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Unique characteristics of informal hospice cancer caregiving

Karla T. Washington,

Department of Family and Community Medicine, School of Medicine, University of Missouri, MA306 Medical Sciences Building, DC032.00, Columbia, MO 65212, USA

Kenneth C. Pike,

Department of Psychosocial Nursing and Community Health, School of Nursing, University of Washington, Seattle, WA, USA

George Demiris, and

Department of Biobehavioral Nursing and Health Services, School of Nursing, University of Washington, Seattle, WA, USA; Department of Biomedical and Health Informatics, School of Medicine, University of Washington, Seattle, WA, USA

Debra Parker Oliver

Department of Family and Community Medicine, School of Medicine, University of Missouri, MA306 Medical Sciences Building, DC032.00, Columbia, MO 65212, USA

Abstract

Purpose—The purpose of this study was to describe the unique characteristics of informal hospice cancer caregiving.

Methods—Researchers conducted a secondary analysis of data drawn from a randomized clinical trial of an informal hospice caregiving intervention ($N=348$). Demographic characteristics and measures of the informal caregiving experience of hospice patients and their informal caregivers were compared based on the patient's diagnosis using chi-square tests for association of categorical variables and t tests for continuous variables.

Results—Informal caregivers of cancer patients differed from their non-cancer counterparts in a number of respects including patient age, caregiver age, patient residence, relationship between patient and caregiver, amount and duration of care provided, likelihood to incur out-of-pocket expenses related to patient care, caregiver problem-solving style, and impact on caregiver daily schedule. There were no statistically significant differences between cancer and non-cancer caregivers in terms of gender, race, employment status, anxiety, and quality of life.

Conclusions—While cancer and non-cancer caregivers are similar in many respects, a number of unique features characterize the informal hospice cancer caregiving experience. Attention to

these unique features will allow hospice providers to tailor supportive care interventions to better address cancer caregivers' needs.

Keywords

Cancer; Hospice; Family; Caregiver

Introduction

In recent years, US hospice statistics have shown a decreasing percentage of cancer patients relative to patients with nonmalignant disease as a percentage of total hospice admissions, yet, despite these decreases, cancer patients continue to comprise over one third of the hospice patient population nationwide [1, 2]. Research comparing cancer and non-cancer patients with advanced disease has revealed important differences and similarities in their end-of-life experiences. Notably, dying trajectories have been found to differ between the two groups, with non-cancer patients experiencing a more gradual functional decline than cancer patients, who tend to show a later and more rapid decrease in functional ability [3]. Some studies have found physical pain to be more common among dying cancer patients [4–6]; however, when present, physical pain has been shown to be as distressing to non-cancer patients as to those with cancer [6]. Dyspnea has been found to be more prevalent among non-cancer patients nearing the end of life than among their counterparts with cancer diagnoses [7]. Psychological distress appears to be similarly common in cancer and non-cancer patients [6], as does the clustering (or co-occurrence) of many other clinically significant symptoms [8]. In their comparison of cancer and non-cancer patients with advanced disease, Steihauser and colleagues [9] determined that the illness experience was more strongly affected by emotional and social factors than by diagnosis, leading them to conclude that, with regard to the subjective experience of illness, in many ways, sick is sick.

Informal caregiving at end of life

As patients' illnesses progress, they often require increasing levels of support from friends or family members who serve as informal caregivers. Informal caregivers perform a wide range of practical, emotional, and direct care tasks for their dying loved one [10]. In addition to enjoying many positive aspects of their experience [11], informal caregivers have been found to be at risk of experiencing a number of negative caregiving outcomes including psychological distress [12–14] and diminished quality of life [15].

While an extensive body of research has examined the experiences of informal caregivers of dying patients, little is known about the extent to which end-of-life caregiving is impacted by the patient's diagnosis. A secondary analysis of survey data from Australia [16] revealed that individuals who had cared for a family member dying of cancer had cared for someone significantly younger than the family members cared for by non-cancer informal caregivers. Further, informal caregivers of cancer patients were more likely to indicate that their deceased family member had received palliative and/or hospice care than non-cancer caregivers. Beyond those differences, however, the caregiving experience between the two groups was found to be quite similar. Likewise, in a hospice-specific study, Haley and colleagues [17] compared informal caregivers of patients with lung cancer and dementia,

concluding that “the negative psychological and health impacts on the caregiver are marked and comparable across diagnosis”(p. 1). In summary, the literature indicates that, just as sick is sick with regard to the patient illness experience, many aspects of the informal caregiving experience are similar, regardless of the care recipient’s diagnosis.

In the study described herein, we sought to expand upon the small but important body of evidence comparing cancer and non-cancer caregiving at end of life. To ensure that our findings had clear implications for hospice practitioners, we specifically focused our study on the informal hospice caregiving experience. The following research question informed all phases of the study: What are the unique characteristics of informal hospice cancer caregiving?

Research methods

We conducted a secondary analysis of data from a federally funded randomized clinical trial (RCT) of an informal hospice caregiving intervention conducted between 2011 and 2014 in partnership with two community hospice agencies in the US Pacific Northwest region (R01NR012213; principal investigator: Demiris). The original study was approved by the Institutional Review Board of the principal investigator’s academic institution prior to the initiation of any research activities. Original inclusion criteria required that participants be 18 years or older, English speaking, with no or only mild cognitive impairment, functional hearing, with access to a standard phone line or internet access at home, and an informal caregiver of a hospice patient. During early recruitment, it became evident that many potential participants became bereaved in the time between referral to the study and the first contact by the research team, a period of time typically lasting 48–72 h. This is not an unexpected occurrence in hospice research, as over 35 % of all US hospice patients die or are discharged within 7 days of enrollment [2]. As a result of these considerations, inclusion criteria were modified to allow recently bereaved caregivers to participate in the study. Caregivers were, however, excluded from analyses if the patient’s diagnosis was unknown/not reported, as these data were necessary to answer the study’s primary research question. Caregivers in the analytic sample did not differ significantly from those excluded on any characteristic or caregiver experience measure except race. Both patients and caregivers in the analytic sample were more likely to be Caucasian than those excluded, indicating that non-Caucasian participants were less likely than their Caucasian counterparts to report the patient’s diagnosis to researchers due to either lack of knowledge regarding the exact diagnosis or a preference not to disclose diagnostic information. In addition, to ensure that the intervention tested in the RCT did not impact the outcomes of our analysis, we selected only baseline (pre-intervention) data for analysis.

Study variables

Demographic characteristics—We considered the following demographic characteristics in our analyses: patient diagnosis (cancer, non-cancer) as reported by the caregiver, patient age, caregiver age, patient gender, caregiver gender, patient race, caregiver race, caregiver’s relationship to the patient (spouse/partner, adult child, other), caregiver bereavement (bereaved prior to intervention: yes, no), patient residence (private residence,

other), caregiver residence (co-resides with patient: yes, no), length of time caregiving (less than 1 year, 1–3 years, more than 3 years), hours per week of caregiving (less than 5 h, 5–10 h, 11–20 h, greater than 20 h), care-related out-of-pocket expenses (yes, no), and caregiver employment outside of the home (yes, no).

Caregiver quality of life—Caregiver quality of life was measured with the Caregiver Quality of Life Index—Revised (CQLI-R) [18]. The CQLI-R consists of four single-item subscales that measure physical, emotional, social, and financial quality of life on a scale of 0–10, resulting in a total possible score of 40. Higher scores indicate higher quality of life in each of the four domains. The CQLI-R's satisfactory psychometrics have been established in previous research [18].

Caregiver anxiety—Caregiver anxiety was measured using the Generalized Anxiety Disorder 7-item (GAD-7) scale [19]. Respondents completing the GAD-7 indicate the frequency with which they experience symptoms of anxiety such as difficulty relaxing, restlessness, and uncontrollable worrying. GAD-7 total scores range from 0 to 21; higher scores indicate greater anxiety. Total scores of 5, 10, and 15 represent thresholds for mild, moderate, and severe anxiety, respectively. Total scores of 10 or higher are generally considered clinically significant, signaling a need for additional evaluation and possible intervention [19]. The GAD-7's satisfactory psychometrics are well-supported [19].

Problem-solving orientation and style—Caregiver problem-solving orientation and style were determined using the Problem Solving Inventory (PSI). The PSI includes 25 Likert-type items, which ask respondents to indicate the extent to which different statements reflect their attitudes toward problem-solving or the strategies that they tend to employ when attempting to solve a problem. PSI results include five separate scores for the following orientations and styles: positive problem orientation, negative problem orientation, rational problem-solving style, impulsive problem-solving style, and avoidant problem-solving style. The psychometric properties of the PSI are supported by a wide range of studies [20].

Reaction to caregiving—Study participants' reaction to caregiving was measured using the Caregiver Reaction Assessment (CRA) [21]. The CRA contains 24 Likert-type items divided among the following five subscales: caregiver self-esteem, impact on finances, impact on schedule, impact on health, and lack of family support. The satisfactory psychometric properties of the CRA have been established in previous research [22]. In the original RCT from which data for this study were drawn, this instrument was completed only by individuals engaged in active caregiving; bereaved caregivers did not complete the CRA. Therefore, data from bereaved caregivers were excluded from analyses in which reaction to caregiving was included as a variable.

Statistical analyses

Demographic characteristics of patients and caregivers and baseline pre-intervention caregiver experience measures were compared for groups based on the patient's cancer or non-cancer diagnosis using chi-square tests for association of categorical variables and *t* tests for continuous variables. Multivariate linear regression models were used to determine

whether potential differences between the cancer and non-cancer diagnosis groups on selected caregiver experience measures could be explained by bereavement status. The interactions between diagnosis and bereavement were also examined in these regression models. Plots of residuals were examined to assess model assumptions. All analyses used listwise deletion of missing data, as there was minimal missing data (<2 %) in the analytic sample.

Results

Baseline participant characteristics ($N=348$) are shown in Table 1. Caregivers were predominately female (73.0 %) and Caucasian (93.6 %) and were mostly either adult children (51.4 %) or spouses/partners (28.5 %) of hospice patients. Caregivers ranged in age from 19 to 100, with a mean age of 60.9. At baseline, 49.1 % of the informal caregivers were bereaved and almost half (48.9 %) had provided care for three or more years. As indicated in Table 2, the most prevalent patient diagnoses were cancer (39.9 %), dementia (23.0 %), and cardiovascular disease (17.8 %).

Cancer and non-cancer caregiver differences

Caregivers of patients with cancer were younger than other caregivers (mean difference=3.4 years, $p=0.02$). Likewise, cancer patients were significantly younger than patients with a non-cancer diagnosis (mean difference=13.5 years, $p<0.001$). Caregivers of patients with cancer were more likely to be a spouse/partner (39.6 %) than other caregivers (21.1 %); conversely, they were less likely to be an adult child (39.6 %) than other caregivers (59.3 %), $p<0.001$. Patients with cancer were more likely to reside in a private residence (79.9 %) and live with their caregiver (60.4 %) than were patients with non-cancer diagnoses $p<0.001$ (46.4 %) and $p<0.001$ (39.2 %), respectively. Caregivers of patients with cancer did not differ from other caregivers in terms of gender, race, or employment status. Caregivers of patients with cancer were more likely to provide greater than 20 h of care/week (66.9 %) compared with 48.3 %, $p<0.001$; however, they were more likely to have provided this care for a less than 1 year (44.6 %) compared to the 62.7 % of caregivers of patients with non-cancer diagnoses who had provided three or more years of care, $p<0.001$. A higher proportion of caregivers of patients with cancer reported out-of-pocket expenses (80.4 %) than non-cancer caregivers (66.0 %), $p<0.01$.

Table 3 shows differences in caregiver experience measures for the diagnosis groups. Caregivers of patients with cancer were less likely to use a negative problem-solving style (mean difference=0.9, $p=0.03$) and had a nearly significant trend (mean difference=0.6, $p=0.08$) to be less impulsive than other caregivers. There were no statistically significant differences between groups in measures of anxiety and quality of life. In terms of caregiver burden, as assessed by the CRA, caregivers of patients with cancer reported more impact on their daily schedule (mean difference=0.5, $p<0.01$) and nearly significant impact on finances (mean difference=0.3, $p=0.07$) and less family support (mean difference=0.3, $p=0.07$) compared to other caregivers.

Among caregivers who resided with the patient, there were no differences in caregiver burden between the diagnosis groups. Differences in quality of life were, however,

identified. Compared with co-residing non-cancer caregivers, co-residing cancer caregivers reported greater financial (mean difference=0.9, $p<0.04$), physical (mean difference=0.8, $p<0.01$), and overall quality of life (mean difference=2.4, $p<0.05$).

We conducted a series of multiple regression analyses to determine whether differences in caregiver experience measures could be explained by bereavement status. There were no statistically significant differences between bereaved and non-bereaved caregivers and no diagnosis by bereavement interactions. Otherwise stated, the lack of an effect of bereavement on the caregiver experience measures was not different for cancer and non-cancer caregivers.

Discussion

Study findings provide insight into the unique characteristics of caregivers of cancer patients at the end of life. The fact that caregivers of patients with cancer were more likely to co-reside with the patient and to provide greater than 20 h of care per week than other caregivers suggests that there may be complex care needs that require more extensive support services. This may point to a pronounced need for respite services for hospice cancer caregivers. Interventions involving the provision of volunteer “sitters” (p. 66) who stay with patients with advanced cancer when their caregiver leaves the house have been met with great satisfaction among informal caregivers [23]. Hospice agencies in the USA are particularly well suited to offer this service, as Medicare Conditions of Participation mandates that at least 5 % of total patient care hours in hospice must be provided by trained volunteers [2]. The intensity of the caregiving undertaken by hospice cancer caregivers suggests that respite, even for brief periods of time, may be decidedly helpful.

Caregivers of patients with cancer were more likely to have provided care for less than a year than caregivers of patients with other diagnoses who were more likely to have provided care for three or more years. This could be explained by cases where the disease was rapidly advancing since diagnosis or where patients may have managed their disease by themselves and needed care only once a transition from curative to exclusively palliative services was deemed appropriate. In contrast, caregivers of patients with dementia, for example, often serve in the caregiving role for many years and some more than a decade. This underscores the need for hospice providers to assess cancer caregivers’ knowledge, skills, and attitudes as they relate to caregiving tasks. Should deficits be identified, a number of evidence-based interventions may be appropriate. For example, Hudson and colleagues [24] tested a psycho-educational group intervention for caregivers of a relative with advanced cancer receiving home-based palliative care. Their intervention, which focused on enhancing caregivers’ feelings of preparedness, competence, ability to acquire necessary information, and positive attitude related to caregiving, was associated with statistically significant improvement in all targeted areas. Similarly, McMillan et al. [25] and Demiris and colleagues [26] have found promising results associated with problem-solving training for informal hospice caregivers. Such approaches may have particular utility for cancer caregivers whose challenges include, but are certainly not limited to, managing patient symptoms. For example, a structured approach to solving problems seems indicated for individuals who experience financial

challenges as a result of out-of-pocket expenses related to caregiving and/or disruptions in their daily schedules, as many of the participants in the current study reported.

The more rapid progression of many cancers relative to diseases such as dementia, coupled with cancer caregivers' greater likelihood of having provided care for less than 1 year, also introduces the possibility that both caregivers and patients may be struggling to adjust to their newly acquired roles. In such cases, dyadic interventions involving both parties may be most appropriate. In their study of women with breast cancer and their informal caregivers, Northouse and colleagues [27] tested a family-based intervention targeting family involvement, attitude, coping effectiveness, uncertainty reduction, and symptom management during the recurrent phase of breast cancer. Results supported the intervention's short-term effectiveness; participants reported significantly less hopelessness and less negative disease appraisal than individuals assigned to a control group 3 months post-intervention. The current study's finding that caregivers of hospice patients with cancer were more likely to be a spouse or partner than other caregivers may support the use of couple-based interventions. Couple-based interventions for individuals affected by cancer have been shown to be particularly effective in improving communication and relationship functioning and in reducing psychological distress [28], outcomes that no doubt contribute to overall quality of life for both hospice cancer patients and their caregivers.

Although little is known about the unique characteristics of informal caregivers of hospice patients with cancer, comparing our study results to the small body of related research is nonetheless informative. In a number of ways, our study provides support for findings that have been previously identified. Specifically, as in Girgis and colleagues' study of end-of-life caregiving in Australia (which included, but was not limited to, those receiving hospice care) [16], informal care-givers of patients with cancer in our study were more similar to non-cancer caregivers than they were different, particularly with regard to sociodemographic factors. In addition, as in the study of Girgis et al. [16], caregivers of patients with cancer in our study were providing care to significantly younger care recipients than caregivers of individuals with other diagnoses. In their comparison of informal caregivers of older adults, Kim and Schulz [29] found that caregivers of individuals with cancer provided more hours of care per week than those caring for family members with non-cancer diagnoses, similar to our finding that cancer caregivers were more likely than non-cancer caregivers to provide 20 h of care per week or more. In contrast with the study of Girgis et al. [16], however, caregivers of patients with cancer in our study were more likely to be spouses of their care recipient than caregivers of individuals with other conditions. Further, unlike in our study, Girgis et al. [16] found no statistically significant differences with regard to level or duration of care when comparing cancer and non-cancer caregivers.

Without question, additional research is needed to determine the extent to which informal cancer caregiving is unique when compared to other types of caregiving. This study makes an important contribution to the existing literature in its clear focus on caregiving within families receiving hospice care, providing important implications for the delivery of hospice care to cancer patients and their families. Understanding caregiver needs and challenges allows hospice providers to more effectively tailor interventions to meet these needs. Assessing how long a caregiver has functioned in that role and how caregiving has affected

their own physical and mental well-being allows for the design and delivery of individualized services to better support caregivers and patients during the hospice experience.

Limitations

A number of limitations are important to keep in mind when interpreting the results of our study. First, our analyses relied heavily upon data provided by caregiver self-report, which is subject to biases in terms of accuracy of recall (to the extent that participants were asked to recall past events) and social desirability. In addition, despite the fact that no statistically significant differences were identified between bereaved and non-bereaved caregivers on any caregiver experience measures, it is possible that data provided by recently bereaved participants were different than what they would have been had they been provided during active caregiving. Further, some of the questions may have been difficult for participating caregivers to answer. For example, caregivers may have struggled to quantify a precise number of hours per week that they spent engaged in caregiving, as this figure likely fluctuates based on patient needs. In a similar vein, participants may have found it difficult to identify the point at which they began self-identifying as a caregiver rather than viewing their work as an extension of their pre-existing relationship with the care recipient [30]. Additionally, our analyses were limited by the nature of the data that were originally collected. Thus, we were unable to exhaustively examine all possible differences between cancer and non-cancer caregiving at end of life. Importantly, caregivers' subjective lived experiences were not captured in depth, as might be possible in a study in which primary data were collected. Further, the statistically significant number of racial minorities whose data were excluded from analysis due to lack of reported patient diagnosis must be noted as a limitation. Given the existence of documented racial disparities in receipt of hospice services [31, 32], the additional reduction in data representing minority experiences is particularly noteworthy. Finally, the exploratory (vs. theory-driven) nature of our investigation merely sets the stage for future research in this emerging area of inquiry.

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Table 1

Characteristics of caregivers and patients

Characteristic	All caregivers (N=348)	Cancer caregivers (n=139)	Non-cancer caregivers (n=209)	p value
Caregivers				
Age, mean (SD)	60.9 (13.1)	58.8 (13.9)	62.3 (12.3)	0.02
Female (%)	73.0	70.5	74.6	0.40
White (%)	93.6	92.8	94.2	0.58
Relationship to patient (%)				<0.001
Adult child	51.4	39.6	59.3	
Spouse or partner	28.5	39.6	21.1	
Other	20.1	20.9	19.6	
Bereaved (%)	49.1	56.8	44.0	0.02
Resides with patient (%)	47.7	60.4	39.2	<0.001
Amount of caregiving (%)				<0.001
<5 h/week	9.8	2.2	14.8	
5–10 h/week	19.3	19.2	23.4	
11–20 h/week	15.2	18.0	13.4	
>20 h/week	55.8	66.9	48.3	
Duration of caregiving (%)				<0.001
<1 year	28.2	44.6	17.2	
1–3 years	23.0	27.3	20.1	
3 years	48.9	28.1	62.7	
Out-of-pocket expenses (%)	71.8	80.4	66.0	<0.01
Employed (%)	47.8	53.2	44.0	0.09
Patients				
Cancer diagnosis (%)		39.9	60.1	
Age, mean (SD)	80.4 (14.3)	72.2 (1.1)	85.7 (10.8)	<0.001
Female (%)	62.4	54.7	67.5	0.02
White (%)	93.4	92.0	94.2	0.42
Private residence (%)	59.8	79.9	46.4	<0.001

Table 2

Patient diagnoses

Diagnosis	No. (%)
Cancer	139 (39.9)
Dementia	80 (23.0)
Cardiovascular	62 (17.8)
Nervous system	18 (5.2)
Respiratory	15 (4.3)
Genitourinary	9 (2.6)
Musculoskeletal	6 (1.7)
Digestive	5 (1.4)
Endocrine	3 (0.9)
Infectious	2 (0.6)
Blood	1 (0.3)
Mental disorders	1 (0.3)
Other	7 (2.0)

Table 3

Caregiver experience measures

Measure, mean (SD)	All caregivers (N=348)	Cancer caregivers (n=139)	Non-cancer caregivers (n=209)	p value
GAD-7—anxiety (range 0–21)	6.9 (5.3)	7.1 (5.2)	6.8 (5.3)	0.68
Anxiety severity (%)				0.86
None (0–4)	41.7	41.0	42.1	
Mild (5–9)	31.3	30.2	32.1	
Moderate (10–14)	15.2	17.3	13.9	
Severe (15–21)	11.8	11.5	12.0	
CQLI-R—quality of life				
Global (range 0–40)	29.7 (7.0)	29.8 (7.0)	29.6 (7.0)	0.87
Physical (range 0–10)	7.2 (2.1)	7.3 (2.0)	7.2 (2.1)	0.55
Social (range 0–10)	8.1 (2.2)	8.1 (2.2)	8.1 (2.1)	0.91
Emotional (range 0–10)	7.2 (2.2)	7.2 (2.2)	7.3 (2.2)	0.65
Financial (range 0–10)	7.2 (2.7)	7.2 (2.7)	7.1 (2.7)	0.82
Problem Solving Inventory (PSI)(range 0–25)				
Positive	19.4 (3.4)	19.8 (3.4)	19.2 (3.4)	0.11
Rational	19.4 (3.9)	19.8 (3.8)	19.2 (3.9)	0.14
Negative	11.4 (3.9)	10.8 (3.4)	11.7 (4.1)	0.03
Impulsive	11.2 (3.1)	10.8 (3.1)	11.4 (3.1)	0.08
Avoidance	11.5 (3.5)	11.2 (3.4)	11.7 (3.5)	0.20
Caregiver Reaction Assessment (CRA) (range 1–5) ^a				
Impact on health	2.6 (0.6)	2.5 (0.6)	2.7 (0.7)	0.17
Self-esteem	4.0 (0.7)	4.0 (0.7)	4.0 (0.7)	0.70
Impact on finances	2.2 (1.0)	2.4 (1.1)	2.1 (1.0)	0.07
Impact on daily schedule	3.6 (0.9)	3.9 (0.7)	3.4 (1.0)	<0.01
Lack of family support	2.2 (1.0)	2.4 (1.1)	2.1 (1.0)	0.07

Higher scores on all caregiver experience measures indicate greater amounts of the measured construct *GAD-7* seven-item Generalized Anxiety Scale, *CQLI-R* Caregiver Quality of Life Index—Revised

^aOnly asked of non-bereaved caregivers