

Patient and Family Involvement

Addressing the Need for Public Reporting of Comparative Hospice Quality: A Focus Group Study

Shoshanna Sofaer, Dr.PH.; Susan S. Hopper, Ph.D.; Kirsten Firminger; Naomi Naierman, M.P.A.; Marsha Nelson, A.C.S.W., M.B.A.

The quality of an ever-increasing range of health care facilities and services is being systematically measured and publicly reported by sponsors at the national, state, and local level. For example, the U.S. Agency for Healthcare Research and Quality (AHRQ) has posted a compendium of quality report cards that includes 221 public reports that compare health plans, hospitals, individual physicians, medical groups and clinics, dialysis facilities, nursing homes, and home health agencies.¹ Hospice care has been an exception.

Although standardized measures are available to assess hospice quality across multiple domains, no information on hospice quality is currently available to the public. Evidence indicates that many who might benefit from high-quality hospice care never use such care or enroll in hospice later than might have been optimal,^{2,3} and that even those who use hospice are likely to learn about some of its features only after services begin.⁴ Further, families referred too late reported lower satisfaction and poorer experiences with respect to many aspects of hospice care.⁵

Recent evidence also indicates that there are significant variations in the mix of services provided to clients and families by hospice agencies,^{6,7} making it likely that there are also variations in the clients' and families' experiences of care, the appropriateness of clinical processes, and relevant outcomes. Such quality variation means that well-designed comparative public reports could help people identify a higher performing provider and lead to more intense quality improvement efforts, as has been found with hospital reports.⁸

We are undertaking research to develop a model hospice quality report to provide both education about hospice and comparative quality information about hospice providers using well-specified measures. Questions have been raised, most recently by Fung et al.,⁹ about whether comparative quality reports are actually used by the public, for example, to choose health plans and providers. However, as noted by Hibbard in an accompanying editorial,¹⁰ much more is known than is used about how to design a user-friendly quality report with com-

Article-at-a-Glance

Background: Standardized measures are available to assess hospice quality across multiple domains, but no information on hospice quality is available to the public. A study was conducted in 2006 to explore the public's knowledge, beliefs, and attitudes about hospice care and their responses to the idea of a public report on comparative hospice quality.

Methods: Six focus groups were conducted, two with individuals with direct hospice care experience and four with people without experience. Focus groups were videotaped, transcribed, and analyzed for themes and patterns of convergence and divergence.

Results: Focus group participants without hospice experience knew of hospice but had little accurate information about hospices services, who could benefit, or how it is financed. Even some with hospice experience were unaware of services such as bereavement support. Participants saw hospice as appropriate only when the family could no longer provide care. They wanted a public report to include information about hospice, help in comparing hospice to other kinds of end-of-life care, details on accreditation, staff and services of individual hospices, quality comparisons, and decision support. Hospice was viewed as providing a broad range of services to the family as well as the patient.

Discussion: This research will provide guidance for the development of an evidence-based model report on hospice quality that includes substantial educational material. It also supports the selection of measures for such a report that would resonate with the public, which makes the use of a comparative quality report more likely. The next step in this research is to develop and formatively test such a report, so that it can be pilot tested with willing hospices in a community offering a choice of providers. Considerable additional work is needed to ensure that hospice becomes more understandable and transparent to the public.

parative data that are easy to understand, interpret, and use. Further, the minimal efforts to promote and market reports to the public mean that few patients and consumers know about them.¹¹ Highly “evaluative” reports, which are designed to make it as easy as possible to identify low- and high-performing health care organizations, increase the likelihood that the assessed organizations will undertake efforts that actually improve performance.^{12,13} Therefore, we have designed our work to follow the principles and strategies that have been demonstrated to improve the likelihood that reports will be understood and used, beginning as recommended with formative research with people similar to the report’s ultimate audience.¹⁴ The focus groups reported in this article represent the first step in that process.

Measuring Hospice Quality

Current projects to measure hospice quality of care include the Family Evaluation of Hospice Care (FEHC) Survey, which is used voluntarily by nearly one fourth of all hospices to measure the experiences of family caregivers.¹⁵ In addition, the National Hospice and Palliative Care Organization (NHPCO) has released a bereavement-specific experience survey,¹⁶ while researchers at the Veterans Administration have developed a system-specific Family Assessment of Treatment at the End-of-life, which addresses inpatient and outpatient services for veterans during the last month of life.¹⁷

Another source of quality data is NHPCO’s National Data Set (NDS), which is used to collect structure and process data from 1,200 of 4,160 hospice agencies in the United States.¹⁸ A small group of hospices is testing several outcome measures that build on conceptual work by the National Hospice Work Group and NHPCO Outcomes Forum.¹⁹

At present, however, no set of measures has been endorsed for public reporting,* but that may change. For example, the Centers for Medicare & Medicaid Services, in partnership with the Carolinas Center for Medical Excellence (their Quality Improvement Organization), has conducted a feasibility study of having Medicare-serving hospices collect a wide range of data. Within the next few years, hospices may either volunteer or be highly encouraged to report publicly on such measures.

Yet all too often, quality measures are developed, endorsed, and reported with little input from the public. This is problematic because the public is unlikely to use quality reports unless

they address its interests.^{11,14} It is therefore useful to identify (1) what the public knows and believes about hospice, and (2) how the public views hospice quality and people’s preferences regarding the content of a potential public report about hospice quality. This article presents findings for focus groups, an efficient way to obtain information from members of the public in multiple communities,²⁰ on these issues.

Methods

FOCUS GROUP COMPOSITION

In June 2006, we conducted six focus groups, two in each of three metropolitan areas, chosen because they (1) had at least six hospices, (2) had a mix of nonprofit and proprietary hospices, (3) were in states where use of hospice was at least in the midrange for the United States, and (4) were home to substantial numbers of ethnic and racial minorities. Two of the six groups were conducted with individuals who had directly and continuously observed the receipt of hospice services by a loved one within the previous two years but not within the last six months.† In the remaining four groups, people had no direct hospice experience, but at least half had lost a loved one in the same time frame.

We sought heterogeneity in the groups’ composition to achieve a mix of age, sex, race/ethnicity, and education levels in each group. We excluded anyone who had been in any kind of focus group in the previous year. As shown in Table 1 (page 424), group composition generally matched our recruitment requirements. We sought and acquired at least 40% participation from each sex to avoid the tendency for women to predominate in caregiver roles. We sought and acquired participants between 45 to 75 years of age, with about 70% younger than 65 and the rest 65 or older. We sought to have at least 40% have a high school education or less, and the final tally came to 40.8%; similarly, we wanted only 20% of participants to have more than a four year college education, and the final tally was 20.4%. As noted earlier, we had chosen to go to Baltimore and Chicago to obtain participation from blacks and to Phoenix to ensure input from Latinos. We had somewhat fewer Latinos than we would have liked (12.2%), but 30% of the group identified themselves as black or African-American. We had few participants from other racial and ethnic groups.

Groups with people who had direct hospice experience were somewhat smaller (six to eight) to allow participants more time

* The National Quality Forum has endorsed the Family Evaluation of Hospice Care as part of a set of measures of the quality of end-of-life care in cancer (National Quality Forum: *National Voluntary Consensus Standards for Clinician Level Cancer Care*. Washington, DC: National Quality Forum, 2009).

† Because of human subjects protection considerations, we excluded from all groups anyone who had lost a loved one within the past six months because we thought they would be at greater risk of extreme distress during the group in a discussion of the end of that loved one’s life.

Table 1. Patient Characteristics*

	Hospice Experience (n = 14)		No Hospice (n = 35)		Total (N = 49)	
	n	%	n	%	N	%
Sex						
Male	7	50.0	13	37.1	20	40.8
Female	7	50.0	22	62.9	29	59.2
Age (years)						
45–54	10	71.4	9	25.7	19	38.8
55–64	1	7.1	15	42.9	16	32.7
65–74	3	21.4	10	28.6	13	26.5
75 or Older	0	0	1	2.9	1	2.0
Education						
Some high school, but did not graduate	2	14.3	1	2.9	3	6.1
High school graduate or GED	6	42.9	11	31.4	17	34.7
Some college or 2-year degree	2	14.3	10	28.6	12	24.5
4-year college graduate	2	14.3	5	14.3	7	14.3
More than 4-year college degree	2	14.3	8	22.9	10	20.4
Hispanic Origin						
Yes, Hispanic or Latino	3	21.4	3	8.6	6	12.2
No, not Hispanic or Latino	11	78.6	32	91.4	43	87.8
Race						
White	8	57.1	23	65.7	31	63.27
Black	4	28.6	11	31.4	15	30.61
Other	1	7.1	1	2.9	2	4.08
Missing	1	7.1	0	0	1	2.04

* GED, General Equivalency Diploma.

to respond to questions and share their experiences. Groups with no hospice experience had an average of about nine participants, as planned. We used a professional focus group firm to recruit without respect to participants' attitudes toward hospice.

FOCUS GROUP PROCESS

Sessions were held in the firm's facilities using a semistructured moderator's guide* and were videotaped and transcribed. The moderator [S.S.H.], experienced in conducting focus groups and in the field of palliative care/hospice, conducted all six focus groups.

Information was presented during the groups to provide background and to stimulate discussion. All groups received a five-minute slide presentation* on quality information in general and the types of quality information about hospice that may become available to them. We have found that without

such background, members of the public are likely not to understand, or to misunderstand, what is meant by a quality measure.²¹ In groups without direct hospice experience, we presented a five-minute slide show* with factual information about hospice after an initial discussion exploring people's knowledge and beliefs about hospice. All groups received and were asked to respond to a list of the services typically offered by hospice providers (Table 2, page 425).

CONTENT ANALYSIS

Transcripts were analyzed to identify themes and patterns (that is, points of convergence and divergence).²² Although it would have been preferable to create a formal coding list and code all transcripts, resource and time constraints made that impossible. Instead, we used a spreadsheet to sort the text and organize it by research question and focus group question. Because statements about a given issue can come up at different points in a focus group, irrespective of the question formally raised by the moderator, we sorted material no matter where

Table 2. List of Hospice Services

A care plan designed for the unique needs and wishes of each patient

Care at home by the hospice team, including physicians, nurses, nurse aides, and social workers

Pain and symptom relief guided by the hospice physician in consultation with the patient's physician

Education for caregivers on how to care for their loved one

Personal care as appropriate (bathing, skin and hair care, oral care, and bed care)

Around-the-clock telephone help from hospice staff for emergencies

Medications, treatments, medical equipment and supplies related to the patient's primary hospice diagnosis

Continuous, short-term, around-the-clock care from a hospice nurse during a crisis

Respite care to relieve caregivers needing a break

Brief inpatient stays, coordinated with the hospice team, when needed, for respite or pain and symptom management

Grief and bereavement support for the patient and loved ones

Spiritual support by pastoral care staff, and if desired, home visits by a hospice-trained clergyman of the patient's choice

Compassionate support from hospice volunteers for patients and caregivers

Special Care as needed, including:

- Physical Therapy
- Speech Therapy
- Occupational Therapy
- Respiratory Therapy
- Nutritionists
- Art and Music Therapists

it could be found in the transcript. We then summarized the range of comments and the extent to which one kind of comment predominated. Analysis took into consideration whether comments changed in response to probes on specific issues or as additional information was provided. We also compared the responses of participants in the groups with and without experience of hospice. We did not make comparisons across demographic characteristics because we were trying to acquire a sense of patterns and themes across a wide range of participants rather than subgroups.

The original analysis was conducted by the focus group moderator. The project's principal investigator [S.S.] then reviewed the transcripts, the spreadsheet, and the analysis. She raised and resolved issues with the moderator about how comments were interpreted and about comments that appeared to have been overlooked. The resulting final analysis on which they reached consensus provides the basis of our findings.

Findings

WHAT DOES THE PUBLIC KNOW AND BELIEVE ABOUT HOSPICE?

Knowledge. Data on this question were gathered at the outset of the groups, before those without experience were provided with information about hospice. Among those without direct experience, at least half knew of a hospice in their community, while a third knew a friend or relative who had used hospice. Some also knew the range of settings in which hospice services could be provided, with many able to identify local residential hospice facilities. In fact, some with no hospice experience thought of hospice primarily as a facility, "a place where you can die with dignity." Both higher education and higher penetration of hospice in local markets increased awareness of hospice.

Even though our questions about hospice asked for *any* comment participants might have, rather than asking for positive and/or negative comments, participants reported hearing good things about hospice and spoke about it providing a "peaceful transition" at the end-of-life and well-trained, professional, and attentive staff. Further, questions regarding services brought accurate responses about some tangible or task-oriented services, such as "personal care," "pain medication," and "medical equipment." However, some with no hospice experience did not know about the option at all.

Moreover, those that had heard of hospice had various misconceptions. Even some with direct hospice experience were unaware of the availability of grief and bereavement counseling and support groups after the death, bereavement services for young children, respite care, or volunteers to sit by the bedside and assist with chores. Experienced participants were also not fully cognizant of the Medicare financing for hospice. Across all groups, many were surprised to learn that hospice is paid for by the Medicare program and is an entitlement to those who meet the eligibility requirements. People asked whether Medicare would "only pay for a month," whether using the services resulted in "I.O.U.s" requiring reimbursement from the patient's estate, or was only for the "well-to-do."

Beliefs. Regardless of hospice experience, participants filtered their understanding and beliefs about hospice through their beliefs and experiences around family caregiving. Participants emphasized that the family should play the primary role in caring for a dying loved one. In every focus group, many saw hospice as appropriate only if families could not manage on their own. Some associated the need for hospice with diminishing caregiver capacity or increases in the patient's care demands.

Opinions varied about exactly when the family should seek help. One woman without hospice experience commented that she would not want to be a burden to her children and would “have it in writing that it is okay to put me in hospice.” However, a man in the same group commented, “That time is very personal. My mother always made [it] known that she wanted to be with family. . . . If they go to hospice then they are being cared for by strangers.” Some families had sought out hospice, despite pride and embarrassment, when they could no longer cope with caregiving. Specific triggers included the dying individual’s increasing physical debility and the consequent pain, other symptoms, and the inability of caregivers to help toilet or perform other physical care. One participant noted of her sister’s case, “There needs to be a way to explain to them that they are not going to die from receiving hospice but are going to be comfortable.” However, another told of hearing about hospice early on but discovering that the rest of her family was not ready to take this step.

Participants with hospice experience, with one exception, said they would recommend hospice to a terminally ill friend. The exception, a man who reported one good and one poor experience with hospice, warned: “Be very careful because there is a wide range of care . . . in different hospices.” (Note that individuals self-selected to participate in a group on this topic so this finding is not generalizable to everyone with hospice experience.)

Among those with hospice experience, beliefs about hospice were also shaped by previous experiences with other settings for dying patients, including nursing homes or hospitals. One recalled, “the doctors had recommended we either put my dad in a nursing home or a hospice . . . we chose hospice . . . [because] if he went to a nursing home he would have been hooked up to the machines and we . . . felt he wouldn’t want to live life like that.” Another woman commented, “I would choose hospice any day and then the care is . . . one-to-one. In a nursing home you have ten patients and one person taking care of them.” Some viewed hospice as more “intensive” and “personalized” than other settings and noted that it has “the potential to be more customized, which is really important.” However, among those without hospice experience, such comparisons arose only after receiving additional information about hospice, hearing the group discussion, and reviewing the list of specific services.

HOW DO MEMBERS OF THE PUBLIC DEFINE LOW- AND HIGH-QUALITY HOSPICE CARE?

Focus group participants’ responses to open-ended questions

about how they would define low- and high-quality hospice care yielded three themes: staff and volunteer competence, staff and volunteer interpersonal interactions, and organizational characteristics. Regarding the first theme, respondents thought that staff in a high-quality hospice would be knowledgeable, well trained and appropriately certified, well-informed about what other members of the team were doing, and good at keeping the family informed. Staff would provide care that was tailored to the individual, advocate for the patient and let him or her rest, keep the patient comfortable, and provide the right medications.

Regarding the second theme, participants thought that a high-quality hospice would have staff and volunteers who are compassionate, respectful, dedicated, and caring and would provide emotional and spiritual as well as physical support. A low-quality hospice would have staff that are cold, unresponsive, lazy, detached, and uninformative, and would see their work as “a job, just a paycheck.” The organizational-level theme drew less attention. A high-quality hospice would be accessible and ensure there was a care plan in place. If it was a facility, it would be clean and open to visits at any time. A low-quality hospice would be dirty and only interested in making money.

An indirect way of learning how the public views hospice quality is to examine responses to the list of services or benefits mentioned by focus group participants, with and without direct experience. Although pain and symptom relief, medications, and personal care were mentioned regardless of experience, those with experience emphasized services directed at the family, including help from staff to guide them through the dying process and realizing their loved one was ready to let go even if they were not. Those without experience were most struck by the idea of a personalized care plan based on the patient’s needs and wishes.

Although our project seeks to develop a model report on hospice quality, many participants were clear, especially after receiving information about hospice, that it is one option among others for end-of-life care and framed their views of quality using a comparative context. Two participants told positive end-of-life stories of nursing home care (without hospice) and two others told positive hospital stories. However, many described negative experiences with settings other than hospice. One compared the list of hospice services to a family member’s nursing home experience: “This is so much more than she received. She was left alone a lot in front of a TV set.” Another commented that “there are low-paying jobs in nursing homes and they can’t deal with the emotional or physical problems that the patients experience.”

WHAT INFORMATION IS NEEDED IN A HOSPICE QUALITY REPORT?

In response to our slides on quality reports, participants across groups expressed interest in them, viewing them positively and comparing them to the familiar *Consumer Reports*. Yet, none were aware of existing public quality reports on other providers. Participants also thought that reports would help “good facilities to grow” and help put bad programs out of business.

Participants wanted a comparative hospice quality report to contain background information and guidance. Although a few were surprised that not everyone knew about hospice, others noted how little is heard about hospice. Requests included “Tell me how to choose a hospice” and how to compare hospices, including measures and minimal standards; “Take me through the process. Map out the steps for me.” Some without hospice experience wanted an explanation of the different settings where hospice is offered and a comparison of services (for example, pain management) across settings.

Several with hospice experience spoke about the importance of addressing bereavement support. Others mentioned that the public needs to know whether the hospice staff are “trustworthy and caring people” who “are coming to the home if you need to go out.” Participants of all kinds wanted reports to explain when the right time was for hospice and how it is financed.

To compare hospice providers, participants wanted to know about services available at each facility, in detail (for example, specific bereavement services provided, to whom and for how long, formal pastoral services), and the extent of special services (for example, palliative chemotherapy) for high-needs patients. They asked for information about (1) how quickly service could begin; (2) ease of accessing a hospice to enroll; (3) when round-the-clock care could be provided; (4) staff ratios, credentials, and training; (5) volunteer training; (6) hospice accreditation; (7) for-profit versus non-profit status; (8) experiences of other families (and patients); and (9) locations where hospices provided their services. Some also wanted to know which hospices had met external standards, that is, whether they had a “seal of approval.”

When asked when they would use a quality report, many said they would not look at reports until they had to (for example, if they had a very sick relative) but that they would be glad to know that the reports existed and that hospice is an option should they need it. Others, primarily middle-aged women and older men, said they wanted to be prepared and would look at reports before a potential need. One man said, “I am interested

for myself,” and several others spoke about using hospice to avoid “putting family through the pain and suffering of trying to make me comfortable.” And some, frankly, did not know when they would look at a report.

Most participants thought the Internet was the best way to disseminate reports. Across all groups, most used the Internet and many cited Internet locations, and if they did not, most had someone to help. Some liked downloading a printed report, and a minority of participants recommended production of separate printed reports.

Participants also recommended health channels and health news segments on television and radio to promote a report. Suggestions for community locations to announce reports included hospitals, doctors’ offices, libraries, and senior centers.

When asked what would help people trust a hospice quality report, participants said that it would depend on which organization(s) sponsor such reports. Acceptable sponsors included Medicare, hospice associations, and others with no direct financial interest. Unacceptable sponsors included health insurance plans, individual hospices, and hospice chains. Participants also suggested listing as supporters of the report easily recognized organizations, including area social service agencies, medical societies, and disease-specific organizations. Several participants mentioned the credibility of faith-based groups. One man noted, “African Americans are more likely to trust the information if it is coming from a church.”

Discussion

Our research suggests that for comparative hospice quality reports to resonate with the public, they should include background information about hospice care in general, as well as the scores on quality measures across hospice providers. Moreover, reports need an element of decision support. This would mean information to enhance understanding of the differences and similarities between hospice care and other end-of-life care options, as well as a framework for identifying the issues people should consider in choosing among hospices.

Many wanted information about when to begin consideration of hospice, although others noted this is a highly personal issue that depends on the family’s ability to provide care as the patient’s situation changes. Indeed, a critical insight in this study is that hospice is viewed as providing a broad range of services to the family as well as the patient, especially among those with past hospice experience. Although families viewed caring for a dying loved one as primarily their responsibility, there is a tipping point at which individual families feel the need to turn to “outsiders.” Thus, it would be useful to provide

guidance on how to anticipate their family's "tipping point."

The public views hospice as one of several options for end-of-life care. Ideally, this means hospice needs to be compared, objectively and fairly, to other settings. However, almost all measures are currently setting-specific, which will make achieving this ideal difficult if not impossible in the short term.

It is important to note the limitations of this study. First, focus groups, although excellent for exploring participants' views in depth, never provide a "representative sample" of a population. Six focus groups are a relatively small sample, but resources did not permit us to conduct more groups. Second, we did not have, in this case, a previously identified and endorsed set of specific measures of hospice quality to share with the group. Thus, we could not use the groups to garner feedback on specific measures. However, we did learn much about how this group of participants viewed hospice quality and what kinds of measures they might view as important. The public would likely be interested in a wide range of hospice quality measures, including the experience of care and the technical and interpersonal quality of staff. Third, it is never possible from focus group research alone to predict whether or not people would read and use such a report. People often indicate a high interest in information even when the likelihood is small that they would ever seek out and use such information. In the case of a situation with a high degree of stress and emotion, it is indeed hard to make predictions based on a relatively small set of focus groups.

In addition, a critical factor in actual use of quality reports is whether the public becomes aware of a report and realizes it is available for use when it becomes relevant. Other factors include whether or not the report is based on the substantial evidence that has been amassed about the content, context and design characteristics that make a report easy to understand and actually use.²⁴ More summative evaluation research (hopefully on an evidence-based, well-publicized report) will eventually be needed to determine whether the public, and other audiences, will look at and use information on hospice quality. It is also unclear whether people are more likely to respond to the "educational" component of such a report, which is essential given ignorance and misunderstanding of hospice, or to the actual comparative data.

Nevertheless, these findings support further efforts to develop an effective public report on hospice services and hospice quality. However, although a hospice public report created in the near future could address some concerns of patients and family members, considerable additional measurement development work and consensus building are needed to ensure that

hospice joins other health care services in becoming more understandable and transparent to the public. Major stakeholders, perhaps in the context of the National Quality Forum, should move to endorse an initial set of measures for public reporting that are scientifically valid and reliable, based on data that are feasible to collect without undue burden on providers and that reflect the public's concerns. However, additional research may be needed to develop and refine measures that reflect the concerns of the public. For example, people really want to know what services a hospice does and does not provide. How can that be accurately measured? If we simply ask hospices about it, they are likely to respond that certainly, they provide all the services in the Medicare benefit. How frequently those services are actually provided and under what circumstances is much harder to assess, especially because all patients do not need all services. Nonetheless, many measures exist today that do resonate with the interests of the public. It should be possible, as in the case of hospitals, to begin with a limited set of measures. We hope that moving toward public reporting of comparative hospice quality will make potential patients more aware of this option and lead to improvements in the quality of care actually provided across hospices. **J**

Shoshanna Sofaer, Dr.PH., is Robert P. Luciano Professor of Health Care Policy, School of Public Affairs, Baruch College, New York City; **Kirsten Firminger** is Research Associate; **Susan S. Hopper, Ph.D.**, formerly Senior Research Associate, is a private consultant. **Naomi Naierman, M.P.A.**, is President and Chief Executive Officer, American Hospice Foundation, Washington, DC. **Marsha Nelson, A.C.S.W., M.B.A.**, is Vice President, American Hospital Foundation, Washington, DC. Please address correspondence to shoshanna.sofaer@baruch.cuny.edu.

References

1. U.S. Agency for Healthcare Research and Quality: *Talking Quality. Gov: Talking to Consumers About Health Care Quality*. <http://www.talkingquality.gov> (last accessed Jun. 24, 2009).
2. Han B., et al.: National trends in adult hospice use: 1991–1992 to 1999–2000. *Health Aff (Millwood)* 25:792–799, May 1, 2006.
3. Rickerson E., et al.: Timing of hospice referral and families' perceptions of services: Are earlier hospice referrals better? *J Am Geriatr Soc* 53:819–823, May. 2005.
4. Casarett D.J., Crowley R.L., Hirschman K.B.: How should clinicians describe hospice to patients and families? *J Am Geriatr Soc* 52:1923–1928, Nov. 2004.
5. Schockett E.R., et al.: Late referral to hospice and bereaved family member perception of quality of end-of-life care. *J Pain Symptom Manage* 30:400–407, Nov. 2005.
6. U.S. Department of Health and Human Services (DHHS), Office of Inspector General (OIG): *Medicare Hospices: Certification and Centers for Medicare & Medicaid Services Oversight*. Apr. 2007. <http://oig.hhs.gov/oei/>

[reports/oci-06-05-00260.pdf](#) (last accessed Jun. 24, 2009).

7. Carlson M.D.A., et al.: What services do patients and their families receive? *Health Serv Res* 42:1672–1690, Aug. 2007.

8. Hibbard J.H., Stockard J., Tusler M.: Does publicizing hospital performance stimulate quality improvement efforts? *Health Aff(Millwood)* 22:84–94, Mar.–Apr. 2003.

9. Fung C.H., et al.: Systematic review: The evidence that publishing patient care performance data improves quality of care. *Ann Intern Med* 148:111–123, Jan. 15, 2008.

10. Hibbard J.H.: What can we say about the impact of public reporting: Inconsistent execution yield variable results. *Ann Intern Med* 148:160–161, Jan. 15, 2008.

11. Shaller D., et al.: Consumers and quality-driven health care: A call to action. *Health Aff(Millwood)* 22:95–101, Mar.–Apr. 2003.

12. Hibbard J.H., Stockard J., Tusler M.: Does publicizing hospital performance stimulate quality improvement efforts? *Health Aff (Millwood)* 22:84–94, Mar.–Apr. 2003.

13. Hibbard J.H., Stockard J., Tusler M.: Hospital performance reports: Impact on quality, market share and reputation. *Health Aff (Millwood)* 24:1150–1160, Jul.–Aug. 2005.

14. Kanouse D.E., Spranca M., Vaiana M.: Reporting about health care quality: A guide to the galaxy. *Health Promot Pract* 5:222–231, Jul. 2004.

15. Teno J.M., et al.: Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage* 22:752–758, Sep. 2001.

16. National Hospice and Palliative Care Organization: *Family Evaluation of Hospice Care*. <http://www.nhpco.org/i4a/pages/Index.cfm?pageID=4067> (last accessed Jun. 24, 2009).

17. Finlay E., Shreve S., Cassarett D.: Nationwide Veterans Affairs quality measure for cancer: The Family Assessment of Treatment at the End of Life. *J Clin Oncol* 26:3838–3834, Aug. 10, 2008.

18. Connor S.R., et al.: Measuring hospice care: The National Hospice and Palliative Care Organization National Hospice Data Set. *J Pain Symptom Manage* 28:316–328, Oct. 2004.

19. Ryndes T., et al.: *Report on the Alpha and Beta Pilots of End Result Outcome Measures: National Hospice and Palliative Care Organization and the National Hospice Work Group*. 1998. http://www.nhpco.org/files/public/Statistics_Research/Report_on_Alpha_and_Beta_Pilots.pdf (last accessed Jun. 24, 2009).

20. Sofaer S.: Qualitative data collection for aging research: Choosing the right method. In Curry L., Shield R., Wetle T. (eds.): *Improving Aging and Public Health Research: Qualitative and Mixed Methods*. Washington, DC: APHA Press, 2006, pp. 39–52.

21. McGee J., Sofaer S., Kreling B.: *Findings from Focus Groups Conducted for the National Committee For Quality Assurance (NCQA) Medicare and Medicaid Consumer Information Projects*. Washington, DC: NCQA, 1996.

22. Miles M.B., Huberman A.M.: *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd ed. Thousand Oaks, CA.: Sage Publications, 1994.

23. Shaller D.: *Consumers in Health Care: The Burden of Choice*. California Healthcare Foundation, Oct. 2005. <http://www.chcf.org/documents/insurance/ConsumersInHealthCareBurdenChoice.pdf> (last accessed Jun. 24, 2009).