Caregiver fear and helplessness associated with exposure to death (SCARED scale)
Redinbaugh, Baum, Tarbell, & Arnold, 2003 (80)	31	68% 84% Caucasian, 16% African American	Cancer	Pre death	Quantitative Descriptive, retrospective	54	Caregiver strain (BSI, Caregiver Burden Screen)
Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005 (36)	953	77% NR	Mixed (predominantly cancer)	Pre post death	Quasi-experimental, retrospective	32	Caregiver gain; Caregiver burden (Revised Caregiving Appraisal Scale)
Speer, Robinson, & Reed, 1995 (67)	160	75% NR	Mixed (predominantly cancer)	Pre post death	Quantitative descriptive, retrospective	30	Caregiver adjustment (Texas Inventory of Grief)
Steele, Mills, Long, & Hagopian, 2002 (56)	443	NR	NR	Post death	Quantitative descriptive, retrospective	NR	Satisfaction with hospice services (created scale)
Tang, 2009 (29)	60	65% 97% Caucasian, 3% African American	Mixed (predominantly cancer)	Pre death	Quantitative descriptive, retrospective	71	Caregiver quality of life (CQOLC)
Tilden, Tolle, Drach, & Perrin, 2004 (70)	1189	71% NR	Mixed (predominantly cancer)	Post death	Quantitative descriptive, retrospective	72	Caregiver strain (4 items)

(continued)

TABLE 1. (CONTINUED)

<i>Study (reference)</i>	<i>Sample size^a</i>	<i>Percent female; race</i>	<i>Primary disease type; data collection points pre/post patient death</i>	<i>Research design</i>	<i>Response rate (%)</i>	<i>Outcomes</i>
Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010 (63)	162	80% Caucasian, 86% African American, 12% Hispanic, 1% Other	Mixed (predominantly cancer) Pre death	Quantitative descriptive, retrospective	NR	Caregiver strain (13-item scale)
Waldrop & Meeker, 2011 (11)	3	81% Caucasian, 94% African American, 3% Hispanic	Mostly Cancer Post death	Qualitative retrospective	32%	Caregiver interview
Weitzner, McMillan, & Jacobsen, 1999 (45)	401	78% Caucasian, 70% African American, 19% Hispanic, 9% Other	Cancer Pre death	Quasi-Experimental, retrospective	NR	Caregiver quality of life (CQOLC)
Wilder, Oliver, Demiris, & Washington, 2008 (35)	76	63% Caucasian, 96% African American, 3% Other	Mixed (predominantly cancer) Pre death	Quasi-experimental, prospective	NR	Caregiver quality of life (CQLI-R)
Wittenberg-Lyles, Demiris, Oliver, & Burt, 2011 (60)	30	77% Caucasian, 97% African American	Mixed (not predominantly cancer) Pre death	Qualitative, retrospective	NR	Caregivers' concerns (interviews)
Wittenberg-Lyles, et al., 2012 (9)	81	79% Caucasian	Mixed Pre death	Qualitative retrospective	NR	Caregivers' concerns (interviews)
Wright, et al., 2008 (48)	332	77% Caucasian, 65% African American, 17% Hispanic, 16% Other	Cancer Pre and post death	Quasi-experimental, prospective	70	Caregivers' bereavement adjustment (SCID, McGill Quality of Life psychological subscale)
Wright, et al., 2010 (72)	342	75% Caucasian, 64% African American, 20% Hispanic, 15% Other	Cancer Pre and post death	Quasi-experimental, prospective	72	Caregivers' mental health (SCID, Prolonged Grief Disorder scale)
York, Churchman, Woodard, Wainright, & Rau-Foster, 2012 (51)	243	48% Caucasian	Mostly cancer Post death	Qualitative prospective	NR	Free text comments by caregivers

^aTotal number of participants in study/number of hospice caregivers in study.

ALS, amyotrophic lateral sclerosis; BAI, Beck Anxiety Inventory; BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CDS, Caregiver Demands Scale; CES-D, Center for the Epidemiological Studies Depression Scale; CQLI-R, Caregiver Quality of Life Revised; CQOLC, Caregiver Quality of Life Index - Cancer; CSS, Caregiver Satisfaction Scale; DSM-IV, Diagnostic and Statistical Manual, 4th ed; ENRICHED, Enhancing Recovery in Coronary Heart Disease; FAMCARE, Family Satisfaction with Advanced Cancer Care Scale; MOS, SF-36, Medical Outcome Item Short-Form Health Survey; MSAS, Memorial Symptom Assessment Scale; NR, not reported; PSS, Perceived Stress Scale; SCARED, Stressful Caregiving Adult Reactions to Experiences of Dying scale; SCID, Structured Clinical Interview for DSM-IV.

services within the United States (i.e., international studies). The complete texts of the remaining 110 articles were evaluated. Of these, 52 were excluded for not clearly distinguishing between palliative care and hospice care, for using single measurement designs, for reporting change based on mean scores without consideration of variability, and/or for not adequately reporting caregiver outcomes. The remaining 58 articles were included in this review.

Design and quality of reviewed studies

Key methodological features of the studies included in this review are summarized in Table 1. The most common study design (22 studies) was a descriptive quantitative design.^{24–29} The next most commonly employed were a prospective quasi-experimental design (15 studies) and a retrospective quasi-experimental design (6 studies).^{30–36} Qualitative methodology was employed in 11 studies,^{9,11,37–39} and 3 studies employed a randomized controlled trial.^{40–42} A few studies were secondary analyses of existing data.^{16,28}

Most of the included studies used non-representative samples of caregivers predominantly of cancer patients. Participants in the included studies were primarily female (with two exceptions^{30,43}) and Caucasian (with one exception³⁹). When reported, participant response varied significantly from a low of 22% to 94%. Few studies reported non-respondent data, making it difficult to exclude selection bias.

The nature and quality of the outcome measures used by the studies varied greatly. Only one study used a biological marker of well-being (mortality),⁴⁴ with most studies using either previously validated self-report measures or satisfaction questionnaires unique to the specific study. The Caregiver Quality of Life Index – Cancer,⁴⁵ Caregiver Quality of Life Index – Revised,⁴⁶ and the CES-D⁴⁷ were the most commonly used self-report measures. The majority of studies evaluated caregiver outcomes prior to the death of the patient. However, a few studies took a broader perspective on caregiving and assessed caregiver outcomes both before and after the death of the patient.^{30,37,48–50}

Synthesis of studies

Synthesis of the included studies showed them to fall into five main groups: (1) caregivers' satisfaction with hospice services, (2) caregivers' well-being, (3) predictors of caregivers' psychological or physical well-being, (4) the impact of hospice services on caregiver outcomes, and (5) the effectiveness of hospice-based caregiver interventions.

Caregivers' satisfaction with hospice services. These studies measured caregiver satisfaction after the death of the patient and found the majority of caregivers to be satisfied or very satisfied with hospice care and services.^{24,27,39,48,51–56} Caregivers of hospice patients reported fewer unmet needs when compared with caregivers of patients who died in traditional hospital settings.⁵⁴ In general, caregiver characteristics (i.e., ethnicity, gender, age, relationship with patient) were not found to be associated with caregiver satisfaction.^{24,52} Factors associated with higher levels of caregiver satisfaction included time spent with the patient, clear goals of care, personalized treatment plans, accessibility and continuity of hospice staff, effective symptom management, and good communication between hospice staff and caregivers.^{51,52,55}

While level of caregiver satisfaction was not found to be associated with caregiver ethnicity, other group differences were reported between Caucasian and Latino caregivers. Caucasian caregivers access hospice services at a greater rate than Latino caregivers and the locus of decision making differs (family versus individual). Critically identified were the need for culturally specific language and improved cultural literacy among medical providers serving Latino communities.³⁹

Caregivers' well-being. Studies in this category reported on one or more aspects of caregiver well-being. Primary caregiver outcomes included mood and anxiety symptoms, complicated grief, self-reported physical health, and quality of life. Anxiety and depressive symptoms as well as caregiver stress were found to be clinically significant in caregivers of hospice patients both while actively providing care and within the first few months after the death of the patient.^{9,11,28,30,32,49,57,58} Caregiver quality of life outcomes were mixed. A few studies reported that caregivers' quality of life was relatively healthy or at least adequate,^{35,59} while others reported caregivers' quality of life was lower than in non-caregiving adults.^{10,46,57}

Subjective indicators of physical health were found to be lower in caregivers at time of hospice enrollment compared with non-caregiving adults.⁵⁷ As the death of the patient approached, caregivers' quality of life was found to decline, and the demands of providing care substantially increased.^{10,11,35,38,59}

Several studies identified caregivers as "second order patients" in need of instrumental and emotional support as well as specialized education in the areas of understanding/interpreting patient symptoms, pain management, and emotional preparation for the patient's death.^{10,37,58,60–62}

Predictors of caregivers' psychological or physical well-being. Studies in this category investigated the impact of caregiver characteristics (e.g., age, gender, health, and religiosity); patient factors (diagnosis and duration of caregiving); caregivers' cognitive appraisals; and social support on caregiver outcomes such as grief, burden, depression, and quality of life. Results for several of the predictors were equivocal. Some studies found specific patient diagnoses (i.e., neurologic disease) predictive of poorer caregiver outcomes,^{53,63,64} while one study that compared two matched groups of caregivers (lung cancer and dementia) found no difference in depression and life satisfaction.⁵⁷ A few studies found female gender predictive of higher levels of depression and less life satisfaction,^{34,57} while others reported caregiving daughters experienced less grief and burden than spousal caregivers.^{30,53} Increased caregiver age predicted less caregiving burden and strain,^{26,63} higher quality of life,⁶⁵ and less complicated bereavement.³⁰ Conversely, some studies found no significant relationship between caregivers' age, gender, and quality of life⁶⁶ or between quality of life and whether the caregiver was a spouse or daughter of the care receiver.⁶⁷

Health status, religiosity, social connections, and cognitive appraisal emerged as more reliable predictors of caregiver outcomes. Poor self-reported caregiver health status predicted higher levels of depression, less life satisfaction, and a more intensive grief response.^{29,30,34,45} Greater religiosity among caregivers on the other hand predicted fewer incidents of Major Depressive Disorder 13 months after the death of the patient.⁶⁸ Limited social networks and restricted daily

activities predicted increased burden, higher levels of depression, and less life satisfaction in active caregivers.^{26,34,36,63} One of the most consistent findings was the importance of caregivers' subjective appraisals or perception of burden. Caregivers who appraised caregiving demands as less stressful and/or who found meaning and benefit in caregiving experienced lower levels of depression and strain and higher levels of life satisfaction.^{26,34,36,63,69}

Impact of hospice services on caregiver outcomes. This category of studies examined the impact of hospice services on caregiver mortality, psychiatric symptoms, burden, quality of life, and complicated or prolonged grief. A large retrospective study found hospice use decreased the risk of mortality for the surviving spouse, but only for women.⁴⁴ However, enrollment in hospice was not found to reduce caregiver burden,⁷⁰ to improve the quality of life for caregivers,^{48,66} or to be predictive of bereavement adjustment.⁶⁷

Although hospice care was not a direct predictor of caregiver quality of life, receiving hospice services for at least a week predicted higher patient quality of life; improved patient quality of life was in turn associated with better caregiver quality of life.^{48,66} Enrollment in hospice services was found to reduce the risk of Major Depressive Disorder following the patient's death⁵⁰ and also reduce the number of complicated grief symptoms.⁷¹ When comparing hospice caregivers to those in other settings, a patient's death in hospice care as opposed to traditional hospital deaths resulted in a decreased risk for Posttraumatic Stress Disorder and prolonged grief in caregivers.⁷²

Effectiveness of hospice-based caregiver interventions. This emerging group of studies developed and tested the effectiveness of caregiver interventions delivered within a hospice setting. Findings suggested brief caregiver interventions can be delivered successfully^{31,41,42,73} and that technology (i.e., videophones and telephones) could improve communication between the hospice team and caregivers, thereby enabling greater participation in care decisions.^{31,41,74,75}

Two pilot studies tested psychosocial caregiver interventions (problem solving) delivered via videophone and telephone and failed to find significant intervention effects.^{33,73} Nevertheless, a subsequent randomized control trial of a problem solving intervention offered to caregivers via videophone was found to reduce caregiver anxiety and improve problem solving skills, but had no effect on caregivers' quality of life.³¹ A comparison study of face-to-face and videophone delivery of a problem solving caregiver intervention found no significant difference in caregiver outcomes between the two methods of intervention delivery,⁴¹ suggesting a role for this technology in hospice care.

In a randomized control trial by McMillan et al., caregivers of cancer patients were found to significantly benefit (as measured by improved quality of life and reduced burden) from a brief three-session manualized psychosocial intervention.⁴⁰ This nine-day (three-visit) intervention, labeled Creativity, Optimism, Planning, and Expert Information (COPE), adapted strategies from the problem-solving research literature to address the needs and issues faced by families caring for persons with cancer. Another psychoso-

cial intervention study used a targeted intervention to enhance the positive aspects of caregiving (meaning, purpose, and value in the caregiving experience), improving caregivers' comfort with caregiving tasks and facilitating emotional closure with the patient.⁷⁶ Results from this nine-session (7.5 hour) intervention found enhanced caregiver perceptions of the positive aspects of caregiving, comfort, and closure.

A second randomized controlled trial by McMillan et al.⁴² tested the effect of providing brief feedback from standardized psychosocial assessments of patient/caregiver dyads at interdisciplinary hospice team meetings. Results were encouraging for patients, but no change was detected in the caregiver outcomes of depression or spiritual needs. Interventions may also include tangible supports, e.g., caregiving assistance, transportation, cleaning, meal preparation. Providing these additional supports to hospice caregivers was found to reduce caregiver stress and inpatient stays when compared with hospice caregivers not receiving these supplementary services.⁷⁷

Discussion

In this review of the literature regarding informal caregiving of hospice patients, several important themes emerged. First, caregivers were found to be generally satisfied with hospice services. Clear goals of care, good communication between hospice staff and caregivers, and additional time spent with patients and families promoted higher levels of satisfaction with hospice services. Second, caregivers were found to have clinically significant levels of anxiety, depression, and perceived stress as well as poorer physical health and decreased quality of life when compared with non-caregivers. Third, when attempting to predict caregiver strain, it was found that lowered social support and worsened physical health could be related to increased depression, grief, burden, and diminished life satisfaction. Conversely, increased age, religiosity, and a self-perception about the benefits and meaning of caregiving appeared to have positive and protective effects.

Hospice care in general was not proven in these studies to reduce caregiver burden, improve caregiver quality of life, or assuage the bereavement process. However, the use of hospice services decreased the risk of mortality for female spousal caregivers and reduced the risk of depression and complicated grief after the patient's death.

Hospice-specific caregiver interventions showed significant promise. These brief structured interventions promoted problem solving and/or meaning-based coping strategies and were found to improve caregivers' quality of life, decrease burden, and enhance positive aspects of caregiving. The psychosocial interventions were offered upon admission to a hospice program and successfully delivered in-person or via videophone.

Limitations

The studies included in this review were diverse in terms of design, assessed outcomes, and sample sizes. The absence of control groups and underutilization of repeated measures or time-series designs over the course of the dying and bereavement process limited the findings of many studies. The vast majority of participants were Caucasian females caring for a person dying of cancer, which may also be problematic

for overall generalizability. Finally, there was an overreliance on self-reporting and study-specific measures to assess outcomes.

Conclusions

This study highlights the invaluable role played by informal hospice caregivers and calls for systematic research on how to maximize the positive aspects of caregiving. With advances in policy, research, and resource allocation, hospices will be better able to support the critical needs of caregivers for the dying, whose vital role enables high-quality end-of-life care for so many.

Future directions

This review was helpful in synthesizing the current literature on informal caregiving in hospice; however, future research is warranted. For example, few studies adequately addressed the impact of disease trajectories on caregivers during the period of actively providing care and during the bereavement process. Future research could consider the impact different disease trajectories have on caregivers and their well-being, and how providing support to caregivers earlier in the course of their loved one's terminal illness could be beneficial. Unfortunately, the disparities apparent in the broader health care system are found in hospice care; most U.S. hospice patients are female (56%), over the age of 65 (84%), of non-Hispanic origin (93%), and Caucasian (82%).⁷⁸ Additional research is needed to better understand how to effectively support diverse caregivers not typically represented here, and to identify their specific needs once services are received.

Further research is needed to assess brief interventions that promote effective coping and enhance the positive aspects of caregiving, while also identifying factors that alleviate the detrimental aspects of caregiving. Since caregivers' cognitive appraisals of burden and stress as well as their ability to find meaning in the caring experience were predictive of enhanced well-being, future studies could more directly target and modify these subjective appraisals. Finally, as social support was associated with increased well-being and reduced burden, developing interventions that help caregivers identify and better use their informal social support networks could be beneficial.

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References

- Given BA, Given CW, Kozachik S: Family support in advanced cancer. *CA Cancer J Clin* 2001;51:213–231.
- Hebert RS, Schulz R: Caregiving at the end of life. *J Palliat Med* 2006;9:1174–1187.
- Talley RC, Crews JE: Framing the public health of caregiving. *Am J Public Health* 2007;97:224–228.
- Harding R, Higginson IJ: What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003;17:63–74.
- Rhee Y, Degenholtz HB, Lo Sasso AT, Emanuel LL: Estimating the quantity and economic value of family care-

- giving for community-dwelling older persons in the last year of life. *J Am Geriatr Soc* 2009;57:1654–1659.
- Wolff JL, Dy SM, Frick KD, Kasper JD: End-of-life care: Findings from a national survey of informal caregivers. *JAMA Intern Med* 2007;167:40–46.
- Grande G, Stajduhar K, Aoun S, et al.: Supporting lay carers in end of life care: Current gaps and future priorities. *Palliat Med* 2009;23:339–344.
- Given B, Wyatt G, Given C, et al.: Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum* 2004;31:1105–1115.
- Wittenberg-Lyles E, Demiris G, Parker OD, Washington K, Burt S, Shaunfield S: Stress variances among informal hospice caregivers. *Qual Health Res* 2012;22:1114–1125.
- Bialon LN, Coke S: A study on caregiver burden: Stressors, challenges, and possible solutions. *Am J Hosp Palliat Care* 2012;29:210–218.
- Waldrop DP, Meeker MA: Crisis in caregiving: When home-based end-of-life care is no longer possible. *J Palliat Care* 2011;27:117–125.
- Zivin K, Christakis NA: The emotional toll of spousal morbidity and mortality. *Am J Geriatr Psychiatry* 2007;15.
- Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van den Bos GAM: Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology* 1998;7:3–13.
- Pinquart M, Sorensen S: Correlates of physical health of informal caregivers: A meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2007;62:126–137.
- Schulz R, Beach SR: Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA* 1999;282:2215–2219.
- Christakis NA, Allison PD: Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719–730.
- Fredman L, Cauley JA, Satterfield S, et al.: Caregiving, mortality, and mobility decline: The Health, Aging, and Body Composition (Health ABC) study. *JAMA Intern Med* 2008;168:2154–2162.
- Argimon JM, Limon E, Vila J, Cabezas C: Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. *Alzheimer Dis Assoc Disord* 2005;19:41–44.
- Lotus Shyu YI, Chen MC, Lee HC: Caregiver's needs as predictors of hospital readmission for the elderly in Taiwan. *Soc Sci Med* 2004;58:1395–1403.
- Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC: Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychol Bull* 2008;134:1–30.
- Zisook S, Irwin SA, Shear K: Understanding and managing adult bereavement in palliative care. In: Chochinov HM, Breitbart W (eds): *Handbook of Psychiatry in Palliative Medicine*, 2nd ed. New York: Oxford University Press, 2009, pp. 202–219.
- Mays N, Pope C, Popay J: Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *J Health Serv Res Policy* 2005;10(S1):6–20.
- Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al.: Guidance on the conducting of narrative synthesis in systematic reviews. Lancaster, UK: ESRC Methods Programme, Institute for Health Research, Lancaster University.
- Archer KC, Boyle DP: Toward a measure of caregiver satisfaction with hospice social services. *Hospice J* 1999;14:1–15.

25. Ganzini L, Johnston WS, Silveira MJ: The final month of life in patients with ALS. *JAMA Neurol* 2002;59:428–431.
26. Goldstein NE, Concato J, Fried TR, Kasl SV, Hurzeler RJ, Bradley EH: Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care* 2004;20:38–43.
27. Goy ER, Carter JH, Ganzini L: Needs and experiences of caregivers for family members dying with Parkinson disease. *J Palliat Care* 2008;24:69–75.
28. Holtslander LF, McMillan SC: Depressive symptoms, grief, and complicated grief among family caregivers of patients with advanced cancer three months into bereavement. *Oncol Nurs Forum* 2011;38:60–65.
29. Tang WR: Hospice family caregivers' quality of life. *J Clin Nurs* 2009;18:2563–2572.
30. Bernard LL, Guarnaccia CA: Two models of caregiver strain and bereavement adjustment: A comparison of husband and daughter caregivers of breast cancer hospice patients. *Gerontologist* 2003;43:808–816.
31. Demiris G, Oliver DP, Wittenberg-Lyles E, Washington K: Use of videophones to deliver a cognitive-behavioural therapy to hospice caregivers. *J Telemed Telecare* 2011;17:142–145.
32. Chentsova-Dutton Y, Shuchter S, Hutchin S, Strause L, Burns K, Zisook S: The psychological and physical health of hospice caregivers. *Ann Clin Psychiatry* 2000;12:19–27.
33. Demiris G, Oliver DP, Washington K, et al.: A problem solving intervention for hospice caregivers: A pilot study. *J Palliat Med* 2010;13:1005–1011.
34. Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R: Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *J Palliat Med* 2003;6:215–224.
35. Wilder HM, Oliver DP, Demiris G, Washington K: Informal hospice caregiving: The toll on quality of life. *J Soc Work End Life Palliat Care* 2008;4:312–332.
36. Salmon JR, Kwak J, Acquaviva KD, Brandt K, Egan KA: Transformative aspects of caregiving at life's end. *J Pain Symptom Manage* 2005;29:121–129.
37. Cagle JG, Kovacs PJ: Informal caregivers of cancer patients: Perceptions about preparedness and support during hospice care. *J Gerontol Soc Work* 2011;54:92–115.
38. Herth K: Hope in the family caregiver of terminally ill people. *J Adv Nurs* 1993;18:538–548.
39. Kreling B, Selsky C, Perret-Gentil M, Huerta EE, Mandelblatt JS; Latin American Cancer Research Coalition: 'The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born white, non-Latino cancer caregivers. *Palliat Med* 2010;24:427–434.
40. McMillan SC, Small BJ, Weitzner M, et al.: Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer* 2006;106:214–222.
41. Demiris G, Parker OD, Wittenberg-Lyles E, et al.: A noninferiority trial of a problem-solving intervention for hospice caregivers: In person versus videophone. *J Palliat Med* 2012;15:653–660.
42. McMillan SC, Small BJ, Haley WE: Improving hospice outcomes through systematic assessment: A clinical trial. *Cancer Nurs* 2011;34:89–97.
43. Bernard LL, Guarnaccia CA: Husband and adult-daughter caregivers' bereavement. *Omega (Westport)* 2002;45:153–166.
44. Christakis NA, Iwashyna TJ: The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc Sci Med* 2003;57:465–475.
45. Weitzner MA, McMillan SC, Jacobsen PB: Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage* 1999;17:418–428.
46. McMillan SC: Quality of life of primary caregivers of hospice patients with cancer. *Cancer Pract* 1996;4:191–198.
47. Radloff LS: The CES-D Scale: A self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;1:385–401.
48. Wright AA, Zhang B, Ray A, et al.: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–1673.
49. Chentsova-Dutton Y, Shuchter S, Hutchin S, et al.: Depression and grief reactions in hospice caregivers: From pre-death to 1 year afterwards. *J Affect Disord* 2002;69:53–60.
50. Kris AE, Cherlin EJ, Prigerson H, et al.: Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *Am J Geriatr Psychiatry* 2006;14:264–269.
51. York GS, Churchman R, Woodard B, Wainright C, Raut-Foster M: Free-text comments: Understanding the value in family member descriptions of hospice caregiver relationships. *Am J Hosp Palliat Care* 2012;29:98–105.
52. Casarett DJ, Hirschman KB, Crowley R, Galbraith LD, Leo M: Caregivers' satisfaction with hospice care in the last 24 hours of life. *Am J Hosp Palliat Care* 2003;20:205–210.
53. Meyers JL, Gray LN: The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncol Nurs Forum* 2001;28:73–82.
54. Dawson NJ: Need satisfaction in terminal care settings. *Soc Sci Med* 1991;32:83–87.
55. Evans WG, Cutson TM, Steinhauser KE, Tulskey JA: Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *J Palliat Med* 2006;9:100–110.
56. Steele LL, Mills B, Long MR, Hagopian GA: Patient and caregiver satisfaction with end-of-life care: Does high satisfaction mean high quality of care? *Am J Hosp Palliat Care* 2002;19:19–27.
57. Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R: Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hospice J* 2001;15:1–18.
58. Prigerson HG, Cherlin E, Chen JH, Kasl SV, Hurzeler R, Bradley EH: The stressful caregiving adult reactions to experiences of dying (SCARED) scale: A measure for assessing caregiver exposure to distress in terminal care. *Am J Geriatr Psychiatry* 2003;11:309–319.
59. Gill P, Kaur JS, Rummans T, Novotny PJ, Sloan JA: The hospice patient's primary caregiver: What is their quality of life? *J Psychosom Res* 2003;55:445–451.
60. Wittenberg-Lyles E, Demiris G, Oliver DP, Burt S: Reciprocal suffering: Caregiver concerns during hospice care. *J Pain Symptom Manage* 2011;41:383–393.
61. Kutner J, Kilbourn KM, Costenaro A, et al.: Support needs of informal hospice caregivers: A qualitative study. *J Palliat Med* 2009;12:1101–1104.

62. Newton M, Bell D, Lambert S, Fearing A: Concerns of hospice patient caregivers. *ABNF J* 2002;13:140–144.
63. Townsend AL, Ishler KJ, Shapiro BM, Pitorak EF, Matthews CR: Levels, types, and predictors of family caregiver strain during hospice home care for an older adult. *J Soc Work End Life Palliat Care* 2010;6:51–72.
64. Jones BW: Hospice disease types which indicate a greater need for bereavement counseling. *Am J Hosp Palliat Care* 2010;27:187–190.
65. Moody LE, McMillan S: Dyspnea and quality of life indicators in hospice patients and their caregivers. *Health Qual Life Outcomes* 2003;1:9.
66. McMillan SC, Mahon M: The impact of hospice services on the quality of life of primary caregivers. *Oncol Nurs Forum* 1994;21:1189–1195.
67. Speer DC, Robinson BE, Reed MP: The relationship between hospice length of stay and caregiver adjustment. *Hospice J* 1995;10:45–58.
68. Fenix JB, Cherlin EJ, Prigerson HG, Johnson-Hurzeler R, Kasl SV, Bradley EH: Religiousness and major depression among bereaved family caregivers: A 13-month follow-up study. *J Palliat Care* 2006;22:286–292.
69. Mickley JR, Pargament KI, Brant CR, Hipp KM: God and the search for meaning among hospice caregivers. *Hospice J* 1998;13:1–17.
70. Tilden VP, Tolle SW, Drach LL, Perrin NA: Out-of-hospital death: Advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc* 2004;52:532–539.
71. Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA: Complicated grief symptoms in caregivers of persons with lung cancer: The role of family conflict, intrapsychic strains, and hospice utilization. *Omega (Westport)* 2010;62:201–220.
72. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG: Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2010;28:4457–4464.
73. Kilbourn KM, Costenaro A, Madore S, et al.: Feasibility of a telephone-based counseling program for informal caregivers of hospice patients. *J Palliat Med* 2011;14:1200–1205.
74. Demiris G, Oliver DP, Courtney KL, Day M: Telehospice tools for caregivers: A pilot study. *Clin Gerontol* 2007;31:43–57.
75. Parker OD, Demiris G, Wittenberg-Lyles E, Porock D, Collier J, Arthur A: Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *Am J Hosp Palliat Care* 2010;27:465–473.
76. Kwak J, Salmon JR, Acquaviva KD, Brandt K, Egan KA: Benefits of training family caregivers on experiences of closure during end-of-life care. *J Pain Symptom Manage* 2007;33:434–445.
77. Empeno J, Raming NT, Irwin SA, Nelesen RA, Lloyd LS: The hospice caregiver support project: Providing support to reduce caregiver stress. *J Palliat Med* 2011;14:593–597.
78. National Hospice and Palliative Care Organization: *NHPCO Facts and Figures: Hospice Care in America, 2013*. Alexandria, VA: National Hospice and Palliative Care Organization.
79. Hull MM: Sources of stress for hospice caregiving families. *Hospice J* 1990;6:29–54.
80. Redinbaugh EM, Baum A, Tarbell S, Arnold R: End-of-life caregiving: What helps family caregivers cope? *J Palliat Med* 2003;6:901–909.

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