

Why is High-Quality Research on Palliative Care So Hard To Do? Barriers to Improved Research from a Survey of Palliative Care Researchers

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Abstract

Background: Substantial agreement has been achieved on research priorities in palliative care over the past 15 years, as evidenced by consensus conferences and systematic reviews. Despite the presence of a widely endorsed research agenda, however, addressing the gaps in scientific knowledge has progressed slowly, suggesting that researchers face significant obstacles to conducting high-quality research on the most pressing topics in the field.

Objective: To systematically identify barriers to improved and expanded palliative care research as reported by researchers.

Design: Semistructured telephone interviews to solicit barriers to research in palliative care.

Setting/Subjects: A purposive, interdisciplinary sample of 61 leading researchers in palliative care.

Measurements: Interviews were transcribed and analyzed using standard qualitative methods.

Results: Respondents named five barriers impeding progress: (1) funding, (2) institutional capacity, (3) researcher workforce, (4) challenges related to the topic and population (e.g., attrition, heightened human subjects protections), and (5) public and professional misunderstanding of palliative care and aversion to topics related to serious illness and end-of-life.

Conclusions: Research in palliative care is being held back by significant barriers that require the attention of institutions and funders. The consensus within the interdisciplinary sample indicates that concentrated effort to address barriers related to funding and researcher workforce could facilitate progress on established research priorities. More research is needed on viable strategies for overcoming the identified barriers.

Introduction

PALLIATIVE CARE CONSTITUTES a relatively new and rapidly expanding field that is poised to be in high demand as the population ages and lives longer with serious illness. The many domains of palliative care cut across disciplines¹; palliative care often consists of multiple interventions delivered by diverse staff. Research on palliative care reflects this diversity and is carried out by physicians, nurses, social scientists, and researchers in other fields, often using methods and focusing on subareas characteristic of their disciplines. In an effort to guide this diffuse field, a number of agendas and consensus documents for research and practice have been produced over the last 15 years by individual researchers, governmental agencies, professional associations, and advocacy groups.²⁻¹⁴

The priorities promoted in the various research agendas are clear and remarkably consistent. However, despite such awareness in the field, assessments of the state of research in palliative care routinely include negative assessments of the quality and quantity of palliative care research.^{2,5,13} Recent reviews of the evidence base for palliative care continue to report lack of strong evidence for important topics, either as a result of insufficient research attention or methodological weaknesses in existing studies.¹⁵⁻¹⁹ The question therefore arises: despite efforts to direct the field in the most productive directions, why is research on palliative care failing to address some of the key questions raised by experts in the field?

The present study addressed this question by focusing on barriers to improved and expanded palliative care research, as reported in in-depth interviews with a purposive, interdisciplinary sample of leading palliative care researchers. The

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goal of the study was to identify specific barriers that respondents believe are preventing improved research in palliative care, in order to generate a list of actionable goals for advocates, policymakers, and funders who wish to advance research in this area.

Methods

In order to capture the widest possible range of responses, we chose to administer a semistructured interview to a diverse sample of researchers working in the area of palliative care, and to use qualitative methods to analyze their responses. Interviews were conducted from November 2012 to January 2013. The purposive sample of 77 researchers was assembled through 3 sources. First, the Research Portfolio Online Reporting Tools of the National Institutes of Health (NIH RePORTer) was searched for all NIH grants in the last 5 years related to palliative care. The principal investigators of these awards formed the core of the sample. The research team identified additional leading researchers in palliative care who were not the recipients of NIH funds by searching the websites of the National Palliative Care Research Center and the Center to Advance Palliative Care for board members, advisors, and grant recipients. In recognition that the RePORTer sample was skewed toward physicians rather than nurses and social scientists, individuals from these and other disciplines were added by the research team in an attempt to broaden the sample. Following common practice in qualitative research,^{20,21} the sample was iteratively expanded until the investigators concluded that thematic saturation had been reached. The final sample consisted of researchers from the fields of medicine, nursing, social work, sociology, psychology, and health services research.

Four members of the research team conducted interviews, two geriatricians board-certified in palliative medicine (M.C.R. and S.M.) and two doctoral candidates in human development (E.C. and C.R.). To enhance consistency of delivery among the interviewers, all interviewers were trained in a standardized protocol by the primary interviewer (C.R.). The semistructured interview consisted of two parts: respondents were asked first to identify knowledge gaps in palliative care research, and then to report on barriers to improved research. Interviewers first provided a broad definition of palliative care that included a spectrum of services from concurrent care (i.e., when a patient receives curative therapies alongside psychosocial care and symptom management from a palliative care team) through formal end-of-life or hospice care. Respondents were then asked, "What do you see as the major barriers to improving and expanding palliative care research?" After each barrier, interviewers asked, "Are there any other barriers that you can think of?" Interviewers continued probing until the respondent failed to generate new barriers. All interview protocols were reviewed by the Institutional Review Board of Cornell University.

Prospective participants were contacted by e-mail and then by telephone to schedule the survey. Eleven researchers did not respond after multiple contact attempts and 5 declined to participate citing scheduling difficulties. With the exception of 7 participants who requested an e-mail version of the survey, participants were interviewed over the telephone. Interviews were completed with 61 individuals, an overall

response rate of 79.2% (61/77). Review of transcripts confirmed that the number of interviews was sufficient to reach thematic saturation.

Data analysis

All telephone interviews were audiotaped and transcribed. Transcripts were verified against audio-recordings for accuracy by one investigator (E.C.), who also used the transcripts to confirm that all interviewers followed the interview protocol. The transcripts and email responses to the survey were loaded into Dedoose qualitative analysis software (Dedoose, Manhattan Beach, CA).

Borkan's immersion and crystallization method of data analysis²² was used to generate the findings. First, two investigators (E.C. and M.W.) reviewed the transcripts to highlight respondents' statements related to barriers to research in palliative care (i.e., in contrast to statements that were made in response to other interview questions). Next, two investigators (E.C. and K.P.), both experienced in qualitative research, and guided by Borkan's method, read all survey responses independently, iteratively reflecting on and reviewing the transcripts to discern specific themes. Finally, the two investigators collaboratively assembled a list of themes that occurred in the responses and sorted the responses into these themes. Disagreements were rare (<5% of cases) and resolved through discussion. These preliminary themes were then presented to the two coinvestigators most heavily involved in interviewing (C.R. and M.C.R.) for verification as a form of member checking²³ during which two themes (public misunderstanding of palliative care and medical provider misunderstanding of palliative care) were combined.

Results

Respondents' characteristics are shown in Table 1. Half of the respondents were physicians or teaching in a school of medicine. Approximately 30% were from the field of nursing, with the remaining respondents from other fields, including the social sciences, public health, social work, or health services research.

Five major barriers were identified (summarized, with percent of respondents who nominated each barrier, in Table 2): funding, institutional capacity, researcher workforce, public and professional culture, and challenging aspects of the study population.

Funding

Respondents described two ways that funding acted as a barrier to the expansion and improvement of research on palliative care: the limited number of funding sources for palliative care and the challenge of the structure and review processes at the NIH for palliative care grant applications.

Respondents recognized that research requires support from inception through to large-scale, multisite studies that measure the wide-ranging effects of palliative care. They noted in particular the lack of non-NIH funding sources, including institutional support and private funds, available to young investigators or researchers who are developing research projects. Respondents reported that limited pilot funding makes it difficult to bring projects to an "NIH-

TABLE 1. RESPONDENT CHARACTERISTICS

	Number of respondents (%) (n = 61)
Field	
Medicine	30 (49.2%)
Nursing	17 (27.9%)
Social science	11 (18.0%)
Other	3 (4.9%)
Institution type	
School of medicine	37 (60.7%)
School of nursing	8 (13.1%)
University	4 (6.6%)
School of public health	3 (4.9%)
Other	9 (14.8%)
Degree	
MD	27 (44.3%)
PhD	14 (23.0%)
PhD/RN	12 (19.7%)
Advanced nursing degree	5 (8.2%)
Other	3 (4.9%)

ready” stage, where research ideas would be well developed, with adequate supporting evidence to be scored highly.

Many funding-related barriers identified by respondents related specifically to the structure and reviewing process at the NIH. Respondents commented on the lack of a “home” for palliative care or symptom-oriented research at the NIH, despite the designation of the National Institute for Nursing Research (NINR) as the lead institute for end-of-life issues. One respondent summarized this barrier by saying, “So much of research in the US is funded by the NIH, not having an institute that is specifically geared towards palliative medicine or symptom oriented medicine is a major handicap.”

The lack of reviewer expertise across the NIH was highlighted as a funding-related barrier, as well as the relative lack of evidence to support research questions, when compared with other areas of medical research. Respondents felt that palliative care grants were commonly

scored by reviewers who lacked expertise in the area. One expert noted:

Another problem is what happens to research when it comes up to the NIH and how it gets evaluated. People will say, just submit the grants, there are RFA’s under which you could submit the grants and that it will be fine. True, but if the committees never see it, if the committees don’t understand it, if there’s no expertise on those committees, that’s an issue.

When competing against proposals from a wide array of scientific subareas, the lack of a strong evidence base in palliative care was also seen as a liability. A typical comment was: “When a palliative care grant is being reviewed with a hypertension grant and chemotherapy grant, it’s really hard to stack up because of the immaturity of the science. The science in those areas is so much more mature.” This theme is similar to other funding-related barriers named by researchers in that it illustrates the challenges of trying to obtain funding for research that is often emerging, interdisciplinary, and patient- or symptom-focused, rather than disease-focused.

Institutional capacity

Respondents cited barriers related to lack of institutional capacity or support for palliative care research. First, although community-based palliative care is an area of growth and increasing interest, there are relatively few outpatient palliative care services overall, and even fewer that have the capacity to conduct or host research. Second, respondents described the structure of academic departments as a barrier to research on palliative care. Because palliative care services are often housed within geriatrics or other disciplines, or have nondepartmental status, there are fewer dedicated resources and less potential for political influence or representation at higher institutional levels.

Researcher workforce

Respondents identified the lack of well-trained investigators as a major factor limiting progress in the field. They attributed this shortage largely to limited training programs.

TABLE 2. BARRIERS TO IMPROVED AND EXPANDED RESEARCH IN PALLIATIVE CARE, AS REPORTED BY RESPONDENTS

Barriers to improved and expanded research in palliative care	Number of respondents naming barrier (%) (n = 61)
1. Funding. Lack of non-NIH funding sources and uneven expertise in NIH reviewer panels impede progress in research on palliative care.	42 (68.9%)
2. Institutional capacity. Many palliative care services lack the capacity to do research. The small number of academic programs in palliative care, especially standalone programs or departments, limits central support available to affiliated researchers.	9 (14.8%)
3. Researcher workforce. The field lacks well-trained investigators who have dedicated time to do research. Junior investigators face limited training and mentoring opportunities.	26 (42.6%)
4. Challenging nature of population and topic. Conducting research on patients receiving palliative care is difficult due to participation and attrition, limitations of serious illness, and increased human subjects requirements.	16 (26.2%)
5. Public and professional misunderstanding and discomfort with palliative care. Because of its association with end-of-life issues, many medical professionals and the public are uninformed about and yet prejudiced against palliative care.	18 (29.5%)

The shortage of formal training opportunities, such as research fellowships for physicians, limited the advanced training in research methods necessary to equip a researcher workforce. “In our haste to develop clinical and educational training programs, a piece has been left out: research training.” Informal opportunities for mentoring or collaborating were also seen as limited.

We have lots of wonderful junior investigators coming in, and we want to continue to grow this [pipeline], but I think we have a pyramid, this big base of people coming in, and yet in terms of number of more mid-level and senior people available to mentor that is much smaller.

Several respondents suggested that palliative care is likely having difficulty attracting and developing researcher talent because of the lack of institutional support for training and early career investigators, and the challenges of obtaining major federal grants for research in this area.

A lot of the people who have been leaders in this area are going to be retiring, so how do we continue to draw people into academia to do research? People are looking at the challenges of having a successful research career—the competition and funding issues—and they are thinking, why would I want to do this?

Challenges of study population and topic

A fourth theme involved the difficulty of studying palliative care, including recruiting and retaining research subjects, and the challenges of measurement and study design in seriously ill subjects. One respondent explained, “The work we do by its nature is challenging and always will be. It’s hard work to do research with such a vulnerable patient population and their families. It’s hard to recruit them, it’s hard to follow them.” Another respondent highlighted measurement challenges as a barrier to better research by comparing the inherent difficulty of measuring symptom burden to the endpoints in other disciplines, such as the size of a tumor as measured by magnetic resonance imaging. Doing research in clinical settings was also seen as presenting unique challenges to investigators, in part because research goals or protocols may not always overlap with usual clinical practice and palliative care practitioners are sometimes reluctant to alter their care practices when dealing with distressed or dying patients.

Ethical concerns were cited by respondents as particularly challenging when doing research on subjects who are seriously ill and/or dying, and their families. However, rather than facilitating human subjects challenges, many respondents reported that overly cautious Institutional Review Boards (IRBs) were a barrier to improved research in palliative care. Some respondents felt that the additional protections for palliative care populations that some IRBs required were based on an inaccurate perception of the vulnerability of seriously ill patients or recently-bereaved families.

In this population, I hear from IRBs, from our colleagues, from other clinicians, about this being a vulnerable population, and therefore needing special protections. I’ve had people say it’s not ethically permissible to conduct research in this population. I think that we, as a field, have got to counter that.

Public and professional understanding and perception of palliative care

The final barrier was misunderstanding of and resistance to palliative care by both the medical community and the general public. Physicians were seen as responsible for failing to refer patients to palliative care or to initiate conversations about the goals of care. Respondents connected the avoidance by clinicians of palliative care to the marginalization of palliative services within many health care settings.

Physicians and other health care professionals—and the people who fund research—they want to make people better. They all went into this wanting to heal, and you really have to reboot their thinking, to help them understand that healing can take different forms—not necessarily recovery or improvement, but relief from pain, healing of the mind.

American culture’s discomfort with and reluctance to discuss death was also named as a barrier to palliative care research. Many respondents made at least a passing reference to public derision of so-called “death panels,” and to the impact of misinformation and misunderstanding on their work as practitioners and researchers. As one participant noted:

America’s whole cultural denial of death is a problem for palliative care. We have to get AARP [American Association of Retired Persons] behind this. And what they are behind is 50 year olds who want to live. The American Cancer Society now is happily on board. So if they are on board, all hope is not lost. But I think it is the American culture’s idea that death is a failure. I think it’s a real problem.

Finally, respondents reflected on the low priority placed on palliative care, a value they saw as coming from cultural discomfort with death and dying. Limited resources dedicated to funding, workforce development, and institutional support for palliative care were offered as evidence that our society is deeply uncomfortable with death and dying, to a degree that we avoid even the things that would improve or ameliorate painful end-of-life experiences or high symptom burden of chronic disease. Respondents saw lack of funding and institutional support for palliative care as being discordant with the potential they saw for palliative care to benefit a large portion of the population. One respondent commented: “It seems to me that at a certain point, in American society, we need to prioritize what we care about the most, and if we really want palliative care to succeed, we need to make it work. We need to set it up to succeed.”

Discussion

The goal of this study was to systematically identify barriers to improving and expanding research in palliative care from the perspective of expert researchers. Respondents described five barriers to improved and expanded research in palliative care, suggesting that progress in palliative care research is prevented by a small set of significant challenges faced by most researchers.

In contrast to research agendas that attempt, at least in part, to persuade researchers to improve or focus their energy on high-priority topics, the list of barriers identified in this study cannot be overcome by the individual physicians, nurses, and social scientist who conduct research on palliative care. For example, many respondents proposed the idea of a dedicated,

cross-NIH study section for palliative care research as one possible avenue to overcome the funding-related barriers. To address workforce issues, it was suggested that investigators pursue funding through the T32 mechanism to establish training programs in palliative care. Respondents also cited the important work funded by The Robert Wood Johnson Foundation in the 1990s, and others recognized current efforts of the National Palliative Care Research Center to support and develop junior investigators through pilot grants and trainings, like the Annual Kathleen M. Foley Palliative Care Retreat and Research Symposium. These examples of funding and workforce development were offered as exemplars of efforts to address barriers to improved research and are a testament to current movement in the field to overcome obstacles. Researchers' ideas for solutions, such as the two given above, may serve as a useful starting point, but dedicated research is needed to identify the most viable and scalable strategies. In that the barriers identified by our respondents are not all unique to palliative care, it may be useful and most efficient to adopt best practices from other fields.

Addressing limited funding and developing a robust pipeline of palliative care researchers requires the combined efforts of policymakers, funders, and research institutions. Other barriers, like cultural avoidance of topics related to death and dying and the difficulty of recruiting participants who are seriously ill may not be suitable for targeted intervention because they are affected by broad cultural trends. However, the recent rapid growth of palliative care services signals a shift toward broader acceptance of palliative care within health care systems and has resulted in more exposure and access to palliative care by patients and their families. This escalation of clinical palliative care services could be the harbinger of greater appreciation of a palliative approach to serious illness, and may increase receptivity to participation in palliative care research. In this way, cultural shifts in attitudes about palliative care may already be in progress, aided by the expansion of palliative care services.

The results of this study highlight significant challenges to palliative care. Despite the open-ended interview format, respondents agreed on a small number of barriers, reflecting a surprising consensus and focus on several key issues. The relatively large and purposive interview sample, together with the saturation of themes observed in the study, provides confidence that these barriers are widely perceived in the field in general. Professional and advocacy organizations should leverage this consensus and sense of urgency around barriers to research in efforts to address the structural constraints identified to foster meaningful growth and progress in the field.

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