Pediatric Palliative Care Programs in US Hospitals

Maggie M. Rogers, MPH,[a] Sarah Friebert, MD,[b] Conrad S.P. Williams, MD,[c] Lisa Humphrey, MD,[d] Rachel Thienprayoon, MD, MSCS,[e] Jeffrey C. Klick, MD[f]

abstract

BACKGROUND AND OBJECTIVES: Pediatric palliative care (PPC) is integral to the care of children living with serious illnesses. Despite the growth in the number of established palliative care programs over the past decade, little is known about the current operational features of PPC programs across the country.

METHODS: The National Palliative Care Registry collects annualized data on palliative care programs' structures, processes, and staffing. Using data from the 2018 registry survey, we report on the operational features of inpatient PPC programs across the United States.

RESULTS: Fifty-four inpatient PPC programs submitted data about their operations. Programs reported a median of 3.8 full-time equivalent staff per 10 000 hospital admissions (range 0.7–12.1) across the core interdisciplinary team, yet few (37%) met the minimum standards of practice for staffing. Programs provided more annual consults if they were longer-standing, had more interdisciplinary full-time equivalent staff, offered 24/7 availability for patients and families, or were at larger hospitals. The majority of programs reported concern for burnout (63%) and an inability to meet clinical demand with available staffing (60%).

CONCLUSIONS: There is considerable variability in PPC program operations and structure in hospitals. This study affirms the need for updated program standards and guidelines, as well as research that describes how different care delivery models impact outcomes for patients, families, staff, and health care systems. Future studies that further define the clinical demand, workload, and sustainability challenges of PPC programs are necessary to foster the provision of high-quality PPC and maintain a vital clinical workforce.

---

[a]*Center to Advance Palliative Care at the Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York;* [b]*Division of Pediatric Palliative Care, Department of Pediatrics and Rebecca D. Considine Research Institute, Akron Children's Hospital, Akron, Ohio;* [c]*Palliative Care Program and Department of Pediatrics, College of Medicine, Medical University of South Carolina, Charleston, South Carolina;* [d]*Division of Hospice and Palliative Medicine, Department of Pediatrics, Nationwide Children's Hospital, The Ohio State University School of Medicine, Columbus, Ohio;* [e]*Department of Anesthesia, Division of Palliative Care, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; and* [f]*Department of Palliative Care, Children's Healthcare of Atlanta and Division of Palliative Care, Department of Pediatrics, School of Medicine, Emory University, Atlanta, Georgia*

WHAT'S KNOWN ON THIS SUBJECT: Pediatric palliative care has increasingly become the standard of practice in caring for children living with serious illness. However, little is known about the impact that program operations and structure have on children, staff, and health care systems.

WHAT THIS STUDY ADDS: Previous studies have described pediatric palliative care program structure and operations. This study updates the literature for a rapidly evolving field and draws linkages among funding, sustainability, burnout, and future research to facilitate program growth and improve patient outcomes.

ARTICLE

The practice of pediatric palliative care (PPC) is focused on providing the best quality of life for children living with serious illness and their families, by using interventions to relieve suffering, improve quality and enjoyment of life, facilitate informed decision-making, and assist with care coordination among clinicians and community stakeholders.[1] This care is practiced across disciplines and may include specific tasks that help manage the pain, symptoms, and stress associated with serious illness, regardless of prognosis.[2]

PPC programs use interdisciplinary, specialty-trained clinical teams to improve the practice of PPC within a health care system and community by providing high-quality direct patient care (often for more complex patients) as well as policy updates, advocacy, education, training, and research.[3] These programs maintain responsibility for fostering patient-centered, family-engaged care that explores, understands, and respects the values of patients and families and create partnerships among all health care providers involved in the patient's care.[1]

PPC has been associated with improvements in quality of life, better communication with parents, and decreased hospital and emergency department use.[4–8] Health care systems have begun to recognize PPC as the standard of practice in providing high-quality care to children living with serious illnesses.[1] The American Academy of Pediatrics recommends that all large health care organizations serving children with serious illnesses have dedicated interdisciplinary PPC programs and that PPC interventions are initiated at diagnosis and integrated throughout the illness.[1] Nationally, the number of palliative care programs has been steadily increasing over the last two

decades; most freestanding children's hospitals in the United States now report having a PPC program.[9–12]

Multiple organizations endorse recommendations and guide minimum practice standards, program responsibilities, and operational features of PPC programs.[1,13–17] Unfortunately, because of cultural, operational, and financial challenges, many programs have struggled to adhere to guidelines and provide equitable access to high-quality PPC.[10,18–21] New programs report rapid clinical growth that quickly outstrips available resources to meet that demand.[9] Programs that grow and become highly valued within their health care systems often experience difficulty securing additional funding to support that growth.[10] Yet reliable funding is a critical component of program sustainability and wellness and ensuring high-quality clinical care.

Such program-level challenges compound the inherent emotional challenges encountered by clinicians who provide PPC. The American Academy of Pediatrics states, "Support of all healthcare professionals … is crucial to the well-being and continued ability of staff to meet the needs of families and children who have serious life-threatening or inevitably life-shortening conditions."[1] Palliative care providers "focus on the needs of caregivers yet suffer from a lack of policies and reimbursement that explicitly support this mission."[22] In addition, recommendations to address these concerns often place the responsibility on clinicians themselves rather than on addressing system challenges on an organizational level.[20,22–24]

Despite the growing importance of PPC in health care systems, there is a paucity of literature describing

PPC program operations and structure and how standardized practices are across programs nationally. The last comprehensive national study was conducted in 2012, and researchers found significant variation in PPC program services.[10] In a newer 2016 study focused only on perinatal PPC, researchers found similar variation and concluded that the field was still developing.[25] In a relatively new and rapidly evolving field, programs need both updated operational benchmarks and a deeper understanding of program challenges to guide program development. To address this gap in knowledge, the authors sought to describe the current structural and operational features of inpatient PPC programs across the country.

METHODS

Study Design and Data Sources

The National Palliative Care Registry ("the Registry") has been collecting self-reported, annualized data on palliative care program structures and processes since 2008.[25] Participation in the Registry is free and voluntary for all specialty palliative care programs in the United States. Programs are recruited through word of mouth, e-mail marketing, presentations, publications, and conference presence.

The Registry platform allows numerous palliative care program members to work collaboratively on a single program dashboard while preventing the submission of duplicate surveys. The fourth edition of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care represent best practices in the field; elements in the Registry align with domain 1: structure and processes of care.[13,25] The Registry elements are organized into 3 categories: core program

ROGERS et al

information, optional program information, and specialty modules (see Supplemental Information).

Program leadership maintains responsibility for the integrity and validity of entered data. Registry administrators monitor data entries, identify outliers and significant changes in program reporting over time, compare submitted hospital data to the data in the American Hospital Association Annual Database for consistency, and follow-up with programs on missing or erroneous data. In addition to this support, participating programs receive annual internal and peer comparison reports that can be accessed at any time.[25]

In 2019, a panel of PPC experts led the development of pediatric-specific data elements for the Registry's hospital survey, including a PPC specialty module and the opportunity for programs to self-identify as a PPC program. Although there are no required questions in the Registry, programs that identify as a PPC program are encouraged to submit all core program information and the PPC specialty module.

Because of the Registry's annual, retrospective nature, programs enter data on the previous year's operations. In this study, we focused on data submitted for the 2018 calendar year by programs that specifically self-identified as a PPC program. In the analysis, we focused on the core program information and the PPC specialty module to increase the usage and generalizability of the study. In alignment with the Registry's historical reporting standards, optional program information questions that met an a priori 70% response rate were also included.

Statistical Analyses

To control for variation in hospital size, PPC penetration rates were calculated by dividing the total number of initial consults by the total number of annual pediatric hospital admissions. Full-time equivalent (FTE) staff were standardized to 10 000 pediatric hospital admissions by multiplying total FTE staff by 10 000 and dividing by the hospital's total annual pediatric admissions. To test data normality, we used the Shapiro-Wilk test and presented medians and ranges for data not normally distributed. Box and whisker plots were used to examine FTE staff by discipline. Descriptive statistics and bivariate analyses, including simple linear regression, were performed by using IBM SPSS Statistics 24 (IBM SPSS Statistics, IBM Corporation). The UpSet plot was created with UpsetR.[26]

RESULTS

Fifty-four inpatient programs, representing 29 states and the District of Columbia, submitted data and identified as a PPC program (11% of all participating programs) (Fig 1). All core program information and PPC specialty

module questions received a 100% response rate, except the subsequent visits (response rate = 72%). Program funding (response rate = 87%) was the only optional program information element that met the 70% inclusion rate.

Hospital and Program Descriptors

The majority of programs operated in hospitals that were not for profit (89%), urban (83%), and teaching (100%) (Table 1). These hospitals varied widely in size, from 75 to 700 beds (median 257). The largest cohort (n = 27, 50% of total) operated within independent, freestanding children's hospitals. The total number of PPC programs across all hospital types is unknown, so the total prevalence could not be determined.

Although the oldest participating program started in 1997, most (N = 33, 61%) were established between 2008 and 2018. New program development peaked in 2011 and 2012 when 25% of participating programs were established (Fig 2). For the 47 programs reporting

FIGURE 1
Geographic distribution of participating PPC programs.

TABLE 1 Characteristics of Hospitals Where Responding PPC Programs Operate

Hospital Characteristic	N = 54
Hospital structure, n (%)	
Freestanding and independent children's hospital	27 (50)
Embedded children's hospital associated with general hospital	24 (44)
Pediatric ward within general hospital	3 (6)
No. beds, n (%)	
50–149	9 (17)
150–249	17 (31)
250–349	11 (20)
350–449	10 (19)
450+	7 (13)
Hospital ownership, n (%)	
Not for profit	48 (89)
Public	6 (11)
Geographic classification, n (%)	
Urban	45 (83)
Suburban	9 (17)
US region, n (%)	
South	20 (37)
West	13 (24)
Midwest	13 (24)
Northeast	8 (15)
Teaching hospital, n (%)	54 (100)

funding sources, 98% used hospital support, 74% used revenue from billing, and 72% used revenue from grants or philanthropy.

Program Coverage and Availability

Forty-six programs (85%) were available for consultation to all pediatric oncology, pediatric intensive care, pediatric cardiac intensive care, and neonatal intensive care beds in their hospitals. Programs that reported limited availability to these units were restricted by either operational design or insufficient staffing. Most programs reported limited availability, with only 46% (25 of 54) of programs providing 24/7 coverage (defined in the survey as 24/7 telephone support and availability for consultation Monday through Friday) to referring clinicians, patients and families, and hospice providers (Table 2). Eighty-two percent of PPC programs reported that hospice services were readily available for pediatric referrals.

Program Services

Clinically, 85% of programs reported providing services beyond inpatient PPC consultation (Table 2). Eighty-seven percent reported staff participation in nonclinicaland academic pursuits (Table 3). More than two-thirds reported staff pursuits of extramural grants and philanthropic funding for clinical care or research.

Patient Reach

Nearly all programs offered services to children from birth to the 25th year of life. Less than half offered prenatal services or services to patients aged >25 years (Table 2).

Programs reported a median of 266 annual initial consults (range 36–1466). When standardized to hospital size, PPC programs reached a median penetration rate of 2.7% (range 0.3%–10.3%). In bivariate analyses, a greater number of annual initial consultations was significantly associated with a greater number of core interdisciplinary FTE staff (b = 34.6; P = .001), longer-standing programs (b = −14.6; P = .011), 24/7 availability for patients and families (b = 125.5; P < .000), and larger hospitals (b = .6; P = .003).

Programs also reported a median of 742 billable subsequent visits annually (range 25–10 000), corresponding to a median of 3.5 billable subsequent visits per initial consult (range <1–29).

Staffing

Program staffing was highly variable, with programs using a wide range of professional disciplines (Table 4). Programs reported a median of 3.8 FTE staff per 10 000 hospital admissions (range 0.7–12.1) across the core
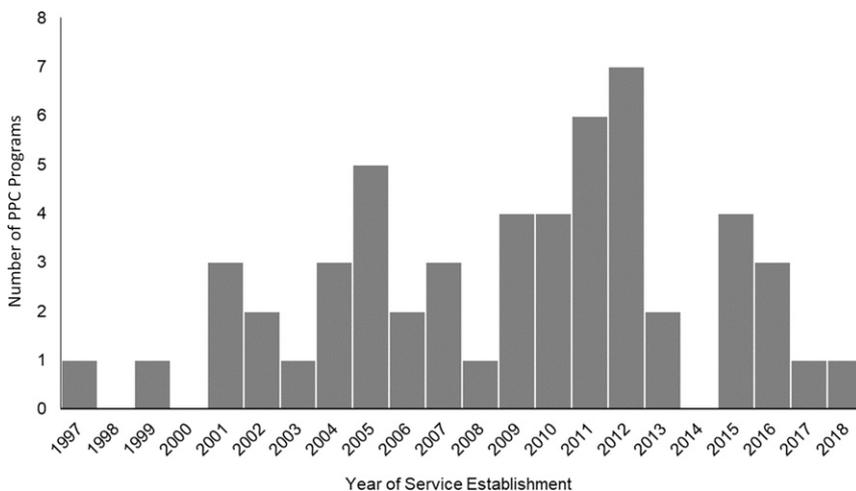
FIGURE 2
The number of PPC programs by the year of inpatient program establishment.

ROGERS et al

TABLE 2 Operational Characteristics of Responding PPC Programs

Operational Characteristic	N = 54
Age groups served, n (%)	
Prenatal	47 (87)
Neonates (birth to 28 d)	54 (100)
Infants (29 d to 11 mo)	54 (100)
Children (12 mo to 12 y)	54 (100)
Adolescents (13–17 y)	53 (98)
Young adults (18–25)	49 (91)
Adults (>25 y)	17 (31)
24/7 availability,[a] n (%)	
For referring clinicians	35 (6)
For patients and families	32 (59)
For community hospice providers	31 (57)
Standardized plans and operations, n (%)	
Team wellness activities	36 (67)
Bereavement plan	36 (67)
Staff education plan	33 (61)
Staff orientation plan	25 (46)
Quality improvement plan	24 (44)
Strategic business plan	23 (43)
Standardized referral criteria	22 (41)
Multiyear budget	18 (33)
Collects patient and family satisfaction	16 (30)
Marketing plan	8 (15)
Additional clinical services offered by the hospital-based PPC program, n (%)	
Ambulatory and/or outpatient palliative care visits	35 (65)
Bereavement services	35 (65)
Home hospice services	22 (41)
Consultative acute pain service	19 (35)
Home palliative care visits	18 (33)
Complex care service	9 (17)
Chronic pain management program	9 (17)
Telehealth services	9 (17)
Inpatient hospice services	8 (15)
Complementary medicine consult service	7 (13)
Inpatient primary medical management	2 (4)

[a] 24/7 availability is defined as Monday to Friday consultation availability and 24/7 availability by telephone.

interdisciplinary team of physicians, advanced practice registered nurses (APRNs), registered nurses (RNs), social workers, and chaplains (Fig 3).

Only 20 programs (37%) met national recommendations for team composition, with at least some FTE staff for the physician team (medical doctor or doctor of osteopathic medicine), nursing (RN or APRN), social work, and chaplaincy (Fig 4). Programs not meeting these recommendations were most often missing chaplaincy (52%) or social work (33%). Four programs (7%) were staffed by only 1 of the recommended disciplines, and 7 (13%) reported having no disciplines with at least 1.0 FTE staff member. Although 52 programs (96%) reported having

TABLE 3 Academic Pursuits of Responding PPC Programs

Clinician Academic Pursuits	N = 54, n (%)
Education and training of other clinicians	46 (85)
Presenting at conferences	46 (85)
Participating in leadership in professional organizations	38 (70)
Garnering grants and philanthropy	37 (69)
Conducting research and submitting publications	36 (67)

FTE physicians, only 42 (78%) had physicians that were board-certified in hospice and palliative medicine.

Nearly two-thirds (63%) of respondents reported subjectively feeling moderately or extremely concerned about burnout risk, and 60% reported being short-staffed and requesting additional staff to meet current patient care demands. Comparatively, only 1 program reported not being concerned about burnout risk, and 19% reported being stable and not requesting additional staff.

DISCUSSION

This descriptive study reveals ongoing variability among PPC programs in the United States related to program structure, staffing, and services. When compared with previous studies, these results reveal a continually evolving field, with larger PPC teams seeing more annual consults.[10]

This study also updates critical benchmarks and draws attention to the inherent risks associated with program development in a rapidly evolving field, including issues related to program sustainability, clinician burnout, and quality of care. As national benchmarks for staffing, care delivery models, and consult volume may be instrumental in fostering program sustainability, PPC leaders can use this study to advance program development, align program structure with national standards, monitor inherent risks to program sustainability, facilitate conversations about resource needs, and guide future research initiatives to advance practice standards.[27]

Across the 54 participating programs, only one item was consistent: providing care to

TABLE 4 Staffing Characteristics of Responding PPC Programs

Staffing Characteristic	N = 54
PPC team members, n (%)	
Physician	52 (96)
APRN	40 (74)
Social worker	36 (67)
RN	33 (61)
Administrative support	29 (54)
Chaplain	26 (48)
Physician fellow	21 (39)
Administrator	18 (33)
Medical director	18 (33)
Child life specialist	16 (30)
Psychologist	12 (22)
Music or art therapist	9 (17)
Physician resident	8 (15)
Ethicist	5 (9)
Massage therapist	4 (7)
Nutritionist or dietitian	4 (7)
Pharmacist	4 (7)
Physical or occupational therapist	4 (7)
Hospice liaison	3 (6)
Physician's assistant	3 (6)
Psychiatrist	2 (4)
Acupuncturist	1 (2)
Bereavement coordinator	1 (2)
Doula	1 (2)
Licensed practical nurse	1 (2)
Nurse practitioner fellow	1 (2)
Social work fellow	1 (2)
Certified in palliative care and/or medicine, n (%)	
Physician	42 (78)
APRN	17 (31)
RN	11 (20)
Social worker	4 (7)
Chaplain	3 (6)

neonates, infants, and children. Notably, programs reported a wide range of annual initial consults, with larger consult volumes associated with longer-standing programs, programs with more core staff, 24/7 availability to patients and families, and programs in larger hospitals. The range of core FTE staff per 10c000 hospital admissions (0.7–12.1) reveals the significantly different approaches that health care systems use to staff their programs.

These results highlight numerous challenges for PPC programs. Many programs are not yet meeting recommended practice standards, such as offering 24/7 availability to patients and families and staffing that includes physician, nursing, social work, and chaplaincy disciplines.[1,4–7] Rather than focusing on meeting these recommendations, programs may pragmatically determine staffing and care delivery models on the basis of organic program growth, the clinical units covered, and currently available funding and staffing. In addition, although the number of annual consults helps define the overall program workload, the clinical demand represented by these numbers may simply reflect the workload capacity of available staff rather than the total clinical demand for PPC services within the health care system. To clearly define ideal PPC staffing and care delivery models, future research efforts should focus on how specific models impact clinical demand, workload, quality, and both staff and patient and family outcomes.

Finally, the Patient Protection and Affordable Care Act of 2010 made it possible for children to qualify for hospice services while concurrently pursuing disease-directed treatments.[28] Despite this expanded access to hospice services, 40% of programs still reported resistance from hospice organizations to the provision of concurrent care, including refusing to enroll patients under the concurrent care clause. Future studies should also focus on how these barriers to access hospice care impact patient and family, staff, and health care system outcomes.

Most programs reported that staff are responsible for multiple discrete tasks, including direct patient care, education and training, academic endeavors, and pursuit of extramural grants and philanthropic funding. It is unclear how these tasks impact staff workload and stress or how these responsibilities compare with other pediatric disciplines. A more in-depth investigation into how these tasks are operationalized and compare with other pediatric disciplines would be beneficial in determining PPC staffing needs and the subsequent impact on patient and family outcomes.

Moreover, the majority of programs reported concern for burnout and an inability to meet clinical demand with available staffing, supporting concerns for PPC clinician burnout. However, further research into modifying factors (staffing and care delivery models, presence of interdisciplinary teams, clinician and program workload requirements, unmet clinical demand, culture and acceptance of PPC services, and financial support)

ROGERS et al
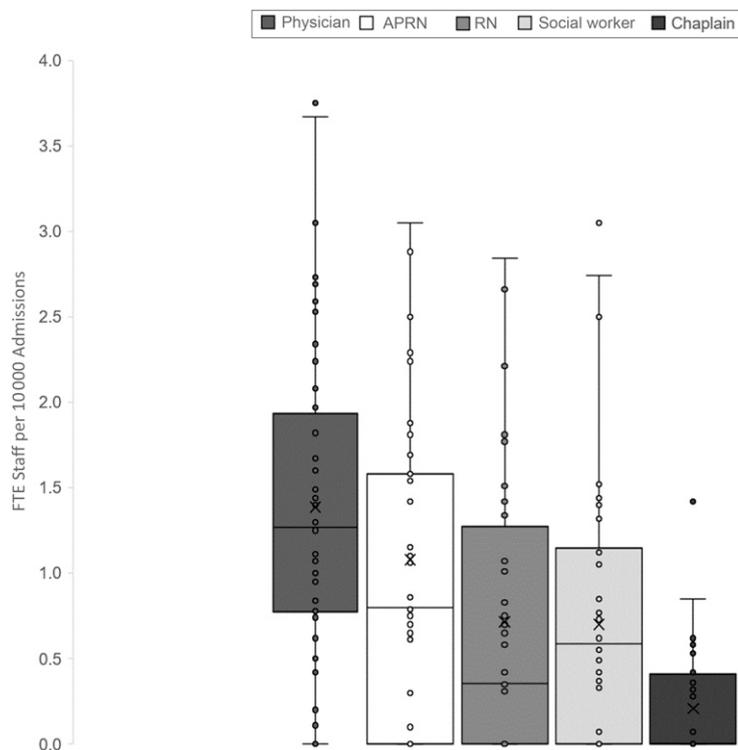
FIGURE 3
PPC program staffing levels (FTE staff per 10 000 hospital admissions) by core palliative care discipline. Core interdisciplinary team members include a physician, an APRN, an RN, a social worker, and a chaplain. Each dot in the box and whisker diagram represents a PPC program. The colored box represents the interquartile range, with the horizontal line in the box representing the median, the "x" indicating the mean, and the whiskers representing the minimum and maximum. Outliers are displayed beyond the whiskers.

is necessary to better understand these risks and design interventions to mitigate them.

Financial constraints remain a significant barrier to the growth and development of high-quality PPC programs.[20] Programs in this study use a variety of funding sources, with the majority reliant on philanthropy and hospital support. However, significant gaps remain in understanding (1) how programs allocate these funds across clinical and academic initiatives, (2) the financial sustainability of different clinical models, (3) the impact of reliable funding on program sustainability and staff wellness, and (4) the sufficiency of payment models for PPC services. Combined with our findings on program

stability and burnout risk, these results raise the concern that some PPC programs may already be at significant risk of closure or restructuring because of operational challenges.[29] Ensuring both the availability and financial sustainability of PPC programs will be critical to safeguarding ongoing high-quality care for seriously ill children and their families.

This study has some notable limitations. As the total number of inpatient PPC programs in the United States remains unknown, we cannot determine how representative the results are of all PPC programs nationally. All Registry data are self-reported, with some questions requiring subjective responses; results are, therefore,

subject to reporting errors and biases. Although the study sheds light on many aspects of PPC, including hospice and concurrent care, a more in-depth investigation is limited because of the data set. Finally, associations could not be meaningfully explored through multivariable models because of the small sample size.

In addition, in this study, we focused on PPC programs before the coronavirus disease 2019 pandemic. The long-term impact of the coronavirus disease 2019 pandemic on PPC programs remains uncertain because many critical variables continue to evolve. In early studies, researchers have suggested that the pandemic may worsen the moral distress and well-being of PPC clinicians.[30,31] In addition, even with these stressors and the potential increased need for PPC services, some programs are reporting staffing model challenges because PPC staff are being diverted to cover other clinical services deemed more critical during the pandemic. Most PPC programs appear to be experiencing challenges related to morbidity, mortality, cultural acceptance, and economic pressures on health care systems and other funding streams; however, it is currently unclear if these variables will ultimately be beneficial or detrimental to challenges facing PPC programs. This study offers a baseline for future comparisons to understand how PPC programs are impacted by the pandemic.

Most importantly, the authors acknowledge that the aim of this study was limited to describing PPC program characteristics. More work is needed to define which care delivery and staffing models lead to the highest quality of care and are most effective at meeting the clinical demand. This study suggests that an annual national registry can help
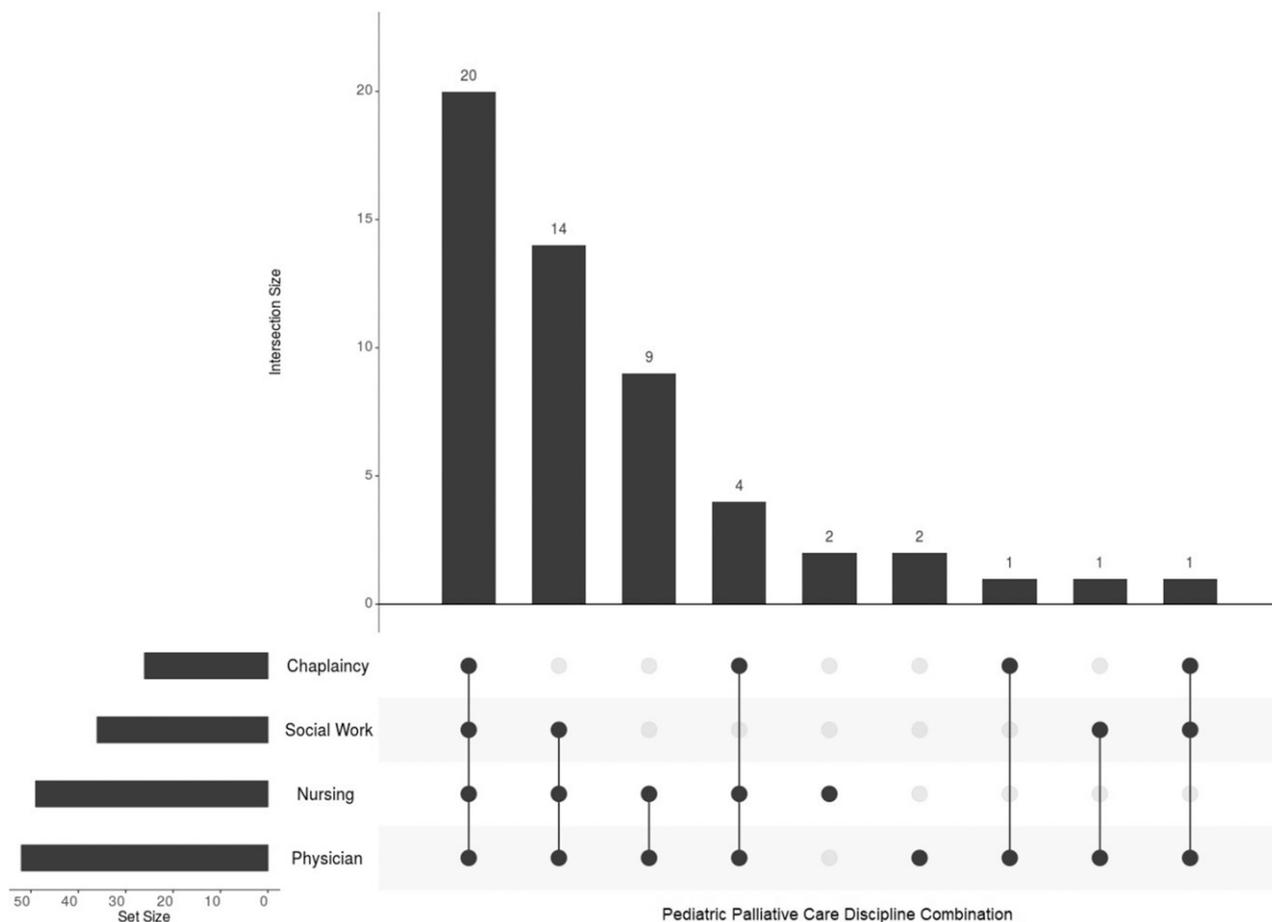
FIGURE 4
Program staffing models in relation to national recommendations for representation from physician (medical doctor or doctor of osteopathic medicine), nursing (APRN or RN), social work, and chaplaincy disciplines. The UpsetR plot highlights the intersections of these disciplines. The left horizontal bars show the number of programs reporting each distinct discipline, and the vertical bars show the number of programs reporting each combination of discipline. The dots on the bottom show which disciplines are included in the combination.

meet this need. Moving forward, the Palliative Care Quality Collaborative will provide the opportunity for PPC programs to collect standardized operational and patient-level data, creating opportunities for standardized practice evaluation, collaborative quality improvement initiatives, and evaluation of different staffing and care delivery models on patient and health care system outcomes.[32,33]

CONCLUSIONS

In this study, we found that variability in PPC program staffing and care delivery models persist. Many programs are not meeting

national guidelines related to minimum standards of practice, and findings indicate that long-term survival may be at risk for some programs. Future research is needed to define the most effective care delivery models, the staffing requirements of those models, and how different models impact patients and families, staff, and health care system outcomes. Additional opportunities exist to define patient care outcomes, refine standards of practice, and understand the clinical demand, workload, and sustainability of PPC programs. This work will be imperative to providing high-quality PPC services, ensuring the

sustainability of PPC programs, and improving care for seriously ill children and their families.

ACKNOWLEDGMENTS

ABBREVIATIONS

APRN: advanced practice
      registered nurse
FTE: full-time equivalent
PPC: pediatric palliative care
RN: registered nurse

ROGERS et al

REFERENCES

1. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics.* 2013;132(5):966–972

2. Klick JC, Hauer J. Pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care.* 2010;40(6):120–151

3. Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med.* 2013;368(13):1173–1175

4. O'Quinn LP, Giambra BK. Evidence of improved quality of life with pediatric palliative care. *Pediatr Nurs.* 2014;40(6):284–288, 296

5. Vern-Gross TZ, Lam CG, Graff Z, et al. Patterns of end-of-life care in children with advanced solid tumor malignancies enrolled on a palliative care service. *J Pain Symptom Manage.* 2015;50(3):305–312

6. Ananth P, Melvin P, Berry JG, Wolfe J. Trends in hospital utilization and costs among pediatric palliative care recipients. *J Palliat Med.* 2017;20(9):946–953

7. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. *J Palliat Med.* 2014;17(2):183–188

8. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children

with cancer. *J Palliat Med.* 2015;18(2):143–150

9. Miller EG, Weaver MS, Ragsdale L, et al. Lessons learned: identifying items felt to be critical to leading a pediatric palliative care program in the current era of program development. *J Palliat Med.* 2021;24(1):40–45

10. Feudtner C, Womer J, Augustin R, et al. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. *Pediatrics.* 2013;132(6):1063–1070

11. Rogers M, Kirch R. Spotlight on pediatric palliative care: national landscape of hospital-based programs, 2015-16. 2019. Available at: https://www.capc.org/blog/palliative-pulse-palliative-pulse-july-2017-spotlight-pediatric-palliative-care-national-landscape-hospital-based-programs-2015-2016/. Accessed July 17, 2020

12. Center to Advance Palliative Care and the National Palliative Care Research Center. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. Available at: https://reportcard.capc.org/. Accessed March 16, 2020

13. National Coalition for Hospice and Palliative Care. Clinical practice guidelines for quality palliative care, 4th edition. Available at: https://www.nationalcoalitionhpc.org/ncp/. Accessed March 16, 2020

14. National Hospice and Palliative Care Organization. Quality. Available at: https://www.nhpco.org/quality/. Accessed March 16, 2020

15. National Hospice and Palliative Care Organization. Standards of practice for pediatric palliative care: professional development and resource series. Available at: https://www.nhpco.org/wp-content/uploads/2019/07/Pediatric_Standards.pdf. Accessed July 17, 2020

16. American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics.* 2000;106(2 pt 1):351–357

17. Weaver MS, Heinze KE, Kelly KP, et al. Palliative care as a standard of care in pediatric oncology. *Pediatr Blood Cancer.* 2015;62(suppl 5):S829–S833

18. Bruera E. The development of a palliative care culture. *J Palliat Care.* 2004;20(4):316–319

19. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics.* 2008;121(2):282–288

20. Friedrichsdorf SJ, Bruera E. Delivering pediatric palliative care: from denial, palliphobia, pallilalia to palliactive. *Children (Basel).* 2018;5(9):120

21. Sisk BA, Feudtner C, Bluebond-Langner M, Sourkes B, Hinds PS, Wolfe J. Response to suffering of the seriously ill child: a history of palliative care for children. *Pediatrics.* 2020;145(1):e20191741

22. Kamal AH, Bull JH, Wolf SP, et al. Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S. *J Pain Symptom Manage.* 2020;59(5):e6–e13

23. Harrison KL, Dzeng E, Ritchie CS, et al. Addressing palliative care clinician

burnout in organizations: a workforce necessity, an ethical imperative. *J Pain Symptom Manage.* 2017;53(6):1091–1096

24. Montgomery A, Panagopoulou E, Esmail A, Richards T, Maslach C. Burnout in healthcare: the case for organisational change. *BMJ.* 2019;366:l4774

25. Rogers M, Meier DE, Heitner R, et al. The National Palliative Care Registry: a decade of supporting growth and sustainability of palliative care programs. *J Palliat Med.* 2019;22(9):1026–1031

26. Lex A, Gehlenborg N, Strobelt H, Vuillemot R, Pfister H. UpSet: visualization of intersecting sets. *IEEE Trans Vis Comput Graph.* 2014;20(12):1983–1992

27. Nemec S; Center to Advance Palliative Care. How to drive program growth with data from the National Palliative Care Registry. 2019. Available at: https://www.capc.org/blog/palliative-pulse-palliative-pulse-march-2018-using-national-data-to-drive-palliative-care-program-growth/. Accessed July 17, 2020

28. Lindley LC, Keim-Malpass J, Svynarenko R, Cozad MJ, Mack JW, Hinds PS. Pediatric concurrent hospice care: a scoping review and directions for future nursing research. *J Hosp Palliat Nurs.* 2020;22(3):238–245

29. Pantilat SZ, O'Riordan DL, Bruno KA. Two steps forward, one step back: changes in palliative care consultation services in California hospitals from 2007 to 2011. *J Palliat Med.* 2014;17(11):1214–1220

30. Rosenberg AR, Weaver MS, Fry A, Wiener L. Exploring the impact of the coronavirus pandemic on pediatric palliative care clinician personal and professional well-being: a qualitative analysis of U.S. survey data. *J Pain Symptom Manage.* 2020;61(4): 805–811

31. Evans AM, Jonas M, Lantos J. Pediatric palliative care in a pandemic: role obligations, moral distress, and the care you can give. *Pediatrics.* 2020;146(1):e20201163

32. Palliative Care Quality Collaborative. Join. Available at: https://palliativequality.org/participate. Accessed June 2, 2021

33. Rogers MM, Kamal AH, Rodgers PE, Meier DE, Pantilat SZ. Response to Bharadwaj et al., challenges of promoting uniformity in programs within a health care system (DOI: 10.1089/jpm.2019.0404). *J Palliat Med.* 2020;23(7): 884–885

ROGERS et al

Updated Information & Services	including high resolution figures, can be found at: http://pediatrics.aappublications.org/content/148/1/e2020021634
References	This article cites 26 articles, 7 of which you can access for free at: http://pediatrics.aappublications.org/content/148/1/e2020021634#BIBL
Subspecialty Collections	This article, along with others on similar topics, appears in the following collection(s): **Administration/Practice Management** http://www.aappublications.org/cgi/collection/administration:practice_management_sub **Standard of Care** http://www.aappublications.org/cgi/collection/standard_of_care_sub **Hospice/Palliative Medicine** http://www.aappublications.org/cgi/collection/hospice:palliative_medicine_sub
Permissions & Licensing	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: http://www.aappublications.org/site/misc/Permissions.xhtml
Reprints	Information about ordering reprints can be found online: http://www.aappublications.org/site/misc/reprints.xhtml

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

Pediatric Palliative Care Programs in US Hospitals

Maggie M. Rogers, Sarah Friebert, Conrad S.P. Williams, Lisa Humphrey, Rachel
Thienprayoon and Jeffrey C. Klick

The online version of this article, along with updated information and services, is
located on the World Wide Web at: