

A Qualitative Inquiry on Palliative and End-of-Life Care Policy Reform

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Abstract

Background: There is increasing recognition of the role of palliative care (PC) in health care delivery, but priorities for state and federal policy to support PC are unclear and have sometimes engendered controversy. We canvassed experts to shed light on general recommendations for improving PC.

Objective: The study objective was to identify challenges to and potential solutions for promoting, adopting, and implementing policies that would support or expand high-quality PC.

Methods: Semistructured telephone interviews were used to solicit challenges to and potential solutions for promoting, adopting, and implementing policies that would support or expand high-quality PC. Interviews were analyzed using qualitative methods. The subjects were a purposive sample of 22 professional state and federal-level advocates who work in the field of aging and/or PC.

Results: Respondents identified four central challenges to advancing PC policies: (1) knowledge about PC in the health care setting, (2) cultural beliefs about PC, (3) payment/reimbursement for PC services, and (4) public understanding of PC. Of the wide range of solutions proposed by respondents, we present the eight most frequently discussed solutions to these challenges targeted towards policymakers, health care professionals, research, and the general public. Respondents' understanding of the relationships between problems and solutions revealed many dependencies and interconnectedness.

Conclusions: A qualitative approach of querying experts identified multiple significant challenges to improving and expanding PC, most of which are acknowledged in existing consensus statements. Proposed solutions were more numerous and diffuse than descriptions of the problems, signaling the need for further consensus building around actionable policy, and better understanding of how to advance a PC policy agenda.

Introduction

IN LIGHT OF THE RAPIDLY AGING POPULATION of the United States and recognition of the poor quality and often inappropriate health care delivered late in life, there have been recent calls to improve palliative care (PC),¹⁻⁴ that is, symptom-focused care for people with life-limited illness, which includes but is not limited to hospice care. Some governmental actions taken to support better PC include measures to monitor and reform hospice care through mandatory quality reporting, included in the Patient Protection and Affordable Care Act,⁵ and state policies adopting and defining physician or medical orders for life-sustaining treatment (POLST/MOLST).⁶ Efforts to authorize Medicare

reimbursement to physicians for advance care planning conversations were stymied by political controversy in 2010,⁷ underscoring the potential for the political climate to limit policy changes focused on PC.

Given the high cost of late-life care and of end-of-life care in particular, changes to PC will be key to improving the efficiency and effectiveness of the health care system. Existing studies have documented research and policy priorities for PC from academic and practitioner perspectives.^{1-2,8-11} The Institute of Medicine (IOM) 2014 report on PC was the most recent effort at identifying broad priorities for the field.¹ We sought to build upon this work by identifying ways that policy could support such priorities. Recognizing the importance of policy experts among the relevant stakeholders,¹²⁻¹³

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we conducted interviews with experienced policy advocates for PC, asking them to identify and prioritize major issues in PC. Their perspectives on key problems and promising solutions inform the ongoing dialogue around what health care reform efforts are needed to improve PC.

Methods

Our study was guided by an advisory group of national and state policy experts with focus areas ranging from cancer to quality improvement to long-term care. The advisory group provided input to conceptualize the project and identify the types of professionals and stakeholders important to include in our purposive sample. The initial sample was developed based on the nominations of advisors, and focused on individuals who were professionally engaged in advocating for improving PC for older adults, who had knowledge of legislative and regulatory practices, and who were located in states with either large older adult populations or recent policy activity in PC (i.e., California, Florida, Texas, Massachusetts, Pennsylvania, Oregon, Washington, New York, Ohio, and North Carolina). The sample was expanded through a peer nomination, or snowball, approach in which respondents were asked to nominate other potential respondents in their professional network. Potential participants were sent an informational e-mail and followed up with by telephone.

Using an interview guide, two researchers (HSB, LX) with training in qualitative data collection conducted 30-minute semistructured telephone interviews with respondents that solicited perceptions regarding (1) the leading problems in PC and (2) potential solutions to these problems. The interview guide led respondents through a structured free association task¹⁴ in which they first identified a set of problems (i.e., problems facing PC), then generated a series of responses (i.e., solutions) organized around those problems. The sequential nature of a free association query allows inference regarding how respondents understand the relationship between problems and associated solutions.

Data analysis

Key quotations were transcribed and entered into a spreadsheet to allow coding by multiple researchers. Two researchers (HSB, LX) first categorized each quotation as either a “problem” or “solution” statement. Next, each of the problem and solution excerpts was reviewed in detail to identify the major categories and emergent themes pertaining to policy challenges and solutions. To do this, researchers first created a list of initial codes and their associated definitions based on mutual review of a subset (25%) of excerpts, under the oversight of the research leader (KL). Using this codebook as a guide, excerpts were then coded independently according to the constant comparison method.¹⁵ New codes and refinements to existing codes were added as needed, with weekly meetings to resolve differences in code application or definition. Disagreements not resolved through discussion were adjudicated by the research leader (KL). Similar codes were then combined to create larger categories. Respondent statements often fell into multiple categories due to their interconnected and dependent nature. Coders agreed on 95% of category assignments. Disagreements at this level were again adjudicated by the research leader. We presented the coding categories to the advisory group at an in-person

meeting. Advisory group members discussed the findings and affirmed the face validity of the results, but did not suggest any revisions or reorganization of the categories.

Results

The 22 respondents worked in a variety of policy and health care settings including nonprofit advocacy groups, health care provider organizations, associations on aging, and state legislatures. Six focused on national policy; the remainder focused on state policy. About half of respondents were located in California.

The four leading problems or policy issues (i.e., raised by five or more respondents) related to PC are described below (see Table 1). All codes are listed in Table 2 in order to convey the breadth of comments, including those mentioned by fewer than five respondents.

Problem 1: Lack of knowledge about palliative care in the health care setting

The most frequently named challenge for advancing policies that would support best practices in PC was misunderstanding of or unfamiliarity with these services by both health care providers as well as consumers, described by half (11, 50%) of respondents. Respondents identified the roots of this problem in a lack of education and training about PC for health care providers, including deficits in medical school curricula and lack of other training opportunities.

The issue is with physicians, to make sure families understand what it means when they're recommending a patient go into palliative care. That goes back to medical school and how we educate the physicians and how we talk to patients about these issues.... They don't have to spend the last six months of their life in a hospital.

TABLE 1. LEADING POLICY PROBLEMS AND POTENTIAL SOLUTIONS NOMINATED BY RESPONDENTS

	Number of respondents who named issue (%)
<i>Problem statements</i>	
Lack of knowledge about PC in the health care setting	11 (50%)
Issues with cultural belief about PC	9 (41%)
Need for changes to incentives and reimbursement for PC	9 (41%)
Lack of public understanding of PC	7 (32%)
<i>Solution statements</i>	
Provide insurance benefits and reimbursement to PC providers	15 (68%)
Support training and education for specialty and nonspecialty health care providers	11 (50%)
Conduct more research on PC	10 (46%)
Develop standards for PC	8 (36%)
Provide comprehensive care	8 (36%)
Create public awareness	6 (27%)
Provide resources	6 (27%)
Change cultural perception about PC	5 (23%)

TABLE 2. ALL QUALITATIVE CODES AND EXEMPLARY QUOTES

<i>Description</i>	<i>Exemplary quote</i>
<i>Problem themes</i>	
Issues about advance directives and POLST forms Statements about lack of communication	<p>“Advance directives and POLST forms are not readily available to the people who need them the most.”</p> <p>“Another challenge is that we don’t have a system that encourages, supports, and rewards care management and communication across settings for care.”</p>
Lack of resources, such as physician shortage or money	<p>“The way that palliative care is discussed, framed, and provided in an acute care setting has very much to do with the resources that are available at that institution.”</p>
A lack of training and education in delivering end-of-life care	<p>“Lack of training among physicians in hospice and palliative care [is a leading challenge]. They are not equipped to have a conversation with a patient about end-of-life goals and wishes.”</p>
Lack of public awareness and lack of understanding about what PC is and when it is appropriate	<p>“Hospice [is] seen by the consumers as equated to dying, so people don’t want to jinx themselves by going there. Palliative care should help bridge that gap.”</p>
Cultural issues including how providers and health care consumers view the end of life	<p>“Our culture emphasizes extending life, rather than comfort and quality of life.”</p>
A lack of standardization in PC and end-of-life care	<p>“Physicians don’t address pain management because the perception is that pain is a part of aging.”</p> <p>“There is absence of consistency among definitions of palliative care in hospitals, what are the essentials, and what can people assume they will receive no matter where they go for care.”</p>
A lack of payment and reimbursement for services at the end of life including physician and hospital services	<p>“Aversion to making the necessary payment changes to be reflective of the value that palliative care and hospice care bring to the health care system.”</p>
Lack of care coordination	<p>“The <i>negativity</i> of electing to use hospice care because, under Medicaid and Medicare, the patient must forego conventional therapies to get more comprehensive end-of-life care benefits.”</p>
<i>Solution themes</i>	
Provide or create an advance directive or POLST Develop standards for PC	<p>“Lack of coordination between providers, not just on the medical side. Multiple providers don’t communicate with each other ever. There’s no information sharing, little continuity.”</p> <p>“Create a state registry or state sponsored storage location for advance directives, like Oregon.”</p> <p>“Create credentialing or licensing of palliative care programs, such as statutes that will guide and direct palliative care providers, or use the National Consensus of Voluntary Standards for guidance on funding and reimbursement standards.”</p>
Provide or create different benefits and/or coverage for PC	<p>“Standardize best practices in palliative care and accreditation policies.”</p> <p>“Eliminate Medicaid and just have Medicare—just have one insurance, because then acute and long-term care would be covered under the same plan and we could budget appropriately, keep track of how much is spent, and not shift costs from one center to another.”</p>

(continued)

TABLE 2. (CONTINUED)

<i>Description</i>	<i>Exemplary quote</i>
Conduct research or development for PC	“Getting a range of players in palliative care together to solve the problem of interoperability between systems, such as what data is important, what do we need to do to communicate consistently, and how we’re going to communicate the information effectively.”
Create and/or conduct training	“Universal, broader training among health care professionals has to emphasize palliative care and hospice medicine part of what all providers do. And not just physicians—include all the supporting professionals.”
Create/develop payment for PC	“Adequate reimbursement would entail coverage for provisions of services beyond MD services because much of what is done is not direct work by physicians but is part of a team, and the only reimbursement structure is for physicians. [Payment] should provide support for a true palliative care team.”
Create public awareness for PC	“Create a robust public education campaign, like through CAPC [Center to Advance Palliative Care], that explains what palliative care is and what it means for different populations of patients.”
Create/provide resources for PC	“Create more Federal bills (similar to the ones American Cancer Society is already doing) for career development and loan forgiveness programs to encourage health professionals—physicians, social workers, etc.—to consider careers in palliative and hospice care.”
Need for cultural shift in how PC is viewed by those in medicine and the public	“Remodel palliative care using celebrities to create a culture change and capture people’s perspectives that would change the demand of palliative care.”
Create comprehensive care	“Use television to change people’s attitudes about taking care of the elderly.”
Create outcome measures and quality indicators to use with PC	“Improve on providing pain management and combining social, emotional, and spiritual needs in palliative care.”
Care needs to be longitudinal without arbitrary distinction between cure and comfort in how it is organized and delivered	“We need to create substantial reform that will measure the quality of the care planning process, demand the care plans are being followed honestly, and a service delivery system that is allowed and required to have different quality measures.” “Create pre-hospice level palliative care that provides hospice-level support, but does not call it hospice and does not include the limitation of foregoing conventional treatments.”

When describing misunderstanding or lack of awareness of PC in health care settings, respondents also consistently included patients' and families' lack of knowledge as part of the problem. Respondents attributed this lack of understanding to a larger failure of health care.

"There is a general awareness of the availability of hospice services...but there is a lack of depth of knowledge and lack of presentation of the full range of options that a particular patient and family might have available to them as they encounter serious and advanced illnesses. Invariably patients will say, 'We wish we had known about hospice sooner.'"

Problem 2: Issues with cultural beliefs about palliative care

Respondents (9, 41%) reported the culture of medicine and the overall "death denying" culture in the United States as obstacles to implementing public policies to support PC. The culture of medicine or medical care in the United States was described as preferring aggressive, intensive care over an informed choice to forego treatment. One respondent stressed, "The high intensity care continues to increase" and went on to describe the large share of Medicare costs that are spent during the final year of life. Respondents felt that the root of this tendency was that "the [medical] culture focuses on extending life rather than quality of life." These norms within medical culture were linked to a broader reluctance to discuss death and dying in U.S. society: "Society is reluctant to engage in conversations around end-of-life care.... We are a death denying society."

Problem 3: Need for changes to incentives and reimbursement

Payment for health care in general and PC specifically was identified as a significant problem by nine (41%) respondents. A general challenge was how the structure of the health care system has failed to incentivize coordinated, proactive care for patients with life-limiting illness. Respondents described alternative models of care of people with serious illness, but saw in the existing typically fee-for-service system,

"barriers that create disincentives to get the right care at the right time and at the right place.... It is time to look at those policies and try to craft something that more closely supports the needs that people actually have."

As part of this theme about the challenge of reimbursement, some respondents cited the requirements that patients had to meet to receive the hospice benefit (i.e., prognosis of <6 months to live, agreeing to forego curative treatment) as obstacles to appropriate care at the end of life. For patients who did not meet these requirements, there were many fewer reimbursable supportive services available to the patient and their family. Respondents connected the lack of reimbursement for certain types of PC services (either in general or specifically for nonhospice PC) with their low uptake outside palliative care specialty teams. One respondent summarized this situation by saying, "If reimbursement for palliative care isn't there, there's no motivation to figure out a way to provide it."

Problem 4: Lack of public understanding of palliative care

One-third of respondents ($n=7$; 32%) discussed lack of public awareness about PC services as an obstacle to improving and expanding PC. Respondents felt that the general public was uninformed about care options, including the appropriateness and timing of PC. Confusion about the difference between palliative care for people with serious illness and hospice care, the subset of PC focused on the dying, was cited as a major problem, as was the misunderstanding of the benefits of hospice care in general. As one respondent reported, "People think hospice means you are going to die. You are, but you don't have to spend the last six months of your life in a hospital."

Respondents felt that a serious consequence of public ignorance about these issues was a lack of demand for access to these services.

"There's clearly a lot of people who don't understand the potential role that palliative care can play in chronic illness, advanced illness, terminal illness.... We have to continue getting people to understand what palliative care is, because we're stuck with the association of palliative care with end-of-life care—and nobody really wants to sign up for that."

Solutions

Respondents identified a broad range of proposed solutions to the challenges facing PC. Solutions were proposed in response to the problems respondents listed in their interviews. The correspondence of solutions to problems was rarely one to one. Rather, respondents noted that many problems required multiple interventions or changes throughout various disciplines, and most respondents proposed solutions or strategies to overcome the problems facing PC that would have positive impacts on many challenges within the current system. The most commonly identified solutions (i.e., identified by five or more respondents; see Table 1) are described below. The problems that were most closely linked to each solution by respondents are noted in each description, with the full list of problem and solutions linkages shown in Table 3.

Solutions focused on the policies and structure of health systems

Respondents proposed several solutions to the policy challenges facing PC that focused on insurance benefits and reimbursement to PC providers. Fifteen (68%) respondents offered suggestions including adjustments or innovations supported by existing payment policy, such as reimbursing doctors for goals of care conversations, creating clearer standards around reimbursement for PC services (e.g., quality measures), and ways to integrate PC into health care contexts through incentives or bundled payments (e.g., bundling palliation within cancer care). Other proposed recommendations included incorporating PC in newer models of care, such as the Accountable Care Organization, rather than supporting continued fee-for-service payment; changes to the system that would incentivize "proactive versus reactive management" of patients, such as supporting advance care planning discussions; and access to symptom-focused, supportive care early in the course of serious illness. These changes to

TABLE 3. COMMON SOLUTION STATEMENTS ASSOCIATED WITH EACH PROBLEM STATEMENT

<i>Problem statements</i>	<i>Solution statements</i>
Lack of knowledge about PC in the health care setting	<ul style="list-style-type: none"> • Provide insurance benefits and reimbursement to PC providers • Support training and education for specialty and nonspecialty health care providers • Develop standards for PC • Provide comprehensive care • Create public awareness
Issues with cultural belief about PC	<ul style="list-style-type: none"> • Create public awareness • Change cultural perception about PC
Need for changes to incentives and reimbursement for PC	<ul style="list-style-type: none"> • Provide insurance benefits and reimbursement to PC providers • Develop standards for PC • Conduct more research on PC
Lack of public understanding of PC	<ul style="list-style-type: none"> • Create public awareness

insurance benefits and reimbursement were proposed as a strategy to overcome lack of knowledge about PC in the health care setting by actively restructuring financial incentives to stimulate proactive patient-centered care.

Another theme that emerged from the solution statements was the promise of comprehensive care for overcoming the problems of PC, mentioned by eight respondents (36%). Respondents emphasized the importance of providing PC across settings, including home. “We must provide care coordination across the continuum of care so it can be in the community.” Other recommendations for comprehensive care included improving pain management by incorporating social, emotional, and spiritual needs and implementing mechanisms within health care systems that would foster more comprehensive care through care coordination. One stated recommendation was to “align finances by making a health plan that has under its umbrella all the various providers that you might need, then effectively coordinate among the providers and monitor utilization to see who is doing it well.” The comprehensive, coordinated care described by respondents was proposed as part of the solution to the lack of general awareness and knowledge about PC in the health care setting.

Solutions focused on palliative care providers and researchers

Respondents proposed professional training and education for palliative care specialists and other health care providers (11, 50%). Mechanisms included increasing PC fellowships in order to grow the field of providers, supporting continuing education in PC among the existing workforce, and broadening medical and nursing school curricula to include PC. One respondent recommended,

“It should be common knowledge to the primary care and specialty practice clinic what palliative care is and that it should be integrated into their practice as primary care or

specialty practice so that they can start to help educate patients about palliative care early on if they’re facing serious illness.”

Respondents also emphasized nonspecialty provider education. “Education and training are the important areas not just for physicians, but for nurses and direct care workers [in terms of] what palliative care means and what can be done in the system.” Education and training were seen as a necessary step in addressing the problem of lack of knowledge about PC in the health care setting.

Ten respondents (46%) proposed conducting more research on PC as a solution to some of the problems facing the field. They described the importance of high-quality focused research in demonstrating the value of palliative care, driving the development of quality measures for PC, and contributing evidence to determine which PC services are reimbursed. In particular, they saw the greatest potential in research that focused on the relationship between PC interventions and salient outcomes, research that could build a case for the effects of program parts and not just programs overall. Respondents’ conviction about the importance of research centered around how research is used in policy making:

“An overarching issue is sufficient research to be able to demonstrate the value and benefit of palliative care. If we are going to ask funders to pay, then we have to be able to show that there is a value for the service that we are being asked to be reimbursed for.”

Demonstration and pilot projects were proposed as ready mechanisms to generate policy-relevant research. In these ways, conducting research was understood as an important step in changing incentives and reimbursement for PC.

The standardization of PC was proposed by eight respondents (36%). Suggestions centered around the potential for credentialing or licensing of PC programs to standardize the way PC is conceptualized, practiced, and delivered from the perspective of both health care providers and institutions. One respondent urged,

“[It is] incumbent upon the leadership of the field to really establish standards for palliative care. We are at the age and era where there are guidelines that are almost universal in everything that is done.... [PC needs] clear, evidence-based criteria for what the spectrum of palliative care needs to be.”

Respondents suggested that measures that assess best practices—such as the National Voluntary Consensus Standards for Palliative Care and End-of-Life Care¹⁶—could then be leveraged to reform incentives and reimbursement of PC by creating clear standards for quality care.

Solutions focused on consumers

Finally, we identified two related themes that were solutions focused on the general public. First, six respondents (27%) stressed the need to create public awareness of PC through public health education campaigns (e.g., television ads, celebrity endorsement), in order to build a broad base of support for PC. According to one respondent, “The public demand [for PC] would probably come first,” and only then would “the health care industry change itself.” Policymakers were highlighted as a key segment of the public that requires education about PC. One respondent complained, “When you talk about end-of-life and palliative care in the

legislature, you can get diverse perspectives that can impact the policy there. People may assume it's about end-of-life care, but it's completely different. There's a need to educate in the legislature itself." Public awareness was noted as a potential solution to the problems of lack of public understanding of PC and the issues with cultural beliefs about PC.

The second theme focused on consumers was the solution proposed by five respondents (23%) to change the cultural perception of PC. Another respondent thought changing the tone of public discourse on end-of-life care in particular was necessary for the continued growth and expansion of PC. "We have to find a better way to have the conversation with the public. When the conversation gets better, it's kind of like AIDS. Nobody wanted to talk about AIDS, but when the conversation became more common, the public became more educated on it." Respondents were not able to be specific about what they believed this solution would require, but felt that interventions to change cultural perceptions were necessary to address the problem of cultural beliefs that inhibit the uptake of PC policies and practices.

Discussion

This research identified major problems in PC and potential solutions to these problems from the perspective of advocates working for improved PC. We found broad consensus across the 22 respondents on the major challenges facing the field of PC; these included a lack of training and education, cultural beliefs, lack of provider payment/reimbursement, and lack of public awareness. There was also substantial consensus on the types of initiatives needed to foster progress in PC, including provider training, reforms to payment systems, and public education, among others. The responses of our experts are similar to key areas of concern for PC noted by other stakeholder groups, such as providers and researchers.^{1,8,17} Our study of these issues reflects much of the consensus achieved in the IOM 2014 report,¹ which is striking given that our study was conducted prior to the IOM research and that we used a different method and focused on a particular stakeholder group. The common findings about leading challenges and potential solutions for PC underscore the value of the IOM priorities as a template for taking action.

While it is tempting to think that such apparent consensus among researchers and policy-focused advocates would lead to rapid policy progression, we posit at least two reasons that more progress has not been made. First, there was not clear delineation between problems or tight one-to-one linkages between problems and solutions. For example, the problems of PC in the health care setting were intertwined cultural beliefs about PC and misaligned financial incentives for providers. Part of one proposed solution—to reimburse providers for time spent in advance care planning conversations outside of the hospice setting—is included in Medicare's 2016 physician fee schedule, but our results demonstrate how provider training, patient education, and cultural changes all need to be involved in order to have effective and broad uptake of such a benefit.

A second likely reason for delays in improving and expanding policies to support PC is that the problems and solutions identified by advocate-participants were not limited to things that could be accomplished through political or legislative action. Most respondents proposed solutions that involved a range of

actors and spanned traditional disciplinary boundaries, including practitioners of all types and across settings, consumers, professional and regulatory organizations, health insurers, academic research, and public health agencies. This finding suggests the need to consider a broader framework of influences—and the potential benefit from understanding what strategies were most effective for shifting policies and popular opinion around other health and behavioral issues, such as tobacco use. Analysis of the tobacco control movement has found that price and tax measures, regulation, and public awareness education and communication are key factors in reducing smoking and other tobacco product use, as well as secondhand smoke exposure.^{18–21} The recognition and use of multiple, interdisciplinary, and synergistic strategies to affect behavior change could be similarly applied to the challenges of PC.

Limitations of this study include the small sample size and the peer nomination sampling method, which may be constrained by social networks and therefore have limited penetration within a population.²² However, our respondents reflected a variety of disciplines, professional roles, and organizational types. Despite efforts to balance the geographic distribution by targeting individuals in several states, respondents from California made up about half of the sample, although no California-specific policy issues were discussed by respondents. We also did not speak with other potential stakeholders, including patients and families, health care providers, and health insurers/payers, all groups likely to have strongly held beliefs and motivations that would influence their own policy priorities for PC.

This comparison between what the advocates contacted in this study recommend and what is supported by current policies should be interpreted as a road map for future targets of PC policy and other efforts revolving around efforts for larger social change.

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