

Hospice staff members' views on conducting end-of-life research

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ABSTRACT

Objective: Hospice staff members have concerns about the appropriateness of enrolling terminally ill people in research studies. These concerns can have profound implications for the advancement of palliative and hospice care as they can impede the empirical investigation of interventions for improving the quality of life of patients with advanced disease. This survey study was designed to examine hospice staff attitudes, beliefs, and values about research with their patients and family members.

Methods: This study utilized a cross-sectional, anonymous survey design to measure hospice staff members' beliefs, attitudes, and values. The survey contained questions derived by hospice and palliative care experts from their experience and review of the literature. It was handed out at staff meetings and returned via mail. The survey contained 14 questions and was able to be completed in less than 5 min.

Results: A total of 225 participants (56.25% response rate) completed the survey and were included in the data analysis. Hospice staff members were largely supportive about the idea of conducting research with patients and family members (mean agreement of 4.08–4.44 on several perception items about research on a 1–5 scale). They also acknowledged a mixture of being protective of controlling access to patients (52% wanted to be the ones to approach patients) and not having enough time for research (59% either had no time or would be willing to spend no more than 10 min on research).

Significance of results: Although many of the opinions derived from the survey appear to indicate a willingness to embrace research in a hospice setting, significant barriers, especially time constraints and protective attitudes, remain. Educational efforts and firsthand involvement in the research process might be a useful first step in attempting to address these barriers and traditionally held beliefs against using hospice patients and families in research.

KEYWORDS: Hospice, Staff perceptions, Research

INTRODUCTION

Bruera (1994) describes the history of palliative care and hospice programs, which began outside

mainstream medicine in the 1960s in the United Kingdom before expanding into Europe and North America in the 1970s and 1980s. The emphasis of the palliative and hospice literature has traditionally been on direct patient and family care, providing a counterpoint to overly scientific and technological aspects of medicine including research. However, research has recently begun to receive more attention. Bruera (1994) states that

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these patients usually experience “devastating physical and psychosocial symptoms” and that families often suffer from “severe psychosocial distress” (p. 7). He also cites studies indicating that “80% of patients develop severe cognitive failure before death,” (p. 8), begging the question as to whether informed consent can be given by these patients. For informed consent to be possible, Dunn and Chadwick (2001) explain that the participant must adequately comprehend the information and participate voluntarily, without any coercion or undue influence. Provider sensitivity to informed consent among the terminally ill appears to be very great and may greatly influence whether hospice staff would support the idea of research with patients and family members.

In addition, de Raeve (1994) cites terminally ill patients’ vulnerability, dependency, and compromised autonomy and makes the case that no research can be justified with dying people. Kristjanson et al. (1994) also found reason for caution after examining 55 empirical studies involving palliative care patients published between 1986 and 1993. Although supporting the need for research and the rights of individuals to participate, Kristjanson et al. expressed concerns about the possibility that unethical research is being done, especially considering the vulnerability of this population as well as the difficulty of obtaining truly informed consent.

Mount et al. (1995) take strong exception to de Raeve’s statements, finding the stand that the terminally ill should not be asked/allowed to participate in research “paternalistic, devaluing and disrespectful” of the patients (p. 165). Arguing that palliative care research is not simply curiosity-based experimentation, they make a strong case for the critical role of research in developing proven therapies that can provide relief from pain and the many other symptoms with which palliative care patients suffer greatly (Mount et al., 1995). Other researchers, too, have noted the inadequacy of research on the many complexities associated with pain management in various clinical populations. Vega-Stromberg et al. (2002) cite data indicating that “pain of all types in all age groups is under treated despite the existence of effective . . . treatments” (p. 15). In addition, the question about participation in research can be considered another area where there is little research about the role of choice among the terminally ill (Drought & Koenig, 2002). There is a great need for research to better understand the issues surrounding decision making by patients, family members, and health care providers at the end of life. However, the decisions about participation in nonintrusive, noninvasive

medical research is less complicated than the end-of-life decisions about organ donation or cessation of life-sustaining interventions (Truog, 2003).

Hermann and Looney (2001) state that although “the hospice movement throughout the years has emphasized the importance of symptom control” (p. 88), research has lagged behind and “information related to the effectiveness of interventions is currently lacking in the literature” (p. 89). Jubb (2002) finds that there is no justification for not going forward with improved research in palliative care. The literature includes passionate as well as contradictory perspectives on research with hospice and terminally ill patients. Given the ambivalence in the literature, there is concern that these unresolved beliefs affect participation in research projects and the ability of science to evaluate or develop clinical practices for the terminally ill.

The future of palliative medicine and hospice research is affected by uncertainty about the appropriateness of enrolling terminally ill patients in research studies. Institutional Review Boards (IRBs) are mandated by Federal law to protect research participants. Some IRB committees have raised questions about the appropriateness and safety of involving seriously ill individuals in research protocols that involve palliative or other medical intervention surveys, interviews, and even questionnaires as well as higher risk studies of medical treatments. As noted by Casarett and Karlawish, (2000) some IRB committees have suggested that these patients should never be asked to participate in research, or if they are, only with a very restrictive set of safeguards. More often IRBs, clinicians, and researchers themselves are uncomfortable with potentially vulnerable patients, yet have no evidence to either support or refute the source of the discomfort. Information on the source of these concerns is mainly developed from experts in research ethics, but, ironically, is not grounded by any research or even qualitative information. The inevitable result of this approach is that information about the needs and treatment responses of the terminally ill is exclusively filtered through expert opinion or care providers who may have vested interests in sustaining current practices. On the other hand, many palliative care researchers think that the opportunity to participate in research protocols can be a positive and meaningful experience for patients (Janssens & Gordijn, 2000; Addington-Hall, 2002; Hudson, 2003). Based on feelings voiced to them by those patients who have been involved in studies, the chance to meaningfully contribute to the care of others meets deep-seated needs for generativity and altruism for some patients. This perspective suggests that instead of research being an unwanted

intrusion into patients' lives it might be a way for patients to contribute to others and to see some meaning in their suffering.

Hospice care patients offer unique challenges to health care professionals due to the advanced nature of their illnesses and the interplay of physical, psychological, social, and spiritual problems. Care providers often have concern about protecting patients and their family members from what may be perceived as "intrusive" research activities (Ross & Cornbleet, 2003). These concerns, which have been raised by IRBs as well as practitioners, researchers, and ethicists, appear to center around the vulnerability of dying patients and difficulty in determining the patient's competency to give informed consent, as well as ethical concerns for practitioners in dual roles. However, concerns about patients' competence to give truly informed consent to treatment have been addressed by showing that special algorithms or multimedia approaches for assessing competence and comprehension among those with cognitive difficulties can allay worry about an individual patient's capacity to give informed consent (Grisso & Applebaum, 1995; Daugherty et al., 1997; Wirshing et al., 1998; Berg et al., 2001). And, conversely, there is reason to worry about overly rigid and literal interpretations of consent processes that could impede any advance of medical science (Pellegrino, 1998).

In fact, there is considerable concern regarding the consequences of *not* doing research, which results in a serious lack of evidence-based interventions, which to some, is a patient right (Thyer & Myers, 1998). To date, little investigation has been done to assess the attitudes of hospice health care professionals regarding their willingness to participate in research. The purpose of this pilot study is to assess the attitudes and beliefs about research with hospice patients and their family members.

As a step toward developing research in hospice and palliative care settings, this project was designed to explore the prevalence of positive and negative beliefs about research among hospice providers. Although a recent study attempted to undertake a similar tact (Ross & Cornbleet, 2003), the researchers focused only on inpatient care and sampled a mix of both patients and providers. However, this study's findings were limited by a very small number of nurses ($n = 13$) as the provider sample. Physicians, social workers, and other bereavement staff were not included in the study. The overall goal of this study was to survey a large number of provider staff across multiple disciplines to better understand hospice staff attitudes, beliefs, and values about research with hospice patients and family members. The specific objectives were to survey

staff beliefs, attitudes, and values about research at Hospice of the Bluegrass, located in Lexington, Kentucky, and to examine differences in those issues among different professions and clinical and non-clinical staff.

METHODS

Participants

Hospice of the Bluegrass has over 400 staff in 23 counties in central, northern, and eastern Kentucky with eight different offices or treatment sites. The staff members include a mix of nurses, certified nursing assistants, social workers, chaplains, bereavement counselors, physicians, and administrative and clerical staff. Four hundred members of the Hospice of the Bluegrass were approached with the opportunity to fill out the anonymous survey in this IRB-approved study.

Instruments

Hospice Survey

The survey is a 14-item instrument that asks key questions about providers' thoughts about research (see the Appendix). This included areas such as informed consent, decision making about participation, and the perceived benefits and risks of participation in research. The survey included a cover page with a script that introduced the study.

Procedure

This study utilized a cross-sectional survey design to measure hospice staff members' beliefs, attitudes, and values using an anonymous survey instrument. The survey contains questions derived from the literature including literature on informed consent by hospice patients and the terminally ill. The survey contains 14 questions and staff were able to complete it in less than 5 min.

Staff members who attended team meetings were invited to participate in the survey during the meeting or immediately following the conclusion of the meeting. The survey was anonymous and included no identifying information. Staff members who did not wish to participate were under no pressure to respond to the survey. Staff members who did not attend the staff meetings (such as those on leave) had an opportunity to respond to the survey. Additional copies of the survey were left at each hospice office for distribution to office mailboxes of staff who were not at the meeting. Self-addressed envelopes were attached to each instrument so that staff

members could seal the survey and mail it to the researchers.

After completing the survey, participants were instructed to fold the survey and place it in the addressed envelope and seal it. The sealed envelopes were collected and mailed to the research team at the University. Supervisory staff did not see unsealed and completed instruments. Data were entered by University staff into SPSS for analysis purposes.

The limited geographic data that were collected were not cross-referenced with individual interviews to protect confidentiality and anonymity. Participants completed the survey either at their work location or by taking the form home and returning it by mail. The locations for distribution of the survey were the offices of the Hospice of the Bluegrass located throughout central, northern, and eastern Kentucky.

RESULTS

A total of 225 employees (56.25% return rate) completed the survey and returned it for inclusion in this study. The respondents had an average of 4.7 years of hospice-related service ($SD = 4.0$, range = 1 month to 20 years). The most common hospice roles occupied by the respondents were nurse or certified nursing assistant ($n = 67$, 30%), nonclinical staff ($n = 62$, 28%), social work ($n = 40$, 18%), home care aide ($n = 34$, 15%), bereavement counselor ($n = 11$, 5%), and chaplain ($n = 9$, 4%).

The first seven items of the survey asked respondents to rate their views toward research on a 1–5 scale, with 1 representing *strongly disagree* and 5 representing *strongly agree*. The items covered the perceived importance of conducting research with family members, surveys of staff members, offering patients the chance to participate in research, offering patients specific drug trials, offering psychosocial treatment trials, and research on family members to evaluate the effectiveness of new services and programs. There was a strong agreement for all the items. Means ranged from 4.08 to 4.44 (SD ranges = 0.88–1.07), indicating agreement or strong agreement to the importance of research in the aforementioned areas.

Along these same lines, one of the later items asked respondents “In general, my view of research with hospice patients is positive if patients are free from coercion to participate,” utilizing the same 1–5 scale. A total of 86% of the respondents agreed or strongly agreed to this statement, with an additional 7% answering in the neutral position. Only 5% disagreed or strongly disagreed with the statement.

It was also of interest to determine attitudes about who might be the most appropriate contact person to approach hospice patients about research. The majority ($n = 117$, 52%) felt that the hospice clinician should approach the patients, whereas 37% ($n = 87$) felt that it should be done by the researcher. A minority ($n = 22$, 10%) felt that the caregiver should be the one to present the research. Given this strong desire to have hospice staff act as gatekeepers for research, it was important to note how much time staff felt they could devote to research. Twenty-five percent ($n = 56$) reported that they had no additional time for research, and an additional 34% ($n = 77$) reported they could spend up to 10 min on research activity with a patient. Few reported that they could spend 20 min ($n = 16$, 7%), 30 min ($n = 11$, 5%), or more ($n = 2$, 0.9%) on research. Thus, there is interest and a desire to control access, but little perceived time for engaging in research activity.

Respondents were also asked to rank perceived barriers to conducting hospice research. The number one perceived barrier to conducting research was reported as research being “too intrusive to privacy” ($n = 110$, 49%), followed closely by a sense that it “takes too much time” ($n = 108$, 48%). The next tier of perceived barriers included fears that research “interferes with patient care” ($n = 53$, 24%), that “staff are not consulted” ($n = 46$, 20%), and that “patients can not give informed consent” ($n = 36$, 16%). Finally, although infrequent, some felt that “hospice does not gain anything from research” ($n = 5$, 2%) and that “research is not that important” ($n = 3$, 1%). To counteract perceived barriers, respondents also listed factors that could increase staff participation in research activities as well as identifying what research topics were of most importance and interest. The top five findings of each query are listed in Table 1.

As a final quantitative analysis, it was of interest to determine if the profession of the respondent or the time spent working for hospice had an impact on the survey items and overall attitude toward research. To this end, a series of correlations were conducted. However, neither profession nor length of time in employment by hospice was found to be significantly related to any of the items covering the perceived importance of research.

Qualitative Data

We included open-ended questions on the survey tool for gathering qualitative data. Specifically, the last item was an open-ended call for any other pertinent comments that respondents might want

Table 1. Top five factors to increase research participation and the top five topics of interest

Item	N	%
Top five factors to increase staff participation in research		
1. Research aims to improve care for patients and family members	184	82%
2. Being assured that privacy will be protected	142	63%
3. Being assured that research is not too time-consuming	131	58%
4. Having input into topic areas	87	39%
5. More time allowed for patient visits	70	31%
Top five research topics of importance to staff		
1. Trials that help families that have caregiver stress	166	74%
2. Trials about medical pain management approaches	133	59%
3. Trials about anticipatory grief among patients and family members	131	58%
4. Trials about patient views of hospice staff and services	128	57%
5. Trials about patients' responses to medication	126	56%

to share. Highlights of these comments are listed in Table 2.

DISCUSSION

This survey provides an opportunity to revisit some of the issues that affect how research will be done with hospice patients and the terminally ill. Barriers to research with medically fragile populations have generally included negative beliefs by the provider professions about doing research with hospice patients. However, this study suggests that there are important factors that can influence acceptance of research in hospice programs.

There are several limitations to this study. There are methodological issues to be addressed when conducting surveys. For instance, it is generally known that those individuals who choose not to respond to surveys are different than those who choose to participate (Groves, 1989; Groves & Couper, 1998). Therefore, there is certainly some degree of nonresponder bias evident in these findings. However, although a response rate closer to 100% in this survey would have improved its generalizability, the return rate was viable for analyses and may have at least cautious generalizability. For instance, Clark et al. (2001) found survey response rates from medical professionals to be between 22

Table 2. Positive and negative quotes about conducting research with hospice patients, family members, and staff

Positive survey quotes
1. "My main concern is that no one is burdened by research being done. If approached with sensitivity, patients and families could feel like they were contributing to a greater good for humanity, thereby making their lives and experiences have more significance."
2. "I am an advocate for research. If we do not understand whether our interventions work or not, how can we improve our quality of care?"
3. "Hospice patients, families, and caregivers (as well as hospice staff) have a wealth of information that could lead to better end of life care. Asking pertinent questions, collecting the information and interpreting the results are essential in making this work."
Negative survey quotes
1. "Research may not be the most important thing for patients that are dying. Other issues take the forefront."
2. "I worry that research attempts to be quantifiable, and that this will not be able to capture the subtleties of our work."
3. "I'm not in favor of clinical staff doing research. We already have an exorbitant amount of paperwork which decreases actual patient contact. Often, patients have very short lengths of stay which prohibits development of rapport."

and 29% depending on the type of paper stock that was used to print the surveys. In other medical populations, researchers have achieved response rates of 69% (Sunshine & Bansal, 1995). Closer to our findings, Fowler et al. (2002) achieved a 46% response rate to mail surveys among health plan subscribers, which was increased to 66% when paired with an aggressive telephone campaign. Thus, our response rate of 56.25% at least mirrors or improves on previous studies. Another limitation is that the survey did not examine attitudes about the role of private industry funding of research and the degree to which the goal of commercial gain might erode trust in the research process (Michels, 2004).

Given the shortcomings of survey methodology, there nonetheless remain some important lessons from these findings. For instance, it is apparent that most staff members in hospice are at least open to the "idea" of research being conducted with patients and family members. However, we uncovered a rather intriguing dynamic regarding this issue. On the one hand, staff felt that they should be largely responsible for presenting research projects to patients and families. This potentially reflects a certain paternalistic desire to protect pa-

tients and to be “gatekeepers” from potential harm and abuse. On the other hand, however, there was a clear trend toward reports of having very little to no time to actually engage in the process of research with patients. This likely reflects a sense of apprehension about adding even more requirements and duties to an already stressful job. Thus, a form of “catch-22” occurs in which staff are interested in research and want to control access to it but won’t get involved and actually let it happen because they do not have time to absorb the extra burden it would create. This could be a fruitful dichotomy to explore further in larger trials.

On a final note, the survey also was useful for identifying the need to engage in staff education about the purposes and real-world functioning of research. The finding that concerns over protection of privacy ranked second on their list of barriers is indicative of this need. Clearly, staff members with this concern are unaware of the modern guidelines and rigor imposed by IRBs and human protections concerns in our country. Although these issues still certainly exist in places and some variability exists between institutions and sites that review protocols (Maloney, 2003; McWilliams et al., 2003), IRBs are in place and are challenged to apply federal standards in a consistent manner (Wagner, 2003). Therefore, education might be a good first step to build on this study’s findings. Indeed, it might be of interest to study the impact of research training on hospice staff to determine if this changes perceptions and desire to conduct and/or allow research to occur with hospice patients and family members. Also, it is unclear from this survey whether staff would feel an equal need to introduce research participation to their patients in every study. Perhaps, were staff brought into the study early in the process and given an opportunity to question confidentiality and other protections, they may have their protective interests satisfied. In addition, researchers might approach administrators to examine ways in which research activities can be done in the least intrusive way for staff. In conclusion, this study clearly shows support from Hospice provider staff for conducting research with their patients and family members. It also suggests the barriers that need to be further examined in future studies.

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APPENDIX: HOSPICE SURVEY USED IN THE STUDY

HOSPICE OF THE BLUEGRASS
STAFF SURVEY

This survey is for the purpose of learning more about attitudes and beliefs of hospice staff about research being conducted in hospice programs. This survey is anonymous and your responses will not affect your employment in any way. If you do not wish to participate in this survey, you may choose to not fill it out. It does not pose any risk to you other than inconvenience in taking the time to complete the survey. If you do not wish to complete the survey, you may stop at any time. Your information will be combined with other responses to learn more about hospice staff views of research. Your participation will help guide the Hospice Research Committee as it reviews research ideas in the future.

Staff Information

- a. I have worked in Hospice (either HOB or other Hospice) for _____ years.
- b. My role or profession is: (check one)
- | | | | |
|--------------------|-------|-----------------------|-------|
| Nurse | _____ | Bereavement counselor | _____ |
| Social worker | _____ | Physician | _____ |
| Home care aide | _____ | Chaplain | _____ |
| Non-clinical staff | _____ | | |
- c. I work primarily in _____ office.

Research Views

1. Research that involves surveys with **family members** of Hospice patients could lead to better understanding of family needs during Hospice care. (Circle one)

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1	2	3	4	5

2. Research surveys of **Hospice staff** are likely to result in important information about patient care. (Circle one)

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1	2	3	4	5

3. **Hospice patients** should be given the choice about participating in research interviews if they are up to it. (Circle one)

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1	2	3	4	5

4. **Hospice patients** could contribute important information about patient needs and treatment experiences by participating in research interviews. (Circle one)

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1	2	3	4	5

5. **Hospice patients** should have the opportunity to participate in research that involves specific drug treatments that are likely to be effective with Hospice patients. (Circle one)

Strongly disagree 1 Somewhat disagree 2 Neither agree nor disagree 3 Somewhat agree 4 Strongly agree 5

6. **Hospice patients** should have the opportunity to participate in research that involves specific psychosocial treatments that are likely to be effective with Hospice patients. (Circle one)

Strongly disagree 1 Somewhat disagree 2 Neither agree nor disagree 3 Somewhat agree 4 Strongly agree 5

7. **Family members** should be included in research that features new services that are likely to be effective with Hospice families. (Circle one)

Strongly disagree 1 Somewhat disagree 2 Neither agree nor disagree 3 Somewhat agree 4 Strongly agree 5

8. Who do you think should be the person to present research participation to **Hospice patients**? (Check one)

- Hospice Clinician
- Caregiver
- Researcher

9. I would be willing to spend more time **with patients/family members** collecting study information. (Check one)

- I do not have any additional time for research during a patient visit
- I could spend up to 10 minutes more per patient visit for research purposes
- I could spend up to 20 minutes more per patient visit for research purposes
- I could spend up to 30 minutes more per patient visit for research purposes
- I could add more than 30 minutes per patient visit for research purposes

10. In general, my view of research with **Hospice patients** is positive if patients are free from coercion to participate.

Strongly disagree 1 Somewhat disagree 2 Neither agree nor disagree 3 Somewhat agree 4 Strongly agree 5

OTHER GENERAL VIEWS ABOUT RESEARCH WITH HOSPICE

11. What do you consider the most important barriers to doing research with **Hospice patients** and their **family members**? (Check all that apply)

- it takes too much time
- it is too intrusive into privacy
- research is not that important
- patients cannot give informed consent
- research interferes with patient care
- staff are not consulted about doing research
- Hospice does not gain anything from research

12. What factors might make you **more willing** to be involved in research activities at Hospice? (Check all that apply and rank top 3 items)

TOPIC AREAS	CHECK ALL THAT APPLY	RANK TOP 3 ITEMS (1=HIGHEST)
Being a co-author on articles		
Having input into topic areas		
Being included in the planning for projects		
To improve care for patients and family members		
Having incentives to offer patients and family members		
Being assured that privacy will be protected		
Being assured that the research is not too time-consuming		
Receiving an incentive (please specify type)		
More time allowed for patient visits		

13. Please check all the following research topics that you think might contribute to better Hospice care.

(Check all that apply and please rank your **top 3 topics** with 1 being most important)

TOPIC AREAS	CHECK ALL THAT APPLY	RANK TOP 3 ITEMS (1=HIGHEST)
Non-medical pain management approaches		
Psychological characteristics of patients		
Patient views of Hospice staff and services		
Family characteristics related to patient comfort and adjustment		
Patients' responses to medication		
Medical pain management approaches		
Bereavement issues among family members		
Anticipatory grief among patients and family members		
Spiritual and religious beliefs among patients and family members		
Staff burnout and provider experiences with Hospice care		
Family member compliance with Hospice instructions		
Cultural issues among patients and family members		
Ways to help families that have caregiver stress		
Other ideas (please specify)		

14. Other comments:

THANK YOU FOR TAKING TIME TO FILL OUT THIS SURVEY