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Perceptions About Hospice From a Community-Based Pilot Study: Lessons and Findings

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Abstract

Research investigating the knowledge and attitudes of diverse older adults about hospice care and end-of-life issues is needed to expand service utilization. This pilot study explored an urban area's perceptions and awareness of hospice through local churches. The sample consisted of 148 adults age 43 and older. Although recruitment efforts resulted in a relatively homogenous sample, findings suggest a lack of knowledge about whether hospice is covered by Medicare, Medicaid, or private insurance. Perceptions of the expense of hospice, however, were not associated with knowledge of coverage. Respondents generally agreed that hospice is important and would recommend its services for their family members.

Keywords

hospice; palliative care; information; education; attitudes; baby-boomers; racial/ethnic disparities

Introduction

Hospice has been touted by some as the “gold standard” for palliative care at the end of life.^{1,2} Its holistic, person-centered approach, interdisciplinary involvement, and focus on pain and symptom management are often considered preferable to other care alternatives such as curative treatments (eg, radiation, chemotherapy, surgery) or artificial life-support.^{3–5} However, more than 40% of individuals who are eligible for hospice care actually receive it,⁶ and, after receiving a life-limiting prognosis, disproportionately lower numbers of qualifying African Americans, Asians, and Hispanics enroll in hospice.^{7,8} Public misconceptions and lack of information about hospice are considered important reasons why many patients and families forego these services.^{9–11}

Reprints and permission: sagepub.com/journalsPermissions.nav**Corresponding Author:** Daniel Van Dussen, Department of Sociology, Anthropology, and Gerontology, Youngstown State University, 440 DeBartolo Hall, One University Plaza, Youngstown, OH 44555, USA, djvandussen@ysu.edu.**Declaration of Conflicting Interests**

The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.

Studies suggest that improving public awareness of hospice and its services can improve access to care and help minimize disparities in end-of-life care.^{12–14} Little is known about what community members know about specific hospice benefits and services, and where they are getting their information. This study used a community-based survey of diverse middle-aged and older adults in northeast Ohio to explore: (1) how knowledgeable community members are about hospice services; (2) attitudes about hospice services; (3) where respondents were getting their information; and (4) differences in hospice-related knowledge and attitudes between those in the baby-boomer cohort relative to older cohorts. The goal of this project was to inform the outreach efforts of local hospice organizations, improve access to these services, and provide pilot data for a larger, more definitive study. Thus, our survey methods targeted historically underserved older adults, including persons of lower socioeconomic status and racial/ethnic minorities. The recruitment efforts of this study were met with limited success and, thus, we also provide an account of the lessons we learned as a result of our experience.

Background

According to the National Hospice and Palliative Care Organization (NHPCO),¹⁵ American hospices provided care to nearly 1.5 million patients in 2008. Despite the wide-spread proliferation of hospice programs, many people who qualify for hospices do not receive its services.¹⁵ Furthermore, for patients who do enroll in hospice care, 35% die within 7 days of admission.¹⁵ These persons and their families often do not receive optimal care because hospice services take at least 30 days to reach maximum benefit.^{16,17} While some individuals delay or forego hospice care to pursue alternate treatments options (eg, chemotherapy or surgery), others may not be fully informed about hospice and its scope of services. This lack of knowledge is hypothesized to be a barrier to hospice care and a potential source of disparities in care at the end of life for racial/ethnic minorities, rural populations, older adults, and the poor.^{9,12–14} However, few studies have investigated knowledge, perceptions, and attitudes about hospice among samples of community-dwelling older adults. This study contributes to the knowledge base by exploring these topics.

Methods

We used a referral-based sampling strategy to conduct a community-based pilot study about the attitudes, perceptions, and knowledge about hospice. The survey was designed to collect preliminary data from a diverse sample of older adults in eastern Ohio, including the counties of Mahoning, Trumbull, and Columbiana. Additionally, the design and procedures used for this project are being used to inform a larger more definitive study on this topic.

Instrument Development

Prior to distribution of the surveys, members of the research team conducted a focus group at Hospice of the Valley's (HOV) Hospice House. Participants included staff members of HOV and HOV volunteers who met the age criteria of 43 years or older to capture the attitudes of the Baby Boomers at the time of data collection. The purpose of this meeting was to approximate the length of time to complete the survey (which was less than 10 minutes), gather feedback for the survey design, such as ease of completion and

understandability of the questions. The survey instrument included general demographic questions regarding gender, age, relationship status, zip code, household income, and race/ethnicity. The main body of the survey used Likert style response options (scale 0–3 with higher scores indicating greater levels of disagreement), close-ended (yes/no) questions, and true/false/don't know statements.

The yes/no questions primarily focused on participants' experiences with, and discussions about, hospice. Respondents were also asked to agree/disagree with statements such as: "I would use Hospice care." "Hospice care is expensive." "Use of Hospice is seen as giving up." The true/false statements were designed to test participants' knowledge, for example to examine whether they were aware that Medicaid and Medicare cover hospice care (Note: the Ohio Medicaid Hospice Benefit provides coverage for hospice services. As of 2008 hospice care was not being covered by Medicaid programs in only 3 states, Connecticut, New Hampshire, and Oklahoma¹⁸). The option of "don't know" was also presented on these questions to avoid nonresponse on specific items. Finally, we assessed whether respondents had private health insurance and whether their insurance covered hospice care.

Sampling Approach

Previous hospice researchers have identified community churches as essential access points to reach underserved populations for study involvement.^{19–21} Following this approach, our research staff compiled a sampling frame of religious congregations within the target counties using a list of tax exempt, not-for-profit organizations provided by Hospice of the Valley. Initially 450 churches were identified and 68 churches were randomly selected for this project. Church leaders were initially contacted by telephone by a member of the research team, informed about the nature of the study, and asked if they would be willing to either: (1) refer eligible persons to participate in the study; or (2) advertise the study to their parishioners. After three unanswered attempts to contact a church by telephone, no further contact was attempted. Out of the original 68 identified churches, 3 refused to participate, 2 did not meet the eligibility criteria, 2 were wrong numbers, 51 did not respond to our 3 attempts to make contact, and 8 agreed to assist with study recruitment (recruitment challenges are addressed in the limitations sections). From these 8 referral sources, a total of 168 participants were recruited to complete the survey. Participants reported being affiliated with following denominations: Baptist (n = 23), Catholic (n = 43), United Methodist (n = 54), and other Christian denominations (n = 22). Study procedures were approved by Youngstown State University's Institutional Review Board before data collection began.

Analysis

Frequencies, descriptive statistics, and bivariate analyses were used to describe the sample. Income was broken down into 10 categories by increments of \$10 000 with a ceiling of "\$100 000 or more." Age was coded as 43 to 59, 60 to 69, 70 to 79, 80-up, with the youngest group representing the Baby Boomer cohort. Based on these groupings, the variables *income* and *age* were treated as ordinal level variables. Nonparametric tests were used to test for associations with categorical and ordinal variables. Inferential statistics were

used to identify group differences on continuous variables. For identified group differences, a standard alpha level was set at .05.

Missing data were resolved using list-wise deletion. Items with the largest amount of missing data were: *hospice care is expensive* ($n = 30, 20.3\%$), *insurance covers hospice* ($n = 22, 14.9\%$), and *income* ($n = 21, 14.4\%$). In reference to the former 2 items, respondents were presented with only a yes or no response option. Because these items presume that responders have preformed beliefs about expense and/or coverage, we hypothesize that including a “don’t know” response option would likely have reduced the proportion of missing.

Results

The sample was 44.2% men and 55.8% women (Table 1). Respondents were more likely to be married (59.6%) and white (81.3%). Approximately half (50.7%) of the respondents were between the ages of 50 and 69. The percentage of black respondents (18.1%) was higher than that of overall populations of Mahoning county (15.3%), Trumbull county (8.2%), or Columbiana County (2.3%).²²⁻²⁴

Associations with Age

In general, older respondents were more likely to be familiar with hospice than their younger counterparts (Mann-Whitney $U = 623, P = .001$) although age was not associated with knowledge that Medicare covers hospice. Respondent’s age was also not associated with having had a family member in hospice. Age was, however, found to be linked to marital status, with older cohorts more likely to be widowed and younger cohorts more likely to be single ($P < .001$). Furthermore, younger cohorts reported higher household income (Spearman’s rho = $-.45, P < .001$).

Overall, respondents had favorable opinions about hospice but older respondents tended to have more negative impressions about hospice than younger respondents. For example, older cohorts were more likely to see it as “giving up” (Spearman’s rho = $-.17, P = .033$). Age was also related to the perceived value of hospice (Spearman’s rho = $.18, P = .043$) with younger cohorts more likely to consider hospice a valuable service. Furthermore, age was negatively associated with the belief that hospice is “only about death” (Spearman’s rho = $-.18, P = .04$). Thus, older respondents were more likely to view it in such a restrictive manner. A negative relationship was also identified between respondent’s age and his or her willingness to discuss hospice with a spiritual leader (Spearman’s rho = $-.22, P = .017$). Older cohorts were more willing to initiate a conversation about it with their spiritual leader/clergy than younger cohorts.

Race/Ethnicity

Reflective of regional demographics, our sample was almost exclusively black and white, with whites making up a majority (81%) of respondents. We tested for racial differences on attitudes, beliefs, and knowledge about hospice services. Results indicated that a respondent’s willingness to use hospice (eg, “I would use hospice”) did not differ based on race. Additionally, race was not related to perceptions about the importance of hospice.

However, black respondents were more likely to view hospice as “giving up” than white respondents ($P = .013$). An examination of the association between perceptions of expense and race were found to be only marginally significant ($P = .076$). There were no differences in income level between blacks and whites. Race was also not related to one’s willingness to start a conversation with their doctor or a spiritual leader. In these cases, findings of nonsignificance should be interpreted with caution as they may be the result of the small sample size and insufficient statistical power.

Income

According to the Census Bureau, in 2007 the median household income for each of the counties from which the sample was drawn is as follows: Columbiana County \$39 580, Mahoning County \$39 141, and Trumbull County \$41 829.^{22–24} Our sample was reflective of the larger population, with the median income ranging from \$30 000 to \$39 999, suggesting that our attempt to recruit economically vulnerable participants was not successful.

The majority of the respondents (86%) reported familiarity with hospice care, leaving 14% who were unfamiliar with hospice services. The next set of analyses examined where respondents were getting their information about hospice. Questions dealt with the respondents’ exposure to sources of information about hospice (Table 2).

Attitudes Toward Hospice Care

Attitudes toward hospice care were generally favorable. Respondents’ generally agreed with the statement “I think hospice care is important” (Table 3) and “I would recommend hospice care to a family member” (78.4% strongly agree).

Attitudes toward the statement “Hospice care is seen as giving up” had a 48.1% strongly disagree and 19.8% mildly disagreement among our respondents. This indicates that, while 13.8% strongly agreed and 19.1% mildly agreed, the majority of the sample did not agree that hospice is giving up.

We also asked about the agreement with the statement “Hospice care is only about death” to determine whether respondents understood the variety of services offered by hospice. The distribution on this variable indicated that a 15.9% of respondents strongly agreed and 22.7% mildly agreed with this statement vs 22.0% mildly disagreeing and 39.4% strongly disagreeing with this statement.

We also asked questions about the perceived cost of hospice care and the respondent’s knowledge about whether hospice is covered by Medicare, Medicaid, or private insurance (if applicable; Table 4). Respondents generally did not think hospice care was expensive, as only 31.3% of the respondents reported agreement with the statement, while 68.6% expressed disagreement with the statement.

The majority of respondents (75%) were uncertain about whether hospice services were covered by Medicare and only 3% ($n = 4$) indicated that they did not believe that Medicare covered hospice at all. However, those who had received information from hospice were

more likely to know that hospice services are covered by Medicare ($\chi^2 = 5.079$, $df = 1$, $P = .024$). Similarly, those who had received information about hospice from their doctor were more likely to know that hospice was covered by Medicare ($\chi^2 = 4.461$, $df = 1$, $P = .035$). This was nonsignificant for other information sources such as television or radio advertisements. Information source was not associated with viewing hospice as “giving up,” including those who had had a family member in hospice ($P = .11$). Perceptions of the expense of hospice was not associated with knowledge of coverage. A prior family history of hospice use was associated with perceptions about the cost of hospice ($P = .033$). Those whose family members had experience with hospice were less likely to perceive hospice as expensive.

Lessons Learned

The goals of this study were somewhat met, but our ability to recruit a truly diverse sample of respondents was limited by a number of factors. We believe that our methods would have been improved by: (1) soliciting the support, buy-in, and input from stakeholder organizations prior to recruitment; (2) additional rapport-building with gatekeepers, ie, clergy members, including face-to-face meetings, and garnering preliminary approvals before initiating the study; (3) increasing researcher controls over data collection; (4) and addressing skepticism about the intent of the research by better informing potential participants of its purpose and human subject protections. Among the churches solicited to participate in this project, reasons for refusal included the following: the church did not feel they were able to accommodate us, or they felt they were a small congregation with limited knowledge of hospice. The churches that provided reasons for participation refusal were from populations this study intended to investigate.

Discussion

Based on our results, our sampling strategy was moderately successful at recruiting the target demographic and eliciting completed questionnaires. The resulting sample had a higher proportion of black respondents and near equivalent income levels relative to census data from the counties from which we recruited. There were several noteworthy barriers to using this sampling approach, which will inform the design of a larger study and may be of interest to researchers conducting research with similar populations. One barrier was gaining access to church members in the target population, which may be attributed to traditional barriers in reaching underrepresented populations. Another limitation to data collection was the lack of close contacts within the urban churches. In response to this survey, Hospice of the Valley hired a full-time outreach person to improve connections with the African American community in the tri-county area. Anecdotal accounts suggest that the coordinator has successfully increased the utilization of Hospice services by African Americans through outreach programs that target African American churches and community groups. In the future, it may be easier to conduct similar research with increased response rates due to the outreach coordinator’s efforts. The outreach coordinator’s role was to work with the local African American community through churches, community centers, and health care providers. She began her job near the conclusion of this study, and since then the proportion

of African Americans in the local hospice care has increased each year. Her efforts include discussions of hospice services with church members, clergy groups, and individual clergy.

Our findings suggest that Baby Boomers (ages 43–59 in our study) may have more favorable beliefs and attitudes about hospice than older cohorts. This positive view of hospice, however, may be due to a lack of experience with hospice. In other words, Boomers may have a more idealized view of what hospice is and does; a view which may change after witnessing the realities of hospice care and the challenges associated with providing support to those at life's end. On the other hand, if these optimistic perceptions about hospice persist as Boomers age, they may be more inclined to utilize hospice care which would have future implications for service growth, staffing levels, and insurance coverage.

When faced with a life-threatening illness, patients and families often report a desire to be proactive and “do something.” Further research should explore the meaning and implications of viewing hospice as “giving up.” For example, did respondents in our study interpret this to mean giving up hope for a cure? Or as resignation to an impending death? This impression that hospice signifies “giving up” may not be deserved. Hospice staff members work hard, and proactively, to provide high-quality symptom management and psychosocial support. In addition, some evidence suggests that hospice enrollment may actually improve patient life expectancy.²⁵ This may also indicate a need to better educate the public about hospice services, particularly among African Americans and the older-old.

Limitations

The study sample was a relatively small convenience sample recruited from 8 area churches. The sample was also limited to only 3 counties within eastern Ohio. Time and budgetary constraints also contributed to the small sample size and the need to use a referral-based sampling strategy. There was also a high refusal rate among churches, which may have left us with a sample of respondents who were highly knowledgeable about hospice care due to selection bias. Finally and despite testing the survey on a group of volunteers, it is possible that respondents interpreted our questions differently than intended. For example, it is possible that respondents may have interpreted the question regarding “giving up” as whether they thought *other people* viewed hospice care as “giving up,” rather than an expression of their own opinion.

Directions for Future Research

Future research should examine knowledge and attitudes toward hospice care among a larger, more geographically and ethnically diverse population including a greater representation of persons of Hispanic origin and other ethnic minorities. Future research should also examine methods to increase participation rates among clergy serving as gate-keepers to medically underserved populations of older adults. Examples of strategies to examine are the hiring of outreach coordinators for underserved populations and the relative effectiveness of various outreach methods. Enhanced recruitment methods can then be utilized to better understand knowledge and attitudes among African Americans and other underserved populations.

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Table 1

Demographic Characteristics, N = 148

Gender	Percentage
Female	55.8
Male	44.2
Race	
White	81.3
African American or Black	18.1
Hispanic	0.4
Marital status	
Married	59.2
Widowed	16.3
Divorced	14.3
Single	9.5
Other	0.7
Age	
43–59	46.0
60–69	27.3
70–79	17.3
80+	9.4

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Table 2

Information Source

I Have Seen an Advertisement for Hospice on TV	Percentage
Yes	86
No	9.8
I have listened to a radio advertisement for hospice	
Yes	57
No	43
I have received information on hospice care from hospice	
Yes	40.7
No	59.3
I have received information on hospice from a physician	
Yes	28.3
No	71.7

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Table 3

Attitudes and Perceptions about Hospice Care

I Think Hospice Care is Important	Percentage
Strongly agree	79.7
Mildly agree	15.8
Mildly disagree	1.5
Strongly disagree	3.0
I would recommend hospice care to a family member	
Strongly agree	79.4
Mildly agree	14.5
Mildly disagree	3.1
Strongly disagree	3.1
Hospice care is seen as "giving up"	
Strongly agree	13.0
Mildly agree	19.1
Mildly disagree	19.8
Strongly disagree	48.1
Hospice care is "only about death"	
Strongly agree	15.9
Mildly agree	22.7
Mildly disagree	22.0
Strongly disagree	39.4

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Table 4

Cost and Insurance Knowledge of Hospice Care

Hospice Care is Expensive	Percentage
Strongly agree	14.4
Mildly agree	16.9
Mildly disagree	28.8
Strongly disagree	39.8
Medicare covers hospice care	
True	22.1
False	3.1
Don't Know	74.8
Medicaid covers hospice care	
True	13.1
False	6.2
Don't know	80.8
Does your insurance cover hospice care ^a	
Yes	13.5
No	1.6
Don't know	84.9

^aOnly asked of those with private insurance.

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