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A Survey of Chaplains’ Roles in Pediatric Palliative Care: Integral Members of the Team

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To date, the field of health care chaplaincy has had little information about how pediatric palliative care (PPC) programs meet the spiritual needs of patients and families. We conducted a qualitative study consisting of surveys of 28 well-established PPC programs in the United States followed by interviews with medical directors and professional chaplains in 8 randomly selected programs among those surveyed. In this report, we describe the PPC chaplain activities, evidence regarding chaplain integration
with the PPC team, and physician and chaplain perspectives on the chaplains’ contributions. Chaplains described their work in terms of processes such as presence, while physicians emphasized outcomes of chaplains’ care such as improved communication. Learning to translate what they do into the language of outcomes will help chaplains improve health care colleagues’ understanding of chaplains’ contributions to care for PPC patients and their families. In addition, future research should describe the spiritual needs and resources of PPC patients and families and examine the contribution chaplains make to improved outcomes for families and children facing life-limiting illnesses.

**KEYWORDS** chaplains and pediatric palliative care, promising practices, spiritual care and pediatric palliative care

**INTRODUCTION**

Whole person care, including spiritual care, is a fundamental principle in palliative and hospice care. This philosophy is incorporated in the developing field of pediatric palliative care (PPC), where there is widespread agreement that spiritual care is integral to good pediatric palliative care. Statements from a number of PPC organizations reflect the need to include spiritual care (ChiPPS, 2001; WHO, n.d.), and guidelines for the spiritual assessment of ill children and their families have been published (Davies, 2002). Descriptions of leading PPC programs also include the importance of spiritual care in PPC (Duncan, Spengler, & Wolfe, 2007; Toce & Collins, 2003). A recent consensus statement describes board certified chaplains as the spiritual care specialists in palliative care (Puchalski et al., 2009).

Two bodies of research affirm the importance of including spiritual care in PPC. The first describes the spiritual needs of parents of children with serious and life-limiting conditions, including the need to make sense of what is happening to their child and to them (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Knapp et al., 2011; Feudtner, Haney, & Dimmers, 2003; Meyer, Ritholz, Burns, & Truog, 2006; Michelson et al., 2009; Milstein, 2003). The second describes the important role of religion and spirituality in helping children cope with illness (Pendleton, Cavalli, Pargament, & Nasr, 2002; Silber & Reilly, 1985; Stern, Canda, & Doershuk, 1992) and in helping parents and staff cope with the stresses of caring for a terminally ill child (Cadge & Catlin, 2006; Catlin et al., 2001; Meert, Thurston, & Briller, 2005; Robinson, Thiel, Backus, & Meyer, 2006).

While clinical practice and ethics guidelines affirm the importance of spiritual care in PPC and the need for spiritual care is documented in research, little is known about how PPC programs actually attempt to meet
the spiritual needs of their patients and families. In light of this, the present study had two specific aims. The first aim was to describe how spiritual care services are provided within PPC programs. In what proportion of programs is spiritual care provided by a staff chaplain on the PPC team, and in what proportion are these services provided in some other way? The second aim was to describe the role of professional chaplains in well-established PPC programs.

In another article, we reported that in 86% of the programs spiritual care is provided by a staff chaplain on the PPC team, and we describe some of the chaplains’ contributions to PPC (Fitchett, Lyndes, Cadge, Berlinger, & Misasi, 2011). In this article, we report on the chaplains’ descriptions of their activities. We describe evidence that the chaplains were integral to their PPC programs and factors that may contribute to this integration. We also report difference in how the medical directors and chaplains described chaplain contributions to these programs.

METHODS

The study was conducted in two phases. Phase 1, which gathered information for the first aim, consisted of a survey of 28 PPC programs. These programs were suggested by an Advisory Committee comprised of clinicians and investigators with extensive experience in PPC and/or pediatric chaplaincy. In these Phase 1 surveys we also gathered information that enabled us to identify programs for Phase 2 interviews. To qualify for the Phase 2 interviews the programs had to meet three criteria: a) spiritual care was provided by a staff chaplain on the PPC team, b) the program had been established for a year or more, and c) the team followed national PPC guidelines (AAP, 2000), and key PPC staff had specialized PPC training. Nineteen of the 28 surveyed programs met these criteria.

Because we lacked the resources to interview staff in all 19 programs, we randomly selected eight for the Phase 2 interviews. We interviewed the medical directors and PPC chaplains for each of these eight programs. These sixteen semi-structured interviews, which lasted 30–60 minutes, elicited descriptions of: a) the PPC program, b) the institution in which the PPC program was situated, c) the spiritual care services, and d) the chaplain’s relationship to other PPC team members. The interviews were tape recorded and transcribed. The interview data were analyzed by three members of the research team with experience in qualitative research. From the transcripts the team extracted key themes in the descriptions of the chaplains’ involvement in these eight PPC programs (Patton, 2002). The project was reviewed and approved by the Institutional Review Board at Rush University Medical Center. Phase 2 participants provided written informed consent.
RESULTS

Twenty-four of the 28 programs (86%) in Phase 1 reported that spiritual care was provided by a staff chaplain who was a member of their PPC team (Fitchett et al., 2011). Four programs (16%) reported that spiritual care was provided in other ways. In one program, unit chaplains cared for the PPC patients and families. In another program, a clinical pastoral education (CPE) resident provided care for the PPC patients and families. In the remaining two programs, chaplains were called when needed. Based on these findings, we concluded that it was typical for the spiritual care in these programs to be provided by a staff chaplain who was an integral member of the PPC team.

Among the eight PPC programs randomly selected for the Phase 2 interviews, seven were in free-standing pediatric hospitals, and the eighth was in an academic medical center. All eight programs had been in existence for at least three years, and their annual caseloads ranged from 100–300. To put these eight programs in context, we calculated the chaplain-to-inpatient bed ratio for the overall chaplaincy programs of these eight institutions (see Table 1). For the chaplain full-time equivalents (FTEs), we requested estimates for staff chaplains involved in direct, in-patient care only. Chaplain FTEs that were assigned to administration, education, or research were excluded whenever possible. CPE residents were counted as .5 direct care FTE. The chaplain-to-inpatient bed ratio in these eight institutions ranged from 1:50 to 1:150. By comparison, Wintz and Handzo (2005) report data from Chaplain Paul Derrickson’s unpublished 2004 survey of 93 pediatric hospitals, which found the average chaplain-to-inpatient bed ratio to be 1:68. Table 2 shows key characteristics of the medical directors and chaplains interviewed in Phase 2 of the project.

Among these eight PPC programs, we found considerable variation in how the chaplains functioned on the PPC team. The weekly amount of time

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**TABLE 1** Chaplain-Patient Ratios for Chaplaincy Departments in Phase 2 of the Study

<table>
<thead>
<tr>
<th></th>
<th>Pediatric hospitals (n = 7)</th>
<th>General hospital – all beds (n = 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADC or licensed beds</td>
<td>150–425</td>
<td>900</td>
</tr>
<tr>
<td>FTEs (range)</td>
<td>1–12.5</td>
<td>5.5</td>
</tr>
<tr>
<td>Chaplain – Patient Ratio (number of hospitals in each range)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 1:150</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Between 1:50 and 1:100</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Less than 1:50</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

ADC = average daily census.
FTE = full-time equivalent.
the chaplains were assigned to PPC families and patients ranged from one to four days per week (.2 to .8 FTE). In most of the programs, unit chaplains who were not specifically assigned to the PPC team also took care of PPC patients. In one program, the PPC chaplain was a CPE resident. In this program, the CPE supervisor was actively involved in education and support activities for the PPC team. In two programs, the chaplains were also care coordinators whose duties included orienting new families to the PPC program and setting up care planning conferences with the families. In two other programs, the chaplains routinely took weekend rotations as the psychosocial team member on call.

WHAT PPC CHAPLAINS DO

Though there is a growing body of research about what chaplains do (Handzo, Flannelly, Murphy, et al., 2008; Handzo, Flannelly, Kudler et al., 2008; Hummel, Galek, Murphy, Tannenbaum, & Flannelly, 2008; Montonye & Calderone, 2010), little has been published about the specific work of chaplains involved in PPC. In the interviews, we asked the PPC chaplains to describe a typical case. They informed us, “There is no such thing as a typical case.” However, chaplains did identify typical activities associated with the delivery of PPC. The Phase 2 interviews in our study elicited detailed information regarding the common activities of chaplains in PPC. We categorized the chaplain involvement into care for patients and families; facilitating communication between the families and the PPC team; and care for the staff.
CARING FOR PATIENTS AND FAMILIES

Which PPC Patients Are Seen by the PPC Chaplain?

The PPC chaplains regularly introduced spiritual care services to PPC patients or families. Sometimes staffing limitations made it difficult for the PPC chaplain to be involved except when the PPC patient or family was in crisis; however, several programs made it a goal to visit every patient who was involved in palliative care.

It’s our goal to [visit] every patient that is contacted for palliative care. … That doesn’t always happen, but [that is] the goal. [Chaplain]

Whenever there is a crisis, they [the staff] call, and I respond. Or the unit chaplain might be called. We share updates and referrals. Sometimes a family or patient self-refers, but not a lot. [Chaplain]

Spiritual Expertise

When asked what is unique about what professional chaplains do, both chaplains and physicians identified the spiritual assessment skills of chaplains; chaplains were often called to complete a spiritual evaluation of PPC patients and families.

I would do a spiritual assessment, trying to determine what their spiritual care needs are. What’s already in place, and what can we enhance, or what can we create for them? [Chaplain]

Another common chaplain activity involved helping patients and families find meaning in their hospitalization and illness experiences. “Deep inquiry,” as it was called by one chaplain, was done through the provision of spiritual care and grief support to families during stressful times, such as when a difficult decision about medical treatment needed to be made, when a child’s condition worsened, or when a child died. Chaplains also provided emotional and spiritual support to children and adolescents who were coming to terms with their life-threatening illnesses.

In the interdisciplinary team meeting, the social worker mentioned that a little boy had a really deep love for Jesus, and his family wasn’t very supportive of that. So the chaplain said to the family, “We, of course, will respect your wishes and would never want to be intrusive, and at the same time this is what the social worker had shared with us. We want to [see if] this child would like some extra support.” And the parents agreed. So [the chaplain] said to this little boy, “I understand that you have a great love for Jesus.” And he said, “Yes, Jesus gets me through every day.” And so they talked about what had happened and how he had found Jesus, and [how] he had latched onto this idea that Jesus heals. And that led to the
conversation about what kind of healing he would like and his own cognizance about his illness. And the mom had tears rolling down her face, so moved, and it was really a wonderful sort of bridge for the family to then talk about what it had been like for this child to be sick, and for this child to be able to say, "Mom and Dad, I'm really scared, and I really, you know, hope I can be healed," and what would healing really mean. [Chaplain]

We had an oncology patient who we were following. She was a very mature young woman, and I followed her from her diagnosis through her death, which was probably a year or more. [During] her last hospitalization, when she knew she was going to die, she wanted to talk with me about what is heaven like. "What do you believe about heaven? How can this be happening to me?" She had a toddler sister. "How will she remember me? How can that be fair? I'm never going to date. I'm never going to get married." And just all the grieving she was doing she was doing very vocally, and [she] wanted me to be the person for her to struggle through that with. And it's just a really holy time to be present with these kids when they're up to struggling with these hard issues. [Chaplain]

The rest of the healthcare team, I think, has their own spiritual support to offer often, and yet the really difficult theological quandaries, I think, the training that the chaplain has is really helpful. That these are all questions maybe none of us really get to answer, but we can think out loud about them together and what does it mean, and how do we maintain a relationship with God that we don't understand, or [provide] whatever spiritual practices might be really helpful. [Chaplain]

Traditional Rituals

Another typical activity among PPC chaplains was the provision of traditional rituals including prayers, blessings, baptisms, funerals, and periodic memorial services at the hospital for families of children who had died. In addition to administering traditional rituals, an important piece of what the chaplains did is the facilitation of traditional rituals of less common faiths.

We chaplains will pray or give blessings if the family or patient requests. [Chaplain]

We will baptize if the family requests. We typically first will see if the family has a particular church or faith community that they're connected with and if their pastor, minister, or priest can come to baptize, and, if not, then we will do it. [Chaplain]

We do [funerals] on occasion if the family asks us, and typically it's with families that don't have their own particular church. [Chaplain]

We have an annual memorial service in which we invite all families of all children who have died in the last five years. We typically have been averaging,
in terms of the numbers of people that show up, over four hundred, and the
number of kids that are represented is typically around a hundred children.
After five years out from the death [the parents] will stop receiving an invi-
tation, but they are welcome to come to the service. [Chaplain]

There was another situation I remember with a Hindu family where the
chaplain was able to understand that there was a water ritual that this
family wanted to have used, and [the ritual] was often, as I understand
it associated with death. But this family really wanted [the ritual] in terms
of a cleansing, and so the chaplain was able to help facilitate that and
really clarify [to the staff] that this wasn’t a Judeo-Christian sort of baptism.
So I think [chaplains] are also the liaison for some religious cultural issues
that can be really difficult.¹ [Chaplain]

Creating Rituals

Chaplains were also innovative in developing rituals that met the unique
needs of patients and families in palliative care situations. For example, one
chaplain described a Time of Transition ritual in relation to a patient who
was being discharged after a long-term treatment process. Though the staff
and family were pleased that the child had a healthy prognosis, they were
grieving the change. The Time of Transition ritual involved an acknowledg-
ment and appreciation of their time and work together as well as the grief they
experienced from the loss of support. The ritual included a Vow of Release
that involved a “letting go” of their current relationships while “keeping the
door open” to future support in case the discharged patient needed their care
again. Chaplains also created rituals for use with their PPC team members.
Some of these are described in the following sections.

Liaison with Community Clergy

Professional PPC chaplains reported serving as a liaison to the patient and
family’s faith community, when appropriate.

We are meeting the family to determine do they have spiritual support or
religous support already in place? Are there gaps in that support that we
can fill? Is there coordination we can do with that local support group?
[Chaplain]

Home Visits and Networking

Another activity reported by some PPC chaplains was home visits.

Today, I visited a family [at] home. The purpose of my visit was two-fold.
The [ill siblings] both expressed an interest in being baptized [and] they
wanted to attend church. One of them is on a ventilator; both are
confined to wheel chairs with very limited mobility, so it was hard for
them to get to a Sunday morning service. So I assisted them in finding
an opportunity where they go to a church [in the] evening. [Chaplain]

FACILITATING FAMILY-STAFF COMMUNICATION

Physicians and Chaplains Reported that Chaplains Helped to
Facilitate Family-Staff Communication

Once I have found out a little bit about who this family is, who this little
person is in their relationship within this family, what role they play, what
hopes and fears the families have for this child, then I have a sense of part-
nership with them [and] can go into the care conference. In one situation,
the child was very much changed by her treatment. So, we projected sev-
eral photographs of this girl at the start of the conference so that we could
actually meet who we were talking about and make this little human being
the center of our conversation rather than her diagnosis or her treatment.
And then [I] facilitated the conference with an eye toward making sure that
this family's goals were not being subsumed by any other agenda. And so
thinking through the filter of a parent as well as somewhat versed in the
medical setting, I can ask questions and hopefully allow parents to really
both relax and focus on what they feel that they need. [Chaplain]

We had a family who had a child who had a [life-threatening illness]. And
the family made a decision that they would prefer not to have any more
active treatment, and no one really questioned their judgment about that.
But the chaplain in that case provided support for that family and contin-
ual education and support for the staff, daily reassurance that this was
okay, and that this was going to cause the child less suffering, and it
was kind of a heroic effort on the part of this [chaplain] to take that on
and to be in that situation for several days. [Physician]

Case Conferences

In each of the eight programs, the chaplain attended the PPC team meetings
and contributed to the discussion of patient/family needs and care plans,
providing chaplaincy perspectives on staffing and care delivery while being
a liaison between the family and the PPC team.

[The staff] will page us, asking us to be a part of a care conference with
the parents of a patient. [Chaplain]

[At team meetings] as we are talking about different patients, I may have
some update on what might be going on with them. [Chaplain]

Mainly when I do contribute [to a team meeting] it's if I know the patient
and the family personally. I will share from my interactions with the
family. Sometimes it’s just asking, phrasing questions in the context of the meeting. [Chaplain]

PROVIDING SUPPORT FOR PPC TEAM

Chaplains also provided support for PPC team members, especially in stressful cases, and when there are disagreements over the intensity of medical interventions. That support included both regular rituals at team meetings and rituals for special needs.

[We spend time] checking in with staff, listening to staff. Maybe it was a particularly stressful patient or family to work with over a long period of time. Or maybe there has been some tension between say, the bedside nurse and physician [with] differing perspectives about what’s best for the child. [Chaplain]

Periodically when we have a patient who has been inpatient for a really long time who dies, and many staff have been connected with that patient sometimes we will have a special memorial service [in support of] that staff. [Chaplain]

Once a week we begin with a bereavement update, any deaths we’ve had in the last week. And then I will do some little ritual and some little offering of blessing or light a candle. Some little moment that is a spiritual care moment. [Chaplain]

Education

Chaplains also educated the PPC team members about spiritual issues in palliative care.

The in-patient staff has really begun to look to our social workers and Chaplain B as a person of expertise and looks to them for advice, counseling, really identifying palliative care needs and asking us to get involved. [Physician]

CRITICAL SELF-REFLECTION

We asked the chaplains to describe any cases where they felt they had been unhelpful. None of the chaplains could think of such a case, but the question led several chaplains to reflect on their perceived limitations.

I guess you always ask yourself did you do enough. [Chaplain]

I think the families who are at a place where they are open to my support, I think, I feel very supportive of them. The families that aren’t
open to my support is when I think it is a little bit frustrating, difficult for me. [Chaplain]

I work hard at trying to separate out what my hopes are, as far as what I do with the family, and whether the hopes are mine or those of the family. So I am fairly successful at identifying, ‘Are those my needs?’ When I experience a kind of tension or frustration, at times, I’ll typically have a conversation with colleagues or with friends to reflect on, ‘Why am I anxious about this? Is this my need or their need?’ There’s always the tension of people doing this work as to what is a good death, what’s a good type of process for a family. And we have our biases. Well, my bias is that they talk openly with each other. Well, certain cultures and certain families don’t talk openly. My bias is, of course, at the core of palliative care that suffering and pain is declining to the absolute smallest amount. But there are times when a family wants the [child] more awake, and so then you draw the line between over-sedating and having them interactive [but with more] pain. So physically, there are those tensions. Psychosocially, spiritually, families have all different needs and interests. [Chaplain]

CHAPLAINS ARE INTEGRAL TO PPC PROGRAMS

Due to the types of activities and high involvement of chaplains in PPC programs, we concluded that chaplains are integral to the delivery of interdisciplinary PPC. We found multiple indicators of chaplain integration in PPC programs.

Medical Directors Value Chaplain’s Role on Team

The first indicator of chaplain integration was the extent to which chaplains were valued as members of PPC teams by medical directors. All of the physicians spontaneously reported how much they valued chaplains’ contributions. Several physicians conveyed their conviction that high quality palliative care required attention to the spiritual needs of the patients and families, and many of the physicians played an active role in ensuring chaplaincy services were included in their PPC team.

Whenever we open a new patient, we always take a spiritual history. [Physician]

Dr. A just happened to negotiate an additional staff [chaplain] to free me up to do more. [Chaplain]

One physician described the value of chaplaincy services with reference to chaplains trained for clinical work, as compared to local clergy:

Sometimes there’s interesting dynamics or distinctions between whether people are trained chaplains or whether they’re trained as clergy, and...
how much they know about true chaplaincy work. I realize I’m treading on territory that’s not my primary bailiwick, but there are people who are really good at doing across-the-board chaplaincy work. “Let’s meet the family, find out where they are, and let’s do what we can to support them spiritually.” And then there are people who are more about the religion. [Physician]

Without exception, all of the physicians interviewed articulated the view that a significant mark of effective PPC is the provision of spiritual care.

I couldn’t run a team, wouldn’t want to run a team without involvement of spiritual care, and I think that obviously it’s a hallmark. [Physician]

Every family deserves the chaplain. [Physician]

Chaplaincy should always be a part of pediatric palliative care. I think that perhaps in the ideal world we’d have more funding available to increase the opportunity to work with chaplaincy, although we are fortunate to have a very robust chaplaincy program at the hospital, so in that way, we haven’t had to worry so much about it. But I think we couldn’t do without it. And I can’t believe there are programs that don’t have strong chaplaincy presence. I do believe very strongly in it. [Physician]

As part of the interviews, we also asked the physicians if they had any stories to share of “unhelpful chaplains.” None of the physicians reported any examples of practice they perceived as unhelpful to patients or families. Some physicians gave examples of bad fits, between the chaplain and a family who lacked a religious affiliation or who perceived chaplains as prophets of doom, or were mismatched with respect to personalities. One physician at the one hospital in the sample that used CPE residents on the PPC team had stopped making referrals to a particular CPE resident who was evaluated as not sufficiently skilled. This same physician reported a regular practice of texting and emailing the current CPE resident regarding patient and family care.

There’s been maybe one chaplain resident who just didn’t seem as skillful; somebody I would tend to just not call. But I don’t think there was any direct ill effects or anything. Just, I didn’t feel the same kind of quality of support that I’m looking for. [Physician]

Chaplains on PPC Teams See Most PPC Patients

The second indicator of chaplain integration was that all or most PPC patients were seen by the chaplain involved with the PPC team. There was little control or gate keeping of chaplain involvement by other members of the
team. Where chaplains did rely on staff for referrals, it was because chaplain staffing levels required help from the team to triage chaplain time. In some cases, the PPC chaplain was the one to make referrals to the PPC program.

I as a chaplain sometimes have contacted the palliative care team, like the APN or one of the physicians and said, “You know, I think this would be a good referral for the palliative care team,” but [the referral] ultimately has to come from the very team following the patient. [Chaplain]

Chaplains on PPC Teams Participate in Team Meetings

A third indicator of chaplain integration was their regular attendance and contributions to team meetings. As noted previously, chaplains contributed to meetings by educating PPC staff about spiritual issues in palliative care, reporting their spiritual assessments of families, clarifying the families’ cultural and religious understandings of care, and helping staff better comprehend how the patients and families made meaning of their experiences.

Contextual Factors Associated with Chaplaincy Integration

This study was not designed to evaluate factors that might contribute to chaplaincy being a well-integrated component of a PPC program. However, three factors that deserve consideration in future research were mentioned in the interviews. One factor was that the institution had well-established and highly regarded chaplaincy programs. A second factor was that the competence of the chaplains on the PPC teams reinforced the physicians’ and teams’ commitment to integrating chaplaincy services. A third factor was the role that some of the PPC chaplains played in creating these programs. In one institution, a chaplain administrator was on the team that helped to establish the PPC program, and in another hospital, the Director of Pastoral Care took a strong leadership role in originating the PPC program. As this chaplain said, “[PPC has] been a dream of mine for a long time.”

Chaplain Relationships with Fellow Team Members

One of the questions we asked both chaplains and physicians was whether chaplains seemed to get into conflict or competition with other members of the PPC team. A few chaplains reported differences in opinion regarding what was the most effective care for the family, or some confusion between social workers, child life specialists, or other chaplains about provision of services. However, there was very little evidence from chaplains or physicians of chaplains in competition or tension with other PPC team members.
HOW PHYSICIANS AND CHAPLAINS PERCEIVE CHAPLAIN CONTRIBUTIONS TO PPC

We asked participants in our study for their views on what chaplains contribute to PPC. When these physicians and chaplains discussed the work and contributions of PPC chaplains, they did so from different professional perspectives. Chaplains emphasized the process of their work, for example, being present. Physicians emphasized the contributions chaplains made to important outcomes. These findings are broadly similar to a recent report by Cadge, Calle, and Dillinger (2011) in which they report that pediatric physicians described the tasks chaplains perform (rituals, counseling, support) while chaplains described the perspective they bring to hospitals (wholeness, presence, healing).

Chaplains’ Perspectives

When chaplains described what they do, they usually focused on the processes they used as providers of spiritual care services: listening, offering hospitality and empathy, and, most often, being present. A few chaplains mentioned outcomes, but by and large, chaplains described what they do in terms such as “presence.”

So I go primarily just to be a spiritual resource, a spiritual presence for them, and often will say, “I’m the chaplain that works with the palliative care team. You can trust me to be a prayerful presence with you. And then we will figure out together what I can do to be helpful.” [Chaplain]

I think that we really provide sort of intangible things. Like staff will also say to me, “You know, you come on this unit, and I feel better. You’re such a calming presence. Your tone of voice is so comforting to me.” [Chaplain]

A slightly different perspective on their contribution to PPC is represented in the next quotes where two chaplains understood the connection between process and outcome, that an important outcome of chaplaincy is improved family communication.

So, I spend a lot of time with the families. I try to understand what their overall needs are, and I try to represent those in discussion with the medical teams and help to craft a decision or at least a course of action that will allow this family to move toward their goal or at least to move toward some resolution. [Chaplain]

I’m often struck by the kind of training we do in CPE, which is around developing listening skills and helping people really hear what someone else is saying, . . . to say to the team sometimes, “I’m not sure you actually heard what that family said.” Or to get down underneath, “How come the
mom isn’t visiting?” And the team gets really judgmental that this mom isn’t there [when] she’s wanting everything done for this child, and she’s not even there to see it. And to understand that, you know, there’s lots of other factors going on here for this mother, and to help them build some empathy about it. [Chaplain]

Physicians’ Perspectives

The medical directors, while aware of the impact of chaplains’ presence, focused their descriptions of chaplain contributions in terms of three key outcomes: chaplains 1) relieved the spiritual suffering of patients and family, 2) improved family-team communication, and 3) addressed the spiritual needs of the PPC team.

Without a chaplain we miss one of the integral parts of suffering for patients and families, and much like I wouldn’t expect the social worker or the chaplain to understand how to prescribe methadone, I would be joking if I thought that I could address spiritual suffering in a way that a chaplain could. [Physician]

And the chaplain’s presence along with our team throughout this young man’s hospitalization and his family’s care was intensely meaningful to the family. I think that they would have said that they wouldn’t have been able to withstand the ordeal, so to speak, without that kind of support. [Physician]

I think there are many instances in which Chaplain B has brought a depth of experience for the families that certainly a physician or a nurse cannot bring, and, for instance, we were taking care of a child in the ICU where we were doing a compassionate extubation, and the family was struggling appropriately with questions about is this interfering with the will of God and Chaplain B’s presence was, I think, imperative in helping this family feel confident and comfortable with the decisions that they made in terms of proceeding with the extubation. [Physician]

Physicians also reported that chaplains help improve the quality of family-team communication about the goals of care.

[Families] hold these values, and we [health care professionals] want to be respectful of those values, and [having the chaplain on the team] helps [health professionals] open their minds a bit, to be more accepting. And I think then that builds better relationships and better trust and better rapport, which means you can have better [family-team] communication, and better shared decision-making. [Physician]

I think sometimes [the chaplain is] just trying to give a possible frame for how patients or families might be interpreting information or where their decision-making may be coming from. [Physician]
You know, I think that [the chaplains] provide another opportunity and choice for families in which they may express themselves. And you need to have a menu of options available to families and give them every opportunity to be able to express their needs and to communicate about their distress. And sometimes the language of that communication is best met through a spiritual conversation, and the authority in that case is the chaplain. [Physician]

Physicians also valued that chaplains have the skill to address the spiritual needs of fellow PPC team members. One physician described a case in which the chaplain helped the PPC team address their own spiritual needs concerning a long-time patient whose mother had died and father was absent. As the patient was dying, the physician called the chaplain to be with the team at the patient’s bedside:

The chaplain’s prayer and scripture readings enabled us to be present with him. So I see [the chaplain] as making it possible for us to be present at that very sacred time. [Physician]

DISCUSSION

Implications for Chaplains: Explaining What We Do

One of the PPC chaplains in our study said to us, “Chaplaincy is not always understood by other clinicians, or the understanding is actually a misunderstanding.” We heard a similar concern from chaplains in a prior study (Lyndes, Fitchett, Thomason, Berlinger, & Jacobs, 2008). Our interviews with the PPC physicians in this study suggest that they in fact have a good understanding of chaplaincy and of what individual chaplains do for PPC patients and families.

The findings about the two differing perspectives we just described have led us to think that the way chaplains typically describe what they do may be contributing to this lack of understanding. The language of process, “being present,” that is so central for many chaplains, while not unknown to other health care colleagues, is not primarily how they think about their work. Health care colleagues are focused on promoting good outcomes. Chaplains share this goal, but frequently do not share its language. If chaplains can begin to describe their work using the language of outcomes, it may help their colleagues to better understand what they do (De Vries, Berlinger, & Cadge, 2008; Lucas, 2001; Wintz & Handzo, 2005). Thinking about their work in terms of outcomes is unfamiliar for most chaplains. Health care colleagues are fluent in this language and can be their teachers. For example, the PPC physicians we interviewed provided helpful examples of outcomes to which chaplains contribute: chaplains reduce spiritual suffering for patients and families and they improve family-team communication about difficult treatment decisions.
In a recent article in *The Lancet*, two physicians and a nurse wrote of palliative care: “Accompanying those in suffering—to be present in the face of suffering, to stay with the sufferer and listen, is an act that reduces suffering” (Liben, Papadatou, & Wolfe, 2008, p. 858). This example captures how it is possible to describe an important outcome (reducing suffering) in terms of processes that promote this outcome (being present in the face of suffering and to the suffering person; listening). A similar thoughtful integration of process and outcome is found in a qualitative study by British hospice chaplain Steve Nolan (2011). His work reports four types of chaplain presence and how they can foster hope in dying patients.

Those responsible for training chaplains need to help chaplains learn to think about and describe the outcomes they are addressing, as well as the processes they use (Nance, Ramsey, & Leachman, 2009). Chaplains also need to accept that an integral part of their job is educating their health care colleagues about what they do and how they contribute to good outcomes for patients, “telling our story, again” as we described in our prior study (Lyndes et al., 2008). A chaplain in this project quoted a physician colleague who described the frequent staff rotations on health care teams and the related need to “educate the parade. There are always new faces, there are always new dynamics, and so, as a result, you can’t count on history to support you.”

**SUMMARY AND CONCLUSIONS**

In reviewing what the physicians and chaplains in this study told us about chaplains’ contributions to PPC readers must remember that it is anecdotal. Future research is needed to move beyond anecdotal evidence to descriptions of the religious and spiritual needs and resources of PPC patients and families and the impact of chaplains’ spiritual care on those spiritual needs (Feudtner et al., 2003).

Our survey results found that well-established PPC programs use chaplains to deliver spiritual care and that nearly all of these programs had a chaplain formally integrated into the PPC team (Puchalski et al., 2009). In this study, we learned that PPC chaplains are engaged in varied activities to meet the spiritual needs of children and families who face life-limiting and life-threatening illness, and to meet the needs of other members of PPC teams. As the eight PPC programs were randomly selected from a list of well-established programs, we are unable to generalize our findings to all PPC programs, and our findings are best viewed as potential models for spiritual care practices in PPC.

We also learned that PPC chaplains are integral and valued members of the PPC teams. We found that medical directors of these PPC programs are interested in spiritual care and are also committed to the provision of chaplaincy services on their interdisciplinary teams. These results are contrary to VandeCreek’s (1999) prediction that chaplaincy would become “an absent
profession.” The physicians in our study reported that they and their staff turn to chaplains as spiritual care experts capable of providing education, support, improved patient-team communication, and cultural competency on behalf of patients, families, and colleagues.

Our study also found that physicians and chaplains focus on different themes, outcomes versus processes, when they describe chaplains’ roles in PPC. Learning to translate what they do into the language of outcomes will help chaplains improve health care colleagues’ understanding of chaplains’ contributions to care for PPC patients and their families.

NOTE

1. In Hinduism there are many rituals in which water is used as a purifying element. It is unclear from this statement exactly what ritual this family had performed for their child.

REFERENCES


