Meeting Basic Needs: Social Supports and Services Provided by Hospice

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Objective: Describe social goods and services for which hospices assist patients and families and the resources hospices use to do so.

Background: Basic social supports and services not routinely covered by insurers may be needed by terminally ill patients and their families. Little is known about hospices' provision of such social supports and services.

Methods: A 2014–2015 cross-sectional survey of hospices nationwide. Participating hospices had been in operation for at least 3 years and were located in any of the 50 states or District of Columbia. Hospices were surveyed about availability and sources of internal funds and referral to obtain basic social supports for patients. Descriptive statistics, bivariate analysis, and categorization were used to describe hospice practices. Measures included frequency and nature of goods and services provision in the prior year; and extent to which hospices used internal funds or community referral for goods and services.

Results: Over 80% (n = 203) reported internal funds covered services not reimbursed by insurers; 78% used funds in last year. Hospices used internal funds for food (81.7%), shelter (57.8%), utility bills (73.5%), and funeral costs (50%). Hospices referred patients/families to community organizations to obtain a similar range of services, including transportation, clothing, linens/towels, furniture/appliances, home repairs, and caregiver support.

Discussion: Hospices are using internal resources and accessing community resources to provide patients with basic social needs not routinely covered by insurance.

Keywords: hospice reimbursement; quality of life; social services

Introduction

GREATER SPENDING ON social services, such as transportation, housing, and nutrition, relative to spending on healthcare is associated with reductions in chronic disease, disability, and mortality.¹⁻³ Yet, among comparable nations, the United States spends the least (9% GDP) on social care and the most on healthcare (16% GDP) and has higher rates of chronic disease, infant mortality, and lower life expectancy.⁴ Although to date, studies examining the importance of the social determinants to health outcomes have largely focused on reductions in rates of chronic disease and mortality, there is growing interest in how expansion of social services may improve the care of patients at the end of life.⁵

This is because despite substantial spending on healthcare for patients in the last year of life, outcomes, including patient satisfaction, preference-concordant care, symptom management, and caregiver support, remain poor.⁵

Social supports are especially important for seriously ill patients and their families. Even with insurance, patients and caregivers often face large out-of-pocket costs related to uncovered medical expenses and paid caregivers to supplement unpaid care provided by family and friends.⁶ In addition, many caregivers face reduced income from missed work while caring for a seriously ill loved one.⁷ Financial burden may make it difficult to pay for basic needs, including food, housing, utilities, and transportation, especially among those with lower financial resources at baseline, such as minorities,

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those with lower education, and unmarried or widowed women.⁸ Inability to meet these basic social needs may compromise patient's quality of remaining life, increase caregiver burden, and lead to use of avoidable acute care services and higher healthcare costs.

To improve the quality of end-of-life care, the 2014 IOM Report, *Dying in America*, recommended greater integration of medical care and social services.⁵ The goals of such integration are to allow more patients to remain in their homes in the final stages of life, address the range of needs of patients and families, and lower the demand for expensive, acute, healthcare services. As a comprehensive model of end-of-life care, hospice services accomplish these goals for many seriously ill patients. The vast majority of hospice care is funded by the Medicare Hospice Benefit, which includes traditional medical services such as those provided by physicians, nurses, and therapists along with medical equipment, supplies, and prescription drugs as well as nonmedical services, such as respite care for caregivers, grief counseling, homemaker services, and access to social workers. Compared to conventional care, this combination of services is associated with both improved quality of care and reduced healthcare costs.⁹

Despite the importance of social supports for dying patients and their families, little is known about how hospices respond to the social needs of their clients. These data could guide changes to hospice reimbursement to more fully meet the social needs of patients and their families, inform partnerships between hospices and community social service organizations, and provide information to guide the development of models of care, which meet the social needs of seriously ill patients who do not want or are not eligible for hospice. Therefore, the purpose of this study was to explore, in a national sample of hospice providers, the frequency and type of social needs among hospice patients and their families and strategies used by hospice providers to address them.

Methods

Data for this study were obtained from a cross-sectional national survey of a convenience sample of hospices conducted between May 1, 2014, and October 31, 2015. The larger study examined best practices among hospice providers in outreach to African Americans. Eligible hospices had been in operation for at least 3 years and were located in any of the 50 states or District of Columbia. Hospices were recruited via advertisements through hospice professional organizations, state organizations, leadership groups, and referrals from participating hospices. All participating hospices completed a letter of agreement (signed by hospices' executive directors) and the person providing the data provided informed consent. All hospices received \$40 for their participation. The study was approved by the Duke University Medical Center Institutional Review Board.

Data collection

We requested permission for study participation from each hospice's executive director who identified a staff member to complete the study. The designee provided data via a web-based survey and a telephone interview. Of the respondents, 50% held the position of President, CEO, or Executive Director and 7.4% were chief medical officers or medical

directors; 11.8% served as community liaisons or held positions in outreach, education, and marketing. The remainder held other clinical (e.g., clinical director, nurse manager, physician, social worker, counselor) and administrative roles (e.g., compliance, quality improvement, administrator/managers).

The web-based survey requested basic descriptive data, including ownership (for-profit, nonprofit, government), type (free-standing or vertically integrated), average daily census, and chain affiliation. The telephone interview included questions about the provision of services that may not be reimbursed by insurers. These questions were initially developed by a panel of hospice and palliative care researchers and clinicians and modified following a pilot study of 79 hospices in North and South Carolina, which included similar questions.¹⁰ Before the national survey, the revised and modified questions were piloted with an additional five hospices.

Hospices were asked the following: (1) whether they had internal funds to pay for goods or services not covered by insurers (yes or no); (2) the source of these funds (open-ended question); and (3) proportion of patients for whom they had used these funds in the last year. We defined internal funds as money raised and managed by the organization. In separate questions, they were asked first about the proportion of patients who they had used internal funds to assist (only those reporting internal funds) and second, the proportion of patients who they assisted with accessing community resources to obtain goods and services generally not covered by insurance over the last year. They indicated the proportion of patients using a fixed scale: 0%, 1%–10%, 11%–20%, 21%–30%, 31%–40%, 41%–50%, and >50%. For the purposes of this study, we included items about nonmedical goods and services for which patients and families often seek assistance from community social service organizations to obtain—food, housing other than a nursing home, utilities, and funeral costs. The question about funeral costs was added because many hospices in the North and South Carolina pilot indicated that they frequently assisted patients with funeral expenses. Finally, in an open-ended question, participants were asked to provide up to three examples of other basic living expenses or needs not routinely covered by insurers and not queried in previous survey questions.

Analyses

We used descriptive statistics (counts, frequencies) to summarize characteristics of participating hospices and their responses to questions about the presence of internal funds and the provision of social supports not routinely covered by insurers to patients and families. We categorized a proportion of patients for whom hospices reported providing social supports either via internal funds or assistance with accessing community resources for any patient (1% or greater) and greater than 10% of patients enrolled in last year. We also used bivariate analyses (*t* tests for continuous and chi-square tests for categorical variables) to examine the association between hospice characteristics and hospice reports of whether or not they had internal funds to assist with social supports. These analyses were completed using SAS 9.4 (SAS Institute, Inc., Cary, NC). Two authors independently reviewed the examples of “other expenses” with which

hospices assisted and then categorized them. The authors then met to discuss and reach a final consensus on categories and services included in each.

Results

A total of 230 hospices participated in the study. Of these, 203 (88.2%) answered the demographic questions and completed the pertinent survey questions for this analysis. Table 1 describes the characteristics of participating hospices. The majority of hospices surveyed were in the southern part of the United States (52.7%). Most (69.9%) were free-standing and not-for-profit (79.3%). The vast majority (89.1%) were part of a hospice chain. The average daily census of participating hospices was 246.8 (SD=491).

Among hospices surveyed, 80.7% reported that they had internal funds to pay for nonclinical services not covered by Medicare or other insures. Compared to vertically integrated hospices, free standing hospices were more likely to report internal funds (70.5% vs. 85.2%, $p=0.02$). In addition, the average daily census was larger among hospices with internal funds (276.2 vs. 130, $p=0.003$). No other hospice characteristics were associated with the availability of internal funds to cover nonclinical social supports. Regarding the source of these funds, 157 (95.7%) of hospices reported using external grants, donations, or fundraising and 9 hospices reported using voluntary employee contributions (i.e., payroll deduction or money pool).

Of hospices reporting they had internal funds to pay for goods and services not covered by insurance, 78.4% had used those funds to assist patients and families in the past year. Table 2 includes hospice reports of the use of internal funds to cover social supports. Of the items included in the survey, the largest proportion of hospices reported using funds to assist

TABLE 2. GOODS AND SERVICES PROVIDED BY HOSPICES USING INTERNAL FUNDS OR ASSISTANCE WITH LINKAGES TO COMMUNITY RESOURCES (ESTIMATED BY HOSPICE RESPONDENTS)

	<i>Used internal funds, N = 164</i>		<i>Linkages to community resources, N = 203</i>	
	<i>≥1% of patients</i>	<i>>10% of patients</i>	<i>≥1% of patients</i>	<i>>10% of patients</i>
Goods or services, <i>n</i> (%)				
Food	130 (81.7)	33 (20.7)	186 (91.6)	114 (56.7)
Shelter	92 (57.8)	35 (8.1)	158 (77.8)	51 (25.1)
Utility costs	117 (73.5)	52 (16.9)	186 (91.6)	93 (45.8)
Funeral costs	79 (50)	19 (12)	176 (87.1)	81 (40.1)

patients with food followed by utilities. Over half reported using their internal funds to assist patients with obtaining or maintaining shelter (other than a nursing home) and funeral costs. One-fifth of hospices reported that they had used internal funds to purchase food for >10% of their patients and 16.9% had assisted >10% of their patients with utility costs in the last year. Compared to our findings for those using internal funds to assist patients, a greater proportion of hospices reported linking patients to community resources to obtain all of the goods and services queried. Of the 39 (19.2%) hospices reporting they *did not* have internal funds, a significant proportion reported assisting 10% or more of their patients in the past year with obtaining food (61.5%), obtaining or maintaining shelter (30.7%), paying utility bills (43.5%), and assisting with funeral expenses (38.4%).

When asked about assisting patients with “other expenses” not covered by insurance, hospices reported a variety of categories of items and services that they either paid for with internal funds or linked patients and families to community resources to obtain. These are summarized in Table 3. The most common included transportation costs, clothing, home improvements (e.g., ramps, safety bars), and furniture or appliances. Although we did not ask about the types of

TABLE 1. SAMPLE CHARACTERISTICS (N=203)

<i>Characteristic</i>	<i>Agencies, n (%)</i>
Ownership ^a	
Not-for-profit or voluntary	161 (79.3)
For-profit or proprietary	39 (19.2)
Government	3 (1.4)
Hospice type	
Freestanding	142 (69.9)
Vertically integrated	
Part of a home health agency	20 (9.85)
Part of a hospital system	37 (18.2)
Part of a nursing home	2 (0.9)
Chain affiliation	
Chain-affiliated	22 (10.8)
Independent	181 (89.1)
U.S. census region	
Southern United States	107 (52.7)
Midwest United States	47 (23.1)
Northeastern United States	32 (15.7)
Western United States	17 (8.3)
Average daily census ^b	
<100	88 (45.1)
100–200	40 (20)
>200	67 (34.8)

^aTwo missing.

^bEight missing.

TABLE 3. TOTAL COUNTS OF ADDITIONAL GOOD/SERVICE WITH WHICH HOSPICES ASSISTED USING INTERNAL FUNDS OR BY REFERRAL TO COMMUNITY RESOURCES

	<i>Internal funds, n</i>	<i>Community referral, n</i>
Transportation (medical, family, recreation needs)	44	41
Clothing	32	44
Home improvements (repairs, ramps, pest control)	16	28
Furniture/appliances	16	18
Caregiving support (childcare, food, hotel rooms)	8	13
Linens	10	8
Personal care items	5	6
Counseling/other therapies (massage, legal)	1	8

organizations that hospices enlisted to assist patients, 30 hospices named organizations as part of their example of “other expenses” with which they helped patients. These organizations included Meals on Wheels, Goodwill Industries, Make-A-Wish Foundation, United Way, Salvation Army, local food pantries, and Veterans service organizations.

Discussion

To our knowledge, this is the first study to describe hospices’ experience with providing or assisting families to obtain social support-related goods and services that are not routinely covered by Medicare or other insurers. The vast majority of hospices (80.7%) reported having internal funds raised through donations and grants to assist patients with basic living expenses. Internal funds were more commonly reported by larger and free-standing hospices. Over three-quarters of hospices reported using these funds in the past year to assist patients with such basic needs as food (most common), shelter, and utilities, as well as funeral expenses, transportation, home improvements, furniture, and appliances. In addition, hospices with and without internal funds reported collaborating with community agencies to help patients and families to access available resources to obtain a similar range of basic necessities and services. These findings highlight the importance of healthcare services that address both the social and medical needs of seriously ill patients and their caregivers.

The influence of social factors on population health and individual health outcomes has been extensively documented.¹ Unmet social needs, such as lack of access to food, transportation, and housing, are associated with worse health and greater use of acute healthcare resources. Healthcare models that involve integration of need-based social services either through direct delivery of services or referral to community organizations have been shown to significantly reduce hospital days, emergency department visits, and nursing home placement for high-risk patients, such as those with multiple chronic conditions and disabilities.¹

Despite the focus on providing holistic care for terminally ill patients, the vast majority of efforts to improve end-of-life care have tended to focus on improving symptom management, emotional support, spiritual care, provider communication, receipt of goal-concordant care, and reducing aggressive treatments that may impair quality of life.⁵ There has been considerably less attention to the importance of addressing patients’ and families’ basic social needs, essential to optimal end-of-life care. The Institute of Medicine noted the importance of caregiver support, retrofitting of homes for safety and mobility, meals/nutrition, and transportation to the effective delivery of care at the end of life.⁵ In our study, participating hospices reported using internal funds or accessing community resources to provide many of these goods and services in addition to supporting other basic needs, such as shelter and utilities. Such supports are likely to have positive effects for patients, caregivers, and health systems. For example, assisting with the costs of shelter, utilities, and retrofitting the home may reduce the need for patients to use acute care services by increasing home safety, facilitating a home death, and creating an environment that promotes ongoing care and comfort of patients. Assisting with meeting basic needs may also re-

duce caregiver burden and improve the overall experience of patients and caregivers.

Hospices are ideally positioned to address the social needs of patients and their families. As in other successful models of social service integration,¹ hospice teams are made up of an interdisciplinary group of providers, which must include a social worker, conduct baseline assessments of psychosocial and medical needs, and provide individualized care planning and coordination. Some provisions for social and caregiver support are part of hospice reimbursement, including home-maker services, respite, and access to social workers. However, the use of internal funds to cover basic needs not routinely covered by insurers, such as food, highlights an important gap in covered services. Although to some extent these needs may be addressed by social workers via linkages to community-based organizations, their effectiveness may be limited by large and complex caseloads, limited access to training, and a lack of administrative support. In addition, vacancy rates for social work positions in hospice are higher than in other healthcare settings and salaries are the lowest.¹¹ Given these limitations, expansion of hospice reimbursement to directly provide basic social supports and to increase number of social workers may more fully meet the needs of patients and families. This may be especially important for patients and families with low incomes, who are disproportionately affected by the costs of end-of-life care.^{5,12} Due to limited personal resources (i.e., time and money), need to take time off work to provide care, and other responsibilities, these families may struggle with meeting basic needs and require additional resources to care for their seriously ill loved ones, particularly in the home setting.¹³ Insurance reimbursement changes, which assist with basic needs, may improve the quality of end-of-life care while decreasing overall healthcare costs through reductions in acute care use.¹

This study has a number of limitations. First, designated informants from each hospice responded to the survey. We do not know whether respondents checked documentation related to the provision of social support or the extent to which hospices recorded such data. Therefore, it may be that the diversity of services provided by these hospices was underreported in this study. In addition, most hospices in this sample were not-for-profit; for-profit hospices make up over 2/3 of U.S. hospices and may have different approaches to meeting patients’ social needs.¹⁴ We also did not have information about the needs of patients and families served by participating hospices or the impact of addressing social needs on care outcomes. Additional research should examine the relationship between addressing social needs and outcomes that seriously ill patients and their families care most about, including quality of life and receipt of care consistent with preferences.

Conclusions

These data contribute to the conversation regarding the synergistic effect of attention to both social and medical needs in improving health outcomes throughout the continuum of care, including at the end of life.² While hospice embraces multiple domains necessary for holistic patient care, the current fee structure for reimbursement may not adequately address the wider social needs of patients and families. Research identifying common social needs and their

impact on end-of-life care may inform models of care, which improve quality, reduce caregiver burden, and make it possible for patients to remain in their homes until death if they so desire. Since such models may also reduce costs related to acute care use, they represent a “win-win” for patients, health systems, and insurers. While the data in this article focus specifically on hospice, the findings may be broadly applicable to patients further upstream in the course of serious illness. Current and future models of palliative care should consider how to assess and address the social needs of patients and families.

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Author Disclosure Statement

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