

# Caregivers' differing needs across key experiences of the advanced cancer disease trajectory

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## ABSTRACT

*Objectives:* Familial caregivers are providing increasing amounts of care to advanced cancer patients. Increased understanding of caregivers' needs is vital in providing necessary support to lessen caregiver burden and morbidity. Current literature has identified caregiver and patient needs at broad stages of the cancer trajectory; however, such broad stages may be too general to inform a practice of targeting specific interventions when they have the greatest utility. This study examines a variety of particular needs across a number of more discrete illness-related transition experiences specifically in the advanced cancer disease trajectory.

*Methods:* One hundred fifty-nine female informal caregivers of people with advanced cancer completed a needs assessment survey.

*Results:* Analyses of these cross-sectional retrospective-report data reveal that cancer caregiver needs vary across specific key experiences occurring within the broader stages of illness identified by current literature. Furthermore, caregivers have unique needs during bereavement.

*Significance of results:* Although the sample characteristics are demographically limited, this study provides preliminary evidence that the broad stages are not specific enough increments for effectively examining caregiver needs and supports the need for more precise distribution of cancer-related information at more discrete times in the illness course.

**KEYWORDS:** Caregiver needs, End of life, Cancer, Palliative care, Bereavement

## INTRODUCTION

Rising health care costs are directing a shift toward community-based care, with family members playing a greater role throughout the continuum of cancer treatment and disease progression (Hileman et al., 1992; Longman et al., 1992; Stetz & Hanson, 1992; Houts et al., 1996; Barg et al., 1998; Arno et al., 1999; Speice et al., 2000). Often family members are ill prepared for the caregiving role and the physical, emotional, and financial burdens inherent in it

(Blanchard, Albrecht, & Ruckdeschel, 1997; Haley, 2003; Wiles, 2003). Interventions aimed to increase caregivers' competence are essential to adequately address cancer patient care and need to be timely, relevant, and efficient, meeting caregivers' needs as they arise (Silveira & Winstead-Fry, 1997). To address this issue, this study examines caregivers' needs along the advanced cancer disease trajectory, expanding current research models by looking at more specific key experiences and extending the trajectory into bereavement.

As the patient transitions along the cancer disease trajectory, each phase presents new challenges and stressors for the caregiver. Patients and families

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must develop new skills or enhance effective coping strategies to meet new demands (Holland, 1989). Cancer patients and caregivers have numerous needs across a variety of areas (Longman et al., 1992; Mills & Davidson, 2002), with a significant number of needs falling into the categories of psychological, household management, and informational (Wingate & Lackey, 1989) and, to a lesser degree, physical and respite, legal and financial, and spiritual needs (Hileman & Lackey, 1990; Stelle & Fitch, 1996; Thielemann, 2000).

Although many information needs exist, receiving general information addressing numerous areas can often be overwhelming. The best circumstances for adult learning are when the person feels there is a need and when the information is relevant (Hardwick & Lawson, 1995). Accordingly, systematic caregiver education requires empirical knowledge about when patients and their caregivers want specific information (Harrison et al., 1999). Current literature provides a foundation for understanding patient and caregiver needs at general stages along the cancer disease trajectory: diagnosis, treatment, and, to a lesser degree, palliative care. However, any one general stage encompasses a variety of experiences and issues. For example, active treatment involves the treatment decision, the start of treatment, the treatment course (including side effects), and the end of treatment. Whereas information regarding treatments may be more paramount in the decision stage, emotional needs for support may be more important in coping with concerns when treatment ends. Further empirical evaluation is indicated on types of information needs across a greater number of specific illness experiences. Even the more extended models of patient or caregiver needs tend to omit bereavement. But, as caregiving experience can impact bereavement adjustment (Bass & Bowman, 1990; Bernard & Guarnaccia, 2003), examination of caregiver needs should naturally include end-stage illness and the aftermath of patient death.

Although current literature has identified caregiver and patient needs at broad stages of the cancer trajectory (i.e., diagnosis, treatment, and end of life), it was hypothesized that needs will vary across specific key experiences that occur within a given stage. Using cross-sectional analyses of retrospective self-report data, this study examines familial caregivers' needs at nine specific cancer-related key transitional experiences along the advanced cancer disease trajectory, including caregiver bereavement. These key transitional experiences include start of treatment, end of treatment, nonroutine hospitalization, leaving the hospital for home, transitioning from curative to palliative care, entering hospice, patient death, immediately after death, and bereavement.

## METHODS

### Participants

One hundred eighty-two current or former primary caregivers of advanced cancer patients were recruited. Primary caregiver in this study refers to the self-identified main person regularly assisting in the care and support of the person with advanced cancer. Former caregivers cared for someone who died within the last 6 years. To participate, caregivers needed to be at least 18 years of age and English literate at a minimum of the sixth grade level.

### Procedure

Cancer caregivers, primarily in Wisconsin and nearby areas of the Midwest, were recruited through fliers and magazine advertisements. Advertisements were also placed in electronic newsletters targeting local health care and university settings and national caregiver populations. Survey packets, including informed consent forms, were mailed to interested respondents. Completed surveys were returned by mail and caregivers were offered \$20.00 reimbursement. This study was approved by the Institutional Review Board at the University of Wisconsin, Madison.

### Measures

To examine a detailed listing of needs along specific experiences of the cancer disease trajectory, including bereavement, the Cancer Caregiver Needs Checklist was developed for this study. This index includes a list of 104 need items covering a broad base of cancer topics, yielded using the critical incident interview technique (Gustafson et al., 2001), and refined through clinician and caregiver review. Caregivers completed the Cancer Caregiver Needs Checklist by indicating whether they "wanted or would want information on" each individual need item at each of 10 key experiences along the disease trajectory (item not checked, scored 0; item checked as wanted, scored 1). The specific experiences are transition events highlighting key opportunities for information interventions, including start of treatment, end of treatment, nonroutine hospitalization, leaving the hospital for home, transitioning from curative to palliative care, entering hospice, patient death, immediately after death, and bereavement. Because this is an index of information needs at given experiences, rather than a psychometric scale measuring a latent construct, examination of psychometric properties is not appropriate (Bollen, 1989). Copies of this measure may be obtained by request from the corresponding author.

## Analyses

Due to the large number of individual need items in the Cancer Caregiver Needs Checklist, analyses of information needs for this study focus on categories of information based on item groupings. Five information categories were determined to represent the current cancer caregiver literature: disease/medical information, caregiving, caregiver well-being, financial/legal, and spirituality. Four additional categories were developed to address content beyond categories in the literature: relating with the patient, family and close others, future outlook, and dying. Items were placed into categories based on the sorting of eight cancer professionals. Seventy-five percent interrater agreement was required for grouping. Eighteen items not meeting criterion were dropped from analysis.

The Cancer Caregiver Needs Checklist identifies 10 specific key illness-related experiences of the advanced cancer disease trajectory. These key experiences can be grouped into general stages that align with the broad stages in previous literature. These general stages include: (1) cancer progression (in this case involving the experience of “being informed of cancer progression or advanced disease,” which may also be conceptualized as the diagnosis of advanced illness), (2) treatment (including “start of new treatment,” “end of specific treatment,” “nonroutine hospital stay,” and “leaving hospital for home”), and (3) end of life (including “curative to palliative care,” “going into hospice,” and “patient death”). Note that for this study “patient death” is inclusive of the period just prior to the patient’s death or the immediate acts of dying, as well as the death itself. This study extends the current literature to include after patient death as a fourth stage of the disease trajectory (including “immediately after death” and “bereavement”). Initial analyses at this general stage-level (Bernard, 2004) support the current literature that needs differ across broad stages of illness. By examining how caregiver needs differ between specific key experiences that occur within each of these broad stages, this study extends the needs literature.

To see if information needs differ across specific experiences within each of the broad cancer stages, pairwise *t* tests were calculated for each combination of two experiences within a stage, using Bonferroni-like corrections to guard against Type I errors. As not all caregivers sampled had encountered all experiences on the Cancer Caregiver Needs Checklist, only those caregivers who had encountered all experiences within a given stage were used for analyses comparing information need across experiences. For example, at the end of life stage, only 75 caregivers

had all three experiences within this stage: transferring from curative to palliative care, entering hospice, and patient death. These were the only caregivers used in analyses comparing information need across these three key experiences. Accordingly, sample size for analyses between experiences in the treatment stage was 115 and for the after patient death stage was 67. Because the cancer progression stage only had one experience—learning that the cancer has progressed—comparisons of information need are not applicable to this stage.

## RESULTS

### Sample Characteristics

Through convenience sampling, our initial sample yielded 24 male (13.1%) and 159 female (87.4%) current and former caregivers. As the number of male caregivers are underrepresented by sampling, and insufficient to power gender comparisons, the male sample was not used in these analyses. For the remaining female sample, caregivers had a mean age of 50.28 years ( $SD = 12.91$ ) and patients’ mean age was 61.51 years ( $SD = 17.34$ ). The majority of this female caregiver sample are former (bereaved) caregivers (117; 73.6%) who live(d) in the same household as the patient (112; 70.4%). Caregivers were predominantly Caucasian, either a spouse/partner or adult child of the person with cancer, and employed full-time, and mean annual household income was \$35,000–\$49,999 (see Table 1 for counts and percentages). Although a variety of cancers were represented in this sample, the following areas comprise the majority of the sample: lung (24.5%), gastro-intestinal (14.4%), breast (13.8%), head or neck (12.0%), liver, kidney or pancreas (10.0%), and leukemia or lymphoma (6.9%). Just over half of the patients were male (83; 52.2%).

### Information Need Comparisons

Table 2 contains the means and standard deviations for endorsement of an information need for each category at each of the nine key experiences.

#### *Treatment Stage*

The treatment stage includes the key experiences starting treatment, ending treatment, nonroutine hospitalization, and leaving the hospital for home. Pairwise *t* tests compared desire for each of the nine information categories between the specific key experiences of the treatment stage (see Table 3). A Bonferroni-like correction was used setting criteria for significance at  $p \leq .008$  (.05/6 paired tests per information category). For all categories except

**Table 1.** Counts and percentages for categorical demographic variables item

		N	%
Caregiver's race/ ethnicity:	Caucasian	150	94.3
	African American	7	4.4
	Asian	1	0.6
Caregiver's employment status:	Employed full-time	66	41.5
	Employed part-time	35	22.0
	On leave from employment	15	9.4
	Full-time homemaker	13	8.2
	Not employed	10	6.3
	Retired	19	11.9
Caregiver's annual income	Less than \$24,999	37	23.2
	\$25,000–\$34,999	18	11.3
	\$35,000–\$49,999	23	14.5
	\$50,000–\$74,999	45	28.3
	\$75,000 or more	29	18.3
Caregiver's highest level of education:	Some high school	2	1.3
	High school degree/ GED	25	15.7
	Some college courses	22	13.8
	Associate or technical degree	16	10.1
	Bachelor degree	45	28.3
	Graduate degree	47	29.6
Caregiver's relationship to patient:	Spouse/partner	60	37.7
	Adult child	59	37.1
	Other family member	29	18.3
	Other relationship	10	6.3

spirituality, information need differed between the specific experiences of the treatment stage. Disease/medical information was most wanted when starting treatment. Caregiving and relating with the patient information were most wanted when starting treatment and leaving the hospital for home. Dying information was least wanted at start of treatment, future outlook least wanted at nonroutine hospitalization, and family and close others least wanted at ending treatment. Financial/legal information was least wanted at the end of treatment and leaving the hospital for home.

#### End of Life Stage

The end of life stage includes the experiences of transitioning from curative to palliative care, going into hospice, and patient death. Pairwise *t* tests compared need for each of the nine information categories across the experiences within the end of life stage (see Table 4). Again, a Bonferroni-like correction was used requiring  $p \leq .017$  (.05/3 paired tests per information category) for significance. For all information categories, information need differed between at least two experiences within the end of

life stage. Disease/medical information was most wanted at the transition from curative to palliative care and least wanted at patient death. Information about caregiving, relating with the patient, family and close others, and future outlook was most wanted at the experiences of transitioning from curative to palliative care and going into hospice and least wanted at patient death. Spirituality information was most wanted at going into hospice and patient death, whereas dying information was most wanted when going into hospice and least wanted at patient death.

#### After Patient Death Stage

The after patient death stage consists of the experiences immediately after patient death and bereavement. Pairwise *t* tests compared information need across these two experiences for each of the nine information categories. Significant differences were found for disease/medical ( $t = 5.00$ ,  $p < .001$ ), financial/legal ( $t = 5.88$ ,  $p < .001$ ), and dying information ( $t = 5.74$ ,  $p < .001$ ), where information need was greater immediately after death than at bereavement.

## DISCUSSION

The literature provides general understanding of information needs at broad stages of the cancer trajectory, demonstrating that caregivers' information needs differ across these general stages. However, the broad divisions of the cancer trajectory limit practical application of this knowledge. Therefore, the more thoroughly we can define and understand the unique needs of caregivers' immediate experience, the more effective educational interventions targeting these caregivers will be. In an effort to expand knowledge of caregiver information needs at more specific cancer-related key experiences, this study compared information needs across key experiences occurring within three broad stages of the advanced cancer trajectory: treatment, end of life, and after patient death. For all three broad stages, information needs were found to significantly differ between specific key experiences. This supports the need for more precise distribution of specific information content at distinct times in the illness course.

The start of treatment is a time that often requires decision making about treatment options. Thus, illness and treatment information is crucial for effective patient and caregiver participation in this decision-making process. Accordingly, caregivers reported greatest desire for disease/medical information at this key experience of the treatment



**Table 2.** Mean endorsement and standard deviations for information categories across experiences of the treatment, end of life and after patient death stages

Information category	Treatment stage				End of life stage			After patient death stage	
	Start treatment <i>M (SD)</i>	End treatment <i>M (SD)</i>	Enter hospital <i>M (SD)</i>	Leave hospital <i>M (SD)</i>	Palliative care <i>M (SD)</i>	Hospice <i>M (SD)</i>	Patient death <i>M (SD)</i>	After death <i>M (SD)</i>	Bereavement <i>M (SD)</i>
Disease/medical	.63 (.25)	.46 (.32)	.43 (.31)	.40 (.26)	.59 (.29)	.51 (.25)	.20 (.21)	.08 (.12)	.04 (.08)
Caregiving	.38 (.27)	.23 (.24)	.23 (.23)	.45 (.29)	.56 (.27)	.55 (.29)	.18 (.20)	.05 (.11)	.04 (.08)
Relating w/patient	.46 (.34)	.38 (.34)	.37 (.34)	.48 (.32)	.59 (.31)	.56 (.31)	.16 (.27)	.04 (.12)	.03 (.10)
Caregiver well-being	.26 (.28)	.22 (.28)	.25 (.30)	.27 (.27)	.41 (.30)	.45 (.31)	.38 (.28)	.33 (.25)	.33 (.26)
Financial/legal	.27 (.33)	.14 (.29)	.24 (.30)	.18 (.29)	.28 (.35)	.38 (.39)	.21 (.28)	.27 (.35)	.11 (.25)
Family/close others	.28 (.26)	.21 (.24)	.25 (.26)	.30 (.28)	.42 (.33)	.44 (.32)	.34 (.27)	.28 (.26)	.26 (.26)
Future outlook	.28 (.33)	.26 (.33)	.20 (.32)	.28 (.33)	.42 (.39)	.42 (.39)	.26 (.38)	.29 (.36)	.31 (.36)
Dying	.08 (.17)	.11 (.21)	.12 (.21)	.17 (.25)	.48 (.33)	.60 (.31)	.21 (.26)	.06 (.11)	.03 (.09)
Spirituality	.08 (.18)	.07 (.16)	.07 (.16)	.07 (.17)	.19 (.27)	.26 (.29)	.27 (.31)	.27 (.29)	.30 (.30)

**Table 3.** Pairwise *t* tests comparing mean information category need between experiences during the treatment stage

Information category: Experience ( <i>df</i> )	<i>t</i> with End of Treatment	<i>t</i> with Non-routine Hospitalization	<i>t</i> with Leaving Hospital
Disease/medical			
Start of treatment (1,74)	6.73**	7.14**	8.68**
End of treatment (1,74)	—	0.93	2.22
Nonroutine hospitalization (1,74)	—	—	-1.26
Caregiving			
Start of treatment (1,74)	6.80**	6.42**	-2.53
End of treatment (1,74)	—	0.11	-7.77**
Nonroutine hospitalization (1,74)	—	—	-8.11**
Relating with the patient			
Start of treatment (1,74)	4.00**	3.12*	-0.71
End of treatment (1,74)	—	1.67	-4.04**
Nonroutine hospitalization (1,74)	—	—	-4.08**
Caregiver well-being			
Start of treatment (1,73)	3.31*	0.52	-0.36
End of treatment (1,73)	—	-2.11	-2.47
Nonroutine hospitalization (1,73)	—	—	-0.99
Financial/lega:			
Start of treatment (1,72)	3.94**	0.96	2.54
End of treatment (1,72)	—	-3.22*	-1.90
Nonroutine hospitalization (1,72)	—	—	1.98
Family and close others			
Start of treatment (1,74)	3.87**	1.74	-1.17
End of treatment (1,74)	—	2.84*	-5.04**
Nonroutine hospitalization (1,74)	—	—	-2.95*
Future outlook			
Start of treatment (1,71)	0.59	3.69*	0.09
End of treatment (1,71)	—	2.28	-0.59
Nonroutine hospitalization (1,71)	—	—	-3.28*
Dying			
Start of treatment (1,72)	-2.09	-2.35	-3.80*
End of treatment (1,72)	—	-0.53	-2.64
Nonroutine hospitalization (1,72)	—	—	-2.44
Spirituality			
Start of treatment (1,72)	0.85	0.84	1.05
End of treatment (1,72)	—	0.34	0.05
Nonroutine hospitalization (1,72)	—	—	0.29

\**p* ≤ .008 (Bonferroni-like correction); \*\**p* ≤ .001.

stage. When leaving the hospital for home, whether to recover from an inpatient procedure or to initiate home-hospice care, caregivers have heightened responsibility for the patient's home-based medical care. Accordingly, caregivers need information about caregiving and dying most during this transition, as many tasks of aftercare are novel to the nonmedical professional and may require complicated regimens.

The change in focus from curative to palliative treatment often involves difficult choices about whether or not to continue curative treatments, as well as among palliative care options. Patients and caregivers likely look for information to inform such decisions. It follows that disease/medical information is most needed when facing this transition at the

end of life stage. Information regarding caregiving, relating with the patient, family and close others, and future outlook is important both when transitioning from curative to palliative care and when going into hospice. This follows logically for patient care at end of life when, outside of the immediate experience of the patient dying, attention can focus more on interactions between the caregiver and the patient and other family members, as well as on preparing for relationship closure. Dying information was most wanted when going into hospice and least at patient death (when the patient is actively dying), reflecting the importance of information to cope through preparation for the future. As discussion of dying is difficult for most people, it is often avoided

**Table 4.** Pairwise *t* tests for mean information category need between experiences during the end of life stage

Category Experience ( <i>df</i> )	<i>t</i> with going into hospice	<i>t</i> with patient death
Disease/medical		
Curative to palliative (1,67)	3.56**	11.68**
Going into hospice (1,67)	—	9.83**
Caregiving		
Curative to palliative (1,67)	0.46	11.19**
Going into hospice (1,67)	—	10.23**
Relating with the patient		
Curative to palliative (1,67)	1.37	9.66**
Going into hospice (1,67)	—	9.62**
Caregiver well-being		
Curative to palliative (1,67)	−1.52	1.60
Going into hospice (1,67)	—	2.53*
Financial/legal		
Curative to palliative (1,66)	−2.65*	1.78
Going into hospice (1,66)	—	4.19**
Family and close others		
Curative to palliative (1,67)	−0.74	2.91*
Going into hospice (1,67)	—	3.98**
Future outlook		
Curative to palliative (1,66)	−0.07	3.05*
Going into hospice (1,66)	—	2.98*
Dying		
Curative to palliative (1,67)	−3.66**	5.93**
Going into hospice (1,67)	—	9.46**
Spirituality		
Curative to palliative (1,67)	−2.46*	−2.40
Going into hospice (1,67)	—	−0.42

\* $p \leq .017$  (Bonferroni-like correction); \*\* $p \leq .001$ .

throughout the course of illness. However, hospice is often considered a marker of acceptance of the approaching end of life. Therefore, it is a time when more information about dying may be either necessitated by the patient's condition or more accepted given outward acknowledgement of death's imminence. Before this acknowledgment, efforts to educate caregivers on dying may more likely be resisted.

The immediate aftermath of a person's death requires the family to focus on practical tasks of legal, financial, and medical issues (such as those involved in notification of the death and implementation of funeral plans) than are needed over the longer course of bereavement. As a result, caregivers have greater need for information regarding these practical issues during the period immediately after death.

### Limitations and Future Directions

Several limitations arise from volunteer convenience sampling. Our recruitment yielded a primarily

homogeneous sample of educated Caucasian female caregivers. Therefore, we were not able to examine other potentially influential factors on caregiver needs, such as gender, ethnicity, or education level. Understanding other groups of caregivers' potentially unique information and support needs is crucial for advancing practical support for such caregivers. Future studies need to consider such caregiver characteristics as a sampling concern. Furthermore, volunteer sampling may bias results toward caregivers with less burden, as those more burdened by caregiving may be less likely to volunteer. Therefore, this sample may underrepresent those with the greatest need.

This cross-sectional study found that differences exist in caregivers' information needs across more specific key experiences within the cancer trajectory. However, retrospective report data have limitations. Longitudinal studies that directly assess needs over the illness trajectory could explore change in information need over time. Such studies could yield more refined and innovative educational interventions.

Furthermore, just as the stages of the cancer illness trajectory were too broad for specific clinical interventions, there is also a need for examining more specific needs across experiences. The information categories examined here offer an index of the general type of needs caregivers face at various experiences. However, to better offer the most relevant educational interventions, we need to identify even more specific needs. This study serves as a foundation for greater efforts to examine individual need items at these key transition events. Although examination of the numerous individual needs in the Cancer Caregiver Needs Checklist was beyond the scope of this study, future work analyzing the individual needs across the 10 cancer-related experiences will further inform development of educational caregiver interventions.

### Clinical Applications

Dependence on informal caregivers is projected to continue to grow, requiring health care systems to develop innovative educational interventions to assure that caregivers are adequately prepared for the care responsibilities they face. Information relevance is a key feature to effective information interventions (Hardwick & Lawson, 1995; Harrison et al., 1999; Thielemann, 2000). With a matrix of information needs by key cancer experience, even a small understaffed cancer treatment program could prepare targeted educational interventions as the need arises. In this way, they could provide patients and caregivers with key experience-linked information in a timely and relevant manner. This study's collection

of systematic information needs data provides the foundation for developing a cancer caregiving information system to address such educational needs.

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