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AM J HOSP PALLIAT CARE published online 4 March 2014
DOI: 10.1177/1049909114524475

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What is This?
What Consumers Want to Know About Quality When Choosing a Hospice Provider

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Abstract
Despite the availability of endorsed quality measures and widespread usage of hospice, hospice quality data are rarely available to consumers. Moreover, little is known about how consumers prioritize extant measures. This study drew on focus group and survey data collected in 5 metropolitan areas. The study found that consumers reported the hospice quality indicators we tested were easy to understand. Participants placed top priority on measures related to pain and symptom management. Relative to consumers with hospice experience, consumers without previous experience tended to place less value on spiritual support for patients and caregivers, emotional support for caregivers, and after-hours availability. The National Quality Forum-approved measures resonate well with consumers. Consumers also appear to be ready for access to data on the quality of hospice providers.

Keywords
hospice, quality, public reporting, consumer

Introduction
The scope of public reporting of health care quality has expanded significantly in the last decade, spurred by federal and state pushes toward transparency and by private sector efforts, local Aligning Forces for Quality coalitions, and other initiatives. State public reporting programs for health care are present in at least half of the United States.1 Coupled with the availability of hospital, home health, and nursing home public reports (and soon, data on physicians) through the Centers for Medicare and Medicaid Services suite of “Compare” tools, consumers today have more access than ever before to information to support their health care choices.

Despite these encouraging changes, public reporting has not yet reached its full transformative potential. Several obstacles stand in the way including confusing presentation2,3 and infrequent use of available data by consumers.4 Commedable efforts have been made to better understand how the formatting and amount of information influence users’ ability to make choices related to quality.5-7 Furthermore, there is some evidence that clearly presented choices may lead to better decisions about quality.8,9 These findings together fuel continued efforts by the Patient Centered Outcomes Research Institute and other agencies to improve care by engaging and involving consumers to the greatest degree possible. However, even in cases where appropriate dissemination and incorporation of best practices for presentation are possible, a more fundamental barrier stands in the way of bringing health care quality information to bear on provider choices: the lack of publicly available reported data on quality for entire sectors of the health care system.

One of the largest sectors for which data are not yet publicly reported on a national scale is hospice care. In 2012, hospice services were provided to approximately 1.6 million patients, and hospice was involved in more than 40% of all deaths in the United States.10 Despite the widespread need for and use of hospice services, consumers selecting a hospice provider rarely, if ever, have access to data on provider quality. Although measures have been approved for public reporting of hospice care by the National Quality Forum (NQF),10 data on hospice quality are currently available to consumers in only 1 state.11 A number of initiatives related to hospice quality

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are in nascent stages, including the development of a Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey for hospice,\textsuperscript{12} slated for data collection beginning in 2015 and possible use in payment by FY2017.\textsuperscript{13} The Centers for Medicare and Medicaid Services’s Hospice Quality Reporting Program requires Medicare hospice providers to begin submitting data on 2 quality measures during 2013. Whether or when these will feed publicly available provider-level reports is not known.

The topic of communicating with patients and families about hospice has been the object of significant scholarship\textsuperscript{14,15} but there has been little exploration of consumers’ understanding of and interest in the quality of hospice care. Our review of the literature uncovered a single article addressing public reporting for hospice. A 2009 study by Sofaer and colleagues\textsuperscript{16} involved a series of focus groups with 2 types of consumers: those with and without previous hospice experience. Their study found important misconceptions of hospice services among consumers with no hospice experience and also identified key priorities for public reporting about hospice, including the provision of data on accreditation, staff characteristics, services available, and quality of services.

Subsequently, there has been some work within the hospice industry to advance public reporting of quality. The American Hospice Foundation convened a panel of experts in hospice care and quality measurement to select measures from the Family Evaluation of Hospice Care (FEHC) that best match the needs and desires expressed by consumers in the Sofaer study. The measures have been incorporated into a model report card that draws upon best practices for public reporting and has the potential to present comparative hospice data for competing hospices.\textsuperscript{17} In addition, the NQF endorsed a number of hospice quality measures in April 2012, including the FEHC measures.\textsuperscript{18} The endorsed measures were originally developed for the purpose of retrospective evaluation of hospice performance and not for prospective assessment by consumers comparing hospice providers. As a result, little is known about how well consumers understand them or whether they find them meaningful when choosing among hospice providers.

To this end, we conducted a series of focus groups among consumers with and without hospice experience to explore 3 questions: (1) What information do consumers want and need to know as they choose hospice care? (2) What are consumers’ understanding of and perspectives on the NQF-endorsed experience-of-care and other potentially useful hospice quality measures? (3) What sources, channels, or methods of delivery would consumers trust for receiving quality information on hospice providers?

**Methods**

We conducted a total of 8 focus groups in late 2012 and early 2013 in 5 metropolitan areas (Essex County, New Jersey; Philadelphia; Richmond, Virginia; Wichita, Kansas; and Sacramento, California). The areas were selected because we were able to work with the state hospice association to identify a cooperating hospice willing to assist with the study, the areas were served by multiple hospices, and they were diverse in sociodemographic composition. At each site, 2 focus groups were conducted. The first group was conducted with a group of individuals who had served as the primary caregiver for a hospice patient. A second group consisted of Medicare-eligible individuals aged 65 and older without direct hospice experience, representing potential hospice consumers. The study protocol was reviewed and approved by an institutional review board.

At each of the sites, hospice consumers were recruited through convenience sampling from the lists of families who had been served by the organization, and individuals without hospice experience were recruited from the panel of a local marketing research firm to mirror the ethnic and racial composition of the local area as closely as possible. We asked hospices to limit their selection to individuals whose last contact with hospice services was more than a year prior to the date of the group. In 3 metropolitan areas, both focus groups were held in the same city. In New Jersey, we were able to secure a hospice to cooperate in drawing a sample of caregivers but unable to locate a commercial market research firm that had availability in the immediate geographic location. The market research firm we identified was approximately an hour away in the northern Philadelphia suburbs. We refer to this location as the Philadelphia/New Jersey site.

The research team developed separate discussion guides for the 2 types of groups. The guides were oriented around the 3 key study questions. The discussion guide focused on the specific measures that are part of the NQF-approved set of FEHC measures and added 2 items which in the judgment of the research team were either of significant consumer interest or likely to be candidates in future Federal reporting mandates. These included the degree to which patients/families had access to the hospice team on weekends and evenings and whether pain was adequately controlled within 48 hours of initial assessment. The measures are summarized by source in Table 1.

In addition to the facilitated discussion, we also administered 2 survey instruments to participants in all groups: one where they were asked to provide basic sociodemographic information and another where they were asked to rate each of the quality measures under discussion as “very important,” “somewhat important,” or “not important.” The first survey was administered at the start of the group while the second survey was administered about 15 minutes into the discussion and was also used as a discussion aid to elicit opinions about which indicators were more or less important.

All focus groups were digitally audio recorded and professionally transcribed. Transcripts were imported into NVivo Version 8 for formal qualitative analysis. A member of the research team with extensive experience conducting qualitative analysis developed an initial set of codes based on her review of the transcripts for the first 2 focus groups. The research team then reviewed and refined the list of codes and transcripts as a group before the lead analyst completed coding the remaining transcripts. The node summary from NVivo along with supporting quotes from participants formed the
basis for the analysis reported here. Data from the demographic and quality rating surveys were tabulated and formatted in Excel.

**Results**

**Characteristics of Participants**

Table 2 describes the sociodemographic characteristics of focus group participants. The distribution of age and educational attainment across groups is roughly similar. The groups with consumers who had previous hospice experience were more heavily weighted toward female participants than the groups among consumers without previous hospice experience due to the predominance of females in the caregiver role. With the exception of the Philadelphia/New Jersey group, the hospice consumer groups were less likely to include nonwhite participants.

**What Information Do Consumers Want and Need to Know as They Choose Hospice Care?**

Consumers with and without previous hospice experience expressed a need and desire for information related to the availability and quality of specific hospice services that they considered most important to patients, caregivers, and families. Information needs and wants reported frequently by consumers from both the groups included round-the-clock availability of comforting, compassionate, and competent hospice staff; types of spiritual and emotional support services for patients and caregivers; education for caregivers and family members about what to expect at various stages of illness and dying; the availability and quality of support services beyond medical care (eg, personal care and running errands); and the effectiveness of pain management medication for the patient.

Participants in both focus groups noted the importance of having 24-hour access to caring and competent hospice staff during a difficult time in the lives of the patient and caregiver. One individual without prior hospice experience wanted to know when and how often hospice staff would be available:

How often would they come, would they be available if I call them or is it just you come certain times during the week or during the day, and it’s always that time?

The constant availability of hospice staff members was a primary component of their ability to provide emotional support to caregivers as explained by 1 consumer with previous hospice experience:

We never felt like we were a burden. We never hesitated to call. And I remember one time particularly calling [P] and said, ‘[P], I’m not calling you because of my mother, I need you, I need you here for me.’ Boom, an hour later, she was in the driveway. That was important.

Consumers in the hospice groups also mentioned some needs and positive aspects of hospice care that were not discussed by
consumers without prior hospice experience. These comments tended to be informed by consumers’ direct experience as caregivers and reflected how hospice services provided emotional support at a difficult time for themselves and their loved ones. These positive aspects of hospice care included the degree to which hospice staff helped make caregivers more confident in their abilities; eased the fears of patients, caregivers, and family members; provided caregivers a needed break; and assisted with logistics and other needs immediately following the patient’s death. One woman noted how a hospice staff member allowed her and her mother-in-law an unlimited amount of time with the woman’s husband after his death:

I think the lady would have stayed there all night before she called the coroner, you know, to give us the time we needed with my husband.

Consumers noted that if they or someone else knew they needed hospice services again in the future, they would search for information related to the availability and quality of these positive aspects.

Consumers without hospice experience more often requested information about the medical training and specific professional experience of hospice staff. Consumers with hospice experience were less focused on formal degrees and spoke more about the benefits of particular hospice staff members connecting with the patient and the caregiver and providing emotional support in addition to physical health services.

What Are Consumers’ Understanding of and Attitudes Toward the NQF-Endorsed Hospice Quality Indicators?

Consumers with and without hospice experience reported that the NQF-endorsed hospice quality indicators were easy to understand and they did not identify any particular indicators as confusing. Although no indicators emerged as difficult to understand, participants did observe that due to the similarity of some of the measures, they were occasionally difficult to differentiate. When asked to identify the most and least important quality indicators, individuals from both the groups had difficulty in distinguishing the most and least important and stated that all of the quality indicators were important. Consumers with hospice experience also had more difficulty being objective in their endorsement of specific quality indicators and tended to rate lower the indicators that were not as relevant to them in their experiences. A comment from 1 consumer with hospice experience provides an example of this tendency:

The “frequency of receipt of confusing or contradictory information about the patient’s medical treatment,” I mean, that just never came up, so I would say that that was not important.

Most important quality indicators. Quality indicators that were rated as most important by both consumer groups included satisfaction with the amount of pain medicine received by the patient, emotional support for the patient and caregiver, satisfaction with the amount of information received about medicines used to manage the patient’s pain, satisfaction with the help provided to the patient in dealing with breathing while under hospice care, and satisfaction with access to hospice care and support overnight and on weekends.

Participants from both groups were concerned with pain management for the patient and not wanting the patient to suffer. As 1 consumer without hospice experience explained:

I think that when a person is terminally ill, the medications to make their transition as painless as possible is something that I would think in my estimation is important for the patient, the person making that transition, that it’s done calmly, and it’s done without any pain or suffering.

Consumers from both groups also recognized the role that hospice staff plays in providing emotional support to the patient and caregiver. One consumer with hospice experience reported being touched by the sensitivity of hospice staff toward her husband’s emotional needs:

I thought that was interesting that they said he looked like he was anxious. The medicine helped with that in regards to settling him down, and I thought that was really good, because I didn’t want him suffering.

Two consumers with hospice experience reported ambivalence about the amount of pain medicine received by the patient. In their experience, the pain medications led their loved ones into a state of semiconsciousness from which they did not emerge, and family
members regretted not being able to say goodbye while the patient was fully conscious. In the words of 1 consumer:

I wish that I had known that she was going to go into a stupor... I didn’t want her to die, and I definitely wanted to have a conversation with her.

When assessing quality indicators, consumers without hospice experience were more likely than those with hospice experience to rate highly the indicators that focused on the needs of the patient. Quality indicators where the focus on patient needs was important included satisfaction with the amount of pain medicine received by the patient, timeliness of pain management (patient’s pain brought to comfortable level within 48 hours of admission to hospice), and satisfaction with the information provided about the patient’s breathing.

Consumers with hospice experience were more likely than those without hospice experience to rate highly the indicators related to supporting the needs of caregivers and family members. Quality indicators related to supporting caregivers and family members that were rated highly important by more consumers with hospice experience included satisfaction with the amount of emotional support provided to the caregiver and family prior to the patient’s death and after the patient’s death.

Least important quality indicators. For the question of least important quality indicators, several consumers with hospice experience declined to identify any of the indicators as “least important.” Consumers without hospice experience were more willing to identify least important quality indicators. Quality indicators that were rated as least important by both consumer groups included discussion of religious or spiritual beliefs and needs for the caregiver, discussion of religious or spiritual beliefs and needs for the patient, and frequency of receipt of confusing or contradictory information about the patient’s medical treatment.

The indicators related to the discussion of religious and spiritual needs for caregivers and patients were rated as least important by the greatest number of consumers. Some consumers explained that religion and spirituality were not very important to them, and others stated that although these needs were important, they had their own churches or other means of meeting religious and spiritual needs and did not need them to be provided through hospice.

One consumer without prior hospice experience stated:

The last, for me, would be religious and spiritual, because like someone said, I feel like that’s a personal thing and I wouldn’t need the chaplain or feel like I needed a chaplain through hospice. I could rely on my church, my minister, and that would be something... I wouldn’t think I would [need] from hospice.

Several consumers without prior hospice experience rated as least important the amount of emotional support provided to the caregiver and family after the patient’s death. These consumers explained that they have a “large support network of family and friends” and did not think they would rely on hospice for their emotional needs after losing their loved one. However, 1 consumer with hospice experience discussed how he felt support from family, friends, and hospice staff decreased once his loved one had died and that hospice support after the death became more important than he had thought it would be. The ratings for this indicator might be different before and after a consumer has had experience with hospice care.

Responses to the survey instrument are displayed in Figure 1, which tallies and displays the percentage of respondents within each of the hospice and nonhospice groups who rated each potential indicator as “very important.” Indicators are sorted from top to bottom by the average percentage of respondents indicating the indicator was “very important.” In general, these results parallel what we heard in the discussions, revealing pain and breathing was almost universally endorsed as very important and matters of spiritual/emotional support were at the bottom of the list (although it should be noted that for those to whom this aspect is important, it is very important). The forced choice responses do, however, highlight some differences between consumers with and without previous hospice experience. Relative to consumers with hospice experience, those without experience tend to rate lower the importance of spiritual/emotional support, overnight and weekend availability of the hospice team, and adequacy of information (trouble breathing, what to do at the time of death, and what to expect at the time of death and from the dying process) and rate more highly the importance of the amount of pain medicine and timeliness of pain management.

What Sources, Channels, or Methods of Delivery would Consumers Trust for Receiving Quality Information on Hospice Providers?

During the focus groups, consumers with and without previous hospice experience were asked what sources they would trust for receiving hospice quality information. As shown in Table 3, consumers from both groups reported that they would trust information that came from a doctor or doctor’s office, the Internet, assisted living facilities or nursing homes, hospitals, and individuals with previous experience receiving hospice services.

Consumers with hospice experience more often cited a preference for receiving information from professionals and settings that typically serve older people, including assisted living facilities, nursing homes, and case managers from facilities serving older people. Consumers without hospice experience were more likely to report trusting more informal sources such as the Internet, people who had previously received hospice services, and friends. The one exception to this was that more consumers from the nonhospice group reported that they would trust information coming from the hospital social worker. The total number of responses for this question was low, so caution should be used in attributing meaning to the differences between the groups.

Discussion

This research yielded several notable findings related to consumer understanding of and opinions about quality measures for
hospice care. First, consumers with and without hospice experience reported that the quality indicators they reviewed were easy to understand and did not identify any of the indicators we reviewed in the groups as confusing. Second, several broad trends were evident from our discussions on the relative priority of quality measures with participants. In general, across both

Figure 1. Focus group participant ratings of Family Evaluation of Hospice Care (FEHC) and other potential quality measures from the survey of participants.

Table 3. Sources That Focus Group Participants Trust for Receiving Hospice Quality Information.

<table>
<thead>
<tr>
<th>Source</th>
<th>Both hospice and nonhospice</th>
<th>Hospice only</th>
<th>Nonhospice only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor or doctor’s office</td>
<td>22 (7)</td>
<td>11 (3)</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Internet</td>
<td>14 (7)</td>
<td>5 (3)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>Assisted living facilities or nursing homes</td>
<td>8 (5)</td>
<td>6 (3)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Hospitals</td>
<td>6 (4)</td>
<td>3 (2)</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Individuals with previous experience receiving hospice services</td>
<td>5 (4)</td>
<td>1 (1)</td>
<td>4 (3)</td>
</tr>
</tbody>
</table>
types of groups, participants placed top priority on measures related to pain and symptom management and ascribed lower importance to other areas. Several key differences in the relative value placed on potential indicators of hospice quality were observed between those with and without hospice experience. Consumers without previous hospice experience tended to place relatively less value on spiritual support for patients and caregivers, emotional support for caregivers, overnight and weekend availability of the hospice team, and adequacy of information and relatively more value on the importance of the amount of pain medicine and timeliness of pain management than consumers with previous hospice experience. Third, there were important differences in preferences for how consumers would like to receive information about hospice quality. Those with previous hospice experience were more likely to prefer receiving such information through established medical channels, such as from a doctor or an assisted living facility, while those without hospice experience expressed trust for more informal channels, such as the Internet.

These findings have important implications for future public reporting initiatives for hospice. First, they confirm the importance of presenting publicly available quality measures with consumers who are most likely to use publicly reported hospice quality information, including those with little hospice knowledge. Second, they underscore the need for ancillary educational material to address the knowledge gap of consumers without hospice experience. Appropriate educational material designed to reach this group of consumers may aid in reducing the knowledge gap and help them make fully informed choices. Third, while our focus groups revealed broad patterns as to what was more and less important to consumers as a whole, the generalizations that accompany the analytic process tend to obscure the unique perspectives and needs of each participant. The accumulated life experiences of consumers produce varying beliefs and expectations, which inform every health care decision they make. For some families, spiritual support is not at all important; for what may be a smaller group of families, the access to pastoral care they gain through hospice is perhaps the defining characteristic of the experience. Although incorporating values and preferences into quality reports may be less important for selecting a cardiac surgeon, for an intensely personal health care choice such as hospice, the presentation of a large number of measures accompanied by a robust education program and the incorporation of consumer preferences into customizable quality reports may be valuable.

Given that hospice CAHPS (H-CAHPS) measures are on the horizon, the focus on the NQF-approved, FEHC-based measures featured here may appear to be out of date. However, there is significant overlap between the 2 instruments. Of the NQF-endorsed measures, most have an analog measure in the draft H-CAHPS measures. Given the similarity of the proposed H-CAHPS instrument to the existing NQF-approved measures, these results are likely to carry over even for a public reporting system based on H-CAHPS data. Although novel, these findings are also limited in important ways. First, given the research design, they are limited in generalizability. We know a great deal about the opinions and thoughts of the individuals who participated in our discussion but have little idea about how typical what we heard is of consumers more generally. Also related to the limited scope of the research design, our research is not able to speak to the opinions or needs of racial and ethnic minority groups. Given these groups’ lower likelihood to use hospice, the need for education and outreach to make public reporting meaningful and useful in these populations is likely even stronger. The findings of this study are also limited in that family-reported outcomes are unlikely to tell the full story with respect to hospice quality. There are important elements to hospice quality such as unwritten rules about admission criteria and actual availability of professional staff to come to the home after hours or urgently that would not be illuminated fully or at all by family experience measures. A complete accounting for hospice quality will likely require the incorporation of some far-reaching and creative provider-reported outcomes that also resonate with consumers.

In short, the evidence that the NQF-approved measure set resonates well with consumers strongly underscores that the public is ready for a well-designed report of hospice quality. Responses from participants in the groups with hospice experience made it clear that choosing the right hospice is an important decision that profoundly impacts both the dying patient and their caregiver. The discussion also suggests that the NQF measures resonate with both potential constituencies with whom we met: those with and without hospice experience. It will be important as public reports are rolled out to make them easily accessible and clearly explained so that families, physicians, discharge planners, and other referral sources may make good use of the information when making or supporting the choice of a hospice.

Declaration of Conflicting Interests
The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: funded by AHRQ Grant 1 R21 HS021870.

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