How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times

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Abstract

Background: How parents of children with life threatening conditions draw upon religion, spirituality, or life philosophy is not empirically well described.

Methods: Participants were parents of children who had enrolled in a prospective cohort study on parental decision-making for children receiving pediatric palliative care. Sixty-four (88%) of the 73 parents interviewed were asked an open-ended question on how religion, spirituality, or life philosophy (RSLP) was helpful in difficult times. Responses were coded and thematically organized utilizing qualitative data analysis methods. Any discrepancies amongst coders regarding codes or themes were resolved through discussion that reached consensus.

Results: Most parents of children receiving palliative care felt that RSLP was important in helping them deal with tough times, and most parents reported either participation in formal religious communities, or a sense of personal spirituality. A minority of parents, however, did not wish to discuss the topic at all. For those who described their RSLP, their beliefs and practices were associated with qualities of their overall outlook on life, questions of goodness and human capacity, or that "everything happens for a reason." RSLP was also important in defining the child's value and beliefs about the child's afterlife. Prayer and reading the bible were important spiritual practices in this population, and parents felt that these practices influenced their perspectives on the medical circumstances and decision-making, and their locus of control. From religious participation and practices, parents felt they received support from both their spiritual communities and from God, peace and comfort, and moral guidance. Some parents, however, also reported questioning their faith, feelings of anger and blame towards God, and rejecting religious beliefs or communities.

Conclusions: RSLP play a diverse and important role in the lives of most, but not all, parents whose children are receiving pediatric palliative care.

Introduction

IMPROVING OUR UNDERSTANDING of how parents of children with life-threatening conditions draw upon their religious and spiritual beliefs and practices when coping with their children's illnesses is a primary goal for pediatric palliative care clinicians and researchers.¹⁻³

In general, religion is thought to provide an orienting system through which many people cope with the consequences of stressful life events and address larger life questions.⁴ Religion is also prevalent, with three-quarters of the U.S. population identifying with a particular religion.⁵ Previous studies in diverse populations have demonstrated a large variation in how ill individuals and their families think about, practice, and experience religion and spirituality. Further-

more, only a handful of published papers,^{3,6-13} chapters,¹⁴⁻¹⁷ and books¹⁸⁻²⁰ address, in a focused manner, religion and spirituality in the setting of serious childhood illness and pediatric palliative care. We therefore sought to clarify and illustrate, using a qualitative research approach nested in a prospective cohort study, the role of religion, spirituality, or life philosophy (RSLP) in the lives of parents of children with life-threatening conditions.

Methods

Sample

Participants in the study were parents of children who had enrolled in the Decision Making in Pediatric Palliative Care Study, a prospective cohort study conducted at the Children's

Hospital of Philadelphia (CHOP) and funded by the National Institute of Nursing Research. Parents were eligible to participate if their children were not able to make medical decisions due to age or impaired cognitive capacity, and if the parent(s) spoke English. Parents who were emotionally unstable or whose children had died, were discharged, or were too critically ill, as determined by the referring physician, were not eligible for the study. In total, 73 parents of 50 patients (62.5% of all palliative care consults during the study period) consented to participate. Most parents participated in person, while 17 (23.3%) participated by phone. The hospital's Committee for the Protection of Human Subjects approved the protocol for this study.

Data collection

To identify the role of RSLP in these parents' lives, 64 (88%) of the 73 parents interviewed, representing 41 (82%) families, were asked the following open-ended question: "Many people have a religion, spirituality, or life philosophy that helps to guide them through tough times. Do you have anything like that in your life?" Follow-up questions or comments sought only to obtain more information from a parent (e.g., "What do you mean?"), acknowledge what a parent said (e.g., "I see"), or express empathy (e.g., "That sounds difficult"). Audio recordings of the interview were transcribed and imported into Atlas.ti (5.2.0) for organization and analysis.

Information on parent and child demographic characteristics was obtained by asking the parent his or her age, gender, relationship to the patient, marital status, and education level,

and the child's age, gender, race, insurance, primary underlying disease, baseline level of cognitive function, and degree of involvement in medical decisions.

Data analysis

Responses were coded and organized thematically according to the qualitative coding and thematic analysis that underlies grounded theory.²¹ Interviews were selected in a randomized order, then sequentially read and coded individually by the study authors. Study authors met regularly to examine emerging themes, which were shaped over time to incorporate similarities between certain codes and emphasize differences among other codes. Any discrepancies amongst coders were resolved through discussion that reached consensus.

Results

Families receiving pediatric palliative care at CHOP represented a heterogeneous group of children and parents. Most children had neuromuscular (32%) or metabolic (27%) diseases (Table 1). A majority of children (69%) and parents (80%) were white and half of the children had Medicaid insurance (Tables 1 and 2). Parents' comments regarding the role of religion and spirituality in "tough times" involved seven major themes (FIG. 1).

Modes of response

RSLP among the parents was divisible into three modes of response: parents who identified as having a formal religion, those with spirituality or life philosophies but without formal religion, and those who denied or were unwilling to discuss religion, spirituality, or life philosophies.

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF 41 CHILDREN RECEIVING PEDIATRIC PALLIATIVE CARE

	No. (%)
Age, 1 year or less	10 (24.4%)
1–4 y	13 (31.7%)
5–9 y	10 (24.4%)
10–17 y	7 (17.1%)
18–24 y	1 (2.4%)
Gender, Female	21 (51.2%)
Male	20 (48.8%)
Race, White	27 (69%)
African American	8 (20.5%)
Asian	1 (2.6%)
More than 1 Race	3 (7.7%)
Insurance, Private	17 (44.7%)
Medicaid	19 (50.0%)
Other	2 (5.3%)
Location, Not in hospital	6 (14.6%)
Hospital Ward	21 (51.2%)
Intensive Care Unit	14 (34.2%)
CCC, Neuromuscular	13 (31.7%)
Respiratory	2 (4.9%)
Gastrointestinal	1 (2.4%)
Metabolic	11 (26.8%)
Congenital	7 (17.1%)
Malignancy	7 (17.1%)
Role in medical decisions, some	8 (19.5%)
No role	33 (80.5%)
Cognitive function, Higher or same as children of same age	5 (16.7%)
Lower	25 (83.3%)

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF 64 PARENTS WHOSE CHILDREN ARE RECEIVING PEDIATRIC PALLIATIVE CARE

	No. (%)
Age, 21–34 years	22 (35.5%)
35–38 years	17 (27.4%)
39–66 years	23 (37.1%)
Type, Mom	37 (57.8%)
Dad	24 (37.5%)
Other*	3 (4.7%)
Race, White	47 (79.7%)
African American	7 (11.9%)
Asian	1 (1.7%)
More than 1 Race	4 (6.8%)
Education, High school	11 (20.0%)
Some college or college graduate	30 (54.6%)
Some graduate school or graduate school graduate	14 (25.5%)
Marital status, Married	44 (71.0%)
Single	12 (19.4%)
Divorced	6 (9.7%)

*Other parent types include 1 aunt, 1 grandmother, and 1 stepparent.

FIG. 1. Hierarchical categories of how parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy to guide them through tough times.

Formal religion. In response to the question, most parents in this sample identified themselves as members of a particular religious faith (mainly Christian, although one family identified as Muslim and one as Wiccan). Many parents described their affiliations very positively, such as one parent who said, “We’re Presbyterian and we have a church that we’re very involved in, and that’s been a wonderful support.”

Spirituality without formal religion. Parents who described themselves as not regular church attendees still often felt a connection to God or sense of spirituality. As one parent said, “If I want to talk to God, I just will.” Another parent said, “I haven’t been drifting toward any type of spirituality; I don’t know what kind of spirituality it would be, but it would probably be my own.”

No response. While most parents reported some level of religious, spiritual, or other beliefs or observances, some answered the inquiry with a quick “No,” “No, not really,” or “Umm, no” that did not invite further questioning. The remaining interviews provided data for the rest of this analysis.

Common aphorisms

In discussing their RSLP, many parents offered aphorisms – short sayings intended to embody a general truth – that could be categorized as pertaining to an overall outlook, goodness, human capacity, and belief that there is “a reason for everything.”

Overall outlook. When asked about RSLP, parents in general offered statements pertaining to their overall outlook on the situation (i.e., “That’s just life”). While some phrases referenced the sacred (i.e., “It’s in God’s hands”), other

phrases (such as “What’s going to happen is going to happen”) did not.

Goodness. Within an overall outlook, parents frequently associated RSLP with the quality of goodness. As one parent said, “God is always good.” Another parent said, “I just believe in God and I try and find the good in things.” Additionally, some parents described their children’s presence in the world as a gift. For example, one parent said, “Every day is a gift, because she was only given three days [to live]. So every other day with her is a gift.”

Human capacity. Certain phrases used by parents spoke to their sense of human capacity, or how a given parent expected to function in the situation. For example, one parent said, “We’re not given more than we can handle.” Another parent summed up her experience as, “One day at a time, one step at a time, one mile at a time.”

Everything happens for a reason. One of the statements that parents used most often was that “Everything happens for a reason.” Parents seemed to identify their religion with that statement. For example, one parent said, “I do believe in that higher faith, so I believe that there was a reason why [our child] was put here, given to us.” Just because parents believed there were reasons, however, did not mean they always found those reasons easy to accept. As one parent said, “I think there’s a reason for everything. I’m not always happy about it.”

Relating to the child

Certain qualities of RSLP pertained directly to the child, including the child’s value and the parents’ belief in an afterlife for the child.

Child's value. Many parents found their RSLP helpful in dignifying their child's existence and specialness. For example, one parent spoke about "where [our child] fits in God's plan and why children like her may be born and, actually, their very special significance." Another parent stressed that, because Jesus always paid attention to children, all children, including her child, were important. As she noted, "It would be wrong for me to just say that, well, her life isn't really important. You know, she is not as important as some of the other kids because she's disabled and she would be much happier in a different place. That's not true because, in my Bible, anyway, every person is important to God, equally important." Other parents saw their children as having a role on earth to help bring people together spiritually. One parent said, "[Our child is] like Mother Teresa; she would walk into a room, and everybody would be around her, you know? And so I say that she's brought down here to bring all these people together and to show [them] something."

Belief in afterlife. Parents used many different words to describe life for their children after their deaths, including "afterlife," "a life after this life," "golden gate," "a better place," "a happy place," and "heaven." Belief in an afterlife was "reassuring," providing "peace" and "acceptance," and helped parents to be "not afraid" of their children's deaths and "trust in God to take care of [our child]." As one parent said, "The peace is there, knowing that, in the end, ultimately, while we won't have immediate perfection, we'll have complete perfection in heaven."

Practices

While there is a wide range of RSLP practices, in this study, parents primarily reported the common religious and spiritual practices of prayer and reading the Bible. Many parents reported praying for their children, both alone and in prayer groups. One important aspect of prayer was that it could happen anywhere. As one parent said, "The chapel is here, but I feel like you don't have to be in a chapel to pray." Parents also mentioned reading the Bible in response to stressful life events. For example, one parent chose to read the Bible stories of Job and of Abraham, saying, "All the trials they went through in life and how their faith in God brought them through – that helps me a lot."

Perspectives

Religion and spirituality also affected parents' perspectives on medical circumstances, decision making, and locus of control.

On the medical circumstances. Parents sometimes contrasted their RSLP beliefs with their beliefs in the medical profession. Sometimes a pastor was seen as being able to mediate between the parents and the doctors. As one parent said, "[Our pastor] can understand a lot of the things that the doctors need him to process [for] us on our belief level."

On decision making. Parents reported that decisions were less difficult when they felt as if they knew or accepted God's will. One parent said, "Knowing that there is a God, that gives me peace, and it helps me to deal with the difficult decisions." Other parents sought the formal guidelines of their

religion; as one parent said, "I want to know what the church teaches on extraordinary measures as to ordinary measures, to give you comfort about DNRs and how far do we go, and just something to really be at peace about."

On the locus of control. Parents talked about what aspects of their child's medical situations they could and could not control. One parent contrasted "wanting to plan things, to control things" with her religion's teachings, which she said helped give her patience and gave her the ability to "think things through."

Positive outcomes

Most parents felt that their RSLP was very important in providing support, peace, comfort, and moral guidance. "Without it," one parent declared, "I wouldn't be standing here."

Support. Participating in a particular religious community resulted in parents receiving support from a large number of fellow congregants, the pastor, and God. Support from others ranged from phone calls, e-cards, and cooking meals to people praying for the child and family. For example, one parent said, "People we don't even know [are] praying for this little guy." Parents benefited from prayer groups, and saw the church as providing "a network" and a source of "unconditional support and love." Pastors were occasionally referred to as "good friends." Parents also felt supported by God. As one parent said, "Casting all your care to Him gives you the feeling that you're not alone."

Peace and comfort. Parents also reported that feelings of trust in God resulted in feelings of peace and comfort. As one parent said, "It comforts us as parents spiritually to think that hopefully, when she passes, she'll have an opportunity [in Heaven] to do [normal] things and it's just a happy place."

Moral guidance. Some parents associated their religion with trying to be good. For example, one parent said that her religion reminded her that "I am supposed to be taking care of my child, and therefore going home and being lazy . . . that would be wrong." Other parents found religion helpful in coping with their anger. For example, one mother remarked on the need to keep her "Christian cool" when communicating with a doctor, and another said, "Every time I'm mad or upset, I start writing to Him."

Difficulties

Even among parents who reported some level of RSLP, many also reported questioning their faith, experiencing feelings of anger and blame toward God, and rejecting of specific religious beliefs and communities.

Questioning. Even those who remained strong in their faith still experienced difficulties. One parent said, "No matter what, it's hard. There is pain. You don't want to let go." Another parent said, "I believe I will have a spiritual connection with my daughter when she passes, but just right now, I have a lot of questions that are unanswered, so I fluctuate back and forth."

Feeling anger and blame toward God. Even while expressing anger at God, parents said that their anger was not incompatible with their faith. As one mother said, "I do believe in God, but I'm kind of angry at him right now." Another said, similarly, "I have the question in my mind, why, why us? What did we do wrong? What did she do wrong?"

Rejecting. Some parents moved away from their faith as a result of a child being seriously ill. One parent said, "I used to be a lot more religious, and I've had a really hard time with it." Another parent, in describing his move away from his faith, said, "I'm not going to sit and pray and hope that [my child] gets better. We're going to bring her to the hospital."

Discussion

In studying of RSLP in medical situations, researchers have focused on three main constructs – religious affiliation, religiosity, and religious coping – and the ability of these constructs to predict mental-health outcomes and decision-making preferences. Many articles regarding religious affiliation have focused narrowly on a religion's prescriptive teachings about death and dying (for adults and for children), based on various authors' reviews of religious texts.^{22,23} When studies actually examine the relationship for a given individual between stated affiliation and actual beliefs and practices, considerable variation is evident.^{8,24} Our findings suggest that, while most parents identify with a formal religion, some parents identify more with a sense of spirituality, and other parents either do not identify in such ways or do not wish to discuss the matter.

Studies of religiosity have attempted to measure the level of intensity of religious and spiritual beliefs and practices by asking questions about church attendance, prayer, and other religious behaviors. These studies fail to find a constant direction of association between behaviors and either mental health²⁵ or decision making.²⁶ Our findings suggest that, while specific religious practices are important to families, these may not be associated with end-of-life care beliefs or behaviors. Instead, parents in this study reported that practices such as prayer and Bible study gave them a more general sense of peace and calm.

Studies of religious coping, which consider how religious beliefs and behaviors inform a stressful life situation, have more successfully identified associations between religious coping and mental health over time in many diverse populations, including medically ill elderly people,²⁷ patients with HIV/AIDS,²⁸ and women with breast cancer.²⁹ Furthermore, in a population of adult patients with advanced cancer, religious coping has been associated with the receipt of intensive life-prolonging care near death.³⁰ In two small studies of parents of children with cancer, parents reported strong religious beliefs and increased religious behaviors following their children's diagnosis, and the positive influence of religious beliefs on coping behaviors.^{9, 13} Most investigations of religious coping in parents of critically ill children, however, have studied bereaved parents, who report that spirituality guided them in end-of-life decision making and provided emotional substance,^{31–33} but these studies are subject to retrospective recall bias. Nevertheless, our findings, gathered from parents whose children had life-threatening illnesses but had not died, support the association between religion and coping.

This study confirms both the diversity and the importance of the role that RSLP plays in the lives of most, but not all, parents whose children are receiving pediatric palliative care. The study's chief limitation was that the restriction to English-speaking families who were willing to receive palliative care consults in a single pediatric hospital, and participate in the study, excluded both patients from a wider geographic and cultural area and those who were unwilling to participate in palliative care for their children. This is likely to have narrowed the range of parental beliefs and practices reported. Clearly, further research is warranted to identify the interrelationships between RSLP coping in parents of children receiving pediatric palliative care with other areas of support and influence, and attention to possible multilevel mechanisms between the family and larger socioeconomic and cultural structures.

Further research is also warranted to understand parents' frequent use of aphorisms that perhaps may function as heuristics or "rules of thumb"³⁴ to explain their RSLP and allow parents to make effective decisions with a minimum of time, knowledge, and cognitive effort. While such phrases may appear clichéd or superficial, the importance of the words people use when framing both their understanding of a situation, and their actions within a situational framework, should not be overlooked.³⁵

We hope that this study, documenting a RSLP catalog of common concerns expressed by this group of parents, assists clinicians in approaching similar families with an informed but minimalist agenda: namely, to gently explore the religion and spirituality resources and needs of patients and families; to effectively facilitate the coordination of appropriate supports and services; and to be fully present and engaged during their journey.

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All authors participated in the design of the study and interpretation of the data; all authors performed the data analysis; Kari Hexem and Chris Feudtner drafted sections of the manuscript; all authors revised the manuscript for key intellectual content. All authors read and approved the final manuscript. Chris Feudtner had full access to all the data in the study and takes responsibility for the integrity of the data and accuracy of the data analysis.

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