

Pediatric Palliative Care Programs in Children's Hospitals: A Cross-Sectional National Survey

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KEY WORDS

pediatric, palliative care, hospice care, hospital care, survey

ABBREVIATIONS

FTE—full-time equivalent

PPC—pediatric palliative care

Dr Feudtner collaborated in the conceptualization, design, and implementation of the survey study, supervised and assisted with the analysis, and drafted the initial manuscript; Mr Womer conducted the initial analysis and reviewed and revised the manuscript; Ms Augustin collaborated in the conceptualization, design, and implementation of the survey study, conducted the initial analysis, and reviewed and revised the manuscript; Ms Remke and Drs Wolfe, Friebert, and Weissman collaborated in the conceptualization, design, and implementation of the survey study and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Over the past 10 years, children's hospitals increasingly have established pediatric palliative care programs, but little is known about the prevalence of these programs or their geographic distribution, range of services offered, staff composition, or funding.



WHAT THIS STUDY ADDS: Among the 162 hospitals that responded to this survey (71.7% response rate), 69% have a pediatric palliative care program, with substantial variation across programs in terms of how they are staffed and funded and what services they provide.

abstract

FREE

BACKGROUND: Pediatric palliative care (PPC) programs facilitate the provision of comprehensive care to seriously ill children. Over the past 10 years many such programs have been initiated by children's hospitals, but little is known about their number, staff composition, services offered, sources of support, or national distribution.

METHODS: In the summer of 2012, we surveyed 226 hospitals as identified by the National Association of Children's Hospitals and Related Institutions. The survey instrument gathered data about whether their institution had a PPC program, and for hospitals with programs, it asked for a wide range of information including staffing, patient age range, services provided, and financial support.

RESULTS: Of the 162 hospitals that provided data (71.7% response rate), 69% reported having a PPC program. The rate of new program creation peaked in 2008, with 12 new programs created that year, and 10 new programs in 2011. Most programs offer only inpatient services, and most only during the work week. The number of consults per year varied substantially across programs, and was positively associated with hospital bed size and number of funded staff members. PPC programs report a high level of dependence on hospital funding.

CONCLUSIONS: PPC programs are becoming common in children's hospitals throughout the United States yet with marked variation in how these programs are staffed, the level of funding for staff effort to provide PPC, and the number of consultations performed annually. Guidelines for PPC team composition, funding, and consultation standards may be warranted to ensure the highest quality of PPC. *Pediatrics* 2013;132:1063–1070

Except for a few pioneering efforts, the establishment of pediatric palliative care (PPC) programs in children's hospitals began in the late 1990s and early 2000s.^{1–8} During this period, an emerging professional consensus and mounting empirical evidence underscored important differences in how adults and children experience life-threatening illness and end-of-life care.^{9–17} In 2003, the Institute of Medicine released a report recommending PPC specialty training, development of collaborative guidelines and protocols specific for PPC, and priorities for PPC research to improve the quality of care for dying children and their families.¹⁸ Significant changes in the PPC landscape followed, including recognition by the American Board of Medical Specialties in 2006¹⁹ and the formation of dedicated fellowship training programs.²⁰ Today, PPC is a rapidly growing medical subspecialty designed to meet the needs of seriously ill children and their families,^{21–23} and has become an integral part of how hospitals throughout the United States are evaluated.^{24,25}

Despite the increasing prominence of PPC programs in US hospitals, however, information on the number and scope of these programs is sparse, with the most recent study of program prevalence now 7 years old, and this limited to Children's Oncology Group institutions.^{26–29} In contrast, the proliferation of adult palliative care programs has been tracked more closely, demonstrating that over the past decade the number of adult programs has more than doubled (although availability varies from state to state).^{30–32} More detailed characterizations of adult palliative care have also been published. For example, a survey of executive leaders of 101 adult cancer centers throughout the United States found that among the 51 National Cancer Institute cancer centers, 92% reported having inpatient palliative

care consultation teams, 59% had outpatient palliative care clinics, and 26% had dedicated acute care beds for palliative care, whereas among the 50 non-National Cancer Institute cancer centers, these percentages were lower, with 56% reporting inpatient consultation teams, 22% reporting outpatient clinics, and 20% reporting dedicated palliative care beds.³³

The characteristics of PPC programs, including their staff composition, range of services offered, financial support, and frequency of consultations, have not been studied on a national scale. Such information is crucial to enable program and resource planning and to assess outcomes in a standardized fashion. In an effort to establish this useful baseline, we surveyed all children's hospitals and related institutions in the United States to determine the number and characteristics of US hospital-based PPC programs.

METHODS

In the summer of 2012, the Center to Advance Palliative Care's Pediatric Advisory Board surveyed 226 children's hospitals and related institutions in the United States, culled from a mailing list provided by the Children's Hospital Association (formerly known as the National Association of Children's Hospitals and Related Institutions). E-mail inquiries were sent to each organization to identify the appropriate person to respond to the survey; an e-mail solicitation for participation was also distributed via a PPC electronic mailing list, with care taken so that each organization received only 1 survey questionnaire. Before general release of the survey, the questionnaire was designed and pilot tested by an expert panel of PPC professionals and program directors. The questionnaire collected information about whether the hospital had a PPC program, characteristics of the hospital, and characteristics

of the PPC program in terms of origins, staffing, scope and nature of practice and services, and relationship to hospice service providers. Once the survey sample frame and questionnaire were ready, the Internet-based survey was administered via SurveyMonkey (SurveyMonkey Inc, Palo Alto, CA). In April 2012 an invitation was sent to an individual respondent at each hospital, with 3 subsequent general e-mail reminders encouraging nonresponders to complete the questionnaire and a few individualized e-mails sent to potential respondents who had expressed an interest in responding but had not yet done so. The survey study closed in August 2012. We collected the name of the hospital of the respondent to ensure that no hospital was reported in our data more than once.

The majority of the analysis consisted of the calculation of counts and proportions. The association between level of hospital support and year of program establishment was tested using linear regression. A negative binomial regression model (suitable for count data) tested the association of the number of new inpatient consultations per year and clinician full-time equivalents (FTEs, defined for this analysis as physicians, registered nurses, and advanced practice nurses), new inpatient consults and hospital bed size, and new inpatient consults and clinician FTEs, adjusting for hospital bed size and year of program establishment. Survey data were analyzed by using Stata 12.1 (StataCorp, College Station, TX).

The conduct of this survey regarding the organizational structure and practice of hospital-based PPC programs does not constitute human subjects research.

RESULTS

Of the 226 children's hospitals surveyed, 162 (71.7%) responded, distributed across the continental United States and Alaska (Fig 1). Among the 162

respondents, 112 (69.1%) indicated that their institution has a PPC program. If the austere conservative assumption is made that all non-respondents do not have a PPC program, then in the entire sample of surveyed children's hospitals, 49.6% (112/226) reported having a PPC program.

Among respondents, the oldest PPC program was established in 1984; the peak year of program establishment was 2008, and the rate of program establishment has subsequently decreased (Fig 2). Hospitals with PPC programs included university (76.8%) and community (27.7%) settings, ranging from small (28.5%, <101 beds) to large hospitals (26.9%, >250 beds); 58% were free-standing hospitals, and 36.6% were hospitals with pediatric beds in a mixed pediatric and adult hospital (Table 1).

There was variation in the types of services provided by the PPC programs (Table 2). Most (88.4%) offered a consultation service, and the majority of these (86.9%) provided consultations throughout the hospital. More than 90% of programs covered the pediatric age span from neonates to adolescents; 53.5% provided prenatal consultations, and 74.1% provided consultations for adult patients being cared for in their hospitals. Only 11.6% of programs reported having dedicated PPC beds or a palliative care suite. Whereas almost all of the PPC programs that offer consultations enable physicians to initiate the consult (97.0%), between a third and half of the programs enable nurses, social workers, chaplains, and parents to initiate a consultation. Consultation service availability was variable (Table 3). Among the 112 hospitals that reported having a program, on-site daytime coverage was provided by 87 (77.7%) during weekdays and by 5 (4.5%) during weekend days; telephone coverage with ability to return to the hospital

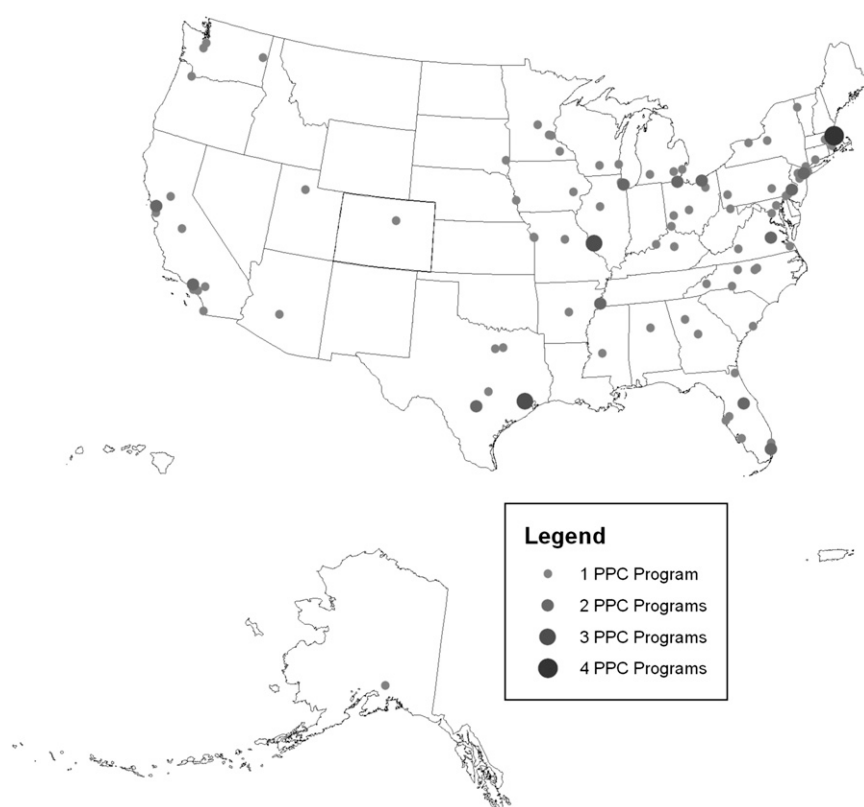


FIGURE 1
National distribution of PPC programs that responded to the survey.

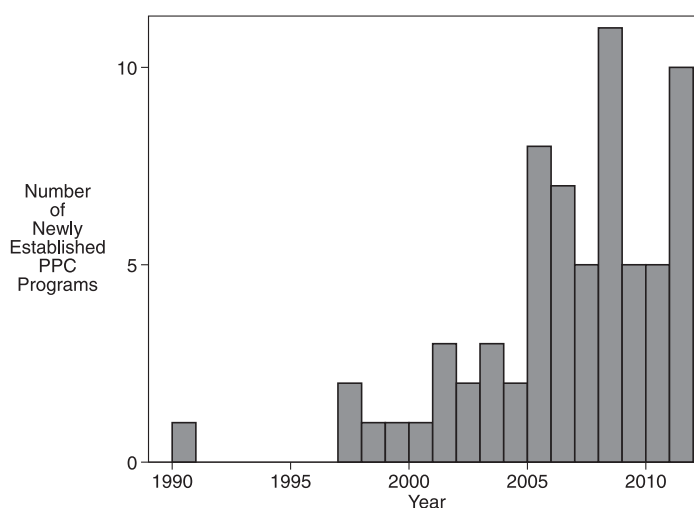


FIGURE 2
Establishment of new hospital-based PPC programs over time.

as needed was reported by 6 (5.4%) for weekdays and 52 (46.4%) for weekend days; one-third of programs are not available either in person or by telephone for night or weekend day coverage.

PPC programs with a consultation service reported a mean of 88 new inpatient consultations per year, with a broad interquartile range (27–127). The ratio of number of new consultations to number of hospital beds

TABLE 1 Characteristics of Responding Hospitals

| Institutional Characteristics | Total <i>n</i> (%) of 112 |
|--|---------------------------|
| Hospital type | |
| University teaching hospital | 86 (76.8) |
| Community hospital | 31 (27.7) |
| Number of beds | |
| 0–50 | 9 (8.0) |
| 50–100 | 23 (20.5) |
| 101–200 | 30 (26.8) |
| 201–250 | 12 (10.7) |
| 251–300 | 13 (11.6) |
| 300+ | 16 (14.3) |
| Hospital category | |
| Freestanding pediatric hospital | 65 (58.0) |
| Pediatric beds within a mixed hospital | 41 (36.6) |
| Other | 2 (1.8) |

was a mean of 0.54 (SD 0.43), median 0.44 (range 0–2.0). Programs with higher numbers of clinician FTEs had significantly more inpatient consultations per year ($P < .01$; Fig 3 left panel), as did PPC programs in larger hospitals ($P < .01$; Fig 3 right panel). In a multivariable regression model, PPC programs with more clinician FTEs had significantly more inpatient consults per year ($P = .04$; incident rate ratio for each additional clinician FTE of 1.20; 95% confidence interval, 1.01–1.42) after adjustment for hospital size ($P < .01$; incident rate ratio for each additional 50 beds of 1.14; 95% confidence interval, 1.04–1.25) and year of establishment ($P = .49$).

All programs had a relationship with hospice programs; 80.2% work with 1 or more independent hospice organizations and 19.8% of programs work in settings in which the hospital operates its own hospice program. Outpatient services include phone support (60.7%) and seeing patients in various outpatient clinic settings (59.8%). Only 18.8% of programs have a PPC outpatient clinic, 29.5% make home visits, and 10.7% provide home-based palliative care services. Bereavement services are commonly provided, including memorial services (77.7%) and routine

TABLE 2 Characteristics of Services Provided by Responding Hospitals

| Service Characteristics | <i>n</i> | % |
|---|----------|------|
| Has a PPC service | | |
| Yes | 112 | 69.1 |
| No | 50 | 30.9 |
| Consultation service | | |
| Yes | 99 | 88.4 |
| No | 8 | 7.1 |
| Missing | 5 | 4.5 |
| Consultation scope | | |
| Entire hospital | 86 | 76.8 |
| Only from certain units | 13 | 11.6 |
| Missing | 13 | 11.6 |
| Age-specific palliative care service | | |
| Prenatal | 60 | 53.5 |
| Neonates | 101 | 90.2 |
| Infants | 106 | 94.6 |
| Children | 105 | 93.8 |
| Adolescents | 106 | 94.6 |
| Adults | 83 | 74.1 |
| Dedicated palliative care beds or suite | 13 | 11.6 |
| Who can initiate consultation | | |
| Physicians | 96 | 85.7 |
| Nurses | 49 | 43.8 |
| Social workers | 48 | 42.9 |
| Chaplains | 42 | 37.5 |
| Patients or families | 50 | 44.6 |
| Hospice | | |
| Relationship with 1 or more hospices | 81 | 80.2 |
| Hospital or health system has own hospice | 13 | 12.9 |
| Palliative care and hospice function together | 7 | 6.9 |
| Outpatient services | | |
| Home visits | 33 | 29.5 |
| Outpatient clinic | 21 | 18.8 |
| Patients seen in 1 or more clinics | 67 | 59.8 |
| Outpatient phone support | 68 | 60.7 |
| Home-based palliative care | 12 | 10.7 |
| No outpatient services | 24 | 21.4 |
| Bereavement services | | |
| Memorial services | 87 | 77.7 |
| Routine follow-up | 84 | 75.0 |
| Support groups | 47 | 42.0 |
| Individual counseling | 35 | 31.3 |
| No bereavement service | 4 | 3.6 |
| Other | 18 | 16.1 |
| Has sought or is seeking Joint Commission certification | 35 | 31.3 |

after-death follow-up such as telephone calls and sympathy letters (75.0%).

PPC programs reported an average of 2.33 FTE personnel devoted to the program, of which 0.85 FTE were licensed independent practitioners (physicians and nurse practitioners). The average FTE for physicians, advanced nurse

practitioners, registered nurses, and social workers was >1 day per week (0.2 FTE) (Table 4). The range of total staff across the programs was very broad; for physicians, 0 to 3.8 FTE, and for nurses, 0 to 6.6 FTE (Table 4). Social workers were members of 66.1% of programs, but with an average FTE of only 0.29 across all programs, ranging from 0 to 3.0 (Table 4). Figure 4 provides a distribution of both total physician FTEs and the number of physicians who provided PPC services, demonstrating great variation across programs in both of these measures, with 51.5% (35 of 68) of programs reporting having only 1 physician.

Among the PPC programs that responded to this survey, 42 provided data about their sources of funding; on average in these programs, 55.8% of operating funds came from the hospitals, 28.2% from philanthropy, 10.3% from billing, and 5.8% from other sources. The level of hospital support was not related to either the size of the hospital ($P = .55$), the year of program establishment ($P = .66$), or the annual number of new consultations performed by the program ($P = .22$). A third of programs reported either having or being interested in seeking Joint Commission palliative care advanced certification.²⁵

DISCUSSION

In this survey of children's hospitals and related institutions across the United States, the results show that almost 50% of all pediatric hospitals reported having a palliative care program; that the majority of programs were established within the past decade; that the staff composition of these teams and the services they provide are highly variable; that the programs receive substantial support from their hospitals; and that programs with more clinical staff perform more inpatient consultations.

TABLE 3 Availability of Consultation Services

| Consultation Availability | Times | | | |
|-----------------------------------|----------------|------------------|--------------------|----------------------|
| | Weekdays N (%) | Weeknights N (%) | Weekend Days N (%) | Weekend Nights N (%) |
| On site | 87 (77.7) | 3 (2.7) | 5 (4.5) | 1 (0.9) |
| Telephone; can return to hospital | 6 (5.4) | 54 (48.2) | 52 (46.4) | 54 (48.2) |
| Telephone only | 0 (0) | 18 (16.1) | 17 (15.2) | 19 (17.0) |
| Not available | 19 (17.0) | 37 (33.0) | 38 (33.9) | 38 (33.9) |

Percentages calculated as a proportion of the 112 hospitals that indicated that they had PPC programs; programs that left these questions blank were presumed not to provide the indicated coverage.

Our findings are in alignment with the scant published data on PPC services in the United States, specifically the 2005 study focused on Children's Oncology Group member hospitals, which had a response rate of 81% of the 232 hospitals surveyed. Among those respondents, 58% reported having a palliative care team available for pediatric patients (but with no data about the nature of these teams).²⁷

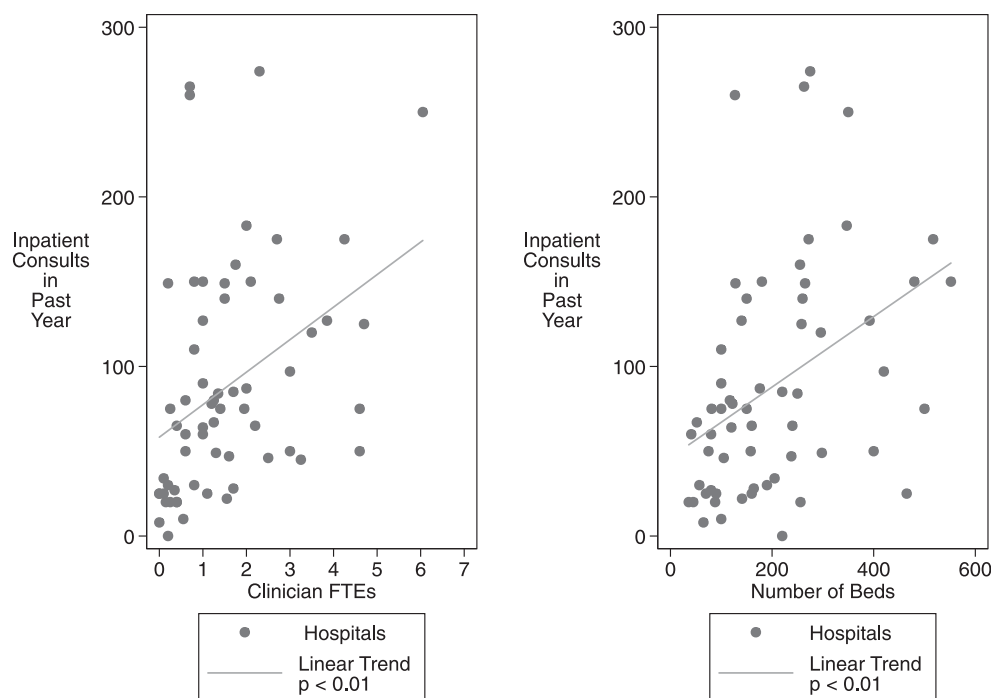
Six key elements of our study findings warrant discussion. First, the number of hospitals with PPC teams is increasing, with broad national representation,

suggesting that PPC is becoming a new standard of practice among children's hospitals. The rapid growth in the past 10 years is consistent with the recognition that PPC is an essential element in the care of children with serious illness and their family members.

Second, PPC teams provide a diverse array of services, including inpatient, outpatient, and bereavement care, to the entire spectrum of pediatric patients including adults, as has been observed previously.³⁴ As noted in a large national cohort study of the

6 largest PPC teams in the United States, patients seen by palliative care teams are in keeping with the trend seen generally across hospitalized pediatric patients.³⁵ They are likely to be increasingly complex,³⁶ use many health care resources,³⁷ and be prone to repeated hospitalizations.³⁸ Some PPC programs, however, do not offer direct patient care consultative services and instead are limited to educational services only (as we know from speaking with representatives of such programs). Defining the core complement of services required of a PPC team is an essential task for the field.

Third, most programs are highly dependent on institutional financial support, because palliative care work, with pediatric or adult patients, does not generate sufficient clinical revenue to be self-supporting.³⁹ Research is needed to better understand both the financial and nonfinancial benefits of palliative care services to patients and

**FIGURE 3**

Number of new inpatient consults per year by palliative care team clinician FTEs and number of hospital beds.

TABLE 4 FTEs for Different Types of Staff by Discipline

| Discipline | Mean FTE | Range | % of Programs With 0 FTE |
|---|----------|--------|--------------------------|
| Physician | 0.45 | 0–3.8 | 41.2 |
| Nurse (advanced practice nurse or registered nurse) | 0.80 | 0–6.6 | 36.6 |
| Advanced practice nurse | 0.40 | 0–3 | 54.5 |
| Registered nurse | 0.40 | 0–5.6 | 67.0 |
| Social worker | 0.29 | 0–3 | 66.1 |
| Administrative assistant or coordinator | 0.26 | 0–2 | 62.5 |
| Chaplain | 0.16 | 0–1.6 | 74.1 |
| Child life specialist | 0.16 | 0–1.6 | 83.9 |
| Bereavement specialist | 0.11 | 0–2 | 84.8 |
| Music or art therapist | 0.05 | 0–2 | 92.9 |
| Psychologist | 0.03 | 0–1.2 | 94.6 |
| Massage therapist | 0.01 | 0–0.75 | 96.4 |
| Pharmacist | 0.01 | 0–0.7 | 97.3 |
| Physical or occupational therapist | 0.01 | 0–0.5 | 98.2 |
| Dietitian | 0.00 | 0–0.25 | 98.2 |
| Physician assistant | 0.00 | 0–0 | 100.0 |

The Joint Commission Advanced Palliative Care Certification, Program Standard PCPM.7.1. The core interdisciplinary team is composed of a licensed independent practitioner, registered nurse, chaplain, and social worker.²⁵

families, hospital staff, and health systems, to maintain the growth and sustainability of these programs. In addition, every palliative care program needs resources to maximize billing practices and to seek philanthropic funding so as to develop a solid and broad-based portfolio of program financial support.

Fourth, the staffing numbers reported by respondents indicated wide variation, both in the types of professionals working in palliative care on any given team and in the number of people

providing coverage for a given FTE. For instance, a program with 1.0 funded FTE, staffed by 1 physician working full-time in palliative care, might have very different attributes and outcomes compared with a program with 5 physicians, each providing 0.2 FTE. These findings underscore the opportunity to clarify essential activities, core services, and minimal staffing standards for PPC teams.^{40,41}

Fifth, a significant trend was observed for hospitals with larger teams (more FTEs), in that they performed more new

PPC consultations, even after adjustment for hospital size. This finding was not surprising, and it speaks to the rapid uptake of palliative care services by referring clinicians, as has been found in adult palliative care programs.⁴² Based on our anecdotal experience providing advice to a wide variety of PPC programs, when programs start, they typically have few staff, yet they are soon inundated with more consultations than can be appropriately managed, leading to allocation of new resources to increase team size. The problem of increasing referrals necessitating more specialist staff has led to a call, in the realm of adult palliative care, for increasing the pipeline of palliative care fellowships and greater generalist palliative care training for all hospital staff so as to offload the demand on specialists.⁴³ With currently only 5 Accreditation Council for Graduate Medical Education–approved fellowship training programs dedicated to PPC (with a few more adult-oriented programs that accommodate pediatric-oriented fellows), similar workforce issues must be addressed for infants, children, teenagers, and young adults. Sixth, this study data reveal that PPC programs are a work in progress in terms of providing round-the-clock services and a full spectrum of services across the continuum of care. A goal of all programs should be to provide round-the-clock care in accordance with the program standards of the Joint Commission's Advanced Certification for Palliative Care.²⁵ Furthermore, given that most pediatric care occurs outside the hospital, it is imperative that programs develop robust services across all settings, including home-based care and clinic services. In addition, the large percentage of PPC programs (>74%) caring for adult patients >18 years of age (which is a growing population within children's

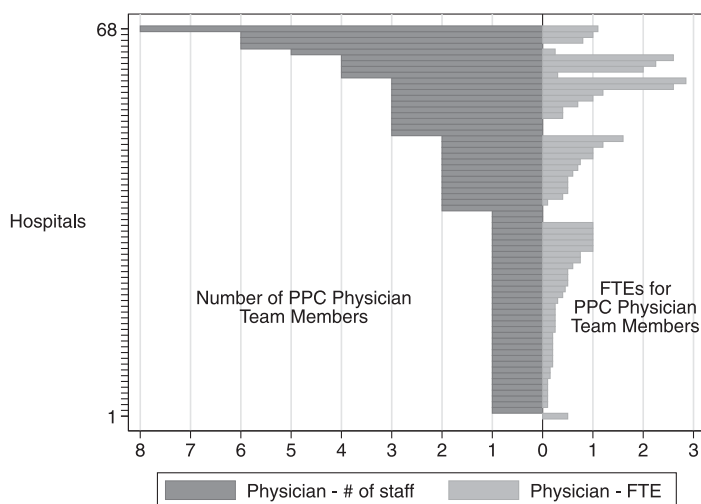


FIGURE 4 Number of physicians on palliative care team and physician FTEs for palliative care team.

hospitals⁴⁴) argues for planning and resources that enable sufficient staffing and expertise within PPC programs to ensure high-quality care for these adult patients and effective transition from pediatric to adult-oriented health care systems when appropriate.

This study has 2 principal limitations. First, although the response rate was high, the findings cannot be extrapolated to nonresponding hospitals or to hospitals that were not part of the sample of children's hospitals identified as such by the Children's Hospital Association. Second, although the study endeavored to identify appropriately knowledgeable respondents for each hospital, the reports provided by the individual responders probably have some degree of error due to incomplete knowledge or faulty internal data collection.

Based on our experience with this survey, along with our knowledge of the field, we encourage future surveys of PPC programs to characterize the clinical conditions that patients have, as distinct from the clinical services that request the PPC consultation or service; describe what PPC programs do on a daily basis, in terms of the types of clinical and nonclinical services provided to patients and families and in terms of quality improvement or research endeavors, and the degree to which PPC teams operate in an interdisciplinary manner; collect accurate, detailed data on clinical billing practices and all the funding sources that support these programs; and seek to achieve a 100% response rate. Furthermore, if data were collected from PPC programs over time, essentially conducting a cohort study of PPC programs, we could identify factors

associated with programmatic success or struggle.

PPC programs are becoming standard in children's hospitals throughout the United States. Now that a critical mass of programs exists, it is important to define program standards regarding staffing, data collection, and scope of services so that the designation of "pediatric palliative care program" has uniform meaning across care sites. From this place of common understanding can come future crucial investigations into outcomes that will define PPC as a standard of care for children with life-threatening conditions and their families.

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