

Spiritual Care Needs of Hospitalized Children and Their Families: A National Survey of Pastoral Care Providers' Perceptions

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ABSTRACT. *Objective.* Although spirituality is viewed as a vital aspect of the illness experience by most Americans, little is known about this domain of pediatric health care. The objective of this study was to profile pastoral care providers' perceptions of the spiritual care needs of hospitalized children and their parents, barriers to better pastoral care, and quality of spiritual care in children's hospitals.

Methods. A cross-sectional mail survey was conducted of pastoral care providers at children's hospitals throughout the United States, with a 67% response rate from 115 institutions.

Results. Respondents estimated that, among patients they visited, 34% were chronically ill and 21% were clearly dying. Half or more of patients were thought to have spiritual care needs regarding feeling fearful or anxious, coping with pain or other physical symptoms, and regarding their relationship to their parents or the relationship between their parents. Among patients' parents, 60% to 80% were estimated to have felt fearful or anxious, had difficulty coping with their child's pain or other symptoms, sought more medical information about their child's illness, questioned why they and their child were going through this experience, asked about the meaning or purpose of suffering, and felt guilty. Respondents agreed on 3 barriers to providing spiritual care: inadequate staffing of the pastoral care office, inadequate training of health care providers to detect patients' spiritual needs, and being called to visit with patients and families too late to provide all the care that could have been provided. Overall, respondents judged that their hospitals were providing 60% of what they deemed as ideal spiritual care.

Conclusions. Pastoral care providers believe that the spiritual care needs of hospitalized children and their parents are diverse and extensive. With system-level barriers cited as limiting the quality of spiritual care, considerable improvement may be possible. *Pediatrics* 2003;111:e67–e72. URL: <http://www.pediatrics.org/cgi/content/full/111/1/e67>; *spiritual care, pastoral care, spirituality, religion, children's hospitals, chaplaincy.*

Most Americans consider themselves either religious or spiritual, with 9 of 10 believing in God or a higher power.¹ Among adult patients in the United States, many view spirituality as a vital aspect of the illness experience.^{2–5} These widely held beliefs lately have joined accumulating empirical evidence of health benefits associated with religious or spiritual activities.⁶ Although skepticism is still warranted,^{7,8} the medical community has shown during the past decade mounting interest in the role of spirituality and religion in health care.^{9,10}

In this context, the spiritual care needs of hospitalized children and their families and the nature of the pastoral care that they receive are revealed as important yet neglected topics. The literature on the spiritual care of sick children consists mostly of case studies, reviews of theories regarding spiritual development, suggested methods, and editorial opinion.^{11–18} More empirically based reports are starting to appear, including the assessment by an expert panel of hospital chaplains of whether a model spiritual well-being index accurately measures how children manifest spiritual distress¹⁹; a survey of health care providers in a single neonatal intensive care unit, which found a "strong undercurrent" of spiritual and religious beliefs and practices regarding patient care work²⁰; and a qualitative study that described a variety of spiritual and religious beliefs or coping mechanisms among children with cystic fibrosis.²¹

To provide additional useful information about the spiritual care needs of sick children, we surveyed pastoral care providers who work at major children's hospitals throughout the United States. Using the pastoral care providers as key informants, we sought to profile 1) their perceptions regarding the spiritual care needs of hospitalized children and their parents, 2) their opinions regarding barriers to better care, and 3) their overall assessment of the current quality of spiritual care in children's hospitals.

For the purposes of this investigation—although consensus has yet to emerge regarding standard definitions of spirituality or religion^{22–24}—we developed a broad model of spiritual care needs (Fig 1). Our model was based on a dynamic and ecumenical interpretation of spirituality as those beliefs, activities, and relationships that mediate, influence, or modify the relationship between several domains of human experience and transcendent issues or concerns. In this view, spirituality is perceived as a mode of living—a process, an inquiry, a conversa-

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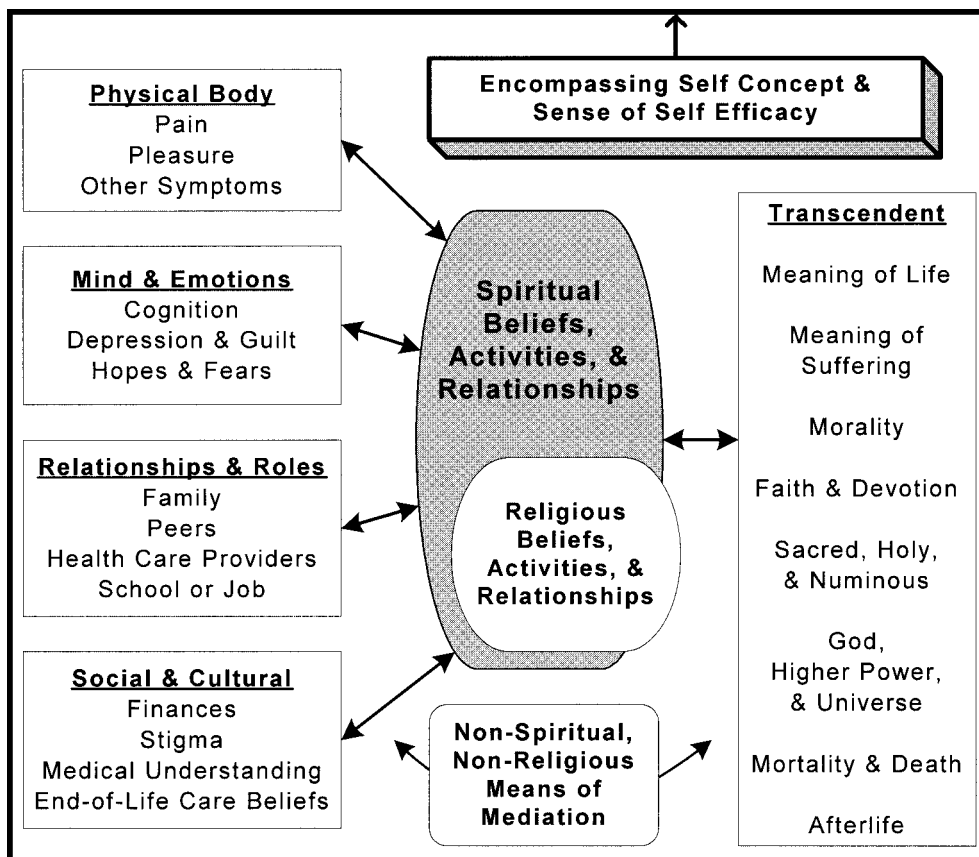


Fig 1. A model of spiritual, religious, or other beliefs, activities, and relationships mediating between domains of ordinary experience and transcendent concerns.

tion—rather than a separate realm of life. The model conceives “religion” and “spirituality” as overlapping beliefs, activities, and relationships while also recognizing other means of mediating ordinary and transcendent concerns, separate from either spirituality or religion. As suggested by this model, we conceptualized spiritual care needs as potentially encompassing a diverse array of human concerns. For example, within the domain of the physical body, the experience of pain can lead individuals to intense spiritual inquiry regarding the meaning of suffering. Similarly, hopes, fears, problematic relationships with family members or schoolmates, financial concerns, stigmatizing cultural beliefs, or one’s understanding of an illness and its medical care are each examples of ordinary human experience that can be connected, through spirituality (or other means), to transcendent concerns. Tending to each of these non-transcendent domains, as well as concerns specifically in the transcendent domain and in the overall mediating processes of spirituality, are necessary aspects of holistic spiritual care.

METHODS

Questionnaire

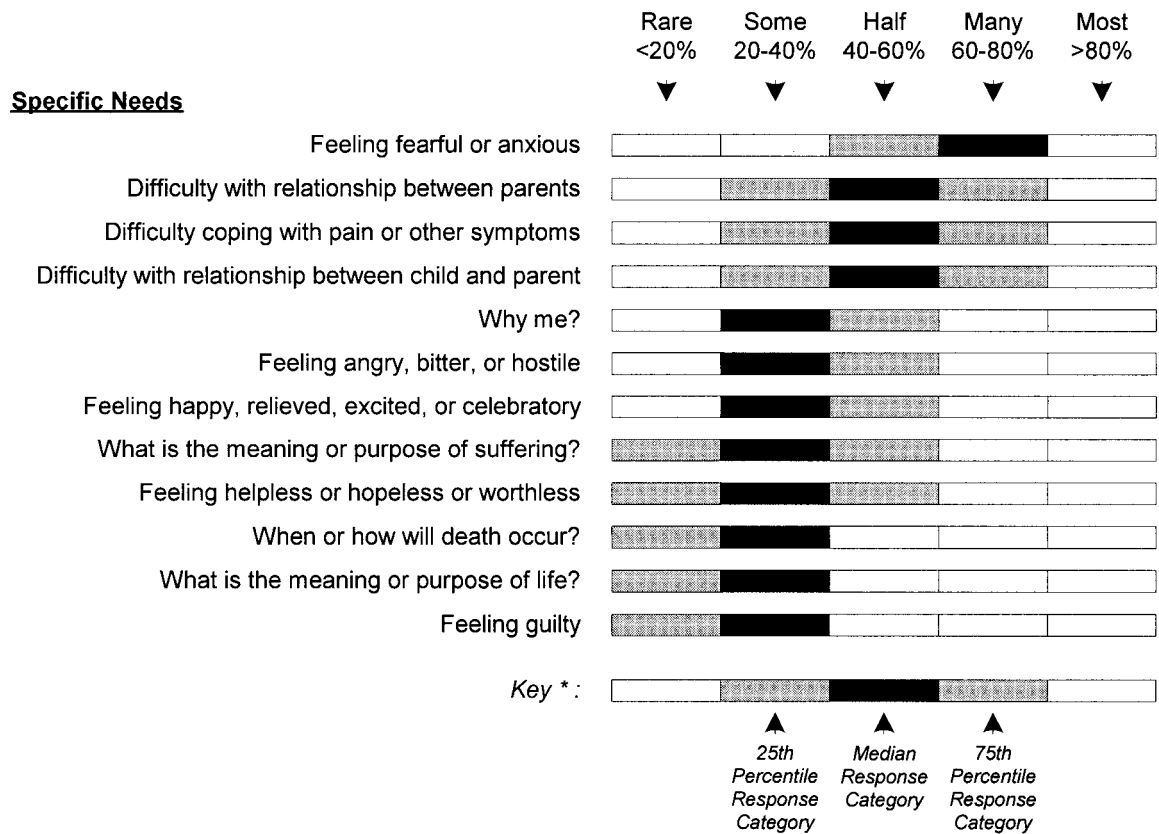
We developed a 5-page questionnaire that, along with a cover letter, was pretested and revised for content and clarity by 5 pastoral care workers and 3 pediatricians. Most of the questionnaire posed closed-ended questions. Answers to 2 of the questions (“In your judgment, what fraction of children [parents] have these needs?”) were constrained to 5 categories, ranging from rare (<20%) to most (>80%). Figures 2 and 3 replicate the question-

naire’s wording of the “need” and the response categories, with the shading indicating the median response as well as the interquartile range of responses. To the statement, “I feel these factors are major barriers to providing spiritual care. . . .” respondents were given a 5-point Likert scale to express their degree of agreement; the wording presented in Fig 4 also replicates the questionnaire’s descriptions of possible barriers. The same scale was used for responses to the statement, “I believe these methods of providing spiritual care are very effective,” with the wording in the text closely paraphrasing that of the questionnaire. Finally, in response to the question, “How close do you feel that your hospital is to providing the best possible spiritual care to the children and families who use your facility?” respondents were presented with 11 categories, ranging from 0% to 100% in 10% increments, with which they could complete the statement “We currently provide this percentage of the goal of 100% ideal spiritual care.” The questionnaire is available in PDF format at depts.washington.edu/chiorg/staff/feudtner.htm.

Survey Technique

We surveyed all 118 children’s hospitals that are members of the National Association of Children’s Hospitals and Related Institutions. These hospitals are dispersed across 42 states and the District of Columbia and constitute a convenient yet fairly exhaustive sample of tertiary children’s hospitals in the United States. Questionnaires were mailed to the “Department of Pastoral Care or Chaplain” at all sites in the summer of 2000 and 2 subsequent mailings to nonrespondents that autumn. Each site was asked to select 1 staff member to respond; the typical respondent was 48 years old, just under half were female, almost all were Protestant or Catholic, and 60% had been working in pediatric pastoral care for <10 years. Of the initial sample frame of 118 institutions, 1 health care institution had closed and 2 institutions had no pastoral care program, leaving 115 eligible surveyed sites. We received 77 completed questionnaires, for a response rate of 67% (77 of 115).

Estimated Proportion of Patients with Needs



* The shading of the bars in the figure depict the interquartile range, with the categories that were the median response shaded black, and the 25th and 75th percentile responses shaded grey. If a single category was both the median and one of the other quartile range responses, then only the blackened shade is shown.

Fig 2. Respondents' estimate of the proportion of patients with specific needs.

Statistical Analysis

We calculated simple proportions of demographic characteristics and mean values of respondents' point estimates of proportions. For 5-category estimates of proportions and responses to the 5-point scale degree of agreement questions, we identified the median response and the interquartile range, which extends from the 25th to the 75th percentiles. Because this study was designed to provide descriptive information, we did not undertake exploratory hypothesis testing. We performed all statistical analyses with Stata 7.0 software.²⁵

Human Subjects Oversight

We obtained approval to conduct this study from the University of Washington Human Subjects Committee.

RESULTS

These respondents estimated that 18% of the children for whom they cared were newborns, 21% were older infants, 37% were between 1 and 10 years of age, and 24% were adolescents. Most often, these children had an illness of recent onset and were likely to recover. Half of the patients, though, were either infants who had been ill their entire lives or older children who were chronically ill. One in 5 patients was thought to be clearly dying.

Respondents consistently estimated that a larger proportion of parents than patients had a variety of specific needs. Regarding patient needs, half or more

were believed to have needs regarding feeling fearful or anxious, coping with pain or other physical symptoms, and regarding their relationship to their parents or the relationship between their parents (Fig 2). Addressing parental needs, respondents estimated that 60% to 80% of parents also felt fearful or anxious, had difficulty coping with their child's pain or other symptoms, sought more medical information about their child's illness, questioned why they and their child were going through this experience, asked about the meaning or purpose of suffering, and felt guilty (Fig 3).

The majority of respondents strongly agreed that the following "methods of providing spiritual care are very effective": empathetic listening, praying with children and families, touch or other forms of silent communication, and performing religious rituals or rites. Conversing with the child or family about their spiritual journey and inquiring how the family had addressed spiritual needs previously were also viewed as being effective. Opinion diverged regarding the effectiveness of mediating between the family and the health care team on either spiritual or medical issues or between the family and their spiritual community or providing written spiritual resources.

Estimated Proportion of Parents with Needs

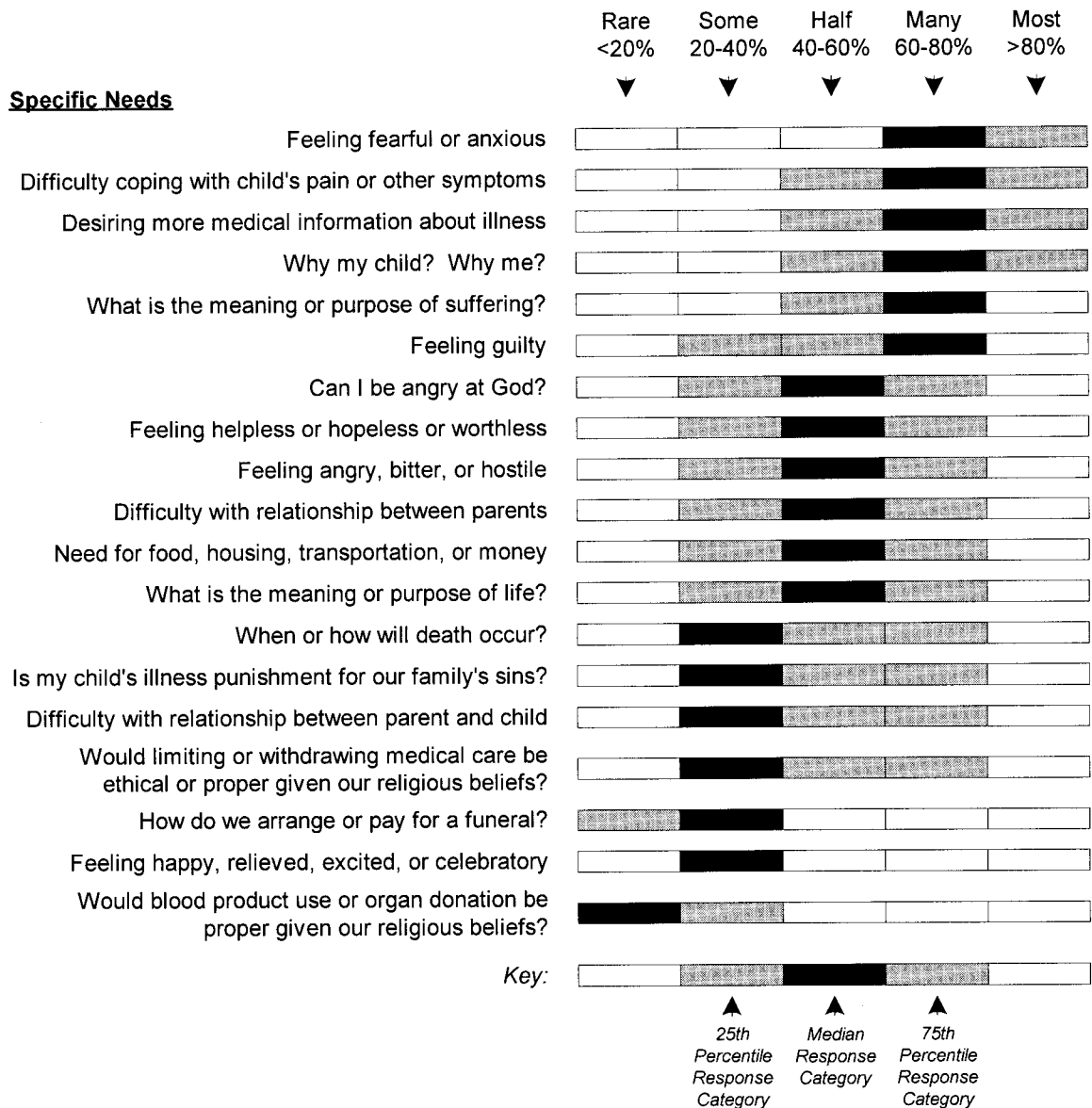


Fig 3. Respondents' estimate of the proportion of parents with specific needs.

These pastoral care workers agreed on 3 major barriers to providing spiritual care: inadequate training of health care providers to detect patients' spiritual needs, inadequate staffing of the pastoral care office, and being called to visit with patients and families too late to provide all the spiritual care that could have been provided (Fig 4). When asked, "How close do you feel that your hospital is to providing the best possible spiritual care to the children and families who use your facility?" the median estimate offered by these respondents was that their hospitals were providing 60% of what they deemed to be ideal spiritual care.

In a space soliciting comments, 2 respondents, both of whom work in different busy hospitals with minimal pastoral care staff, wrote, "I tend to live in the ICUs," and "We obviously cannot provide adequate spiritual care to anyone with these kinds of numbers. We do crisis." In a similar vein, another

respondent noted that "we often meet many families around the time of death." Two other respondents commented that "spiritual care is often the first to go with budget cuts" and "managed care has made the climate in our large teaching hospital become very sparing in their support of a pastoral care team."

DISCUSSION

The pediatric pastoral care providers who responded to this survey believe that the patients and parents for whom they care in children's hospitals have diverse and substantial needs, yet judge the quality of the spiritual care provided in their hospitals to be far from ideal.

We encourage the reader to keep several shortcomings of this study in mind, not only because they limit the conclusions that one should draw but also because they point to areas that need additional investigation. First, our survey relies on the reports of

"I feel that these factors are major barriers to providing spiritual care ..."

Possible Barriers

- Inadequate training of health care providers to detect patients' spiritual needs
- Inadequate staffing of my pastoral care office
- Being called to visit with patients and families too late to provide all that could have been provided
- Difficulty surmounting cultural or language differences between myself and patients
- Health care providers indifference to spiritual concerns
- Difficulty relating to infants & young children because they do not talk or other developmental limitations

Key * :

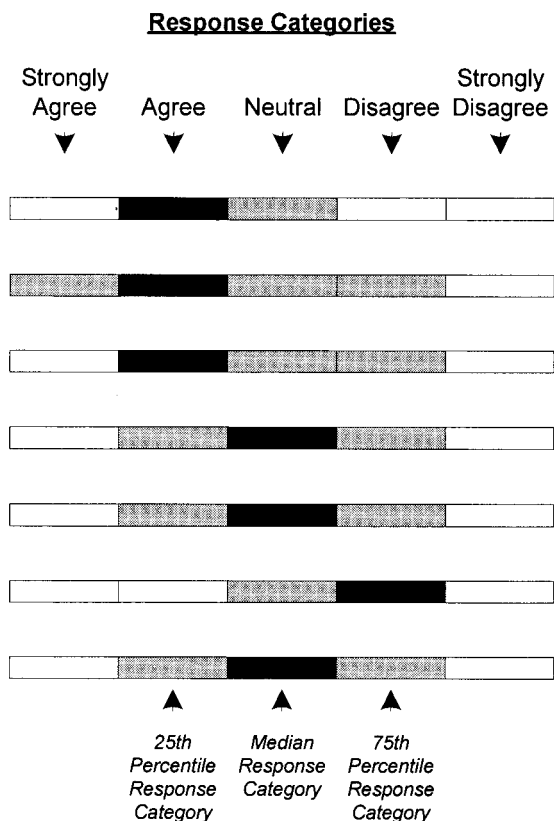


Fig 4. Barriers to provision of spiritual care.

pastoral care workers to provide information by proxy regarding the needs of hospitalized children and their parents. These proxy judgments are problematic, as they reflect the potentially inaccurate views of the pastoral care worker, who may be thought likely to overestimate the degree of patient or parental needs. We chose this method, however, because of the limited information published on these questions and the expense of conducting direct interviews with children and parents. Second, although the respondents identified several barriers to the provision of spiritual care, we cannot interpret their clinical significance or create means to overcome these barriers until we know more both about the "spiritual history" of how children and parents experience a serious illness or hospitalization and about how the pastoral care services intervene in the course of this spiritual history. Third, we did not provide a definition of what constitutes "ideal spiritual care." Instead, this survey reports the subjective judgments of 80 individuals who provide pediatric spiritual care. The resulting aggregated opinion, although providing some useful information and motivation, could be greatly improved by a systematic assessment based on clearly articulated objectives regarding what exactly spiritual care interventions aim to accomplish in children's hospitals. Finally, the broad model of spiritual care on which we based the design of the survey, although a useful heuristic and the only model we have found in the literature, undoubtedly needs additional refinement.

We recommend that future efforts to improve our understanding and provision of pediatric spiritual

care consider several issues. First, we should seek to elucidate further the spiritual care needs and preferences of hospitalized pediatric patients and parents by asking them directly. To proceed effectively with this line of investigation, the underlying concepts of spirituality and spiritual care must be developed further so that the correct questions are asked. Second, this inquiry should aim to understand the illness experience longitudinally, during the course of prolonged hospital admissions or repeated admissions, so as to clarify how the spiritual history of individual patients or families develops over time. Third, to better guide the design and evaluation of pastoral care interventions, we need a theoretical model not only of spiritual care needs but also of how spiritual care would improve outcomes, both spiritual (eg, a sense of spiritual well-being) and secular (eg, patient satisfaction or quality of life). One aspect of such a model linking spiritual care to outcomes likely would focus on 2 areas that warrant additional research, namely the role of physicians, nurses, and other health care workers in the provision of spiritual care and on the impact of the time and nature of referral to spiritual care providers.²⁶ Then, innovative spiritual care programs or interventions ought to be tested using the most rigorous methods possible, which whenever feasible and ethical should be randomized, controlled trials. Finally, hospitals should seek to improve the quality of their spiritual care services. Although national organizations could assist this endeavor by defining the minimally acceptable standards of spiritual care in children's hospitals, ultimately it will be the respon-

sibility of hospitals to ensure—through adequate funding, staffing, and quality improvement efforts—that all hospitalized children and their families receive the best spiritual care possible.

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REFERENCES

1. Bishop G. Americans' belief in God. *Public Opin Q.* 1999;63:421–434
2. Maugans TA, Wadland WC. Religion and family medicine: a survey of physicians and patients. *J Fam Pract.* 1991;32:210–213
3. King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *J Fam Pract.* 1994;39:349–352
4. Oyama O, Koenig HG. Religious beliefs and practices in family medicine. *Arch Fam Med.* 1998;7:431–435
5. Ehman JW, Ott BB, Short TH, Ciampa RC, Hansen-Flaschen J. Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med.* 1999;159:1803–1806
6. Chatters LM. Religion and health: public health research and practice. *Annu Rev Public Health.* 2000;21:335–367
7. Sloan RP, Bagiella E, Powell T. Religion, spirituality, and medicine. *Lancet.* 1999;353:664–667
8. Sloan RP, Bagiella E, VandeCreek L, et al. Should physicians prescribe religious activities? *N Engl J Med.* 2000;342:1913–1916
9. Levin JS, Larson DB, Puchalski CM. Religion and spirituality in medicine: research and education. *JAMA.* 1997;278:792–793
10. Sulmasy DP. Addressing the religious and spiritual needs of dying patients. *West J Med.* 2001;175:251–254
11. Fowler JW. *Stages of Faith: The Psychology of Human Development and the Quest for Meaning.* San Francisco, CA: Harper Collins; 1981
12. Chapman JA, Goodall J. Dying children need help too. *Br Med J.* 1979;1:593–594
13. Fulton RA, Moore CM. Spiritual care of the school-age child with a chronic condition. *J Pediatr Nurs.* 1995;10:224–231
14. Meyers HI. Spiritual care in pediatric hospice. *Am J Hosp Care.* 1989;6:12
15. Hart D, Schneider D. Spiritual care for children with cancer. *Semin Oncol Nurs.* 1997;13:263–270
16. Kenny G. Assessing children's spirituality: what is the way forward? *Br J Nurs.* 1999;8:28, 30–32
17. McEvoy M. An added dimension to the pediatric health maintenance visit: the spiritual history. *J Pediatr Health Care.* 2000;14:216–220
18. Davies B, Brenner P, Orloff S, Sumner L, Worden W. Addressing spirituality in pediatric hospice and palliative care. *J Palliat Care.* 2002; 18:59–67
19. Pehler SR. Children's spiritual response: validation of the nursing diagnosis spiritual distress. *Nurs Diagn.* 1997;8:55–66
20. Catlin EA, Guillemin JH, Thiel MM, Hammond S, Wang ML, O'Donnell J. Spiritual and religious components of patient care in the neonatal intensive care unit: sacred themes in a secular setting. *J Perinatol.* 2001; 21:426–430
21. Pendleton SM, Cavalli KS, Pargament KI, Nasr SZ. Religious/spiritual coping in childhood cystic fibrosis: a qualitative study. *Pediatrics.* 2002; 109(1). Available at: www.pediatrics.org/cgi/content/full/109/1/e8
22. Astrow AB, Puchalski CM, Sulmasy DP. Religion, spirituality, and health care: social, ethical, and practical considerations. *Am J Med.* 2001;110:283–287
23. Daaleman TP, Kuckelman Cobb A, Frey BB. Spirituality and well-being: an exploratory study of the patient perspective. *Soc Sci Med.* 2001;53: 1503–1511
24. Barnes LL, Plotnikoff GA, Fox K, Pendleton S. Spirituality, religion, and pediatrics: intersecting worlds of healing. *Pediatrics.* 2000;106:899–908
25. Stata Statistical Software: Release 7.0. College Station, TX: Stata Corporation; 2000
26. Daaleman TP, Frey B. Prevalence and patterns of physician referral to clergy and pastoral care providers. *Arch Fam Med.* 1998;7:548–553

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