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Home Hospice Caregivers' Perceived Information Needs

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Abstract

Background—Although home hospice organizations provide essential care for and support to terminally ill patients, many day-to-day caregiving responsibilities fall to informal (ie, unpaid) caregivers. Studies have shown that caregivers value receiving clear information about end-of-life (EoL) care. Meeting the information needs of this group is critical in improving their experience in hospice.

Objectives—To identify the information needs of informal home hospice caregivers.

Design—One hundred five semi-structured phone interviews with informal caregivers were conducted. Study data were analyzed using a standard qualitative method (ie, content analysis).

Participants—Informal home hospice caregivers whose loved ones have been discharged (death or live discharge) from an urban, nonprofit hospice organization.

Measured—Participants' information needs were ascertained by assessing whether information regarding hospice was or was not fully explained or whether there was information they wished they knew prior to the hospice transition.

Results—Among study participants, 48.6% had unmet information needs related to (1) general information about hospice (n = 17, 16.2%), (2) what to expect at the EoL (n = 19, 18.1%), and (3) support provided by hospice (n = 30, 28.6%). Specifically, caregivers expressed the need for more information on what hospice is, caring for a dying patient, and the day-to-day care hospice provides.

Conclusion—Our study indicates that approximately half of the informal caregivers had unmet information needs. Further research is needed to identify efficacious strategies to best meet the

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information needs of this group. Specific topics that need emphasis include what hospice care is, what to expect at the EoL, and what level of support hospice offers.

Keywords

hospice; informal caregivers; information needs; home hospice; end of life; hospice caregivers

Introduction

Some of the important benefits of hospice care include better quality of life, fewer hospitalizations, and greater satisfaction with end-of-life (EoL) care.¹ Although home hospice provides an extra layer of support for informal (ie, unpaid) caregivers, caring for a terminally ill loved one at home is often challenging. Patients typically rely on informal caregivers to administer medications, provide assistance with activities of daily living, and make important decisions on their behalf.² Given the central role informal caregivers play in patient care—and the impact that their well-being has on patients³—it is crucial that we better understand how to improve the home hospice care experience for these individuals.

Providing caregivers with clear and sufficient information at the appropriate time is a critical aspect of the caregiving experience and various studies have examined the information needs of this group.^{4–6} For example, 1 qualitative study of patients with cancer, who were not yet referred to hospice, and their informal caregivers found that participants desired more information on hospice services provided, the frequency of home visits, and insurance coverage for hospice.⁷ Another study of patients and families who had attended a hospice informational visit found that participants were most interested in learning about hospice payment, the practical help that hospice offers, and visit frequency.⁸

Although these studies help illuminate what information those considering hospice desire, relatively few studies have examined informal caregivers' information needs after their loved one has enrolled in home hospice. In order to understand whether caregivers' information needs are being met while their loved ones are transitioning to and receiving home hospice care, it is important to understand the perspectives of caregivers who have already cared for a loved one on hospice care. One qualitative study conducted in 2004 of 100 family members of patients who died during hospice care found that 99% felt that there were aspects of hospice care that they wanted to know about sooner, such as the 24-hour availability of hospice and bereavement counseling.⁹ Another study that examined bereaved home hospice caregivers' perceptions of communication at the EoL 3 years after the patient's death found that participants wanted information on what to expect at the EoL earlier in the hospice transition process.¹⁰ Although these studies provide insight into the information needs of this group, capturing current and timely issues facing caregivers—while simultaneously building on past research—is needed to better support caregivers at the EoL.

This exploratory study sought to better understand informal caregivers' information needs in the home hospice setting soon after a care recipient's death or discharge from hospice care. By understanding the perspective of informal caregivers who have experienced hospice care, future efforts can be undertaken to help guide referring physicians and hospice organizations

as to what information to communicate prior to and during the EoL experience. Addressing these knowledge gaps could positively impact the quality of care delivered to both patients and caregivers.

Methods

Design

This qualitative study used content analysis to analyze data collected in phone interviews with 105 informal hospice caregivers of home hospice patients. The institutional review boards at Weill Cornell Medicine and the Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC) approved the study and all participants provided informed consent.

Participant Recruitment and Sample Assembly

We recruited participants from a weekly list of discharged home hospice patients provided by VNSNYHPC. The VNSNYHPC is a nonprofit organization that serves over 1100 hospice patients daily. Along with visits provided by an interdisciplinary team, patients receive a medication kit for pain and symptom management along with an admission packet, which outlines hospice support services. A 24/7 phone service is staffed by the hospice call team or by a hospice nurse supervisor after hours in which a hospice nurse, nurse practitioner, or physician may be dispatched based on the needs of the patient and family.

The patient list contained patient demographic data (ie, age, gender, race, hospice diagnosis, and hospice length of stay), which was abstracted from the hospice medical record, as well as the contact information (ie, name, address, and phone number) of the informal caregiver. After receiving the list, a letter was mailed to the caregiver describing the study and informing them to expect a call in 2 to 3 weeks. During the subsequent phone call, participants were introduced to the study and verbal informed consent was obtained. Participants had to be 18 years or older, provided care to a patient on home hospice, and English speaking.

Phone Interview Methodology

One investigator (A.S.), trained in qualitative interview techniques, interviewed participants using a semistructured interview guide with follow-up probes. New topics were introduced based on participants' responses. Information was also collected regarding participants' age, gender, race/ethnicity, relationship to the patient, education level, and average number of hours of caregiving they provided during the last week the patient received home hospice care.

Participants were asked questions, which were developed by the coinvestigators, based on clinical experience and a review of the literature. Information needs were assessed by asking the following questions: "Were there things that you felt were not fully explained or that you were unaware of in regards to the hospice care?" and "Is there anything else you wish you knew before making the decision to transition the patient to hospice care?" Based on the participant's response, follow-up questions were then asked to help interviewees clarify and

elaborate their initial answers. If participants mentioned any information needs or replied “yes” to either question they were considered to have unmet information needs.

Interviews were conducted between October 2017 and March 2018 and lasted between 1 and 8 minutes.

Analysis

Audiotaped interviews were analyzed using content analysis. Pairs of investigators (V.P., A.S.) trained in qualitative research methods independently reviewed phone interview recordings and systematically organized data into a structured format. Codes, categories, and themes were constructed individually and continually revised and reformulated after reviewing each new transcript. No categories or themes were predetermined beforehand. The investigators then met to compare and discuss findings and reconciled any differing themes until there was an agreement on a framework of themes and their definitions. The final agreed-on framework was subsequently reapplied to each transcript. NVivo 11 qualitative software was utilized for the analysis. Thematic saturation was achieved after 105 interviews.

Results

A total of 679 caregivers were phoned, 214 (31.5%) did not answer after 3 attempts, 360 (53.0%) were reached but refused to participate, and 105 (15.5%) completed the interview. Participants were predominately white ($n = 48$, 45.7%), college educated ($n = 50$, 47.6%), female ($n = 85$, 81%), and provided care to a parent ($n = 77$, 73.3%). Caregiver and patient demographic information is shown in Tables 1 and 2, respectively. Among the participants, 51 (48.6%) had unmet information needs. The remaining 54 (51.4%) participants felt that there was nothing else they wish they had known prior to or during home hospice. Among the responses of participants with information needs, the following 3 themes emerged, including (1) general information about hospice ($n = 17$, 16.2%), (2) what to expect at the EoL ($n = 19$, 18.1%), and (3) support provided by hospice ($n = 30$, 28.6%).

General Information About Hospice ($n = 17$, 16.2%)

Participants ($n = 10$, 58.8%) reflected on how they would have liked more information about the type of care hospice provides, the duration of hospice services, and the different settings where care can be provided. A number of caregivers ($n = 11$, 64.7%) also wished they had considered hospice sooner or known how beneficial it could be for themselves and the patient. As 1 participant stated, “I was surprised. I didn’t know hospice has all these (resources). They have their own facilities, their own doctors, their own nurses, it’s 24/7 . . . it was a very pleasant surprise . . . If I had known what I know now, I would have been more adamant about trying to get my father on it much sooner.”

What to Expect at the EoL ($n = 19$, 18.1%)

In regard to the patient ($n = 15$, 78.9%)—A subset of participants reflected on needing more information about death and dying, particularly regarding their loved one’s terminal condition and the symptoms to expect during the dying process. One participant felt that the

educational pamphlets provided by hospice were helpful but not always sufficient. She said, “Explain to people the stages of dying . . . (Hospice) needs to give you a lot of information on what to expect. They have a little pamphlet . . . I’m sure there’s more information on dying.”

As a caregiver (n = 9, 47.4%)—Participants also expressed the need to better understand what to expect as a home hospice caregiver in terms of time commitment, responsibilities, and the level of support they could receive from hospice. Some caregivers (n = 5, 55.6%) were surprised by the difficulty of caring for a loved one at home and felt unprepared. One participant felt that if she had had a better understanding of her responsibilities as a caregiver, it would have allowed her to better manage her time. She remarked, “(I wish I had known) how taxing it would be on the caregiver. I feel like there was no real support for the caregiver. I didn’t know what to expect or maybe I would have managed work differently.”

Support Provided by Hospice (n = 30, 28.6%)

Day-to-day care (n = 24, 80%)—Although many participants felt supported through the services that home hospice provided, a subset of caregivers felt misinformed and thought they would have more support and care than they actually received. Some caregivers (n = 16, 66.7%) felt there was a lack of information about the hands-on aspect of hospice caregiving, such as administering medications and bathing patients, and on the degree of caregiver support. As 1 person stated, “I expected somebody to be here, not 24 hours, but someone here everyday that would give (the patient) health care, bathe him . . . and it wasn’t that way at all.” Others (n = 11, 45.8%) noted that the information they received regarding hospice implied that they would be in frequent contact with the hospice team and that hospice would be easily reachable which was not always the case. In addition, caregivers (n = 10, 41.7%) felt they needed more detailed information on hospice home visits. These participants did not realize that home visits might occur with home health aides or nurses, who have differing capabilities, and that hospice team members cannot necessarily make home visits on short notice. As one participant said, “I thought I would be able to make a phone call and someone would be there by my side within ten to fifteen minutes not two hours.”

Logistical challenges (n = 14, 46.7%)—Participants also desired additional information on certain logistical issues after having gone through the hospice experience. The most commonly mentioned issues were information on what to do in an emergency (n = 4, 28.6%), how to obtain and return medical supplies (n = 5, 35.7%), how being on hospice affects the patients’ access to certain treatments (eg, blood transfusions, intravenous antibiotics; n = 4, 28.6%), and what to do after a patient dies, including funeral planning (n = 4, 28.6%). One caregiver explained her confusion over what supplies she could ask hospice for, stating, “nobody says, ‘look here is the menu (of supplies) that’s available through hospice’ . . . I just didn’t think about it . . . I knew I had to get the diapers, I knew I had to get the wipes . . . but a hospital bed, probably somebody should have suggested that.”

Discussion

Our study indicates that although many caregivers feel they received adequate information in their transition to and during home hospice care, about half had unmet information needs. Unmet information needs resulted in both positive and negative experiences for caregivers, with some participants surprised by the amount of care they received while others thought hospice would be providing more care and support. In addition, care-givers reflected on needing more information about what to expect at the EoL, both in terms of what caring for a terminal patient entails and the process of dying.

Studies examining what caregivers perceive is important to know regarding hospice care have uncovered themes similar to those found in our investigation. Various studies have found that caregivers want information on what to expect at the EoL (eg, life expectancy, expected symptoms, and stages of dying).^{10–12} Caregivers in previous studies also expressed a desire for information regarding hospice services, such as the availability of hospice staff, the support services available for loved ones, and the frequency of home visits.^{7,9,12} These existing studies, along with our results, show similarities between caregiver information needs before transitioning to and during the receipt of home hospice care and imply that caregivers' information needs are not necessarily being addressed during the hospice transition or during their loved ones' time in hospice care.

In addition to confirming previous findings, an interesting aspect of our results was participants' desire for more information regarding their responsibilities as caregivers, in particular, a need for more information about the challenges of caregiving for a terminally ill patient. Participants who voiced having information needs regarding the day-to-day care that hospice provides were at times unclear about which responsibilities would fall to them, such as administering medication. Although previous studies have noted caregivers' desire for more information on what support hospice provides, our results also imply that caregivers' need more clarification regarding their responsibilities. Future research should work to identify strategies to best prepare caregivers for their roles in the home hospice care setting.

Given that existing studies have shown a correlation between caregiver satisfaction with hospice care and the perception of receiving sufficient information,^{4,5} future research should also explore caregivers' perceptions of what constitutes sufficient information as well as identifying correlates of unmet information needs so at-risk caregivers can be targeted for interventions. Furthermore, additional research is needed to identify strategies to improve communication and education at the EoL. One specific area should include improving face-to-face hospice communication in order to ensure that care-givers and patients are receiving the necessary information prior to and during the course of their home hospice experience. A communication analysis study examining hospice intake conversations found a need for standardization and clearer communication of information.¹³ Creating guidelines for hospice conversations that take into account the unique needs of individuals and ensure that each family caregiver receives specific essential information on hospice and EoL should be explored as a way to close information gaps.

Exploring the utilization of various educational materials and strategies could also help identify other effective techniques for addressing informal caregivers' information needs. One study of family caregivers of older adults found that a series of booklets on EoL-related topics was considered helpful by 98% of participants and led to an increase in caregiver knowledge of these topics.¹⁴ Other studies have found success in providing classroom-based sessions or educational videos to informal caregivers in improving caregiving abilities.^{15–17} Recent studies focusing on hospice caregivers have also found receptivity to and success with technology-based communication and education interventions such as video conferencing and apps.^{18,19} The feasibility, usability, and efficacy of these various educational information formats should be evaluated among home hospice caregivers, taking into consideration the cultural, religious, and ethnic issues that may arise in different populations.

Limitations

Our study attempted to illuminate the information needs of home hospice caregivers, however, there were limitations to our study that should be considered. First, participants were recruited from a single nonprofit hospice organization in an urban setting, and our findings may not reflect the information needs of informal caregivers served by other hospice programs. Second, while we used 2 open-ended questions to have care-givers reflect back on their information needs, this approach may not have captured all the information needs of the participants. Lastly, we had a low response rate (15.5%) because most individuals were either not reachable by phone (31.5%) or refused to participate (53%). We may therefore not have captured the full spectrum of opinions held by informal caregivers regarding information gaps. The low response rate may have been influenced by the recent loss many caregivers were experiencing after their loved one was discharged from home hospice. However, this can also be viewed as a strength of our study as we were able to assess caregivers' informational needs soon after the home hospice discharge of their care recipients.

Conclusion

In conclusion, our results reflect a need to address information gaps for informal caregivers transitioned to home hospice care through improved communication and education, specifically on the topics of what hospice care is, what to expect at the EoL, and what level of support it offers. Given the importance of informal caregiving in the home hospice setting, further research is needed to ascertain caregivers' information needs and to explore the efficacy of various solutions to address these needs.

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Table 1.**Caregiver Participant Demographic Data.**

Characteristics	Without Information Needs (n = 54)	With Information Needs (n = 51)	All participants (N = 105)
Age, years			
Median	59	55	57
Mean	58.4	54.7	56.8
Standard deviation	11.7	11.7	11.8
Gender			
Female	44 (81.5%)	41 (80.4%)	85 (81%)
Male	10 (18.5%)	10 (19.6%)	20 (19%)
Relationship to patient			
Child	40 (74%)	37 (72.5%)	77 (73.3%)
Spouse	5 (9.3%)	11 (21.6%)	16 (15.2%)
Other relative	8 (14.8%)	3 (5.9%)	11 (10.5%)
Friend	1 (1.9%)		1 (1%)
Race/ethnicity			
White	28 (51.9%)	20 (39.2%)	48 (45.7%)
Black	7 (13%)	10 (19.6%)	17 (16.2%)
Hispanic	11 (20.4%)	6 (11.8%)	17 (16.2%)
Asian	4 (7.4%)	11 (21.6%)	15 (14.3%)
Other/mixed	3 (5.5%)	2 (3.9%)	5 (4.8%)
Undisclosed	1 (1.8%)	2 (3.9%)	3 (2.8%)
Education level			
High school	17 (31.5%)	5 (9.8%)	22 (21%)
College	24 (44.4%)	26 (51%)	50 (47.6%)
Grad school	13 (24.1%)	19 (37.2%)	32 (30.5%)
Undisclosed		1 (2%)	1 (.9%)

Table 2.

Patient Demographic Data.

Characteristics	N = 105
Age, years	
Median	83.5
Mean	81.1
Standard deviation	13.5
Gender	
Female	70 (66.7%)
Male	35 (33.3%)
Race/ethnicity	
White	52 (49.5%)
Black	18 (17.1%)
Hispanic	17 (16.2%)
Asian	16 (15.2%)
Undisclosed	2 (2%)
Hospice diagnosis	
Cancer	45 (42.9%)
Noncancer	60 (57.1%)
Length of stay, days	
Median	38
Mean	120.8
Standard deviation	236.6