

## Research Funding for Palliative Medicine

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### ABSTRACT

**Background:** Medical care for seriously ill patients has been acknowledged to be inadequate and multiple reports have called for increased investment in palliative medicine research.

**Objective:** To identify funding sources of palliative medicine research published from 2003–2005 and to examine National Institutes of Health (NIH) funding of palliative medicine research from 2001–2005.

**Methods:** We sought to identify United States publications related to adult palliative medicine research from 2003–2005 and their funding sources. We reviewed all articles published in the major palliative medicine journals and additionally, we reviewed all articles published in major medicine journals and relevant sub-specialty journals which were identified in Pub-Med using the key words “palliative care,” “end-of-life care,” “hospice” and “end-of-life.” From all identified articles, we abstracted all sources of funding detailed. We then compiled a list of U.S. palliative medicine researchers from 2001–2005 using the published first and last authors in the above article review, the editorial boards of palliative medicine journals, and other organizations. To examine NIH funding, we cross-matched this list of researchers against all NIH grants funded from 2001–2005.

**Results:** We identified 388 palliative medicine research articles and 2,197 investigators. Seventy-two percent of papers identified received extramural funding: 31% from the NIH, 51% from foundations, and 16% from other sources. Only 109 investigators received NIH funding and the National Cancer Institute (NCI), National Institute of Nursing Research (NINR), and National Institute on Aging (NIA) funded 85% of all NIH awards.

**Conclusions:** Research funding, particularly federal funding, for palliative medicine research is inadequate to support improvements in care for the most seriously ill patients and their families.

### INTRODUCTION

PALLIATIVE MEDICINE is the sub-specialty that focuses on relieving suffering and improving quality of life for patients with serious illness and their families.<sup>1</sup> The development of the specialty of palliative medicine has been a critical step in addressing the unmet needs of patients with serious illness and their families. The growth of this field has been remarkable. From 2001–2003, the number of hospital based pal-

liative medicine programs has grown by more than 60%, such that now one in four U.S. hospitals has a palliative medicine program, all U.S. medical schools must provide training in palliative medicine and, as of 2006, palliative medicine is now an official subspecialty of internal medicine and nine other specialties.<sup>2,3</sup>

Nevertheless, the field faces some sizeable challenges if care for seriously ill patients and their families is to improve. Unlike other areas of medicine, the

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knowledge base to support the basic elements of palliative medicine clinical practice (i.e., pain and symptom management, communication skills, care coordination) is small and inadequate and systems of care that truly support the needs of patients and families have yet to be developed.<sup>4</sup> Indeed, during the past 8 years, reports from the Institute of Medicine (IOM) in 1997,<sup>5</sup> 2001,<sup>6</sup> and 2003<sup>7</sup>; the Research Task Force of the American Academy of Hospice and Palliative Medicine<sup>8</sup> (the membership organization of palliative medicine physicians) in 2003; and the National Institute of Health's (NIH) State of the Science Conference on End-of-Life Care in 2004<sup>4</sup> have identified the critical need for palliative medicine research and have called for major investments in palliative medicine research so as to broaden and strengthen the evidence base of this growing field. This study was designed to examine sources of extramural funding for published palliative medicine research from 2001–2005 and specifically to examine NIH funding over the same time frame.

## METHODS

### *Extramural funding sources of published palliative medicine research*

We undertook to identify U.S. publications related to adult palliative medicine research from 2003–2005 and their sources of funding. We reviewed all articles published in the major palliative medicine journals (*Journal of Palliative Medicine*, *Journal of Pain and Symptom Management*, *Palliative Medicine*, *Journal of Palliative Care*, and *Palliative and Supportive Care*). Additionally, we searched PubMed using the key words “palliative care,” “end-of-life care,” “hospice,” and “end of life” for all articles published in major adult internal medicine journals (*Annals of Internal Medicine*, *New England Journal of Medicine*, *British Medical Journal*, *Lancet*, *Archives of Internal Medicine*, *American Journal of Medicine*) and relevant subspecialty journals, representing conditions with the highest death rates (*Journal of Clinical Oncology*, *Journal of the American Geriatrics Society*, *Journal of General Internal Medicine*, *Journals of Gerontology*, *American Journal of Respiratory and Critical Care Medicine*, *Critical Care Medicine*, *Thorax*, *Circulation*, *Circulation Research*, and *Journal of the American College of Cardiology*).

From all identified articles, we abstracted the first and last authors' names and all sources of funding detailed in the manuscripts. We used the NIH Computer

Retrieval of Information on Scientific Projects (CRISP) database to identify the principle investigator (PI) for all acknowledged NIH grants.<sup>9</sup> Similarly, we searched the Veterans Affairs (VA) Health Service Research and Development Study database to identify the principal investigators of all acknowledged VA awards.<sup>10</sup> Whenever possible, we searched foundation and industry websites to collect additional information about other grants acknowledged in the identified publications.

### *NIH funding of palliative medicine research*

In order to examine NIH funding in palliative medicine research, we compiled a list of U.S. palliative medicine researchers and then cross-matched this list against all funded NIH research projects from 2001–2005. To compile a list of palliative medicine researchers, we undertook the following steps. First, we completed a Pub-Med search as described above for the years 2001–2005 and abstracted the names of the first and last authors from each identified article. Second, we abstracted the names of editorial board members of the palliative medicine journals described above. Finally, we abstracted the names of the 87 Project on Death in America (PDIA) Faculty Scholars. The Faculty Scholars Program was a 9-year initiative underwritten by the Open Society Institute that supported 87 palliative medicine clinicians in more than 50 U.S. medical schools. The resulting 2197 names were submitted as a Freedom of Information Act (FOIA) request to the NIH Department of Statistical Analyses. The Department of Statistical Analyses used the NIH internal database to search for each name as a Principle Investigator (PI) of an NIH-funded grant. From the Department of Statistical Analysis, we obtained the PI's name, the grant number, the grant title, the PI's institution, the dollar value for each grant, and the start date and end date of the grant.

The two authors independently hand reviewed all the identified grants for relevance to palliative medicine, as determined by the National Consensus Project's for Quality Palliative medicine's definition.<sup>1</sup> Relevant grants then were categorized independently by each author into one of the following 10 categories: (1) studies focused on pain and physical symptom management and quality of life, (2) studies examining psychological, spiritual and emotional symptoms, (3) studies focused on instrument development and measurement, (4) health services research evaluating systems of care, (5) decision-making and communication studies, (6) studies focused on education and training in palliative medicine, (7) studied focused on care-

givers and families, (8) pediatrics studies, (9) career development awards, and (10) other. The authors agreed on the categories for 402 of 418 NIH grants. For the 16 on which the authors disagreed (3.8%), grant topics were discussed until consensus was reached.

## RESULTS

We identified 388 original palliative medicine research manuscripts published from 2003-2005 (Table 1). Of these 388 papers, 298 (77%) were published in palliative medicine journals and 90 (23%) in general medicine and relevant subspecialty journals.

Two hundred and seventy-nine papers (71.9%) received some form of extramural funding: 122 (31.4%) from NIH, 35 (9.0%) from the VA/military, 197 (50.8%) from foundations and 28 (7.2%) from industry. Eighty-nine of the 388 first authors (22.9%) acknowledged funding sources: 38 (9.7%) from the NIH, 13 (3.4%) from the VA/military and 46 (12%) from foundations. Of 381 senior or last authors, 75 (19.7%) acknowledged funding sources: 31 (8.1%) from the NIH, 8 (2.1%) from VA/military, and 33 (8.7%) from foundations.

We used PubMed to characterize the study types of these published manuscripts. Of these 388 papers, 7 (1.8%) were identified as controlled clinical trials, 2 (0.5%) as controlled clinical trials/validation studies, 1 (0.3%) as a randomized control trial (RCT)/validation study, 22 (5.7%) as RCTs, 11 (2.8%) as validation studies, 17 (4.4%) as evaluation studies, 1 (0.3%) as a multicenter evaluation study, 11 (2.8%) as multicenter studies, 8 (2.1%) as multicenter RCTs, 7 (1.8%) as clinical trials, and 5 (1.3%) as comparative studies.

We identified 2,197 palliative medicine researchers from our second search strategy. One hundred nine individuals (5%) were listed as PIs on a total of 418 NIH awards (mean of 3.8 grants/investigator). Of the awards identified, 69 (17%) were career development awards (44 to junior investigators, 17 to midcareer/senior investigators, and 8 to investigators whose status could not be determined); 275 (66%) were research awards (220 R01s [80%], 55 R21/R03s [20%]); 49 (12%) were education awards (R25); and 25 (6%) represented other funding mechanisms (Table 2).

Three NIH institutes (National Cancer Institute [NCI], National Institute for Nursing Research [NINR], and National Institute on Aging [NIA]) funded 85% of all awards. Specifically, 189 (45%) were funded by NCI (0.4% of all NCI grants awarded); 94 (22%) by NINR (3% of all NINR grants); 74 (18%) by NIA (0.5% of all NIA grants); 21 (5%) by the Na-

tional Institute of Mental Health (0.1% of all NIMH grants); and 40 (10%) were funded by eight other Institutes/Centers (Table 3).

Finally, of 418 NIH grants, 122 (29.3%) funded studies focused on pain, nonpain symptoms and quality of life; 50 (12%) funded education and training in palliative medicine; 42 (10.1%) funded decision-making and communication studies; 40 (9.6%) funded studies examining psychological, spiritual, and emotional symptoms; 36 (8.6%) funded health services research evaluating systems of care, 33 (7.9%) funded studies related to measurements or instrument development, 34 (8.2%) funded studies related to caregivers and families of seriously ill patients; 8 (1.9%) funded pediatrics studies and 53 (12.7%) funded other areas of research.

## DISCUSSION

To our knowledge, this is the first study to examine research funding in palliative medicine. Despite multiple reports from both private organizations and government agencies calling for investment in palliative medicine research, this study found that more than 25% of published palliative medicine research was performed without any acknowledged extramural funding and less than one-third of published studies were supported by NIH funding. Furthermore, although the leading causes of death in this country are due to cancer, dementia, and diseases of the heart, lung, and kidney, fewer than 1% of all funded grants by the National Cancer Institute, National Heart, Lung and Blood Institute, National Institute on Diabetes, Digestive and Kidney Diseases, and the National Institute on Aging were awarded to investigators performing palliative medicine research. Finally, although palliative medicine research implicates all NIH Institutes, three institutes—NCI, NINR, and NIA, funded 85% of grants awarded for palliative medicine research. These findings have important ramifications for the field of palliative medicine and for the care of patients with serious illness and their families.

In spite of the acknowledged need for palliative medicine research by the U.S. government's major research institutions, our study suggests that federal funding for palliative medicine research remains low. The absence of a federal agency specifically charged with that mission may be a contributing factor to low levels of research support for care of people with serious and complex illnesses. With few exceptions, the NIH institutes are disease-specific and thus palliative medicine, with its applicability to all serious illnesses,

TABLE 1. FUNDING SOURCES FOR PUBLISHED PALLIATIVE CARE (PC) ORIGINAL RESEARCH PAPERS IN 2003–2005

Research area	Overall number	PC journals <sup>a</sup> no. (%)	Other journals <sup>b</sup> no. (%)	Received extramural funding no. (%)	Funding source		
					NIH	VA/Military	Foundation
Pain/symptom/quality of life	84	77 (92)	7 (8)	57 (68)	20 (24)	4 (5)	30 (36)
Psychological/spiritual/emotional	29	25 (86)	4 (14)	18 (62)	8 (28)	3 (10)	14 (48)
Measurements	46	45 (98)	1 (2)	33 (72)	14 (30)	5 (11)	20 (44)
Systems of care	90	50 (56)	40 (44)	66 (73)	33 (37)	7 (8)	47 (52)
Communication	45	25 (56)	20 (44)	31 (69)	17 (38)	6 (13)	24 (53)
Education/training	33	28 (85)	5 (15)	21 (64)	8 (24)	2 (6)	16 (49)
Caregivers	27	24 (89)	3 (11)	24 (89)	14 (52)	4 (15)	17 (63)
Pediatrics	10	8 (8)	2 (20)	9 (90)	3 (30)	0	9 (90)
Other	24	16 (67)	8 (33)	20 (83)	5 (25)	4 (21)	18 (75)
Total published manuscripts	388	298 (77)	90 (23)	279 (72)	122 (31)	35 (9)	197 (51)

<sup>a</sup>PC journals include *Journal of Palliative Medicine*, *Journal of Pain and Symptom Management*, *Palliative and Supportive Care*, *Journal of Palliative Care*, and *Palliative Medicine*

<sup>b</sup>Other journals include *Journal of Clinical Oncology*, *Annals of Internal Medicine*, *N Engl J Med*, *British Medical Journal*, *Lancet*, *Archives of Internal Medicine*, *Journal of the American Geriatric Society*, *JAMA*, *Journal of General Internal Medicine*, *American Journal of Medicine*, *American Journal of Respiratory and Critical Care Medicine*, *Critical Care Medicine*, *Circulation*, *Circulation Research*, *Journal of the American College of Cardiology*.

TABLE 2. NIH FUNDING FOR PALLIATIVE CARE RESEARCH BY RESEARCH INSTITUTE (2001–2005)

Institute	PC grants no (% of all grants)	Career development awards no (%)				Investigator initiated research no. (%)		Education <sup>f</sup> no. (%)	Conference <sup>g</sup> no. (%)	Other <sup>h</sup> no. (%)
		Junior CDA <sup>a,b</sup>	Midsenior CDA <sup>c</sup>	Other CDA <sup>d</sup>	Pilot <sup>e</sup>	ROI				
NIA	74 (18)	20 (45)	9 (53)	3 (38)	5 (9)	37 (17)	0	0	0	
NCI	189 (45)	10 (23)	4 (24)	5 (62)	24 (44)	87 (40)	49 (100)	2 (100)	8 (35)	
AHRQ	0	0	0	0	0	0	0	0	0	
NHLBI	7 (2)	0	4 (24)	0	0	3 (1)	0	0	0	
NCCAM	11 (3)	0	0	0	4 (7)	7 (3)	0	0	0	
NIMH	21 (5)	6 (14)	0	0	2 (4)	13 (6)	0	0	0	
NINR	94 (22)	8 (18)	0	0	19 (36)	65 (29)	0	0	2 (9)	
NIDDK	0	0	0	0	0	0	0	0	0	
Other	22 (6)	0	0	0	1 (2)	8 (4)	0	0	13 (57)	
Total	418	44	17	8	55	220	49	2	23	

<sup>a</sup>CDA, Career Development Award.

<sup>b</sup>K01, K08, K23, R29, F31, F32, T32.

<sup>c</sup>K05, K24, K02.

<sup>d</sup>K07.

<sup>e</sup>R03, R21.

<sup>f</sup>R25.

<sup>g</sup>U13, R13.

<sup>h</sup>P20, G08, R32, M01, R43, R44, R15, U54, R24.

NIA, National Institutes of Aging; NCI, National Cancer Institute; AHRQ, Agency for Healthcare Research and Quality; NHLBI, National Heart, Lung and Blood Institute; NCCAM, National Center for Complementary and Alternative Medicine; NIMH, National Institutes of Mental Health; NINR, National Institutes of Nursing Research; NIDDK, National Institute of Diabetes and Digestive and Kidney Diseases.

TABLE 3. NIH FUNDING OF PALLIATIVE CARE RESEARCH BY RESEARCH AREA

Research area	# PC grants no. (% of all grants)	Career development awards no. (%)			Investigator initiated research no. (%)		Education <sup>f</sup> no. (%)	Conferences <sup>g</sup> no. (%)	Other <sup>h</sup> no. (%)
		Career development awards no. (%)			Investigator initiated research no. (%)				
		Junior CDA <sup>a,b</sup>	Midsenior CDA <sup>c</sup>	Other CDA <sup>d</sup>	Pilot <sup>e</sup>	ROIs			
Pain/symptom/quality of life	122 (29)	0	0	0	28 (23)	81 (66)	0	1 (1)	12 (10)
Psychological/spiritual/emotional	40 (10)	8 (20)	0	0	6 (15)	26 (65)	0	0	0
Measurement	33 (8)	0	0	0	4 (12)	27 (82)	0	0	2 (6)
Systems of care	36 (9)	2 (6)	0	0	0	25 (69)	4 (11)	0	5 (14)
Communication	42 (10)	5 (12)	0	0	8 (19)	27 (64)	0	0	2 (5)
Education/training	50 (12)	3 (6)	0	0	0	1 (2)	45 (90)	0	1 (2)
Caregivers	34 (8)	1 (3)	0	0	6 (18)	25 (74)	0	1 (3)	1 (3)
Pediatrics	8 (2)	0	0	0	3 (38.5)	5 (62.5)	0	0	0
Other	53 (13)	25 (47)	17 (32)	8 (15)	0	3	0	0	0
Total	418	44 (11)	17 (4)	8 (2)	55 (13)	220 (53)	49 (12)	2 (1)	23 (6)

<sup>a</sup>CDA, Career development award.

<sup>b</sup>K01, K08, K23, R29, F31, F32, T32 awards.

<sup>c</sup>K05, K24, K02.

<sup>d</sup>K07.

<sup>e</sup>R03, R21.

<sup>f</sup>R25.

<sup>g</sup>U13/R13.

<sup>h</sup>G08, R32, M01, R43, R44, R15, U54, R24.

does not fit well within a particular institute's scope. Recent budget cuts have further hampered the NIH Institutes' abilities to fund new research or new investigators that might be perceived as outside their core missions. Additionally, neither an Institute-specific nor a Center for Scientific Review (CSR) Study Section that specifically focuses on palliative medicine has been established. Existing study sections have, at most, one or two reviewers with expertise in palliative medicine research.<sup>11</sup> Thus, peers with appropriate content and methodological expertise in palliative medicine rarely review palliative medicine grant submissions.

Although some absence of federal investment in palliative medicine research might be attributable to a lack of qualified investigators or lack of grant submissions, it is difficult to attribute our findings to this explanation alone. Our study identified a substantial number of high quality published research studies (many of which were performed only with intramural funding) demonstrating the existence of a sizeable community of both qualified and experienced investigators. Due to NIH regulations forbidding disclosure of information regarding unfunded grants, we were unable to determine the number of applications involving palliative medicine research submitted to NIH and not funded. Nevertheless, the response to a recent American Cancer Society funding initiative in palliative medicine research modeled after the NIH R21 mechanism (pilot/exploratory grants), in which more than 150 letters of intent were received and more than 100 full applications requested (R. Elk, personal communication) suggests the high probability that the NIH is receiving a similar number of applications, if not more, on an annual basis. In addition, because of the small size of the palliative care research community, the (anecdotally) large number of research and educational collaborations in the field, and NIH conflict of interest rules, the small numbers of palliative care experts on study sections may be recused from reviewing the studies upon which they are most expert.

There are a number of potential approaches that could successfully address the funding gap we have identified. First, private philanthropic foundations have played a critical role in promoting and funding palliative medicine research. Indeed, more than 50% of the studies we identified were supported by philanthropic grants. Support for palliative medicine research initiatives by both committed foundations (e.g., The Robert Wood Johnson, the Brookdale Foundation, the Kornfeld Foundation, and the American Cancer Society) and organizations that have not yet funded

palliative medicine research is critically needed. Second, a strategic focus on supporting junior investigators is needed; these efforts should include funding pilot projects that can support NIH investigator initiated research applications (R01) and career development awards. In addition, the development of collaborative palliative medicine research networks by the major palliative medicine professional organizations (American Academy of Hospice and Palliative Medicine, Hospice and Palliative Care Nurses Association and National Hospice and Palliative Care Organization) in conjunction with major philanthropic foundations has the potential to rapidly grow the research infrastructure much as the American Geriatrics Society and the American Federation for Aging Research have accomplished for the field of Geriatrics. The recently established National Palliative Care Research Center ([www.npcrc.org](http://www.npcrc.org)) is an example of a mechanism by which private foundations can strategically invest in palliative medicine research and ensure funded research addresses established priorities that are both scientifically rigorous and rapidly translated into clinical practice.

Finally, it is clear that NIH funding available for palliative medicine research needs to be increased and concrete strategies to promote palliative medicine research and palliative medicine investigators need to be undertaken. Strong consideration should be given to establishing a palliative medicine scientific review group under CSR to ensure appropriate peer review of submitted applications. Dedicated research funds for palliative medicine should be established under each NIH Institute whose scope encompasses patients with serious and life threatening illness through program announcements for investigator-initiated research under the R01, R21, and R03 mechanisms, center grants, and junior and midcareer career development awards. This approach has been undertaken at the Canadian Institutes of Health Research (CIHR), the Canadian equivalent of the NIH, and this has resulted in a dramatic increase in the number of palliative medicine applications submitted to CIHR and a corresponding increase in funded palliative medicine research projects.<sup>12</sup> In the United States, successful models for these types of programs already exist and include NIA's Older Adults Independence (Pepper) Centers—interdisciplinary research centers focused on funding research promoting independence in older adults, and the recently established Paul Beeson K23 program—an NIH-foundation partnership that continues a successful philanthropically funded career development pro-

gram that under the auspices of NIA is now funding and developing a community of young investigators in aging research.

This study has several limitations that should be noted. First, as described above, it was impossible for us to determine the number of research applications submitted to the NIH that went unfunded due to NIH regulations preventing the disclosure of this information. Second, our study was designed specifically to identify palliative medicine studies and researchers and thus did not include studies in related areas that might have implications for palliative medicine research (e.g., treatments of chemotherapy induced nausea, interventions to improve postoperative pain). Third, we focused specifically on studies in adult internal medicine such that we may have underreported funding in pediatrics, psychiatry, surgery, neurology, and anesthesiology. Finally, because we identified researchers from published manuscripts, it is possible that we did not identify funding for junior investigators who have not yet published their results. We suspect, however, that the number of such researchers is small.

In conclusion, despite increasing recognition of the need for a solid evidence base to improve care for seriously ill patients and their families and the need for research to develop this evidence base, federal funding for palliative medicine research remains inadequate. Critically needed are focused efforts to ensure appropriate peer review of palliative medicine research applications, earmarked funds for palliative research across major NIH institutes, and ongoing and increased investments by private foundations to support pilot work and junior and career development awards for junior and midcareer researchers.

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