Assessment of the Spiritual Needs of Primary Caregivers of Children with Life-Limiting Illnesses Is Valuable Yet Inconsistently Performed in the Hospital

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Abstract

Background: Religion and spirituality influence how many patients and families experience illness, but knowledge of the level of spiritual care provided to caregivers of pediatric patients within the hospital is limited.

Objective: We evaluated patient caregivers' perceptions of the extent to which their religious and spiritual (R/S) needs were assessed and addressed in the hospital.

Methods: We surveyed primary caregivers of children referred to palliative care <1 year prior at an urban, pediatric academic medical center. Participants completed a structured questionnaire with quantitative and qualitative measures of the provision of spiritual care in the hospital. Nonparametric tests were used to compare various measures of perceived and desired R/S support.

Results: The majority (16/24) of caregivers desired inquiry about R/S needs by the medical team. Fewer than half (12/25) had these needs assessed. No subjects were uncomfortable with questions regarding R/S needs. Only 35% (8/23) specifically wanted a physician to inquire about R/S needs. Subjects whose R/S needs were assessed perceived higher levels of support from the medical team (4.40 versus 3.08, $p=0.02$). A significant correlation existed between number of hospital-based R/S resources used and reported R/S-related comfort ($r_s=0.438$, $p=0.043$).

Conclusions: Assessment of R/S needs of caregivers of pediatric palliative care patients is performed less often than desired, even though it can improve perceptions of support from medical teams. Use of hospital-based R/S resources can increase spiritual comfort. Standardizing assessment of caregivers' R/S needs and referral to appropriate resources is a target for quality improvement in pediatric palliative medicine.

Introduction

RELIGION AND SPIRITUALITY are important to many Americans¹ and influence the illness experience and receipt of medical care. Parents of seriously ill children indicate that religion and spirituality are important factors in end-of-life decisions, attaining peace, and finding meaning in the child's death.²⁻⁵ In adults, religious and spiritual (R/S) support has been positively associated with quality of life,⁶⁻⁸ increased likelihood of receiving hospice care, and decreased likelihood of dying in an ICU.⁹ Further, patients, nurses, and physicians believe that spiritual care positively influences the patient-practitioner relationship, with patients noting the greatest impact.¹⁰

For these reasons, various bodies recommend assessment of R/S needs for PICU admission,⁴ palliative care referral,¹¹

and end-of-life care.¹²⁻¹⁴ Formal guidelines exist for addressing spiritual issues in pediatric palliative and hospice care,¹⁵ noting that assessment of R/S needs is integral to patient- and family-centered care.¹⁶ Unfortunately, R/S needs of adult patients are often neglected by the medical team,⁶ with some studies finding that R/S needs were assessed for less than 10% of adult patients.^{10,17} Among pediatric populations, pastoral care providers indicate that while nearly 80% of families demonstrated spiritual needs, only 60% were provided ideal spiritual care.¹⁸

Little is known about the level of R/S care provided to pediatric patients and their families.¹⁹ Hypothesizing that seriously ill children and their families do not perceive adequate attention to their R/S needs, this study seeks to determine the extent of R/S assessment and intervention by the medical team prior to palliative care referral. Improved

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TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF 25 CAREGIVERS WHOSE CHILDREN WERE REFERRED FOR PEDIATRIC PALLIATIVE CARE

<i>Characteristic</i>	<i>No. (%)</i>
Type of caregiver	
Mother	19 (76%)
Father	4 (16%)
Other (1 grandmother, 1 aunt)	2 (8%)
Age	
21–30	6 (24%)
31–40	8 (32%)
41–65	11 (44%)
Race	
White	22 (88%)
Black	2 (8%)
Other/multiple	1 (4%)
Marital status	
Married	12 (48%)
Single	8 (32%)
Divorced	5 (20%)
Education level	
High school diploma/GED	7 (28%)
Some college	8 (32%)
College degree	7 (28%)
Advanced degree	3 (12%)

understanding of spiritual care provision can hopefully lead to interventions aimed at optimizing the psychosocial well-being of patients and caregivers while enhancing relationships between children, their caregivers, and practitioners.

Methods

Sample and setting

Subjects were recruited at an urban pediatric academic medical center. Eligible subjects were primary caregivers of pediatric inpatients referred for palliative care <1 year prior for a life-limiting illness. Patients were <25 years old and were diagnosed >4 weeks before the interview. Caregivers exhibiting significant emotional distress as agreed upon by the palliative care team were not eligible.

Instrument

Eligible subjects were administered a survey developed, pretested, and revised by two palliative care physicians, a palliative care nurse, and a medical student. Demographic

data were collected, and five-point Likert scales measured the importance of religion and spirituality to the subject and the extent of R/S support by the subject's religious community and medical team. The nine-item Attitudes Toward God Scale-9²⁰ was included to assess how religion and spirituality produced comfort or anger for subjects. Closed- and open-ended items evaluated how adequately R/S needs were assessed and addressed by the medical team prior to palliative medicine consultation.

Protocol

Caregiver interviews were performed in-person by an investigator (JK) with no involvement in the patient's care. Responses were audio- and hand-recorded to ensure fidelity. To mitigate selection bias, eligible subjects were informed: "Even though the study focuses on religious and spiritual support, we want to survey those who are religious or spiritual and those who are not. Everyone can provide valuable information." Informed consent was obtained as per guidelines of the quality improvement branch of the University of Pittsburgh institutional review board.

Data analysis

Wilcoxon signed-rank testing compared the levels of R/S support received from a religious community to the levels of R/S support received from the medical team. McNemar's test compared the percentage of caregivers whose R/S needs were assessed to the percentage who desired assessment. The Mann-Whitney U test compared perceived R/S support from the medical team between subjects whose R/S needs were and were not assessed. Spearman's rank correlation tested for correlations between the number of hospital-based R/S resources used and R/S-related comfort, anger, and perceived R/S support from the medical team. Statistical analyses were performed using SPSS 20.0 (IBM, Armonk, NY). All reported *p* values are two sided and considered significant when *p* < 0.05.

Results

Population characteristics

Of eligible caregivers, 25/26 (96% response rate) participated. Most subjects were mothers (76%) and identified as white (88%). Mean age of respondents was 37.9 years. Subjects came from varied backgrounds (see Table 1).

TABLE 2. COMPARISON OF ATTITUDES TOWARD ASSESSMENT OF R/S NEEDS BETWEEN RELIGIOUS AND NONRELIGIOUS SUBJECTS

	<i>Would you like for a member of the medical team to ask about your R/S needs?</i>		
	<i>Yes (%)</i>	<i>No (%)</i>	<i>Declined to answer</i>
Member of organized faith/religion (<i>n</i> = 19)	13 (68.4%)	6 (31.6%)	0 (0.0%)
Nonmember of organized faith/religion (<i>n</i> = 6)	3 (50.0%)	2 (33.3%)	1 (16.6%)

Religiosity of population

Most subjects (22/25, 88%) considered religion and spirituality important to them. The average rating of the importance was 4.08/5.00 (95% CI 3.61–4.55). Seventy-six percent reported membership in an organized religion. Of those, all were Christian (nine Protestant, four Catholic, six non-denominational).

Assessment of religious/spiritual needs

The majority of subjects (16/24, 67%) desired assessment of their R/S needs by the medical team, while only 48% (12/25) reported this assessment occurred prior to palliative care referral. These percentages were not significantly different ($p=0.18$). Members and nonmembers of organized religion similarly reported desiring R/S assessment (see Table 2). A minority (8/23, 25%) reported that they would have specifically liked a physician to assess R/S needs. Six caregivers directly expressed the opinion that R/S care was outside the physician's role. Only 8% (2/25) reported that a nonpalliative care physician assessed R/S needs. All subjects noted they would not be offended by or uncomfortable with inquiry regarding R/S needs by any member of the medical team.

Provision of religious/spiritual support

Many (18/25, 72%) subjects were informed of R/S resources offered by the hospital, and 16/25 (64%) endorsed using at least one. Chaplain visits (14/25, 56%) and visits to the hospital chapel (10/25, 40%) were the most commonly used resources. Except for a chaplain visit for one subject, every utilized hospital resource was reported as beneficial. The mean level of R/S support from the medical team (3.68/5.00, 95% CI 3.11–4.25) was not significantly different from mean level of R/S support from the subjects' religious communities (4.18/5.00, 95% CI 3.71–4.65, $p=0.145$).

Effects of assessment of religious/spiritual needs and provision of religious/spiritual resources

Subjects whose R/S needs were assessed by the medical team perceived significantly higher R/S support from the medical team than those whose needs were not assessed (4.40 versus 3.08, $p=0.02$). The number of hospital-based R/S resources used positively correlated with reported R/S-related comfort ($r_s=0.438$, $p=0.043$) but did not significantly increase perceived R/S support from the medical team ($r_s=0.301$, $p=0.18$) or decrease R/S related anger ($r_s=-0.343$, $p=0.12$) despite trends in those directions.

Discussion

This survey of caregivers for children referred for palliative care found that assessment of R/S needs was inconsistently performed, with less than half noting assessment prior to palliative care referral. Additionally, subjects indicated that the medical team was "somewhat" to "highly" supportive of their R/S needs, similar to previous estimates by hospital chaplains.¹⁸ It seems that discrepancies exist between caregiver and physician perceptions of R/S assessment, given a previous survey of physicians that found >90% indicated willingness to assess R/S needs in the context of life-threatening illness.²²

In our study, two-thirds of subjects desired R/S assessment, and none indicated that it would be offensive. Moreover, caregivers whose needs were assessed provided significantly higher ratings of perceived support from the medical team. This suggests that simply asking about R/S needs may help families feel more supported by medical staff. Performing a simple assessment (e.g., FICA Spiritual History)²⁴ of faith/spirituality, its importance, involvement in a religious community, and how needs can be addressed could provide benefit without risking harm to the caregiver.

While this study supports routine assessment of R/S needs, it questions the physician's role in this assessment. Unlike adult patients,^{10,17,21} most caregivers in our study did not specifically want a physician to assess R/S needs. Many considered it outside of that role. This sentiment may exist because families have not observed pediatricians assessing R/S needs. If so, routine assessment of the R/S needs of this population may change caregiver perception of the pediatrician's role. Regardless, neglecting spiritual needs runs contrary to the physician's responsibility to provide holistic care. Given that caregivers are not opposed to assessment of R/S needs, physicians should be encouraged that such an inquiry is acceptable. Our finding that assessment of R/S needs increased caregiver perception of support by the medical team suggests that physician assessment of these needs could benefit the physician-caregiver relationship.

Beyond promoting assessment of R/S needs, our study correlated greater spiritual comfort with increased use of hospital-based R/S resources. Spiritual comfort supports a parent's well-being,^{2–5} and hospital-provided spiritual guidance enhances end-of-life decision making.⁸ Importantly, this high level of spiritual comfort was achieved using existing resources, further emphasizing the importance of assessment followed by referral to pastoral services.

Our study was limited by potential recall bias and small sample size at a single institution. Additionally, a more diverse patient population would have provided greater generalizability and perhaps amplified the importance of R/S care.²³

Conclusion

Caregivers of children with life-limiting illness welcome assessment of their R/S needs, but it is inconsistently performed. Assessing R/S needs correlated with a greater sense of spiritual support from clinicians, and use of existing hospital-based R/S resources was associated with greater spiritual comfort. Although families may not view addressing R/S needs as part of a pediatrician's role, greater physician involvement in assessing these needs could enhance total care of the patient and benefit the caregiver-physician relationship.

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