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Chaplain care in pediatric oncology: Insight for interprofessional collaboration

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ABSTRACT

BACKGROUND

Although attending to spiritual and religious needs is part of high quality care of pediatric cancer patients, oncology clinicians may not understand the role of the chaplain, resulting in underutilization of resources and failure to fully integrate the chaplain into the clinical team. We provide a description of what the chaplain does in the care of pediatric oncology patients.

METHODS

We conducted a qualitative content analysis of chaplain chart notes over a one-year period on the pediatric oncology service at a freestanding children's hospital. Using criteria designed to capture multiple potential factors in chaplain referral, we selected 30 patients for thematic analysis.

RESULTS

In 2016, 166 pediatric patients were diagnosed with cancer and received ongoing care at our institution. From the 30 patients selected, 230 chaplain encounters were documented in the medical chart. Three major themes emerged. (1) The chaplains provided a rich description of spiritual and psychosocial aspects of the patient and family's experience; (2) chaplains provided diverse interventions, both religious and secular in nature; and (3) chaplains provided care within a longitudinal relationship. All three themes depend on the empathic listening by a chaplain.

CONCLUSIONS

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The chaplains' observations about patient and family beliefs, experiences, and emotional/spiritual states have the potential to inform the interdisciplinary care of the patient. Chaplain documentation provides insight into how spiritual care interventions and close relationships may promote patient and family well-being. In future work, we will explore how to give voice to their insights in caring for pediatric oncology patients.

Keywords: *spirituality; pediatric cancer; chaplain; interprofessional; supportive care.*

1. INTRODUCTION

High quality care of children with cancer requires a whole-person approach, in which attending to spiritual and religious needs is a crucial aspect.1, 2 Spirituality contributes to resilience and patients' ability to cope with cancer.2-4 Religious concerns influence parental decision-making in advanced pediatric cancer.5 In some cases, these concerns lead to ethical challenges in regard to refusal of standard cancer care.6 Interdisciplinary spiritual care may be improved by collaboration between physicians, nurses, social workers, therapists, and the acknowledged spiritual care specialist, the hospital chaplain.

Non-chaplain clinicians in pediatric oncology may not understand the role of the chaplain, leading to both underutilization of chaplain resources and a failure to fully integrate the chaplain into the clinical team. In a study of pediatricians and pediatric oncologists, pediatric oncologists more readily recognized the value of chaplains in the medical team.7 However, their perception of what chaplains do differed significantly from the view of the chaplains. Pediatric oncologists saw chaplain care as primarily religious and sometimes relegated this care to the end of life. In contrast, chaplains saw their work as pertaining to people of any background, as it is directed to spirituality as a fundamental aspect of humanity.

There is a relative paucity of research literature on chaplain care. Although an evidence base is growing to describe chaplain interventions and outcomes, the majority of the literature pertains to chaplain care among adult patients.8, 9 One study has given a quantitative account in a pediatric hospital, comparing utilization of chaplain care in general and psychiatric wards.10

A rich description of spiritual care requires a methodology that emphasizes meaning and themes. For this reason, qualitative methods are sometimes well suited to this topic.[11] In this study, we examined chaplain chart notes in order to describe the chaplain's contribution to the care of the pediatric cancer patient. This analysis may provide insight into the role the chaplain plays in patient care and family support and provide information for optimizing their contribution to interdisciplinary team care.

2. METHODS

We conducted a qualitative content analysis of chaplain chart notes from patients on the pediatric oncology service of a large, freestanding children's hospital. These notes were written by chaplains with a Master of Divinity (M.Div.) or equivalent credentials. They were either board certified or in a program to become board certified. The program is nationally accredited for supervised interfaith training in a medical setting. After receiving Institutional Review Board approval, we obtained a list of all newly diagnosed oncology patients in 2016.

We screened patient charts for study eligibility as follows. Inclusion criteria included: age 0 to 21 years old, diagnosed in 2016, patients with any malignant solid or liquid tumor, and patients with any brain tumor. We excluded patients who were primarily cared for and monitored by other services (otolaryngology, endocrinology, and neurosurgery). We also excluded patients who may have been diagnosed at our institution but subsequently had their care provided at other hospitals.

In qualitative analysis, participants are enrolled, and their data are analyzed until no new themes emerge from the data.[12] As this process usually requires 15 to 30 patients in a study, we chose 30 patients for our initial review. See Table 1 for characteristics of these patients. Patients were selected for analysis by dividing them by tumor groups (liquid, solid, and brain). We then used a purposeful sampling approach, in which we selected patients who varied as to these factors: tumor type, age, risk (prognosis), and mortality. We first selected 14 patients from the liquid tumor group, 8 from the solid tumor group, and 8 from the brain tumor group. A higher number of patients with a liquid malignancy were chosen

to reflect the higher number of patients with leukemia in the sample population. Diagnoses were assigned to one of two groups, favorable and unfavorable risk (see Table 2). Each patient was classified according to status at time of analysis (alive or dead), risk assignment (favorable and unfavorable), and age (< 10 years or ≥ 10 years). We randomly exchanged charts in an iterative fashion until we had a representative sample with at least five patients in each subgroup. The observation period began with the date of hospital admission leading to cancer diagnosis. The observation period ended nine months after the diagnosis of cancer.

Table 1. Participant characteristics

Age	**<10 years**	**16**
	≥ 10 years	14
Tumor group	Brain	8
	Solid	8
	Liquid	14
Prognosis	Favorable	11
	Nonfavorable	19
ICU stay	Yes	24
	No	6
Alive at time of analysis	Yes	22
	No	8

Table 2. Prognostic scheme

A. Lower risk tumor groups
Acute lymphoblastic leukemia—standard and high risk
Acute promyelocytic leukemia
Chronic myeloid leukemia—chronic phase
Early-stage (I-II) solid tumors + any stage Hodgkin lymphoma
Low- and intermediate-risk neuroblastoma
Nonmetastatic, “standard risk” medulloblastoma
Low-grade gliomas

B. Higher risk tumor groups
Acute lymphoblastic leukemia—very high risk and infantile subtypes
Acute myeloid leukemia
Chronic myeloid leukemia—blast phase
Juvenile myelomonocytic leukemia
Advanced stage (stage III-IV solid tumors) other than Hodgkin lymphoma
Metastatic rhabdomyosarcoma, osteosarcoma, and primitive neuroectodermal tumors

B. Higher risk tumor groups
Metastatic medulloblastoma
Pontine glioma
Atypical teratoid rhabdoid tumor
Rare tumors about which there is no upfront known prognostic information

All chaplain notes within the observation period from the first three patients were analyzed for themes by all four qualitative researchers (two physicians and two chaplains). This generated a preliminary code book. The code book was further expanded and refined by analyzing all chaplain notes of the remaining 27 patients. The charts of these 27 patients were analyzed by researcher pairs, of whom the principal author was a member for every note analyzed. Although theme saturation was reached at the 23rd patient, we completed analysis of all 30 patients to ensure representation from each tumor group. After the final code book was derived, the data were further discussed by all four qualitative researchers together to look for overarching themes.

3. RESULTS

A total of 166 patients were primarily cared for in the pediatric oncology department at our institution. A total of 107 patients had a documented chaplain encounter. Among the 30 patients selected for qualitative analysis, there were 230 total chaplain encounters. Three major themes emerged: rich description, diverse interventions, and longitudinal relationship.

3.1 Rich description

In their notes, chaplains provided a rich description of the psychosocial and spiritual dimensions of the patient and family.

3.1.1 Responding to bad news

After the cancer diagnosis had been rendered, both patients and families expressed their distress during chaplain encounters. One chaplain noted “the patient is very scared and has raised the question to MD about his death.” The enormity of information received at time of diagnosis is also a distressing factor, as one father said, “he was getting a great deal of information very quickly and that he was losing track of what floor he was on and what day it was.”

3.1.2 Physical symptoms of distress

The chaplain witnessed times when the family was reaching their limit in coping ability. One mother told a chaplain “she tries to eat, but it does not stay down.” Another mother talked about her sleep deprivation, saying “I haven't slept in a year.”

3.1.3 Parental fear

While awaiting the result of a tumor biopsy, which the mother feared to be cancer, a mother told a chaplain that she “imagines the worst and overthinks things.” In this case, the feared reality was true.

3.1.4 Hidden anxiety

The chaplain also recognized when the patient was hiding his/her anxieties in order to protect a parent: “[the patient] does not even acknowledge anxiety or pain until it is unbearable in order to not worry dad more.”

3.1.5 Anticipatory grief

A chaplain listened as an uncle shared his disappointment in an end-of-life decision, which he called “defeat.” As the chaplain explained, the uncle “has struggled to cope with the decision [for hospice] believing that there may be another option….” The chaplain's work also reached the siblings of a patient. Near a patient's end of life, a chaplain described the sister “who is struggling with her own grief that ‘her brother isn't going to be there anymore.’”

3.1.6 Communication frustrations

The chaplain bore insight into the quality of physician-patient communication, listening to the frustrations some families bear. One parent spoke to a chaplain about the manners of the physician. “He also expressed anger at [the physician] who the father described as being abrupt in his manner. The father questioned whether the doctors would make the same decisions for their own children.” Another parent spoke to the chaplain about the difficulty in having multiple providers giving information. The chaplain reports, “mom shared some of her emotional distress over hearing from some doctors ‘he is going to die’ and from other doctors ‘we will keep trying chemo and see if it keeps working.’” In this situation, the empathic listening led the chaplain to advocate for a care conference. Another parent shared her frustration with how decisions were being made. “She shared some of her feelings about ‘being left out of decision making… she is angry because she feels like the medical team is not listening to her concerns and she feels like she has not been able to be a partner with them to support her daughter.’”

3.1.7 Separation

Several parents were seen taking turns at the bedside, while the partner is at home with other children: “After this round, Mom will be here from Sunday-Thursday and then go home so she can continue working. Dad will be home working, but will come down on his off days.”

3.1.8 Struggle with “why?”

In multiple encounters, spiritual struggle manifested as the family member asking the question “why?” In regard to a toddler with a brain cancer, a grandmother asked “why someone so little would have to go through this.” The chaplain gave reassurance “her questioning of Why was a normal human reaction to a serious situation with her Grandchild. She expressed thanks to me for listening and reminding her that it was ok to question.”

3.1.9 Mental health seeking

Chaplains also wrote about the mental health seeking behaviors of parents. One parent spoke about the way psychiatry had helped her and how antidepressants had helped her

cope. In contrast, another parent “refuses to see a counselor stating that ‘they talk too much and waste my time.’”

3.1.10 Faith-derived meaning in illness

Several patients talked to the chaplain about the way they found meaning in their illness by their spirituality and faith. One child spoke about a positive meaning, saying “he feels that he is being tested by God.” An adolescent told a chaplain about the way the cancer had affected his faith in God. “Patient spoke … that the Leukemia has made his faith stronger.”

3.1.11 Faith-based parental coping

Multiple parents spoke about how their faith was a key component of their ability to cope. One parent told the chaplain, “they cope with their son's hospitalization through faith.” Another mother said, “she could not have gotten through the past month without faith in God.”

3.1.12 Beliefs regarding miracles

The chaplain noted the specific beliefs of families, including about how several parents spoke about their hope for a miracle. The chaplain noted in one case, “[Mother] has a strong faith that God can do miracles, but also is aware that God does not always choose to do them.”

3.2 Diverse interventions

Caring for both parents and patients, chaplains provided both universal and age-specific interventions. Some interventions were religious and some were secular.

3.2.1 Listening

“Active listening” was regularly listed as one of the chaplain interventions in their notes. In one note, a chaplain describes listening to a patient's mother. “I spent time with her, listening to the story of the last few weeks…” The chaplain noted as “an outcome of intervention” that “mom hugged me and thanked me for coming and for listening.”

3.2.2 Prayer

Chaplains prayed at various times and for multiple people. One chaplain prayed for a child before going to a procedure. Another chaplain prayed a blessing for the medical team. In addition, a chaplain prayed for parents near the end of a child's life. The chaplains' prayers contained multiple petitions, for both external and internal qualities. Internal qualities included comfort, mercy, "the peace that surpasses all understanding," thanksgiving, and wisdom for decision-making. Chaplains prayed for healing, but did not always specify in their notes if this was for spiritual, emotional, or physical healing. Chaplains also said silent prayers.

3.2.3 Sacrament

Chaplains either provided sacraments or facilitated visitation for such provision. Chaplains and community volunteers provided communion, sacrament of the sick before surgery, anointing of the sick, and baptism, including at the end of life. Finally, for families who asked for other religious resources, chaplains provided directions to the hospital chapel and gave the schedule for Mass services.

3.2.4 Sacred texts and theological questions

The use of sacred texts was evident in a minority of chaplain notes. A chaplain provided a Bible to a family who asked for one. One chaplain led parents in a breathing exercise for relaxation, using a Bible verse Psalm 46:10, "Be still and know that I am God." One chaplain noted, "the parents and I spoke about whether God tests human beings. I suggested that many events, including an illness, can encourage human beings, including their son, to grow into a fuller understanding of God."

3.2.5 Boundary setting

As documented in the notes, some religious families were very vocal about their faith, to the point of relational tension with the medical team. In one encounter, the chaplain noted the parent "has been praying during daily rounds… which was making several members of the care team uncomfortable." The chaplain established boundaries for the family's practice. The boundaries included not praying during rounds, but praying with the chaplain

and care members who were open to this practice. These boundaries ensured a respect for both the family's value in prayer and the medical team's diversity of beliefs. In a subsequent visit, the chaplain noted an outcome of this conversation, "…it seems to have improved relationships with staff."

3.2.6 Child's play

Chaplains documented how they played with younger patients, including drawing pictures and playing video games. One chaplain wrote, "I did my best, although my drawing skills are not the best." Later, she tried on a mask the child created. When the child began to use her IV pole as a skateboard, the chaplain responded, "I will let the nurse know about the skateboard use of the IV pole just to check."

3.2.7 Presence

A patient had a seizure, for which he was taken to have stat brain imaging done. The chaplain noted, "I remained with father in the room and escorted him to the new room in the PICU… Father was encouraged that he was not alone." Another chaplain narrated presence during a patient's distress, saying "I sat with [the patient] for awhile while she cried."

3.2.8 Physical touch

Although chaplains also wrote about playing with infant children, their care in this age group more often was expressed in touch. As one chaplain wrote, "[the infant patient] was sleeping in her crib, whimpering and stirring. She got quiet when she was touched." While in the ICU, the chaplain described "laying my hand gently on [the infant's] head."

3.3 Relationship

In walking alongside the patient and family from diagnosis to end of therapy, the chaplain provided not only interventional actions, but also a longitudinal therapeutic relationship.

3.3.1 Awaiting diagnosis

The chaplain's relationship may even precede the first encounter with the oncologist. After a child has been transferred from an emergency department hours away, a chaplain noted,

"he did not have any parents with him." She estimated that they "won't get to [the hospital] for one and half hours." So she waited with the child. Another kind of waiting was documented several times as general pediatricians are carrying out their diagnostic work-up. The chaplain hears the parents relay the initial thoughts on diagnosis which they have heard. A child with persistent fever was thought to have an infection. A child with intracerebral hemorrhage was thought to have brain trauma.

3.3.2 The bad news talk

The chaplain also documented encounters during and after the initial delivery of "bad news." One chaplain described the outcome of her presence when the doctor communicated the diagnosis of cancer to a mother: "As hard as the meeting with the doctors had been, it really helped knowing that I was by her side, even though she could only see me in her peripheral view." The chaplain noted this was an "encouragement that she is not alone."

3.3.3 Companionship

The chaplain-patient and chaplain-parent relationships emerged as a companionship through the journey of suffering. As one chaplain wrote, "we are here to walk with her whatever road may be ahead of them."

3.3.4 Names

One way chaplains demonstrated a deep knowledge of patients was through describing their names. One chaplain asked and listened to an explanation of a patient's name. Another chaplain learned the nicknames of a patient's siblings. Finally, a chaplain reported the nickname they came up with for a patient.

4. DISCUSSION

This chart review study of 30 pediatric oncology patients both describes the work of the chaplain in this setting and provides a rich source of information for other clinicians. The chaplain's rich description of patients helps fulfills a guideline from the Joint Commission that every patient have a spiritual assessment performed. At the minimum, some chaplain

notes reported “spiritual assessment completed.” More often, the chaplain reported the history of patients and families in regard to religious experience and other ways they found meaning in illness, such as in family, community, and hope for the future.

Consistent with a recent review of chaplain notes in an adult intensive care unit, we did see variability in the amount of information documented. Similar to that study's findings, we also saw several examples of notes that merely documented that the chaplain had met the patient without providing clinically useful information.[13] On the other hand, we also saw many notes in which chaplains identified elements readily actionable by the medical team (Table 3).

Table 3. Actionable elements in chaplain notes

Documented in chaplain note	Action that could be taken in response
- Quality of medical team communication	- Care conference or alteration of communication strategy
- Progress in processing anticipatory grief	- Deeper conversations concerning goals of care, end-of-life wishes
- Response to mental health care	- Continuation or alteration of mental health recommendations
- Hidden physical pain	- Provision of pain medication
• - Role of religion/spirituality in decision-making	• - Acknowledgment by medical team of the patient's spirituality and discussion of what may be integrated from it into their care

The rich description provided by chaplains served as the basis for diverse interventions. End-of-life interventions (Table 4) account for only some of these chaplain interventions. Whereas chaplains may be commonly perceived as providing solely religious sacrament or end-of-life care, chaplains in fact documented several universal interventions provided anywhere along the disease trajectory, such as listening, child's play, presence, and physical touch.[7] Chaplain interventions were provided within the context of a longitudinal relationship.

Table 4. End-of-life chaplain interventions (provided at the study institution)

End-of-life chaplain interventions
Religious rituals
Contact of requested religious leaders
Standing in for religious leaders upon their request
Memory making/mementos (locks of hair, footprints, photos, memory box)—with child life
Funeral planning including consultations, visitation, and leadership
Bereavement counseling and follow-up by phone calls and letters
Attendance with family at the time of autopsy reports
Performance of memorial services

The chaplains developed trust with patients and were able to hear distress concerning breakdowns in relationship and communication with the medical team. When conflict arises in such situations, the chaplain's relationship may be a source of reconciliation. All three themes derive from the single chaplain intervention of empathic listening. Empathic listening leads to rich description to be shared appropriately with the medical team. By means of empathic listening, a chaplain perceives opportunity for diverse interventions. Empathic listening and meaningful interventions provide a foundation for longitudinal therapeutic relationships.

The chaplain notes describe a depth of open communication from patients. The skills required to gain this confidence relate to their unique training. Chaplain training has been described as learning from “living human documents,” namely, the patients and providers themselves.[14] Such a narrative approach to training in patient care involves deep listening.

The importance of listening has been recognized in multiple disciplines and some patients view listening itself as “a healing and therapeutic agent.”[15] Pediatric oncology social

workers have ranked “listening to concerns, fears, and hopes” as the most important aspect of their work.[16] Listening has been identified as both an important skill to learn and a challenge to teach to physicians. In the 1980s, research reported that the majority of physicians interrupted patients within 18 seconds of the conversation.[17] The latest study on this topic shows an average of 11 seconds to interruption by a physician.[18]

In contrast, chaplain listening appears to involve a substantial amount of time, with one large adult study reporting time spent between five minutes and over two hours.[19] Given that patient satisfaction is largely dependent on the quality of communication with the medical team, it is possible that deep listening is the means by which patient satisfaction is improved by visits from a chaplain.[20], [21]

Active areas of research within the chaplaincy profession involve screening for spiritual distress, including the use of patient-reported measurements of distress.[22] Further research is needed to determine outcomes of chaplain interventions.

5. LIMITATIONS

Regional and geographic variations exist in religion and spirituality.[23] For this reason, this study is limited by its single-institution design. Documentation in the medical chart may not fully reflect the depth of conversations and relationships chaplains engage in. Prospective studies aligned with a standardized approach to documentation may identify some variables not obtained in a retrospective design.

6. CONCLUSION

Pediatric oncology physicians, nurses, and psychosocial team members play important roles in the spiritual care of patients and their families. Medical schools have begun to consider attention to patient spirituality as a matter of clinical competency, including growth in deep listening and screening for spiritual needs.[24]

The chaplain plays a unique role within the interdisciplinary team in supporting patients and families facing pediatrics cancer. In providing whole-person care, the pediatric oncology

chaplain bears witness to the deeply human experience of both children with cancer and their families. Insights gained in turn provide immediately actionable opportunities for other clinicians. In reading the chaplain note, the oncology team member may come to know their patient on a deeper level. More prospective research is needed to test integrated spiritual care interventions in a team setting.

CONFLICTS OF INTEREST

The authors do not have any conflicts of interest to declare.

DATA AVAILABILITY

Given the raw data for this qualitative study are composed of patient notes, due to our institution's legal policies, we are unfortunately unable to share the raw data.

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