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Does Caregiver Knowledge Matter for Hospice Enrollment and Beyond? Pilot Study of Minority Hospice Patients

Kyusuk Chung, PhD, Elizabeth Essex, PhD, and Linda Samson, PhD

Department of Health Administration, College of Health and Human Services, Governors State University, University Park, Illinois

Abstract

We examined the level of hospice knowledge of caregivers of minority elderly hospice patients and determined how it influences the hospice enrollment decision and the decision on the use of hospice services after enrollment. Based on qualitative analysis of medical records and interviews with caregivers of minority elderly hospice patients who received personal care from paid caregivers (eg, other than family caregivers), we found that hospice knowledge increased access to hospice among minority patients who otherwise would not opt for hospice or enroll too late for comprehensive hospice care services. Furthermore, the highest level of knowledge—acquired through caregivers' health care occupations—appears to influence hospice care after hospice enrollment. Caregivers with that level of knowledge made requests for changes in site of care and/or additional services that may enhance the quality of hospice care that their loved ones receive.

Keywords

hospice knowledge; caregiver issues; quality of hospice care Introduction

Because Medicare added the Medicare Hospice Benefit (MHB) in 1983, increasing numbers of elderly populations and their families from all ethnic groups have taken advantage of end-of-life care provided through MHB services.¹ However, minority groups have never narrowed the gap with non-Hispanic whites in MHB usage rates.^{1,2} Absent or problematic communication from health care providers has been suggested as a major barrier to MHB enrollment for minorities.^{3,4} When asked if MHB was presented as an option for care at the end of life, slightly more than half of the caregivers of African American decedents in 2000 who were not enrolled in hospice reported that they had not been informed.⁴ Lack of communication with physicians may particularly hamper access, because physicians are the persons most likely to inform patients of the need for hospice care,⁵ and eligibility rules for MHB require difficult decisions from both physicians and family/patients.⁶⁻⁹

Hospice knowledge on the part of patients and family may affect not only hospice enrollment decisions but also hospice care after enrollment. Upon admission to hospice, a written plan of care must be established by the attending physician, the medical director, and the hospice interdisciplinary group.¹⁰ Knowledgeable patients and family members may be able to influence the plan of care, obtaining an appropriate mix of both core and noncore services. Furthermore, they may be better positioned to ensure that services are delivered in line with MHB standards. Finally, knowledge about hospice and medical services may increase the

ability of patients and family members to bring about changes in the setting where hospice care is delivered (eg, from private home to nursing home). The ability to obtain the most appropriate setting may have an impact on the quality of hospice care.

This qualitative study was designed to lay the groundwork for strategies to increase the level of hospice knowledge among minority elderly patients and families, particularly African Americans. There is a need for interventions targeting those least likely to use hospice care: noncancer patients, residents of nursing facilities, or patients lacking reliable care-givers at their homes.¹¹⁻¹⁴ We therefore limited our study participants to patients who had experience receiving care from formal caregivers, defined as staff members in nursing homes or assisted living facilities, adult day care center staff, or home care workers from an aging agency. Because they were placed in out-of-home facilities or resided at home with care from part-time or in-house aides, they may have experienced lack of “constant” family member caregivers. The 2 major tasks of our research were (1) assessing the level of hospice knowledge on the part of patients and/or family members; (2) investigating the decision process of hospice enrollment, range of services used, and transitions in the place of hospice care by patients'/ family members' level of knowledge.

Methods

Sample and Data Collection

This study recruited participants from an urban nonprofit, Medicare-certified hospice selected based on 3 characteristics. First, the hospice is large, with a daily census of more than 250. Because minority elderly populations account for less than 15% of MHB users,¹ it was important to have a large enough pool from which to recruit minority patients. Second, the program contracts with numerous facilities, making it relatively easy to recruit residents of nursing homes or assisted living facilities. Third, the provider has its own hospice inpatient facility, thus making it possible to recruit patients who used short-term inpatient care or inpatient respite care. By recruiting all participants from 1 hospice, we could exclude any potential hospice effect on the range of services received by our patients in this study.¹⁵

Study participants were interviewed between November 1, 2005 and June 30, 2006. The interviews were conducted face to face by research staff using a semistructured qualitative protocol with questions related to the following 5 domains: levels of hospice knowledge at time of hospice discussion, initiating the hospice discussion, readiness to forgo treatment, transfers, and requests for additional noncore services (see Table 1).

Twenty interviews were completed, including 1 patient-only interview, 10 family-only interviews, and 9 combined patient-family interviews. In the case of the patient-only interview, there was no family caregiver available to the patient. In the case of family-only interviews, the patients were either too cognitively impaired or too sick to complete the interview themselves. To be eligible for the study, all patients had to meet the following characteristics: (1) ethnic minority status, (2) age ≥ 65 years; (3) enrolled from a nursing homes or assisted living facility or receiving home hospice care but receiving personal care from paid caregivers including adult day care staff or part-time caregivers provided by a local aging agency.

Following the interview, we asked the clinical nurse director to extract basic demographic and clinical data from the patient's records, including birth date, referral source, initial diagnoses, admission date, and name/address of nursing home or assisted living facility if the patient was a resident of the facility at enrollment. Finally, approximately 2 months after the interview, we asked the clinical nurse director to collect discharge status (dead/alive in hospice or discharged alive) and length of stay as of the follow-up date.

This study was reviewed and approved by the Institutional Review Boards (IRBs) of both the participating hospice organization and the Governors State University.

Analysis

Using NVivo Version 2 (QSR International, Australia), interview transcripts were coded to identify distinct patterns of attributes related to each of the 5 interview domains. Specifically, a classification was developed regarding patients' or family members' level of knowledge about hospice before their hospice enrollment decision. Next, these “knowledge level” groups were compared across the other 4 domains—initiating hospice discussion, readiness to forgo treatment, transfers, and requests for additional noncore hospice service.

Results

Patient Characteristics

Demographic/clinical profiles of the study patients are presented in Table 2. The study patients averaged 84.6 years in age, with a standard deviation of 7.5. The majority of the subjects (N = 16) were African Americans. The majority of the patients (N = 12) were widowed. Dementia was the leading hospice diagnosis: 10 patients had dementia as a primary diagnosis and 8 patients had dementia as a secondary diagnosis. Nondementia-related primary diagnoses included cancer, chronic renal failure, and stroke.

Levels of Hospice Knowledge

A 3-level categorization appeared to best describe level of knowledge on the part of caregivers/patients before the hospice enrollment decision: (1) no/little knowledge (no knowledge group), (2) knowledge acquired by prior experience or education (some knowledge group), and (3) knowledge acquired by health care-related occupations (insider knowledge group). The highest level of hospice knowledge was found among 3 caregivers who reported their occupations as health related. They included a physical therapist at a hospital, a nurse working with elderly patient, and a hospice nurse. The second level of knowledge, found among 7 cases, came from prior direct/indirect experience or education. Direct experiences included family/patient hospice experiences such as “family members were hospice patients.” Indirect experiences included reports such as “a caregiver's best friend's mother had hospice care.” Some families with no prior experience reported that they were well educated and had a thorough knowledge of hospice. The lowest level of knowledge—no knowledge—was found among 10 cases where patients/caregivers knew nothing or very little about hospice until it was presented to them as an option.

Levels of Hospice Knowledge and Initiating Hospice Discussion

Only 2 distinguishable relationships between level of hospice knowledge and enrollment decision making emerged. The first pattern was observed among the Insider group—the 3 cases armed with knowledge acquired through health care-related jobs. The caregivers took the initiative and asked a physician for referral to hospice. For the remaining 17 cases, including both the “some knowledge” and “no knowledge” groups, health care providers (an attending physician and a doctor or nurse at a hospital or other facility) first mentioned hospice, and the patients accepted it by forgoing treatment. This is consistent with findings of previous studies that health care providers most often play the leading role in hospice referrals.^{5,16}

Levels of Hospice Knowledge and Readiness to Forgo Treatment

To be eligible for hospice care, the patient must waive all rights to Medicare A payments for any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected or a related condition. Patients in our study were determined to be

“likely to forgo” treatment if the interviewees (1) expressed goals for care that focused on comfort; and/or (2) their responses included sentences such as “life-prolonging care is no longer available,” “effective treatment options have been exhausted,” or “have been rejected” by the patient. In addition, hospice admission diagnosis was considered to assess the patients' readiness to forgo treatment. Traditional hospice patients have diseases with a relatively predictable time frame for death, such as cancer. However, some chronic diseases, particularly dementia, do not have a predictable time frame but are likely to impose high burdens of caregiving on family caregivers, increasing their willingness to forgo treatment.^{17,18}

We questioned why the 10 cases with the lowest level of knowledge (no/little prior knowledge or experience of hospice) accepted the recommendation to enroll in hospice. Examining their clinical profiles revealed that 6 had medical conditions unlikely to respond to medical treatment. Two of these suffered from renal failure and rejected dialysis, suggesting that their goal was suspension of curative treatment. Three others were in the last stage of cancers with a low survival rate (lung, pancreatic, and bone) and reported no success with previous treatments. The sixth patient was a long-stay nursing home resident in the last stage of dementia and debility; the patient had been tube fed before hospice enrollment and died soon after hospice enrollment.

The other 4 “no knowledge” hospice users did not fit this “likely to forgo” profile. All of them were male patients who had been discharged from hospitals to skilled nursing facilities for rehabilitation services following stroke. They appeared to view hospice as a means for obtaining extra rehabilitative help to become more functional rather than to ease the process of dying. One of them was later discharged alive from hospice care because his condition had improved; the other 3 had received hospice care for more than 6 months by the time of our follow-up.

Of the 7 patients in the some knowledge group, 5 suffered from dementia. One woman dying with dementia was discharged from a hospital to a nursing home facility where she developed bedsores. The primary caregiver, having had very positive experiences with hospices in the past, felt that hospice would provide extra care to help her sister be more comfortable. Another patient with Alzheimer's had lived at an assisted living facility for 10 years when she was hospitalized with pneumonia. Her daughter, who knew about hospice through the experience of her best friend's mother's, witnessed her mother's discomfort and followed the hospice option suggested by the hospital. One male patient with dementia was living alone at his own house with hospice services and Alzheimer's day services after his wife had died under hospice care. When interviewed, his daughter said, “It is a good thing that hospice and day care exists.” The caregivers of 2 other patients dying of dementia were aware of hospice from indirect hospice experiences. Finally, the remaining 2 patients in the “some knowledge group” had stomach cancer and thus fit the traditional hospice clinical profile, but persons with their diagnosis of stomach cancer generally have a longer prognosis than the kinds of cancer found among the no knowledge group.

Level of Hospice Knowledge and Transfers

To track changes in place of hospice care, the sample was first classified into 2 groups (home vs facility group) depending on whether the patient was at home or at a facility (nursing home or assisted living) at the time of the hospice enrollment decision. Current nursing facility residents were further categorized based on length of stay. Following a previous study,¹⁹ nursing facility stays of 90 days or less were considered short stays, and those over 90 days were considered long stays²⁰ (Table 3).

Some transfers occurred at the time of hospice enrollment to receive hospice care. Of the 7 short-term nursing home/assisted living facility residents, 2 moved from facilities to home and

received hospice care at home. Of the 9 patients who stayed at home at the time of hospice enrollment, 4 moved to facilities and received hospice care there. Of those 4 patients, 3 lived alone at the time that the enrollment decision was made, consistent with previous findings that living alone is a major determinant of nursing home placement.

In only 2 cases, transfers occurred while the patients were receiving hospice care. One “short-term” resident patient, who initially received hospice care in a nursing home, later moved back home; the other patient, who initially received home-based hospice care, moved to a nursing home. For both of these patients, the family caregivers were in the insider knowledge group—that is, their caregivers had health care-related occupations. The first patient had lived with her family before her short stay in a nursing home, where she first received hospice care. Her daughter worked for a hospice and took the initiative in obtaining hospice enrollment by talking to family and doctor. Later, she moved her mother back home, where the mother lived for 2 weeks, and then transferred her to the hospice inpatient facility where she died. The second patient, with dementia, received home-based hospice care and stayed at home with her aging husband; she then moved to a nursing home and continued to receive hospice care there. The primary caregiver, the patient's daughter, was a nurse working in a long-term care facility. She not only first mentioned the hospice option and spoke with her doctor but also made the decision to change the place of care to the nursing home.

Level of Hospice Knowledge and Request for Additional Services

Hospices are required to provide any noncore, discretionary services to patients for which a need is determined. These services can be outsourced at the hospice's discretion and may include continuous home care; occupational, intravenous, speech, and physical therapy; durable medical equipment and supplies; respite care; personal care; homemaker/household services, and other high-tech care.

Of the 3 caregivers in the highest level of knowledge group, 1 was a hospital-based physical therapist who knew about hospice and first mentioned hospice to the neurologist. The patient was a long-stay (more than 3 years) nursing home resident with a degenerative neurological brain condition when she enrolled in the hospice. The caregiver did not change the place of residence but made sure that the relative received therapies, including physical therapy, that the nursing home had not provided. The caregiver mentioned

Not enough people know about services. Many think that hospice is for ‘when you are dying tomorrow.’ Many don't know about other services that would make quality of life better, like therapies.

Discussion

This study explored how patients'/caregivers' level of knowledge affected the hospice enrollment decision and hospice care after enrollment for an ethnic minority elder population. The level of hospice knowledge varied considerably from no/little knowledge to insider knowledge among the elderly populations and their caregivers. Consistent with previous studies, half of the sample had no/little knowledge of hospice at the time of hospice enrollment decision. The remaining half of the sample had some knowledge or insider knowledge.

We questioned why the patients in the no knowledge group enrolled in hospice despite no or very little prior knowledge. Our ability to address this question was somewhat limited because our sample consisted of hospice users only. That is, all our study patients were already enrolled in hospice regardless of the level of hospice knowledge of caregivers/patients. Despite this limitation, however, we found differences in case-level characteristics that distinguished the no knowledge group from the some knowledge group. The majority of those with no prior

hospice knowledge fit the profile of the traditional hospice population: highly likely to forgo curative treatment and to die from conditions such as advanced cancer and end-stage kidney failure. Such patients reported that no treatment options were left and thus were likely to accept hospice recommendations even if they had no prior knowledge of hospice. In contrast, many of those with some prior hospice knowledge did not fit the profile of the typical hospice user; they had conditions with less clear prognosis and time until death. Without prior hospice knowledge through experience or education, they may not have opted for hospice. Thus, our findings suggest that hospice knowledge increases hospice access for those not likely to enroll at all. In addition, for some patients, it may enable enrolling early enough to benefit from comprehensive hospice care.

Two recent studies^{21,22} present a potentially promising strategy for increasing knowledge among minority group members who lack prior experience with hospice or whose education level limits their understanding of written information. According to the studies, underuse of hospice observed among minority elderly decedents may actually reflect inadequate comprehension of hospice information—mostly written material—among patients and family. Use of video images dramatically reduced the proportion of Latino patients who desired “aggressive” life-prolonging care from 41% before to 8% after the video.²¹ Similarly, for African Americans, health literacy and not race was an independent predictor of end-of-life preferences.²²

Whereas “some” knowledge appears important for access to hospice among nontraditional hospice users, the highest level of knowledge may be critical in deciding who will control the hospice care. Only the highest knowledge group, with knowledge of hospice acquired from related occupations, took the initiative in the enrollment process by requesting hospice referrals from their physicians. Furthermore, the knowledge of hospice acquired from related occupations enabled these caregivers to tailor care to their loved ones' needs through residential transfers and/or requests for therapies. Based on our study findings, therefore, an optimal knowledge-building strategy would help caregivers acquire the level of hospice knowledge found among family caregivers in health-related occupations. How to achieve this, however, remains a subject for further investigation.

Study limitations should be noted. These results from a single hospice's data and a small sample are suggestive and should not be considered generalizable to all Medicare hospice patients. There is a need for further research with larger samples to investigate the implications of our research.

Conclusion

Our qualitative study explored knowledge about hospice among patients and caregivers and the relationship of this knowledge to hospice access and care. This research adds to previous studies about hospice knowledge in 2 major ways. First, it focused exclusively on a subgroup likely to underuse hospice—patients of minority ethnic status, particularly African Americans, who experience personal care from formal caregivers (ie, paid workers). Second, whereas previous research has addressed the relationship between knowledge and access to hospice, we went a step further, investigating the role of hospice knowledge in influencing care after hospice enrollment. By differentiating the levels of hospice knowledge, we were able to find that the highest level of caregiver knowledge, acquired by insiders in the long-term health care industry, can influence the type of hospice services and the place of hospice care.

Although our findings do not establish a direct link between hospice knowledge and quality of care, we speculate that a high level of knowledge can empower family members to improve

the hospice care that their loved ones receive. We hope that our research is an impetus for further studies on the role of hospice knowledge beyond the initial enrollment decision.

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Table 1

Interview Domains and Questions

Domain	Interview Questions
Levels of hospice knowledge at the time of hospice discussion	<ul style="list-style-type: none"> • Who first recommended hospice option? • Why did you decide to enter the hospice program? • Who helped you make this decision? • Who gave you information about hospice care? • How long (in days) did it take you to decide to enter hospice program after it was recommended?
Initiating hospice discussion	<ul style="list-style-type: none"> • Who first recommended hospice option? • Who made hospice decision?
Readiness to forgo treatment	<ul style="list-style-type: none"> • Why did you decide to enter the hospice program? • Do you think that your enrollment in hospice was (a) at the right time? (b) too soon? (c) should have been earlier? • (Referring to the question above) why do you think so? • What did you expect the hospice program to do for you? • How do you feel about the decision now?
Transfers	<ul style="list-style-type: none"> • Where were you (or patient) located at the time of decision to enter hospice? • How long (in weeks) have you (or patient) been in this nursing home (or assisted living)? • What was the reason for entering this nursing home or assisted living? • Where were you (or patient) located immediately before coming to this nursing home (or assisted living)? • Did anyone live with you 6 months before you were diagnosed with this illness? • How nearby is your closest family member/friend? • How nearby is another close family member/friend?
Request for additional noncore services	<ul style="list-style-type: none"> • What kinds of practical support and assistance did you expect from hospice? • What kinds of service providers did hospice offer?

Table 2

Characteristics of the Study Patients

Characteristics	Value
Age of patient, mean	84.6 (standard deviation of 7.5)
Gender of patient	13 female; 7 male
Patient ethnicity	3 Hispanic; 1 American Indian; 16 African Americans
Marital status	4 single/divorced/separated; 4 married; 12 widowed
Relationship to patient of caregiver interviewees	3 husband/wife; 3 son; 9 daughter/grand daughter; 2 sister; 1 cousin; 1 niece; 1 self
Patient diagnosis (primary)	10 dementia, 4 cancer, 2 chronic renal failure, and 4 stroke
Follow-up status	4 died at the follow up; 15 alive at hospice, and 1 discharged alive
Place of residence at the time of hospice enrollment decision	11 nursing facilities; 9 in private residence

