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Brief Reports

Materials to Prepare Hospice Families for Dying in the Home

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Abstract

Many changes occur in the final hours of life. Family members of those dying at home need to be prepared for these changes, both to understand what is happening and to provide care. The objectives of this study were to describe (1) the written materials used by hospices to prepare families for dying in the home setting and (2) the content of such materials. Questionnaires were sent to 400 randomly selected hospices, of which 170 responded (45.3%) sending their written materials. The most frequently used publications were *Gone from My Sight* ($n = 118$ or 69.4%), *Final Gifts* ($n = 44$ or 25.9%) and *Caregiving* ($n = 14$ or 8.2%). Half (56.5%) of the hospices used other publications and a majority ($n = 87$ or 51.2%) used multiple publications. Materials were given to the families by nurses (78.2%) or social workers (67.6%). More than 90% of the hospices had materials that addressed the following signs of impending death: decreased fluid intake, decreased food intake, breathing pattern changes, cold extremities, mottling, increased sleeping, changes at the moment of death, audible secretions, urinary output changes, disorientation, incontinence, overall decline and restlessness. Seven signs were addressed less than 30% of the time; pain (28.2%), dyspnea (19.4%), bed-bound state (18.2%), skin changes (18.2%), vital sign changes (17.1%), surge of energy (11.8%) and mandibular breathing (5.9%). Hospice staff should know the content of the materials offered by their agency so they can verbally address the gaps between the written materials and family needs.

Introduction

MANY CHANGES occur in the final hours of life.[1,2] Family members of those dying at home need to be prepared for these changes, both to understand what is happening and to provide care.[3] Families that are better prepared have more confidence in their caregiving ability and better closure.[4] Lack of preparedness is associated with anxiety,[5] major depression,[5,6] and complicated grief.[6]

While there is widespread agreement that families need to be prepared,[7–13] no interventional studies on preparing family for the final hours in the home setting were found. One study focuses on the intensive care unit (ICU) setting and dying following withdrawing life-sustaining measures.[14] A theoretical framework of caregiver preparedness has been proposed that links health care provider–caregiver communication, caregiver preparedness, and clinical outcomes for the caregiver.[15] The authors hypothesize that better communication about dying will improve caregiver preparedness, mental health, and ability to cope.

Although many hospices provide families with written information to assist in preparation for dying, these materials have not been clearly described. The objectives of this study were to describe (1) the written materials used by hospices to prepare families for dying in the home setting and (2) the content of such materials.

Methods

A questionnaire and a request for copies of all materials used to prepare families for the final hours of life was sent to 400 hospices that are members of the National Hospice and Palliative Care Organization (NHPCO) or state hospice organizations. Forty hospices were randomly selected from each of the 10 Center for Medicare Services (CMS) regions. A variation of Dillman's[16] mail survey method was used.

Data analysis

All materials received ($n = 275$) were evaluated for appropriateness. Appropriate materials included information that pertained specifically to the last hours to 5 days of life commonly referred to as "imminently" or "actively" dying, and information about one or more of the signs of active dy-

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Table 1. Signs of Imminent Dying

Sign of dying	*Percentage of hospices with documents addressing*
Decreased fluid intake	93.5%
Decreased food intake	93.5%
Breathing pattern changes	92.9%
Cold extremities	92.4%
Mottling	92.4%
Increased sleeping	91.8%
Changes at the moment of death	91.8%
Audible secretions	91.2%
Urine output changes	91.2%
Disorientation	90.6%
Incontinence	90.6%
Overall decline	90.0%
Restlessness	90.0%
Decreased socialization	87.1%
Emotional changes	85.3%
Increased temperature	82.4%
Dysphagia	77.1%
Visions	62.9%
Unusual communication	47.7%
Coma	42.4%
Sensory changes	31.8%
Pain[a]	28.2%
Dypsnea[b]	19.4%
Bed bound state[b]	18.2%
Skin changes[b]	18.2%
Vital sign changes[b]	17.1%
Surge of energy[b]	11.8%
Mandibular breathing[b]	5.9%

[a]Present in less than 30% of hospices.
[b]Present in less than 20% of hospices.

ing. Documents that were part of large manuals were divided by topic into separate documents. If a side-by-side comparison of two documents showed identical content, they were considered one document. All questions were referred to an expert panel consisting of two hospice nurses and a hospice social worker. Appropriate materials were recorded and analyzed ($n = 150/275$ or 54.5%).

Since there are no accepted standard of signs of imminent dying, this study used signs developed from a review of the literature, inductive coding of the documents and recommendations from the expert panel. The 28 signs are listed in Table 1. QDA Miner (Provalis Research, Montreal, Quebec, Canada) was used to record investigator coding of documents and each was reviewed and coded at least twice.

Results

Materials were returned from 170 hospices (45.3% return rate). The demographic information received was roughly similar to nationally reported figures (Table 2). There was approximately equal representation in each of the CMS regions except for areas affected by Hurricanes Katrina and Rita (Florida, Louisiana, Mississippi and Texas), which occurred about 4 months before data collection.

Gone from My Sight,[17] a booklet written in 1987 by Barbara Karnes, was the most frequently used publication ($n = 118$ or 69.4% of the hospices). *Final Gifts*,[18] a 1992 publication by Callanan and Kelley that addresses nearing death awareness and communication was used by 25.9%. *Caregiving*,[19] a book published by the American Cancer Society and not aimed at end-of-life care was used by 8.2% of the hospices. Other publications were used by 56.5% of the hospices. About half of the hospices (51.2%) distributed multiple publications, and the remainder (48.8%) used a single publication. Hospices provided anywhere from one to seven publications (mean = 1.9, median = 2). Significantly more signs were addressed when more than one document was used ($p < 0.01$). Preparatory materials were available in eight languages: English (90%), Spanish (37%), Russian (2.9%), Chinese, French, Portuguese, Vietnamese, and Hebrew (0.6% each).

Materials were most often given to the families by nurses (78.2%) or social workers (67.6%). Materials were most often reviewed with the primary caregiver (85.3%) and/or with the family members present (92.4%) or the patient (54.1%).

More than 90% of the hospices (Table 1) had materials that addressed the following signs: decreased fluid intake, decreased food intake, breathing pattern changes, cold extremities, mottling, increased sleeping, changes at the moment of death, audible secretions, urinary output changes, disorientation, incontinence, overall decline, and restlessness.

There were serious deficiencies noted in the comprehensiveness of the materials. Seven common signs were addressed less than 30% of the time: pain (28.2%), dyspnea (19.4%), bed-bound state (18.2%), skin changes (18.2%), vital sign changes (17.1%), surge of energy (11.8%), and mandibular breathing (5.9%).

Discussion

Content of materials: What is missing?

The most disturbing finding of this study concerns the information that is rarely addressed in the documents. Seven signs are present less than 30% of the time; pain, dyspnea, bed bound state, skin changes, vital sign changes, surge of energy, and mandibular breathing. Some of these signs, like pain, dyspnea, and vital sign changes are present in most individuals before death[20,21] and can cause considerable distress to the patient and the family. Other signs, such as mandibular breathing, may not be critical to the patient's comfort, but can be especially distressing to family members.[22]

It is imperative that families have information about pain and dyspnea management specific to the final hours of life because of the prevalence of the symptoms and the past reports of dissatisfaction in management. Pain management often changes in the final hours to days of life. A recent national study showed that more than 18% of home hospice families believed that the patient did not get enough help with pain.[23] Dyspnea is also distressing to both the patient and the family, and occurs in up to 70% of patients in the last weeks of life.[24] More than 26% of families of recent home hospice families believed that dyspnea was not well managed.[23]

Content of materials: Too much information?

Considering the demands on families whose loved one is dying at home with hospice, it is reasonable to expect that

Table 2. Demographics

	Number of hospices	*Percentage of hospices responding*
Hospice size (70.6% responding)		
Small—0–99 patients per year (ppy)	30	25%
Mid-sized—100–489 ppy	59	49.2%
Large– ≥ 490 ppy	31	25.8%
Locale of patients served (75.8% responding)		
Urban	18	14.0%
Rural	59	45.7%
Mixed	52	40.3%
Race/ethnicity of patients served (56.7% responding)		
White		88%
Hispanic		5%
Black		5%
Asian		2%

most will not have the time or motivation to find the bits of information that are relevant to their situation. A document that fully addressed each of the possible signs would be unwieldy. Since not all of the signs occur in each dying, much of the information is irrelevant for a particular family. There is clearly a need for a system to guide families to the information that is pertinent for them so they can quickly access needed information.

Limitations

The primary limitation of this study is the response rate of less than 50%, which limits the generalizability of the findings. It is unknown whether nonresponders were too busy to respond, or did not have the requested information. Another issue limiting the strength of this study was that half of the materials returned were not appropriate for analysis. Many hospices sent notes stating that they were simply sending all of the materials they gave to family members on admission, and it was not clear if other hospices understood what materials were desired. Attempts were made to limit bias and increase generalizability by using a national sample with multistage random sampling.

Implications for future research and clinical practice

Since this is the first study to empirically examine the materials used by hospices to prepare families for dying, it raises as many questions as it answers. Additional research is needed to determine which signs of impending death are most concerning to families, occur with sufficient frequency, and are most important to their psychological health. It is critically important to learn the best way to deliver needed preparatory information to family caregivers at this stressful time. The depth and breadth of written information that is available to family caregivers must be improved. Ideally, materials should be tailored to include critical signs that are likely to be observed. One way of addressing the need for family-specific content would be to develop a database of preparatory information so that hospice staff could choose signs likely to occur for that patient and create a customized preparatory document.

Hospice staff should know the content of the materials offered by their agency so they can verbally address the gaps between the written materials and the family needs. Careful assessment of materials might decrease the number of documents families receive and help hospices focus their efforts on narrowing the gaps in the information provided.

Conclusion

Despite the careful efforts of many hospices, and the many documents used to prepare families for dying in the home setting, there are serious and substantial gaps in the information. It is critical that we work to develop interventions that provide key knowledge to families in a way that is accessible to them as their loved one is dying. Such an intervention may improve the experience for the family member and the care provided to the dying person, which can enhance the experience of dying for all.

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