

# The Role of Professional Chaplains on Pediatric Palliative Care Teams: Perspectives from Physicians and Chaplains

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## Abstract

**Context:** Pediatric palliative care (PPC) specialists recognize spiritual care as integral to the services offered to seriously ill children and their families. Little is known about how PPC programs deliver spiritual care.

**Objective:** The goal of this pilot study was to begin to describe the role of professional chaplains in established PPC programs in children's hospitals in the United States.

**Methods:** In 2009 we surveyed 28 PPC programs to ascertain how spiritual care was provided. Of the 19 programs with staff chaplains who met additional study criteria, we randomly selected eight to study in detail. Based on interviews with the medical director and staff chaplain in these eight programs, we qualitatively delineated chaplains' roles in PPC.

**Results:** Twenty-four of the 28 surveyed programs (86%) reported having a staff chaplain on their clinical team. Among the 8 interviewed programs, there was considerable variation in how chaplains functioned as members of interdisciplinary teams. Despite these variations, physicians and chaplains agreed that chaplains address patients' and families' spiritual suffering, improve family-team communication, and provide rituals valued by patients, families, and staff.

**Conclusions:** Our survey of these PPC programs found that spiritual care was typically provided by staff chaplains, and our interviews indicated that chaplains appeared to be well-integrated members of these teams. Further research is needed to evaluate how well the spiritual needs of patients, families, and staff are being met, and the organizational factors that support the delivery of spiritual care in children's hospitals.

## Introduction

IT IS WIDELY ACCEPTED that spiritual care is an important component of palliative care in general, and pediatric palliative care (PPC) specifically.<sup>1-11</sup> Research also suggests that childrens'<sup>12-14</sup> and parents'<sup>15-19</sup> spirituality is integral to coping with serious or terminal illness. While research and clinical practice guidelines affirm the importance of spiritual care in PPC little is known about how PPC programs meet the spiritual needs of their patients and families. This pilot study had two specific aims: (1) to describe how spiritual care is provided in established PPC programs and (2) to describe the role of staff chaplains in these programs.

## Methods

The study had two phases. Phase 1 was a survey of 28 U.S. PPC programs identified by an advisory committee of PPC clinicians and investigators. This survey permitted identification of candidate programs for Phase 2. These were programs in existence for more than 1 year, with an interdisciplinary team and established referral procedures, able to provide data about their annual caseload. Phase 2 programs also reported adherence to the AAP PPC guidelines,<sup>3</sup> and staff with specialized PPC training. From the qualified programs eight were randomly selected for Phase 2 interviews with the chaplain and medical director. These semistructured interviews were all conducted by the same member of our research team

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TABLE 1. CHARACTERISTICS OF PEDIATRIC PALLIATIVE CARE PROGRAMS IN THE STUDY

	Phase 1 surveys (n = 28) Number	Percent	Phase 2 interviews (n = 8) <sup>a</sup> Number	Percent
Age of PPC programs				
1–2 yrs	7	25%		0%
3–5 yrs	9	32%	2	25%
6–12 yrs	12	43%	6	75%
Program annual caseload <sup>b</sup>				
10–99	13	46%	2	25%
100–199	10	36%	3	38%
200–299	3	11%	1	13%
300+	2	7%	2	25%
Region <sup>c</sup>				
Northeast	5	18%		
Midwest	8	29%		
South	10	36%		
West	5	18%		
Evidence of quality <sup>d</sup>				
Yes	23	82%	8	100%
No	5	18%		
Program qualified for Phase 2 interview <sup>e</sup>				
Yes	19	68%		
No	9	32%		

<sup>a</sup>The programs in Phase 2 were a subset of the programs in Phase 1.

<sup>b</sup>For most of the programs this represents the total cases seen in the previous 12 months. In several cases it only represents the new referrals in the previous 12 months. In several cases the figure represents the total active cases on the date the survey was completed. Where bereavement follow-up cases were reported they were omitted from this estimate.

<sup>c</sup>Region is not identified for the Phase 2 centers to protect their identity.

<sup>d</sup>The two quality criteria were: (1) program follows American Academy of Pediatrics PPC Guidelines and (2) key PPC staff have specialized PPC training.

<sup>e</sup>The three criteria for selection for Phase 2 were: (1) established PPC program, (2) evidence of quality, and (3) spiritual care provided by staff chaplain on the PPC team.

PPC, pediatric palliative care.

(K.A.L.) and focused on descriptions of the PPC program, its institutional setting, its spiritual care services, and the chaplain’s relationship to other team members.

These interviews lasted 30–60 minutes and were tape recorded and transcribed. Three members of the research team reviewed the interviews and extracted key themes.<sup>20</sup> The project was approved by the Rush University Medical Center Institutional Review Board. Phase 2 participants provided written informed consent.

**Results**

Key characteristics of the programs in both phases of the study are shown in Table 1. Twenty-five of the 28 (89%) surveyed programs had a staff chaplain on their team (Table 2). The two programs that did not have a PPC team chaplain called the institution’s chaplaincy department as needed.

Among the Phase 2 programs seven were in free-standing pediatric hospitals and one was in the pediatric department of an academic medical center. There was considerable variation in these eight programs. For example one program had two full-time physicians plus a full-time fellow, while another program’s medical staff consisted of a part-time physician. All eight of the Phase 2 programs provided inpatient consultation (range 65–375 cases per year). Five teams also provided outpatient care, four provided hospice care, and four provided bereavement support. Support came from philanthropic

funds, billing revenue, and allocations of unrestricted funds. Seven of the eight medical directors were board certified in hospice and palliative medicine. Seven of the eight chaplains were board certified by a national chaplaincy organization.

Three models of chaplaincy involvement were found among the interviewed programs. The most common model was a staff chaplain on the PPC team who saw most new cases and participated regularly in PPC rounds. In the second model, unit chaplains cared for any PPC patients on their units, and one of these chaplains was liaison to the PPC program. The third model used a clinical pastoral education (CPE) student chaplain to care for PPC patients and families and attend rounds. The CPE supervisor participated in other PPC education and support activities.

Some of the chaplains focused on outpatient and hospice care. Others focused on inpatients and their families. A few

TABLE 2. HOW SPIRITUAL CARE IS PROVIDED IN PEDIATRIC PALLIATIVE CARE PROGRAMS (N = 28)

	Number (%)
Staff chaplain on PPC team	24 (86%)
Unit chaplains on PPC team	1 (4%)
Student chaplains on PPC team	1 (4%)
PPC team call chaplain when needed	2 (7%)

PPC, pediatric palliative care.

provided inpatient and outpatient care. The chaplains' involvement in the PPC programs ranged from 1 to 4 days per week. In two programs, in addition to providing spiritual care, the chaplains also functioned as care coordinators with broader responsibilities including facilitating team-family conferences. In two other programs the chaplains took weekend rotations as the psychosocial team member on call. In most hospitals the PPC chaplain's salary was paid from the chaplaincy department.

Medical directors described chaplains' contributions to PPC programs in three ways. First, some described how chaplains helped relieve the spiritual suffering of patients and families. One physician described a young man with cancer who "[H]ad a great deal of pain. He didn't respond well to medication. It was a concern that we were missing something. The thing we were missing was his existential suffering that the chaplain was able to address. The pain was improved not only by narcotics but by the chaplain's interventions."

Second, some physicians described chaplains' contributions to improved family-team communication about goals of care. One physician mentioned a case where the chaplain's knowledge of a family helped the physician see they were ready for him to discuss topics he was worried would be too distressing. Another physician reported chaplains' interpretations of families' cultural and religious beliefs often enhanced the staffs' understanding of parents' decisions, goals, priorities, and values.

Finally, several physicians described the support chaplains provided to team members. One said, "A trained chaplain brings a whole other level of knowledge, skill, and comfort in dealing with these issues. That helps the team be a better team, be more resilient in this care."

Chaplains' reports of their contributions to the PPC team were broadly similar to the physicians'. However, the chaplains' tended to focus on the process of their work rather than on how it led to good outcomes. For instance, one chaplain said, "I try to emphasize a ministry of presence more than anything else and to be a consistent or trustworthy presence in their child's journey."

Both physicians and chaplains discussed the need to train the PPC team to address patients' and families' concerns about what to expect from a chaplain. For example, a common belief among families was that chaplains visit only when a child is dying. Additionally, some families fear that chaplains wish to convert them or will be judgmental of their faith. One chaplain described coaching his colleagues to probe further with families who say they prefer not to see a chaplain. By assuring these families, "Of course, we will honor your preference" and also asking them, "Can you tell us if you had a bad experience or are concerned about something?" he reported their team was able to assess the family's needs and respond to those with past painful experiences with chaplains or clergy or misperceptions about the chaplain's role.

Both physicians and chaplains described team members' differing levels of expertise in spiritual care. Several described all PPC team members as spiritual care generalists and the chaplain as the spiritual care specialist. One physician said if a spiritual issue arose when she was with a patient she provided what spiritual support she could and then made a referral to the chaplain.

The physicians were also clear about distinctions between chaplains and local clergy. They understood that local clergy

play an important role in supporting some families, particularly through faith-specific rituals. They also recognized that professional chaplains were trained to understand the spiritual and developmental issues of children and families facing life-threatening illnesses and to care for patients and families from a variety of religious, and secular, perspectives.

## Discussion

Evidence from this pilot study suggests that, in established PPC teams in U.S. hospitals, spiritual care is typically provided by a staff chaplain. In these PPC programs, chaplains were active and valued team members. The PPC medical directors described chaplains' contributions to critical issues that have also been described in the PPC literature including patient/family spiritual suffering<sup>16,21,22</sup> improving family-staff communication,<sup>21,23-28</sup> and providing rituals for families and staff. The active involvement of chaplains in these PPC programs is consistent with recent consensus guidelines for palliative care.<sup>29</sup> These study results also suggest that integration of chaplains on these PPC teams may reduce barriers to optimal spiritual care identified in an earlier survey of pediatric chaplains including lack of staffing, colleagues not trained in how to make referrals, and late referrals.<sup>30</sup> We found considerable variation in the ways these chaplains functioned within their PPC programs. Future research is needed to understand factors which may be associated with these variations.

The limited scope of this study precludes concluding that all PPC programs have similar well-integrated chaplaincy services. Because the eight PPC programs were selected from well-established programs, these findings are best viewed as models of spiritual care for PPC. Future studies should examine a representative sample of programs, interview additional staff, and include direct observation. More detailed information about chaplains' involvement with and influence on the PPC team would also be important.

Many authors have described the importance of research for evaluating and improving the quality of PPC.<sup>5,21,22</sup> In this study we found that the only evaluations of the quality of chaplains' care being conducted were patient satisfaction surveys. Future research should examine whether the PPC chaplain's spiritual care is meeting the spiritual needs of the patients and families served by these PPC programs.<sup>30</sup>

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## Author Disclosure Statement

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