



ORGANIZATIONAL ASSESSMENT OF END-OF-LIFE CARE

The vision of Supportive Care of the Dying: A Coalition for Compassionate Care is to "promote cultural change with regard to supportive care, compassionate relief of suffering, and pain and symptom management for persons affected by and living with life-threatening illness." The coalition's first research project, *Living and Healing During Life-Threatening Illness* (1997), was designed to listen to those affected by illness and suggest practice changes based on the needs they identified. However, healthcare providers and organizations need feedback on their performance to measure progress. Thus in 1999, the coalition (comprising 12 Catholic healthcare systems, Healthcare Services of the Archdiocese of Philadelphia, and the Catholic Health Association) undertook the Organizational Assessment Project.

Although the primary purpose of this project was to test and refine tools that organizations could use on their own, we hoped the data would provide baseline information for the individual organizations participating in the pilot as they developed strategies to improve care for those affected by life-threatening illnesses. This proved

*Surveys
Tailored to
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Important
Information*

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to be the case, and we also obtained information that was not organization specific. This article reports on two phases of the assessment: first, a survey of patients, caregivers, and bereaved people, and, second, a survey of healthcare providers.

DEVELOPING THE TOOLS

The project team, led by Via Christi Health System, the coalition's executive director, and board members Carroll Quinn, RN, director of quality management, Catholic Healthcare Partners, and Colleen Scanlon, RN, senior vice president, Advocacy, Catholic Health Initiatives, met to review measurement tools that would enable the team to compare feedback from patients, family caregivers, and bereaved family members.

Modified from the City of Hope Quality of Life Patient and Family Tools, the final questionnaires included 70 to 81 questions on quality of life (physical, spiritual, emotional, and relationships) and healthcare experiences. (The tools are available on the coalition's Web site, www.careofndying.org.) Ten patients, family, caregivers, and bereaved persons gave us feedback on the questionnaire before we began the pilot test process. The Providence Health System Institutional Review Board reviewed and approved the project.

THE PILOT TEST PROJECT

Nine healthcare facilities, both large and small, from coalition member systems participated in the pilot test project (see **Box**, p. 51). These organizations recruited volunteer participants in three groups: dying patients (those whose physician would not be surprised if death occurred within 12 months), their family caregivers, and recently bereaved people. The recently bereaved who participated were not matched to the dying



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patients or family caregivers because of time constraints. Bereaved participants had had loved ones die six weeks to three months before the survey. Each participating organization planned to obtain data from at least 30 participants per category, but this turned out to be unrealistic for reasons described later.

PARTICIPANTS

Age and Gender Of 74 patient participants, 63 percent were female and 37 percent were male. They ranged in age from 36 to 95 years; the mean age was 70.

Eighty-eight percent were Caucasian; 26 percent were Catholic, and 49 percent were Protestant.

In the family caregiver category, 61 percent of the 67 participants were female, and 39 percent were male. They ranged in age from 27 to 88 years; the mean age was 60. Eighty-one percent were Caucasian. Twenty-six percent were Catholic, and 35 percent were Protestant.

Thirty-three bereaved people took part in the project. Although they had been caregivers, they were asked to answer a survey only after their loved ones had died. They did not answer the family caregiver survey. Seventy-seven percent of them were female; 23 percent were male. They ranged in age from 30 to 81 years, with a mean age of 57. Eighty-eight percent were Caucasian; 24 percent were Catholic, and 61 percent were Protestant.

No effort was made to determine how active the participants were in their stated religions.

Living Arrangements Eighty-six percent of the ill participants lived at home or with family members. All the bereaved participants lived at home or with family members.

Use of Supportive Services Fifty-one percent of the patients had used supportive services. Thirty-one percent had used hospice; 19 percent had used home health or visiting nurse services. However, the bereaved participants reported that 73 per-

cent of their deceased family members had not used supportive services.

QUESTIONNAIRE RESULTS

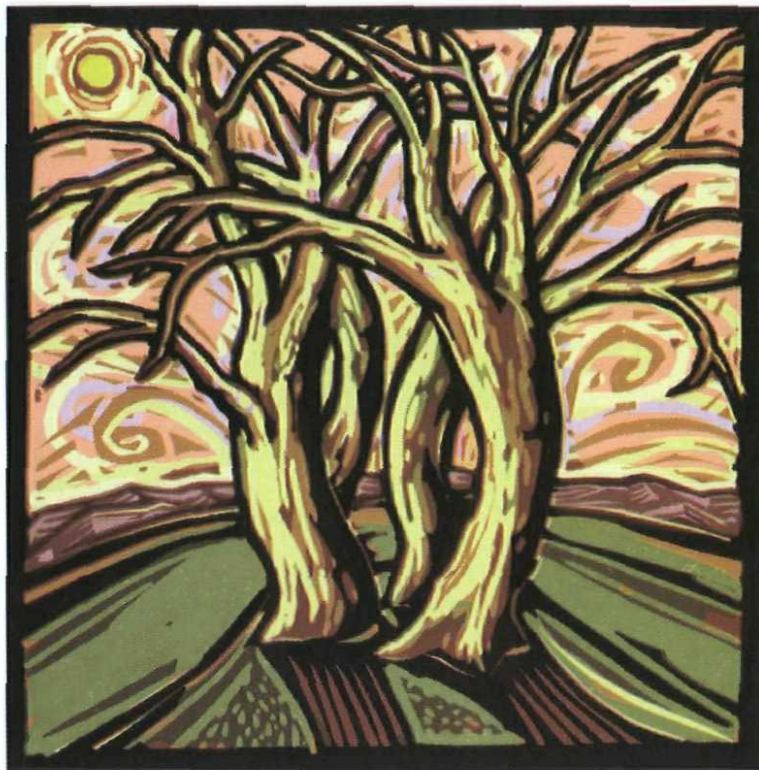
The questionnaire results were divided into sections on the physical, spiritual, emotional, and relationship aspects of the end-of-life experience. Participants rated problems or events on a scale of 0 to 10. They also rated their experience with the healthcare system and the quality of their communication with physicians and nurses. The

patient questionnaire asked patients to rate their experience "at the current time." The caregiver questionnaire asked caregivers to rate their experience as well as their perception of what the experience was for their loved ones. The bereaved family members answered questions based on their memory of their loved ones' final two weeks.

It is important to keep in mind these different perspectives and that the study involved a small nonrandom sample of participants and therefore may have limited application. In spite of these limits, however, some results suggest that new or different interventions would be appropriate for end-of-life care.

Management of Physical Symptoms Overall, patients reported treatment of physical symptoms to be adequate (see Table 1, p. 51). However, the percentage who reported severe problems with aches and pain was 15 percent higher than the percentage who rated their current pain as severe. This indicates that, in order to treat symptoms adequately, professional caregivers should ask for more than a current pain rating.

The fact that 50 percent of the bereaved recalled their loved ones' pain, shortness of breath, fatigue, and aches and pains as severe during their last two weeks is troublesome. Either their family member received poor care or the bereaved needed additional information about nonverbal indicators of discomfort during the dying process. Helping the ill person and family





SYSTEMS AND ORGANIZATIONS PARTICIPATING IN THE PILOT PROJECT

St. Joseph Healthcare, Albuquerque, NM
 Mercy Health Services, Farmington Hills, MI
 (professional survey only)
 Sacred Heart Medical Center, Eugene, OR
 Providence Medford Medical Center, Medford, OR
 Providence Services, Spokane, WA
 (professional survey only)
 St. Clare Hospital and Health Service, Baraboo, WI
 Mt. Carmel Medical Center, Pittsburg, KS
 St. Rose Hospital, Hayward, CA
 St. Joseph Regional Medical Center, Ponca City OK
 Via Christi Regional Medical Center, Wichita, KS
 Hospice, Inc., Wichita, KS

communicate about the extent of pain and problems with physical symptoms may help prepare the family when the ill person can no longer communicate. Unfortunately, we cannot determine the best intervention until we learn why the bereaved participants rated their relatives' comfort at the end of life so poorly.

Emotional, Spiritual, and Relationship Aspects of Care All the participants reported anxiety as their most troublesome emotional symptom. The bereaved had the highest anxiety rating (an average of 7.21 on a 0-10 scale), followed by caregivers (5.97) and patients (4.77). Providing opportunities and encouraging patients, family caregivers, and the bereaved to talk about their anxieties may decrease this distress.

The patients worried a moderate amount about being a burden to their families (5.22 on a 0-10 scale). However, the bereaved family members did not view the care of their loved ones as burdensome (3.77).

We also assessed participants' views on whether life is satisfying (the ratings were 5.92 for patients, 5.93 for caregivers, and 3.97 for the bereaved) and whether life is precious (8.23, 8.22, and 6.13, respectively). Obviously the bereaved appear in special need of support. It may be important for professionals who cared for the bereaved's loved ones to take opportunities to talk with them about the care and death. The fact that the bereaved perceived their loved ones as no longer seeing life as satisfying or precious, and their perceptions of unmanaged physical suffering, are very troublesome.

Respondents in all categories reported little fear of being abandoned by their physicians. They

All the participants reported anxiety as their most troublesome emotional symptom.

also reported that family and friends were providing adequate support. However, the patients experienced less workplace support than the family caregivers or bereaved family members did.

The Healthcare Experience Overall, the experiences in healthcare were positive and met participants' expectations (see Table 2, p. 52). The individual physician, nurse, or other healthcare person made an important difference to the experience for the patient and family. For example, a family member wrote, "She acted like Mom was a total waste of time, and the things that were being done were totally a waste of time—especially hers." This family, because of their concerns, arranged for one of them to be with their mother each night during her hospitalization.

The importance of communication with the physician was also highlighted. For example, one person wrote, "Doctors need more training in expressing understanding for families' point of reference, point of view. We take what they say on faith. People die. It's a matter of medical terms and symptoms for doctors. For us it's mom, dads, brothers, sisters, children, and friends." Perhaps caregivers miss opportunities to talk openly about death and dying and to refer patients and their families to counselors or support groups. This may also be a factor in the reported anxiety levels.

Participants overall rated communication with physicians, nurses, and other healthcare professionals very high (7 or higher for all areas). They reported that communications were understandable and supportive.

PROVIDERS' PERSPECTIVES

As organizations seek to bring about practice changes in end-of-life care, it is also important to determine the perspective of the healthcare providers.

Using the same process as with patients, family caregivers, and bereaved family members, we developed a questionnaire for professionals in which we asked them to rate their effectiveness in

Table 1
Physical Indicators

Participant	Current Pain Rating		Problems with Aches and Pain		Fatigue		Shortness of Breath	
	Average*	Severe Rating†	Average*	Severe Rating†	Average*	Severe Rating†	Average*	Severe Rating†
Patients	4.34	28%	5.46	43%	6.45	50%	5.36	43%
Family caregiver			3.37		4.63			
Bereaved	6.52	55%	7.03	67%	7.19	67%	7.78	70%

*On a scale of 0 to 10.

†Percentage who gave a rating higher than 7 on 0-10 scale.



Table 2
Healthcare Experience*

Participant	Overall Quality of Healthcare	Followed Care Wishes	Information about Death and Dying	Chaplains Available	Access to Information Counselors, Support Groups
Patient	8.39	8.28	5.66	8.00	6.00
Family caregivers	8.22	8.27	6.27	7.64	5.71
Bereaved	8.16	7.42	5.71	7.55	4.74
Healthcare providers	NA	6.30	5.46	7.57	5.60

*Average ratings on a scale of 0 to 10.

addressing patient and family concerns regarding physical, emotional, relationship, and spiritual issues, and to indicate the extent to which workplace structures, procedures, and policies influence the care they provide. These two questions were followed by 95 individual items that the person rated from 0 to 10.

Participants The number of volunteer participants totaled 225, from nine organizations. Sixteen percent were physicians, 43 percent were nurses, 5 percent were pastoral care workers, and 21 percent worked in other capacities. The participants were predominantly Caucasian (87 percent) and female (74 percent). Thirty-six percent described their religion as Protestant, 32 percent as Catholic.

Most of the participants—48 percent—had been in practice six to 20 years. Twenty-five percent had been in practice less than five years, and 27 percent had been in practice longer than 20 years. All the participants had cared for patients who had died in the preceding year.

Fifty-nine percent said they referred patients to or suggested hospice services, and 70 percent said they referred to or suggested home healthcare. Only 17 percent referred to or suggested a church ministry, and only 5 percent referred to or suggested parish nurse support. The latter two figures may be due to an absence of those services or a lack of knowledge about how they could assist the patient and family. There is no way of knowing from this survey.

QUESTIONNAIRE RESULTS

Professionals have a much different perspective from that of patients, family caregivers, or bereaved family members. Professionals respond to questions from an aggregate of experiences. Patients, family caregivers, and bereaved family members may have had only one, deeply personal experience.

We asked participants to rate the effectiveness

of treating physical symptoms on a scale of 0 to 10 (see Table 3, p. 53). Comparing this table with Table 1, it is apparent that patients and family caregivers' perceptions of the efficacy of pain relief might differ sharply from professionals' perceptions.

Different perspectives also emerge in the emotional, spiritual, and relationship areas (see Table 3). The healthcare providers rated the effectiveness of their work much more positively. However, in the area of healthcare experience, the patients and family members rated their healthcare experience higher than did the professionals (see Table 2).

PERSONAL PROFESSIONAL EXPERIENCES

We asked the participants to provide information about their experiences in today's tightly managed healthcare environment. Overall, professionals who participated in the survey felt positive about their ability to connect to their patients and to ease patients' suffering. However, individual responses described unmet needs and sources of stress.

Seventy percent of the participants provided additional information through comments. Recurring themes related to questions of time, team support, personal beliefs and faith, personal experiences with death and dying, and systemic changes

Time Many participants commented on the time constraints of day-to-day practice. Most of the comments concerned short hospital stays and rapid transfers between levels of care. Others mentioned the lack of time planned for staffing when a patient is near death. Respondents also expressed a desire to be available to dying patients and their families.

Representative comments included:

- *I feel truly sorry for patients as some are pushed through healthcare. We often see patients who are returned to health only to leave the hospital and die in the nursing home two days later.*

- *Sometimes there isn't enough time in my schedule to grieve when a client dies or to talk with family at the funeral.*

Support of the Team Many respondents commented on the role of the interdisciplinary team. Comments were both positive and negative:

- *I have felt support from the care team and felt I have been able to discuss feelings and have received recognition for being successful at decreasing family suffering, even if just a little.*

- *I don't feel I'm able to give a lot of staff spiritual and emotional support, but the hope is to foster an environment where we do this for one another.*

"I feel truly sorry for patients as some are pushed through healthcare."



Personal Beliefs and Faith Professionals generally were committed to good end-of-life care and described beliefs supportive of their personal approaches. However, personal lack of comfort with death did affect their ability to meet the needs of the ill person and family.

- *Death is not a failure; for me a failure would be to be unable to support the patients and family in the dying process.*

- *I treat my patients as I would hope they would treat me. Families want to discuss death, and have expressed relief when I brought the subject up.*

- *God is in control and I will not face anything that I can't face with him. I always look for the positive but I will always be honest with patients and families. Death is a very special event—no one should be alone or unsupported.*

- *[I am] not comfortable with talking about death. It scares me personally, therefore I have a difficult time talking about it and dealing with it.*

Learning about Death from Personal Experience

Professionals described learning about death from personal experience and from reflecting on the deaths of patients they had cared for:

- *My daughter's death led to personal discoveries after a lot of questions and soul searching. I wish my professional role allowed time to assist others along the path of grief and healing.*

Suggestions for Change Participants suggested strategies to improve care of those affected by a life-threatening illness. Some of the suggestions focused on hiring and competency standards:

- *I feel our facility could provide better patient and family support by making sure that this is an important value in the person they are hiring to provide care for our patients.*

Other suggestions focused on organizational changes:

- *I personally feel a phone call or at least one home visit from the physician would be more appropriate for a dying patient. Very seldom do physicians do that.*

- *When families have someone dying, I find they like the same nurses and caretakers to care for them throughout the dying process.*

- *Too many people [are] in a big hurry. Everyone needs to put themselves in the patient's place and slow down.*

ASSESSMENTS

Our goal for this project was to gather information from 300 patients and 300 family caregivers. We were unable to do this. It was very difficult for nurses and physicians to identify patients who

might die in a year's time. This might be due to an inability to accurately predict the course of many chronic progressive diseases, reluctance to dispel "hope" of the ill person or family by predicting that death is approaching, or the professionals' own discomfort with death. Whatever the reason, we will not be able to improve care for people with life-threatening illnesses unless we can address these topics.

One clear finding was that professional caregivers must find ways to assess discomfort more fully in order to provide appropriate and adequate treatment. The data in this area were striking. The physical suffering of many patients was evident in their responses, despite the healthcare facilities' commitment to pain and symptom management. It may be that the problem lies in the questions we ask and thus the symptoms we treat. We must continually think about the control of symptoms from the perspective of the ill person and his/her life. It is also clear that one way to improve care is to provide more support for family members before the death of the patient and through bereavement.

Perceiving the Need for Change Since the professionals overall rated their effectiveness as very high, they are unlikely to see a need to change practice. But when we compare the perspective of the patients and bereaved family members with that of the professionals, the need for change becomes obvious. We recommend that healthcare professionals and organizations collect baseline data comparing the perspective of the patient and bereaved family

Continued on page 58

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Table 3
Providers' Evaluation

		Average Rating (on a 0-10 Scale)	Not Very Effective (0-3)	Moderately Effective (4-6)	Extremely Effective (7-10)
Effectiveness of Treating Physical Symptoms	Aches and pain	7.50	4%	15%	81%
	Fatigue	6.43	10	34	56
	Shortness of breath	7.59	4	18	78
Emotional, Spiritual, and Relationship Care	Anxiety	6.56	7	34	59
	Worry about burden	5.99	17	36	64
	View time as precious	6.71	9	32	59
	Opportunity to talk about illness/possible death	6.66	9	32	59
	Physical signs/symptoms of approaching death	7.19	7	14	72

ORGANIZATIONAL ASSESSMENT

Continued from page 53


members with that of professionals who cared for that patient. With this comparison, areas in need of practice changes will become evident. We also recommend systematically gathering anecdotal information and searching for opportunities to improve care on this basis.

It also appears that professionals need to verify that patients and families have adequate information about available supportive services and are offered referrals more than once during the course of the illness. Both patients and family members rated referrals to these services lower than professionals did, leading to the conclusion that offering services once without follow-up is inadequate from the point of view of the patients and family members.

The survey results also show that caring for those who are dying and helping their families require knowledge, skills, and a certain comfort level with death and dying. Grand rounds or seminars that describe excellent care at the end of life can help professionals develop new skills. These presentations should include information from all involved. Teaching caregivers how to provide *emotional and spiritual support* will also be of value.

Facilities need to question whether they allow enough staff time to care for and support dying patients and their families. Current time allotments and their actual application on a shift-by-shift basis should be assessed and evaluated for appropriateness.

Finally, caregivers' beliefs should be considered during hiring and patient assignments. How professionals relate to their work and their faith can have a powerful impact on their practice and the experience of those that they care for. □

 For more information, contact Supportive Care of the Dying: A Coalition for Compassionate Care at 503-215-5053, or visit its Web site at www.careofdying.org.

COMMUNICATION STRATEGIES

Continued from page 55


RN, is leading efforts in a partnership with Hawaii's Executive Office on Aging, St. Francis Healthcare System, and other organizations as part of a three-year Robert Wood Johnson Foundation grant on end-of-life care. The goal is to raise awareness of the issues surrounding dying and encourage use of advance directives, better pain management, increased education of clergy and parishes, and access to hospice.

- Development of improved end-of-life healthcare curriculum. St. Francis Healthcare System, through its International Center for Healthcare Ethics and as part of the Robert Wood Johnson Foundation grant, is conducting research with student and practicing nurses and physicians to develop end-of-life curriculum. The objective is to raise the standard of end-of-life care throughout the state. In addition, more than 20 long-term care facilities are participating in evaluating the assessment and treatment of pain in long-term care. The goal is to set standards and provide education for facilities whose patients rarely use hospice.

- Public relations and community outreach. St. Francis Hospice produces videos and brochures, places stories in the media, and offers many programs during the year. It provides speakers to schools, churches, businesses, and community groups.

- Encouragement of timely referrals. One of the greatest challenges facing America's hospices is the generally brief amount of time patients spend in hospices—a period far short of experts' recommendations. "Many patients are referred just moments prior to death, therefore denying them and their families access to all that hospices can offer them," says Sr. Francine Gries, OSF, RN, executive director of the hospice.

- A bereavement program and other activities for family members, including support groups. □

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