Hospice social care workers' views of end-of-life research

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Recommended Citation
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Abstract
Hospice social care workers are a valuable referral source for participants in end-of-life research. This qualitative dissertation seeks to clarify social care workers' views of end of life research including their opinions on the ethicality and value of end-of-life research, risks and benefits of end-of-life research, and preferences for the referral process. Twenty-eight social care workers rated their agreement with several statements and provided open-ended responses on their opinion of end-of-life research. Overall themes are discussed and recommendations for researchers of these populations are presented.

Degree Type
Dissertation

Degree Name
Doctor of Psychology (PsyD)

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Subject Categories
Psychiatry and Psychology

Comments
Library Use: LIH

This dissertation is available at CommonKnowledge: https://commons.pacificu.edu/spp/429
HOSPICE SOCIAL CARE WORKERS’ VIEWS OF END-OF-LIFE RESEARCH

A DISSERTATION
SUBMITTED TO THE FACULTY
OF
SCHOOL OF PROFESSIONAL PSYCHOLOGY
PACIFIC UNIVERSITY
HILLSBORO, OREGON
BY
ASHLEY M. WOHLEBER
IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY
APRIL 19, 2013

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“IN GENERAL, WOULD YOU CONSIDER REFERRING PATIENTS ON YOUR CASELOAD TO A RESEARCH STUDY IF THEY MET INCLUSION CRITERIA?”

SUMMARY

PERCEIVED RISKS AND BENEFITS
Hospice social care workers are a valuable referral source for participants in end-of-life research. This qualitative dissertation seeks to clarify social care workers’ views of end of life research including their opinions on the ethicality and value of end-of-life research, risks and benefits of end-of-life research, and preferences for the referral process. Twenty-eight social care workers rated their agreement with several statements and provided open-ended responses on their opinion of end-of-life research. Overall themes are discussed and recommendations for researchers of these populations are presented.

Keywords: hospice, palliative care, gatekeeping, recruitment, social care workers
Acknowledgements

I would like to thank Shawn Davis and Paul Michael for their invaluable feedback and enthusiasm throughout the several false starts and setbacks that encountered throughout this process. It has been a comfort to have the support of such a wonderful committee, especially when the going got tough.

Many thanks go to Keesje Hoekstra for the invaluable role she played in the recruitment process for this dissertation. I cannot thank her enough for her effort throughout this project. Also, thank you to Deborah Whiting Jaques at the Oregon Hospice Association for her assistance with recruitment efforts.

I also thank my friends and fellow graduate students for their invaluable phone time, coffee dates, and the many times they held me accountable for actually putting words on paper. It has been an honor to go through the past six years with them.

Most of all, I would like to thank the social care workers who, despite busy schedules and heavy patient caseloads, took the time to respond to my survey. They have my utmost gratitude and respect for the difficult work that they do.

Last but not least, thank you to my family – Rick, Karen, and Brian Wohleber – for their loving support and encouragement and to Christopher Scott for his cheerleading and tolerance for my taking over the kitchen table with academic papers for the last eight months.
Introduction

Hospice care is an interdisciplinary system designed to increase the comfort and quality of life of individuals at the end-of-life (Richman, 1995). Approximately 1.58 million individuals received hospice services in 2010, with an estimated 41.9% of all deaths in the United States occurring under hospice care (National Hospice and Palliative Care Organization [NHPCO], 2012). Hospice care is provided in a number of locations including the patient’s residence (e.g., private residence, nursing home, or residential facility), an inpatient hospice facility, or an acute care hospital (NHPCO, 2012). The mission of hospice care programs is to provide end-of-life care that supports death with dignity, rather than curative attempts that diminish quality of life. As the NHPCO explains, “Hospice focuses on caring, not curing” (2009, p. 3). The hospice team provides holistic, person-centered care which includes pain and symptom management; assistance with psychological and spiritual facets of dying; provision of medications and medical supplies; support for the family; respite or short-term inpatient care; and bereavement services (NHPCO, 2012). In order to enroll in hospice, an individual must be diagnosed with a terminal illness (often operationally defined as a life expectancy of six months or less) and must forgo curative medical interventions (Richman, 1995). The focus of medical interventions is to increase comfort rather than to prolong life.

As the number of individuals receiving hospice care has increased, so have concerns about providing empirically supported care to this population. However, the vulnerable nature of this population has made research with hospice and palliative care patients a challenging endeavor (Wohleber, McKitrick, & Davis, 2012). As officials at the National Institutes of Health [NIH] note, “While there is a growing body of [end-of-life] research covering a wide range of issues, the research is, in many ways, still in its infancy in terms of rigorous testing and
evaluation of models of care, in terms of patients and family outcomes, and in terms of resource

There are strong reasons for conducting research with hospice and palliative care patients
despite their vulnerable status. Providing opportunities for patients to participate in research
projects demonstrates respect for their autonomy (Addington-Hall, 2002; Bruera, 1994; Gysels,
Shipman, & Higginson, 2008; Hudson, Aranda, Kristjanson, & Quinn, 2005; Kaasa & De
Conno, 2001). There is also the potential for benefits stemming from research participation. For
example, research on new medical interventions may provide an opportunity for increased
quality of life or improved symptom management (Casarett, 2005). Subjectively, research
participants may benefit from having their voices heard (Plant, 1996; Wilkie, 1997) or knowing
they have done something to benefit others (Dobratz, 2003; Plant, 1996). Despite some of the
difficulties conducting hospice research, it appears that many patients are interested in
participation. In one study, 46% of hospice patients expressed an interest in interview or survey
research (Williams, Shuster, Clay, & Burgio, 2006). Hospice patients have named giving back to
the community, receiving validation that they still have something to offer, and improving future
patient care as reasons for participating in research (Terry et al., 2006).

Despite patient interest, hospice researchers frequently encounter difficulty accessing this
population. Gatekeeping occurs in all research, but may be especially prominent and problematic
in hospice research. All human-subjects research must first obtain approval from an ethics board
in order to ensure the safety of participants. While ethics reviews are a necessary and important
step of the research process, the paternalism of ethics board is a frequent complaint of end-of-life
researchers (Kendall et al., 2007). In particular, researchers expressed concern that ethics boards
‘[acted] as gatekeepers for perceived ‘vulnerable’ participants, rather than seeing them as
individuals capable of making their own decisions” (p. 3). Hospice staff are frequently used to refer patients who are most likely to be able to participate in research successfully and without harm. However, problems may arise when these professionals apply criteria other than the formal inclusion/exclusion criteria to block patients from participation. This may introduce sample bias and decrease study validity (Barnes et al., 2005).

Despite these risks, hospice personnel appear to be patients’ preferred method of being introduced to potential research studies (Terry et al., 2006; A. Williams et al., 2005; C. J. Williams et al., 2006). Thus, it is essential to understand hospice professionals’ attitudes towards end-of-life research in order to understand and reduce inappropriate gatekeeping. The goal of this dissertation is to present a qualitative, exploratory study examining hospice social care workers’ views of end-of-life research. This includes their opinions on the ethicality and value of end-of-life research, risks and benefits of end-of-life research, and preferences for the referral process. This study will assist future researchers to design studies that fit the needs and preferences of hospice referral sources.
Literature Review

Gatekeeping occurs when individuals are denied access to participate in research studies for reasons other than formal inclusion/exclusion criteria. Although gatekeeping is often well intentioned, it may cause harm by weakening the methodological rigor of the study. As Hudson et al. (2005) explain, “When patients or families participate in a study weakened by gate-keeping that prevents sound conclusions, their time and energies are misused” (p. 166). Additionally, gatekeeping violates the individual’s autonomy and right to decide whether or not they are interested in research participation.

Gatekeeping by Hospice and Palliative Care Staff

Despite the growth of hospice research in recent years (Fainsinger, 2008), gatekeeping continues to be a serious problem. Of 15 palliative care research studies funded by the National Institutes of Health, 80% reported difficulty recruiting participants (O’Mara, St. Germaine, Ferrell, & Bornemann, 2009). The protectiveness of staff was cited as the most common barrier to recruitment. In a community-based study of older adults with heart failure, researchers identified several instances of protective gatekeeping (e.g., not introducing the study to individuals with sight or hearing impairment, despite this not being criteria for exclusion; Barnes et al., 2005). Incidences of gatekeeping may be increased by certain study methodologies, including lengthy surveys or burdensome participation procedures (Addington-Hall, 2002), or decreased by education of clinical staff and communication of research importance, process, and findings (Bakitas, Lyons, Dixon, & Ahles, 2006).

Although it has been suggested that clinical staff be excluded from the research process in order to decrease inappropriate gatekeeping (Hudson et al., 2005), this goes against patient wishes (Terry et al., 2006; A. Williams et al., 2005; C. J. Williams et al., 2006) and sacrifices a
valuable source of information on the suitability of participants (Kendall et al., 2007). A thorough understanding of the gatekeeping phenomena may be more beneficial to hospice and palliative care research than the exclusion of clinical staff.

Gatekeeping occurs for a variety of reasons. Hospice professionals may choose not to introduce a particular patient to a research study due to concerns about participant burden (Hudson et al., 2005). Additionally, providers may selectively introduce studies to patients, excluding those they know to be having difficult life circumstances (Kirchhoff & Kehl, 2008). A clearer understanding of professionals’ attitudes and concerns regarding end-of-life research is essential in understanding the underlying causes of gatekeeping.

Professional Attitudes Toward Hospice and Palliative Care Research

Given the prevalence of problematic gatekeeping in end-of-life research, there is a paucity of empirical studies focused on the underlying attitudes. However, the research that is available reflects the emergence of several themes in the attitudes of hospice and palliative care professionals concerning research studies.

Willingness for patient participation. Ross and Cornbleet (2003) surveyed 13 palliative care nurses on their willingness to allow their patients to participate in research. Overall, 92% percent of this sample reported they were ‘very happy’ or ‘quite happy’ for patients to participate in research in general. However, these ratings fluctuated when three specific hypothetical research studies were described. Fifty-four percent of nurses reported they were ‘very happy’ or ‘quite happy’ for patients to participate in a controlled trial of two anti-nausea medications requiring extra blood tests and daily record keeping by the patient, whereas 46% of the sample reported they were unsure. When the research study involved a randomized controlled trial of reflexology versus foot massage for pain management in which the patients were required to
receive weekly therapy and to keep daily records, 77% of the sample reported they were ‘quite happy’ or ‘very happy’ for patients to participate while 23% reported they were unsure. In a hypothetical study screening for anxiety or depression which involved completing a mood rating scale and an hour long interview with a specialist, 62% reported they were ‘quite happy’ or ‘very happy’ for patients to participate, 31% reported they were unsure, and 8% reported they were ‘quite unhappy’ or ‘very unhappy’ for patients to participate. While it appears that overall willingness for patients to participate in research is relatively high, clinical staff may become more reluctant to allow patients to participate in studies that they perceived as burdensome or risky for patients.

**Value of research.** Overall, hospice and palliative care professionals appear to value research in this population. Kirsh et al. (2004) found that only 2% of hospice employees surveyed agreed with the statement “hospice does not gain anything from research” and only 1% agreed that “research is not that important.” Grbich et al. (2008) found that palliative care professionals participating in focus groups regarding end-of-life research agreed that end-of-life research is valuable; however, they expressed concern when the specific benefits and potential value of a study were not made clear to them.

Concerns about the value of research may be greater in studies involving comparative treatments or placebos. In one study measuring the effectiveness of anti-nausea medications in palliative care, the referring hospice nurses expressed concern about using a new treatment rather than a standard treatment which they believed to be effective based on their experience with the drug (Buss & Arnold, 2004). While hospice and palliative care professionals appear to value research overall, this may vary depending on the methodology and perceived risks and benefits of a particular research project.
Lack of understanding. Gbrich et al. (2008) found that many palliative care professionals involved in research were concerned about their own knowledge and understanding of the project. For example, focus group participants reported despite their participation in informational sessions, they were not always clear on their role in the study or what was required of them.

Risks and burden to patients. Ross and Cornbleet (2003) found that palliative care nurses were less willing for their patients to participate in research studies that they felt would be burdensome (i.e., which required daily written records) or risky (i.e., which required extra blood work or the possibility of emotional distress). Buss and Arnold (2004) also reported hospice nurses’ concern that, although the research question was valid and understandable, research participation would pose too much of a burden on their patients.

Increased workload. The concern of research burden extends beyond the fear that patients will be overly strained by study requirements. Kirsh et al. (2004) uncovered a troubling double-bind in which hospice professionals felt they should be responsible for presenting research projects to patients but reported having very little time to engage in research processes. In this study, 25% of hospice staff members surveyed reported they had no time to engage in research-related tasks. Thirty-four percent reported they could spend up to 10 minutes per patient on research-related activities. Few reported greater availability, with 7%, 5%, and 0.9% reporting availability for 20, 30, or more than 30 minutes, respectively. Forty-eight percent of professionals surveyed reported that the time involved was the largest barrier to conducting research. Concerns about staffing and time commitment were also noted among hospice administrators (Casarett, Karlawish, & Hirschman, 2002).
**Change in role.** In conjunction with the concern that research takes too much professional time to conduct is the finding that many hospice professionals are concerned that research involvement will affect their role in patient care. One group of hospice nurses reported that their priority was to care for patients rather than to conduct research (Buss & Arnold, 2004). Grbich et al. (2008) reported a similar finding, with palliative care clinical staff reporting a fear that they would become “data collectors” rather than patient caregivers and advocates. Twenty-four percent of hospice employees surveyed by Kirsch et al. (2004) reported concern that research would interfere with patient care.

**Research ethics.** Ethical concerns may be especially worrisome for hospice and palliative care professionals who are working to ensure the comfort and quality of life of their patients. Concerns may be especially high during placebo-controlled studies. Buss and Arnold (2004) reported such concerns from hospice nurses in a placebo-controlled study of anti-nausea treatments. The perceived ethicality of research design may be a key factor underlying gatekeeping, particularly in research involving the use of a placebo.

**Organizational Barriers and Attitudes**

Hospice and palliative care professionals’ views may also be impacted by organizational research culture. Without organizational initiatives to support and encourage hospice care workers to participate in research, internal projects may be negatively impacted by staff concerns or poor communication (Grbich et al., 2008). Grbich et al. reported changes in a three-year longitudinal research study of a palliative care program. At the onset of the study, hospice employees reported uncertainty about the premise of and their role in the research study. Increased workload due to research-related tasks and fear of change in their clinical role were also concerns. Focus groups were held periodically throughout the study to elicit feedback and to
implement strategies to support a research culture. For example, monthly research coffee
meetings were initiated to increase communication and employee involvement. By the end of the
study, employees reported changed attitudes toward the research project, including a feeling of
pride in their research involvement and a belief in the value of the research project.

Although hospice organizations also appear to value research (Casarett, Karlawish, &
Hirschman, 2002), there are many institutional barriers to research participation. As Buss and
Arnold (2004) point out, palliative care services may struggle to financially support a research
program. In a nationwide survey of hospice research involvement, Casarett, Karlawish, and
Hirschman (2002) found that hospices within an urban area that were affiliated with an academic
institution were more likely to have participated in research. Hospices that are geographically
isolated from other hospices or academic institutions may also have more difficulty developing
research programs (Richards, Corner, & Clark, 1998).

Summary

Although hospice administrators and hospice clinical staff appear to value research in
hospice and palliative care populations (Casarett, Karlawish, & Hirschman, 2002; Grbich et al.,
2008; Kirsh et al., 2004), their willingness to participate in research or to refer patients to
research studies may be influenced by a large number of factors including concern about
increased workload or shifting roles (Buss & Arnold, 2004; Casarett, Karlawish, & Hirschman,
2002; Grbich et al., 2008; Kirsh et al., 2004), lack of understanding and communication between
clinical staff and researchers (Gbrich et al., 2008), and fear that research participation will
unduly burden patients at the end of life (Buss & Arnold, 2004; Ross & Cornbleet, 2003).
Despite the recent increase in hospice and palliative care research and the frequent discussion of
gatekeeping as a barrier, there is still a paucity of research directly studying the processes
underlying inappropriate gatekeeping. It will be difficult to decrease inappropriate gatekeeping until the reasons underlying this phenomenon are more fully understood.
Method

The purpose of this survey study was to explore the views of end-of-life research among hospice social care workers (e.g., social workers, spiritual care coordinators, etc.). Study questions included social care workers’ preferences for screening procedures and research introduction to patients, hospice patients’ appropriateness for research participation, the value of end-of-life research, the ethicality of end-of-life research, coercion in the research process, and risks and benefits of research participation. Both quantitative and qualitative responses were elicited during the survey process.

Sampling Procedures

The study sample was selected using a purposive sampling procedure. Key contact individuals were identified in two hospice agencies in a large metropolitan area in the Pacific Northwest as well as in a statewide hospice association. These individuals then introduced the study to social care workers in their respective organization or association. Inclusion criteria included being at least 18 years of age and currently employed as a social care worker in a hospice organization. Recruiting procedures began in June 2012 and ended in October 2012.

Sample demographics. In total, 28 participants completed the study procedures. Limited demographic information was collected in order to protect participant anonymity. Of the 28 total participants, 26 (92.8%) identified themselves as residing in Oregon and 2 (7.2%) identified themselves as residing in Washington. In providing informed consent, all participants agreed they were over 18 years of age and employed as a social care worker in a hospice organization.

Data Collection Method

Potential participants were provided with a brief information sheet (see Appendix A) introducing the study purpose and procedures. They were also provided with a web link to the
survey should they choose to participate. Informed consent was obtained on the first page of the survey (see Appendix B). Upon entering the secure study website, individuals were provided with inclusion criteria and informed consent information and were asked to click the ‘I agree’ button to be taken to the survey if they met inclusion criteria and agreed to participate in the study or the ‘I disagree’ button to be redirected away from the survey.

The survey itself (see Appendix C) consisted of one demographic question regarding state of residence, nine statements regarding possible views of end-of-life research with a 5-point Likert scale rating agreement or disagreement for each (strongly disagree, slightly disagree, neither disagree nor agree, slightly agree, or strongly agree) as well as an open-ended response box, and five open-ended qualitative response questions regarding opinions on end-of-life research. Participants were able to skip any question they did not wish to answer.

**Data Analysis Method**

Qualitative and quantitative data were collected. Quantitative data was used to provide visual representations of response patterns and was compared to qualitative response patterns. Qualitative data was used to create an overall impression of attitudes towards end-of-life research. This data was initially sorted by question. Each response was read by the primary investigator and open coded for overall themes. Responses were then grouped by theme and re-read. Categories were identified using an emergent approach. Sub-categories were also identified during the second reading. After categories were identified, relative importance was measured by counting the number of unique respondents who cited a particular theme. Qualitative data was then sorted by respondent and analyzed a second time. Material again was open-coded for overall themes, again being categorized using an emergent approach. Each respondent’s answers
were analyzed for relationships between responses. Overall patterns were identified and compared among all respondents.

Ethical Considerations

The Pacific University Institutional Review Board provided project approval before the initiation of recruitment procedures and informed consent was obtained for all participants. No identifying information was collected in order to maintain participant anonymity. Participants were informed that they could exit the study at any time and that their participation was strictly voluntary.
Results

The purpose of this study was to identify hospice social care workers’ views regarding research with hospice patients. A number of domains were investigated, including hospice social care workers’ views on the appropriateness and ethicality of this type of research, desire to be involved in the research process, and perceptions of risks and benefits. Initially, the responses to each statement were analyzed independently and results are organized according to these three broad categories. Secondly, the overarching themes of the responses are discussed.

Appropriateness and Ethicality of Research

“I don’t believe that hospice patients should participate in research.”

Figure 1.1 Respondent rates of agreement to the statement “I don’t believe that hospice patients should participate in research.”

Response Options

Overall, participants expressed disagreement with the idea that hospice patients should not participate in research studies. The most frequently named theme in the qualitative responses...
involved concern for patient autonomy. This was followed by statements indicating the value of research, namely the need for research to advance hospice patient care. In line with the quantitative data, not all respondents believed that hospice patients should participate in research. A minority of participants expressed concern that research participation could take patients away from more important priorities, such as spending time with loved ones. As demonstrated, several participants felt unable to agree or disagree with this statement. In the qualitative comments, participants reported that their opinion would depend on characteristics of the patient and/or the research study.

“I think hospice patients are too sick to participate in research.”

Figure 1.2 Respondent rates of agreement to the statement “I think hospice patients are too sick to participate in research.”

Qualitative data was roughly in agreement with quantitative responses. Overwhelmingly, participants reported that it was impossible to outright agree or disagree with this statement as so
much depended on the individual patient and the demands of the research study. Limited time was cited as a concern both for patients, who may have other priorities, and in terms of research attrition. Overall, hospice social care workers reported that the determination of whether or not a patient was too sick to participate in research could only be made after careful consideration of study demands and patient characteristics.

“I think research at the end-of-life is unethical.”

Figure 1.3 Respondent rates of agreement to the statement “I think research at the end-of-life is unethical.”

Overwhelmingly, participants disagreed that there was anything inherently unethical about end-of-life research. Some social care workers pointed out specific concerns, such as the vulnerability of this population. As one participant stated, “[Patients] and families [sic] are very vulnerable and may fear that saying no would affect their care.” Another respondent pointed out the importance of providing careful informed consent to ensure that participants understood that
they could end their participation at any time without fear of negative consequences. Concern for patient care was apparent in many of the responses. A number of respondents expressed belief that research participation could be beneficial if done correctly. One participant reported concern of how research could fit with the overall goals and aims of hospice, stating, “Sensitivity to the needs of the patient should be the focal point, not research.”

**Summary.** Overall, the hospice social care workers who participated in this study appear to value the autonomy of their patients and to see end-of-life research as not inherently problematic, and possibly quite beneficial. However, many reported a desire for solid information about a prospective study before offering a firm opinion and stated that they would need to take an individual patient’s characteristics and situation into account before judging the appropriateness of research. The next section will focus on the extent to which hospice social care workers desire to be involved in the screening and recruitment of hospice patients for research studies.
Desired Involvement in Research

“I would rather screen my hospice patients for a research study (i.e., see if they meet inclusion criteria and refer them to a researcher for follow-up) than have a researcher do it.”

Figure 1.4 Respondent rates of agreement to the statement “I would rather screen my hospice patients for a research study (i.e., see if they meet inclusion criteria and refer them to a researcher for follow-up) than have a researcher do it.”

Response Options

The majority of participants agreed that they would prefer to be involved in research screening. Participants provided a variety of reasons for this preference. Most frequently, participants expressed value for the patient/social-care-worker relationship, although a small number of participants also mentioned concern that selection bias may enter into the recruitment process because of this pre-existing and important relationship. Concern for patient privacy, the importance of minimizing the number of new contacts at this stage of life, and the social care
worker’s knowledge of the patient were also named as important reasons for social care worker involvement. Of the qualitative responses that were not in favor of social care worker screening, one response cited trust in the researcher’s competence and one cited general disinterest in end-of-life research.

“I would rather introduce a research study to the hospice patients on my caseload than have a researcher do it.”

Figure 1.5 Respondent rates of agreement to the statement “I would rather introduce a research study to the hospice patients on my caseload than have a researcher do it.”

The majority of participants agreed that they would like to be involved in research by introducing a prospective study to hospice patients on their caseload. Once again, the importance of the patient/social-care-worker relationship was most frequently named as the reason for this preference. Two participants expressed concern that contact with a researcher would make the patient feel like a “spectacle” or “subject.” Of the qualitative responses that did not agree with
this statement, general disinterest in end-of-life research was named twice and one participant expressed concern that involvement in research would cause confusion about his or her role in the patient’s hospice care. Three participants suggested a joint approach in which a researcher and social care worker approached the patient together, with the social care worker supporting the development of the new relationship with the researcher and the researcher providing information about the study, risks, and benefits.

“I’m too busy to screen the hospice patients on my caseload for research or to introduce a study to them.”

Figure 1.6 Respondent rates of agreement to the statement “I’m too busy to screen the hospice patients on my caseload for research or to introduce a study to them.”

Responses to this question were remarkably even. Participants who provided qualitative responses agreeing that they were too busy named limited resources, high caseloads, and little time as their reasons for this response. Those who disagreed reported a belief that they could
make time for things that they felt were important, even though it may be a challenge to fit research responsibilities into an already busy schedule.

“I’m uncomfortable bringing up research with the hospice patients on my caseload because I don’t want them to feel coerced or pressured.”

Figure 1.7 Respondent rates of agreement to the statement “I’m uncomfortable bringing up research with the hospice patients on my caseload because I don’t want them to feel coerced or pressured.”

Response Options

Generally, participants did not appear to be concerned that their introducing a research study to hospice patients on their caseload would cause the patients to feel coerced to participate in research. Many participants cited comfort in their competence and ability to discuss difficult decisions with patients without pressuring them in a particular direction. As one participant stated, “I have to talk about Advance Directives, treatment preferences, goals, dying, unreconciled grief. Talking about research would not be hard for me at all.” Other participants
reported concern that introducing research would complicate their clinical role. As one participant reported, “[Research] is not the focus of the plan of care we coordinate with patient and family systems. Rather, hospice social workers would be more appropriately used as emotional or psychological support to the patient and family as they participate …” Concern that patients’ choice to participate was purely voluntary was also present.

“In general, would you consider referring patients on your caseload to a research study if they met inclusion criteria? Why or why not?” In general, most participants reported they would be willing to refer patients to research. Several participants stated that they would be willing so long as they were involved with recruitment and felt comfortable that the research process would support quality patient care. The value of patient autonomy was frequently cited as a reason for this opinion. Only 2 of the 26 responses unequivocally expressed unwillingness to refer. One of these participants reported feeling that research was beyond the scope of the social care worker’s role and one reported they were too busy to be involved in extraneous projects such as research.

**Summary.** Overall, the majority of participants reported they would like to be involved in research to some extent in order to ensure patient care. Unfortunately, almost half of the participants reported they were too busy for this kind of research involvement. The next section will focus on the risks and benefits of research to patients, social care workers, and the field as a whole perceived by social care workers.
Perceived Risks and Benefits

“I think participating in research is valuable for hospice patients.”

Figure 1.8 Respondent rates of agreement to the statement “I think participating in research is valuable for hospice patients.”

Response Options

Very few participants expressed the opinion that research was not valuable for patients, with the majority expressing neutrality or overall agreement. Of the participants who provided qualitative responses, approximately half believed that research would benefit future patients and approximately half reported intrinsic benefits, including contributing to something larger, leaving a legacy, and creating meaning, to participants through the research process. Only one participant reported a belief that end-of-life research provides minimal or no benefit to participants.
“I don’t think research results will be worth the burden of participation for hospice patients.”

Figure 1.9 Respondent rates of agreement to the statement “I don’t think research results will be worth the burden of participation for hospice patients.”

Response Options

Overwhelmingly, participants expressed disagreement or a neutral opinion of this statement. Of the qualitative responses, almost all participants reported that their opinion would depend on the specific patient and research study. One participant pointed out that even the burden may be seen as valuable to some patients, stating “Sometimes carrying a burden is a source of pride, dignity, and/or self-esteem.” Several participants discussed the importance of patient autonomy, prioritizing the patient’s right to decide whether or not research participation was worth the potential burden.
“In general, what do you see as the benefits of research being conducted with hospice patients?” The vast majority of participants discussed the role of research in improving end-of-life care. Several participants reported the importance of research in providing increased understanding of the end-of-life process as well as patient perspectives on important issues. A few participants noted intrinsic benefits, such as a sense of purpose or opportunities to provide meaning.

“In general, what do you see as the risks of research being conducted with hospice patients?” Responses fell into one of four main categories: risks to the patient, risks to the research, risks to the field, or no risks. Most responses addressed risks to the patient. The most frequently named risks included emotional burden, stress, or discomfort. Many participants expressed concern that researchers could be insensitive or disrespectful of the rights of the patient in a way that caused harm. The invasion of privacy, fatigue/physical stress, and interference with other priorities that patients may have were also mentioned as possible risks.

Possible risks to research studies in this population included selection bias, validity problems, methodological issues, inappropriate recruitment techniques, patient attrition, low participation rates, and difficulties with informed consent. One participant reported fear that overreliance on research and evidenced-based treatments may decrease the amount of clinical freedom available to hospice workers. Interestingly, four participants reported seeing no possible risks of end-of-life research.

“In general, do you think research with hospice patients is valuable? Why or why not?” Most responses cited the importance of research in improving understanding of the end-of-life experience and the quality of patient care. Four out of twenty-seven participants reported that the possible value of research was dependent on the study, and another four discussed
possible intrinsic patient benefits. One participant reported seeing no possible benefit of hospice research. One participant mentioned benefit to the hospice field in the medical world, stating, “Hospice is valuable and the scientific world requires ‘evidence’ of this.” Another participant pointed out the importance of considering the risks and benefits when determining the value of research, stating “Research is always somewhat valuable but at what cost?”

**Summary.** Overall, participants agreed that hospice research had the potential to be valuable for hospice patients and the field as a whole. Despite potential risks and burdens, social care workers’ generally expressed belief in respecting patient autonomy to decide whether or not participation was worthwhile. The implications of these findings will be discussed in the next section.
Discussion

The purpose of this study was to identify hospice social care workers’ views regarding research with hospice patients in a number of domains, including hospice social care workers’ views on the appropriateness and ethicality of this type of research, desire to be involved in the research process, and perceptions of risks and benefits. First, overarching themes of the data will be presented and conclusions drawn. Second, recommendations for future research will be provided.

Important Themes of Research Findings

Importance of information and involvement. Overall, the topic of end-of-life research was well received by the hospice social care workers who responded to the survey. However, numerous participants pointed out the importance of having full and complete information on a perspective study before determining if they felt it was appropriate for hospice patients in general or for a specific patient on their caseload. Based on these findings, it appears that it is essential for social care workers to feel informed and included in the research process. While hospice social care workers recognize and value the autonomy of their patients, they also appear to view the individuals on their caseload as potentially vulnerable. Social care workers who are empowered to participate in the research process by screening and introducing the study may be more willing to refer patients to research studies.

One important consideration of involving social care workers into participant recruitment is the potential for selection bias. It could be argued that allowing social care workers to determine when, how, and to which patients they present a possible research study may result in biased participation. Including social care workers in research preliminaries, such as refining the inclusion/exclusion criteria, and providing opportunities for social care workers to consult with
the researcher on patients whom they are unsure of whether or not to approach may work to minimize this potential for bias.

**Aligning values between researchers and social care workers.** Participants offered contrasting responses regarding their confidence in researchers. Several participants reported feeling confident in researchers’ abilities to work appropriately with hospice patients and to respect patient rights and care, while others had reservations that researchers would hold the patients’ best interests at heart. This finding supports the need for researchers to establish rapport and trust with the social care workers serving as gatekeepers. First and foremost, researchers need to establish competency in working with individuals at the end-of-life through research, training, and direct experience with hospice patients. Researchers must also assure social care workers that they can sensitively and compassionately work with this vulnerable population by prioritizing patient care, confidentiality, sensitivity, and careful informed consent.

**Double bind between time and involvement.** Although social care workers want to be involved in the research process in order to ensure appropriate patient care and sensitivity, many social care workers reported that they had very little time in their workday to complete research tasks. This finding is consistent with the results of Kirsh et al. (2004) who found that, although hospice workers wanted to assist with research, they had very little time available. There are a number of possibilities that may help to balance this discrepancy. Social care workers’ involvement may be more supported in hospice organizations that are formally committed to a research partnership, either internally or with an outside organization. Given the high caseloads and heavy work pressures that many social care workers experience, it will be important that their involvement in the research process be supported on an organizational level. In addition, it is possible that hospice social care workers may be willing to abdicate more research tasks to
researchers should they have more faith and confidence in the researchers’ abilities to work appropriately with this population.

As several participants noted, social care workers were often willing to make time for activities they felt had potential to improve the patient’s life through either intrinsic or extrinsic benefits. Providing thorough education on all possible risks and benefits of research participation may encourage social care workers to refer patients who may benefit in some way from their involvement. Additionally, careful explanation of the steps in place to ensure patient comfort, safety, and privacy may also allay some of the concerns surrounding end-of-life research.

**Recommendations**

Researchers face multiple challenges when conducting studies with hospice patients, including how best to coordinate with the social care workers involved in hospice patient care. The following recommendations, based on the findings of this study, are intended to assist end-of-life researchers to design studies that address the concerns and preferences of the social care workers they are likely to coordinate with. It is recommended that researchers in this population:

1. Take advantage of the knowledge and experience of social care workers by including them in study design and recruitment when possible. Social care workers have valuable knowledge about the abilities and limitations of patients on their caseload, and a strong patient/worker relationship may smooth the process of research recruitment and participation for patients.

2. Use a joint approach to patient recruitment, that is, approach potential participants with their hospice social care workers. Based on the results of this study, it appears that social care workers generally desire to be involved and may be more comfortable referring patients to research studies if they know they will be present to ensure patient care.
3. Invest time and effort in establishing open and transparent communication with the hospice social care workers involved. In order for social care workers to feel comfortable referring patients to research, they must feel they can trust the researchers to look out for the best interest of the patients and to minimize research stress and burden on participants.

4. Establish regular and consistent opportunities for social care workers to consult, ask questions, or present concerns regarding the research process. Again, an open and transparent research process is likely to increase workers’ comfort in making referrals to research studies. Additionally, regular opportunities for consultation may increase adherence to inclusion and exclusion criteria, particularly if social care workers are responsible for screening and/or introducing studies to potential participants.

5. Work with the hospice organization to support social care workers’ research involvement. Although social care workers generally desire to be involved, high caseloads and heavy responsibilities may interfere with their participation in research. Research will likely progress most smoothly in organizations that have formally partnered with researchers and that include research as a priority.

**Summary**

Conducting research with hospice patients can be exceptionally difficult, and it is important that researchers be aware of and are sensitive to the needs, attitudes, and preferences of hospice social care workers in order to conduct successful research with this population. By including social care workers in the research process, optimally with the support of their hospice organization, researchers may allay concern and minimize the detrimental effects of inappropriate gatekeeping. In addition, researchers may profit from social care workers’
knowledge and wisdom to improve research design and recruitment. Although hospice research is fraught with challenges, it is essential to continue to understand the end-of-life and to improve patient care during this difficult time.
References


Appendix A

Hospice social care workers’ views of end-of-life research

Investigators: Ashley Wohleber, M.S. & Shawn Davis, Ph.D.

Pacific University, School of Professional Psychology

You are invited to participate in an examination of social care workers’ opinions on end-of-life research. This exploratory study will examine opinions and attitudes which may influence social care workers’ willingness or hesitation to refer hospice patients for research studies. The purpose of this project is to assist researchers in end-of-life to better understand how hospice personnel view research in hospice populations. This may assist researchers to better design research for this population.

Eligible participants are over the age of 18 and employed as a social service worker (e.g., social worker, spiritual care coordinator, etc.) in a hospice organization. Should you choose to participate, you will be asked to complete an open-ended survey regarding your opinion of end-of-life research. It should only take about 20 minutes to complete your participation in the study. Your participation is completely anonymous. There is no means of associating any information that you provide with you personally. Any answers you provide will be available only to the experimenters. If a publication or other educational use results from this experiment and case reports are presented, all identifying material will be substantially modified so that participants’ identities will be safeguarded. This study has been approved by Pacific University’s IRB.
Please feel free to contact the primary investigator, Ashley Wohleber, M.S. (503 734-0910) or the research chair, Shawn Davis, Ph.D. (503 352-7319) if you have any questions or concerns.

The link for the survey is: http://www.surveymonkey.com/s/hospicesurvey

Thank you for your time and consideration!
Appendix B

1. Study title

Hospice social care workers’ views of end-of-life research

2. Study personnel

Ashley Wohleber
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3. Study invitation, purpose, location, and dates

You are invited to participate in this examination of social care workers’ opinions on end-of-life research.

The study is expected to begin May 2012, and to be completed by July 2012. All study information will be collected via the Internet and stored on a computer located at the Pacific University School of Professional Psychology, Building II, Suite 286, within the College of Health Professions.

4. Participant characteristics and exclusionary criteria

To participate in this study, you must be at least 18 years of age and be employed as a social care worker (e.g., social worker, spiritual care coordinator, etc.) in a hospice organization. If you are below the age of 18 or are not employed as a social care worker in a hospice organization, or do not understand something on this page, please exit this survey immediately by closing the browser window.

5. Study materials and procedures

In this study, you will be asked to complete an open-ended survey regarding your opinion of end-of-life research. It should only take about 20 minutes to complete your participation in the study.
Your participation is completely anonymous. There is no means of associating any information that you provide with you personally.

6. Risks, risk reduction steps and clinical alternatives

a. Unknown risks

Your participation in this project involves no foreseeable risks.

b. Anticipated risks and strategies to minimize/avoid

Any risks involved in participation in this study are minimal and are not greater that those ordinarily experienced in daily life or during the performance of any routine computer operation.

All data collected will be strictly anonymous. While SurveyMonkey allows the survey administer to determine whether or not to collect IP addresses as part of the survey data, IP addresses will not be collected during any phase of this study.

c. Advantageous clinical alternatives

This study does not involve experimental clinical trials.

7. Adverse event handling and reporting plan

If you experience discomfort during the study procedure you should stop your participation immediately and Shawn Davis, Ph.D. at (503) 352-7319.

The Institutional Review Board office will be notified by Dr. Davis on or before the next normal business day if minor adverse events occur. Study investigators will consult with the IRB about changes that may need to be made to the protocol or other changes deemed necessary to minimize any minor adverse events.

The Institutional Review Board office will be notified by Dr. Davis within 24 hours if major adverse events occur. In such a situation, the study investigators will immediately discontinue recruitment and discuss with the IRB office the best solution in order to minimize any and all adverse events.

8. Direct benefits and/or payment to participants

a. Benefit(s)

There is no direct benefit to you as a study participant.

b. Payment(s) or reward(s)

You will not be paid for your participation.
9. Promise of privacy

Your participation is completely anonymous. There is no means of associating any information that you provide with you personally.

Results from participants will be available only to the experimenters. If a publication or conference presentation results from this experiment and findings are presented, all personally identifiable information will be removed prior to data analysis and prior to any publication or presentation of the research finding. There will be no means of associating your responses with your identity.

10. Medical care and compensation in the event of accidental injury

During your participation in this project it is important to understand that you are not a Pacific University clinic patient or client, nor will you be receiving care or treatment of any kind as a result of your participation in this study. If you are injured during your participation in this study and it is not due to negligence by Pacific University, the researchers, or any organization associated with the research, you should not expect to receive compensation or medical care from Pacific University, the researchers, or any organization associated with the study.

11. Voluntary nature of the study

Your decision whether or not to participate will not affect your current or future relations with Pacific University. There are no costs to you for your participation other than the time involved in completing the surveys. If you choose not to participate, you are free to withdraw at any time; withdrawal will not result in penalty.

If you withdraw (by closing your browser window) from the study at any point prior to completing the survey, your participation will be ended. In this situation, all data collected to that point will be erased and not used in any analyses. It will not be possible to withdraw from the study after completing the entire study survey, due to its anonymous nature. However, all data will be erased (and not used in any analyses) for any individual that does not complete the entire study survey (defined as not reaching the final page of questions and answering any questions on that page).

Participation in this project is voluntary and the only other alternative to this project is non-participation. If you decide to participate, you are free to not answer any question or withdraw at any time without prejudice or negative consequences.

12. Contacts and questions

The researcher(s) will be happy to answer any questions you may have at any time during the course of the study. If you are not satisfied with the answers you receive, please call Pacific University’s Institutional Review Board, at (503) 352-1478 to discuss your questions or concerns further. If you become injured in some way and feel it is related to your participation in this study, please contact the investigators and/or the IRB office. All concerns and questions will be
kept in confidence.

13. Statement of consent

Since this is an on-line survey, signatures cannot be obtained.

By clicking “I agree” below, you will be taken to the research study.

If, however, you do not agree with any portion of this informed consent document, please select the “I do not agree” option below and your participation will be concluded.

Remember that if you choose not to participate or to withdraw from participation, you can close your web browser to cease your participation at any time.

Please indicate your agreement with the following:

I have read and understand the above. All my questions have been answered. I am 18 years of age or over, am employed as a social care worker in a hospice organization, and agree to participate in the study. I have read and understand the description of my participation duties and I understand that I can print a copy of this form to keep for my records.

  o  I agree with the statement above

  o  I do not agree with the statement above
Appendix C

1. In which state do you currently reside?

Please indicate your level of agreement with the following statements and describe your reasoning for each.

1. I would rather screen my hospice patients for a research study (i.e., see if they meet inclusion criteria and refer them to a researcher for follow-up) than have a researcher do it.

![Strongly Disagree] [Slightly Disagree] [Neither Disagree nor Agree] [Slightly Agree] [Strongly Agree]

Please select: [ ] [ ] [ ] [ ] [ ]

Please explain why you made this selection.

2. I would rather introduce a research study to the hospice patients on my caseload than have a researcher do it.

![Strongly Disagree] [Slightly Disagree] [Neither Disagree nor Agree] [Slightly Agree] [Strongly Agree]

Please select: [ ] [ ] [ ] [ ] [ ]

Please explain why you made this selection.

3. I’m too busy to screen the hospice patients on my caseload for research or to introduce a study to them.
4. I don’t think hospice patients should participate in research.

5. I think hospice patients are generally too sick to participate in research.

6. I think participating in research is valuable for hospice patients.
7. I don’t think research results will be worth the burden of participation for hospice patients.

8. I think research at the end-of-life is unethical.

9. I’m uncomfortable bringing up research with the hospice patients on my caseload because I don’t want them to feel coerced or pressured.
10. In general, what do you see as the benefits of research being conducted with hospice patients?

11. In general, what do you see as the risks of research being conducted with hospice patients?

12. In general, do you think research with hospice patients is valuable? Why or why not?

13. In general, would you consider referring patients on your caseload to a research study if they met inclusion criteria? Why or why not?
14. Please include any other information you would like us to know regarding your beliefs about research being conducted with hospice patients in the box below.