November 2006 Article of the Month

This month's article selection is by Chaplain John Ehman,
University of Pennsylvania Medical Center-Penn Presbyterian, Philadelphia PA.

Robinson, M. R., Thiel, M. M., Backus, M. M. and Meyer, E. C. "**Matters of spirituality at the end of life in the pediatric intensive care unit**." *Pediatrics* 118, no. 3 (September 2006): e719-729.

[*Editor's Note: This month's article is available on-line from the American Academy of Pediatrics at http://pediatrics.aappublications.org/content/118/3/e719.*]

SUMMARY: This month's article presents a qualitative analysis of questionnaire responses from the parents of 56 children who had died "after the foregoing of life-sustaining treatment" in the Pediatric Intensive Care Units of Children's Hospital Boston, Massachusetts General Hospital, and Tufts New England Hospital [p. 720]. The data were derived from a larger study of parental perspectives on end-of-life care in the PICU, which did not explicitly ask about spirituality but to which 73% of the parents "offered spiritual/religious responses when asked what had been most helpful to them and what advice they would offer to others at the end of life" [p. 721]. The results indicated:

> Many parents drew on and relied on their spirituality to guide them in end-of-life decision-making, to make meaning of the loss, and to sustain them emotionally. Despite the dominance of technology and medical discourse in the ICU, many parents experienced their child's end of life as a spiritual journey. [p. 719 (abstract)]

The authors, two of whom are chaplains (Mary R. Robinson and Mary Martha Thiel, who is a CPE Supervisor), not only offer a careful presentation of their research but an engaging discussion of the place of spiritual care in the PICU. They illustrate with quotes the spiritual/religious themes identified in parents' responses: four *explicit* themes of "prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death" [p. 721], and several *implicit* themes pertaining to "wisdom borne of their experience, guidance according to one's own values, and virtues such as hope, trust, and love" [p. 722]. They also address spiritual care in light of the practical context of the health care setting and line out important issues in five tables based upon the literature of spirituality & health: "Diversity in Prayer in Hospital Settings: Representative Range of Prayer Practice," "Complementary Roles of Community Clergy and Hospital Chaplains," "Roles and Tasks of Spiritual Care Generalists and Specialists," "Suggested Sample Assessment Questions for Spiritual Care Generalists and Specialists," and "When a Spiritual Generalist Should Consult a Chaplain." The authors effectively interpret the role of spiritual caregivers to clinicians. The article emphasizes clinical implications, and one of the remarkable findings from the study is that "parents wrote much more freely about spiritual/religious beliefs and themes when they offered advice to other parents than to clinicians," which "suggests that although many parents experience the death of their child in spiritual ways, they may be reluctant

to share this perspective with health care providers..." [p. 723]. This, and the findings in general, lead the authors to encourage "[s]taff members, hospital chaplains, and community clergy...to be explicit in their hospitality to parents' spirituality and religious faith, to foster a culture of acceptance and integration of spiritual perspectives, and to work collaboratively to deliver spiritual care" [p. 719 (abstract)].

It is noteworthy that the spiritual material considered here emerged "spontaneously" [p. 721] from open-ended questions that had no specific prompt in that regard. The five key questions from the Parental Perspectives Questionnaire were [--see p. 721]:

- What was most helpful to you in getting through the time at the end of your child's life?
- What was least helpful to you in getting through the time at the end of your child's life?
- How can the hospital staff improve their communication with parents at this difficult time?
- What advice do you have for hospital staff members in helping parents during this difficult time?
- What advice do you have for other parents who are facing a similar situation?

This study is a good example of how chaplains can work, together with other disciplines, to further analyze data that may not have been central to the originating research but which can yield significant value when explored in particular.

In a special communication to the Research Network, co-author Mary Martha Thiel comments on the experience of pursuing this research and its publication:

> 1) This is the sort of research project in which chaplains without strong backgrounds in research can take part. In the summer of 2004, I took Harold Koenig's Summer Research Workshop on Religion and Health, at the Center for Spirituality, Theology and Health at Duke University. One of Dr. Koenig's suggestions to new researchers was to look for previously existing data sets that are available for analysis on issues of religion/spirituality. This is what happened with us. A number of papers were already published from the data of this study, but no one had looked in depth at the write-in responses that clustered around religious and spiritual issues. The study's original authors had noted the presence of these issues but did not feel equipped to interpret them. We were offered the chance to work with the data specifically because we were chaplains. Having an experienced researcher on the team with us was essential in helping us present our material in the medical model.
>
> 2) Our work group (two chaplains, a psychologist/nurse, and a psychology intern) made the strategic decision to try to publish this study in a journal where the readers would find the material new and "outside the box," to encourage teams to broaden the scope of pediatric ICU care to include spiritual needs. If we had published this material in a journal aimed at people from our own disciplines, it would not have challenged the readership in the same way nor invited leading decision-makers to adapt their practice models.
>
> 3) While our findings might not be surprising to chaplains, they seem to be surprising to many pediatric clinicians. This article is receiving quite a bit of press and is highlighting for the pediatric world that religious and spiritual issues are an important though under-studied aspect of pediatric ICU care. This is good news for pediatric patients and their families, and, of course, for chaplains.
>
> 4) Chaplains tend to work and think in inductive ways. Even though we focused on qualitative research methods in this study more than on quantitative methods, in deciding to publish for a medical audience we had to learn to think and evaluate the data using deductive methodologies. To make this work, we, too, had to operate outside *our* box! Deductive methodologies felt constraining to us chaplains. We would have loved to say "more" from our data. We think there is indeed more to say from it, but the seriousness with which our article is being taken by the pediatric establishment tells us that our labors of translation have paid off, and that some important interdisciplinary communication has taken place. *--Mary Martha Thiel, October 2006*

The article is a fine contribution to the spirituality & health literature in general, it is an up-to-date source on the topic of spirituality and pediatric end-of-life care (--see the bibliography), and it should be instructive for chaplains who are endeavoring to conduct research and/or develop interdisciplinary strategies for spiritual care in ICUs. As convener of the Network, I would also like to thank Rev. Thiel for her additional insights.

[NOTE (added 7/14/07): Bibliographic reference #21 is misprinted and should read: deVeber, L. L. "The Influence of Spirituality on Dying Children's Perceptions of Death." Chapter 15 (pp. 295-316) in Adams, D. W. and Deveau, E. J., eds., *Helping Children and Adolescents Cope with Life-Threatening Illness and Dying.* Vol. 2 in the series, *Beyond the Innocence of Childhood*. Amityville, NY: Baywood Publishing Co., 1995.

Suggestions for the Use of the Article for Discussion in CPE:

Students should find the article very readable and should appreciate the illustration and assessment of the major themes identified in the parents' responses. Discussion could focus on the themes themselves and how students have seen these in their own work with patients. In health care institutions that do not have a PICU, the generalizability of the findings to other end-of-life care settings could be debated. The information in the article's five tables also offers much for discussion, especially the comparison of the roles of chaplains, community clergy, and clinicians in tables 2 and 3 [pp. 724 and 726]. The paradigm of spiritual *generalists* and *specialists*, laid out in table 4, may be particularly striking to chaplains in training. In addition, CPE students and pastoral care staff alike should look carefully at table 5, regarding spiritual assessment questions: note the contrasting tenor and approach of the questions intended for use by clinicians and those for use by chaplains. Finally, students may want to consider the implications of the finding that parents' responses indicated a greater willingness to bring up spiritual themes when writing in relation to other parents than in relation to clinicians. How does the suggested *audience* of a survey affect the way that people respond to open-ended questions? Members of a PICU staff could be invited to discuss the article with students.

Related Items of Interest:

I. The bibliography in this month's article is an excellent source for further reading. In addition, the following recent articles may be of interest:

Anderson, M. J., Marwit, S. J., Vandenberg, B. and Chibnall, J. T. "**Psychological and religious coping strategies of mothers bereaved by the sudden death of a child**." *Death Studies* 29, no. 9 (Nov 2005): 811-826. [Among the findings of this study of 57 bereaved mothers was that "the interaction of task coping and positive religious coping was also associated with lower self-reported grief" (--from the abstract).]

Donnelly, J. P., Huff, S. M., Lindsey, M. L., McMahon, K. A. and Schumacher, J. D. "**The needs of children with life-limiting conditions: a healthcare-provider-based model**." *American Journal of Hospice & Palliative Care* 22, no. 4 (July-August 2005): 259-267. ["The purpose of the…study was to develop an empirically based conceptual model of the needs of children with life-limiting conditions. Recognizing the value of both qualitative and quantitative data, concept mapping methodology was selected as an effective way to obtain data that reflected both the "big picture" and subtleties of pediatric end-of-life needs. ...This model includes the following clusters of needs: 1) pain, 2) decision making, 3) medical system access and quality, 4) dignity and respect, 5) family-oriented care, 6) spirituality, and 7) psychosocial issues." (--from the abstract)]

[ADDED 11/5/07]: Ecklund, E. H., Cadge, W., Gage, E. A. and Catlin, E. "**The religious and spiritual beliefs and practices of academic pediatric oncologists in the United States**." *Journal*

of Pediatric Hematology/Oncology 29, no. 11 (November 2007): 736-742. [This study compares data from surveys of 77 pediatric oncology faculty (from a total sample of 122) working in 13 "honor role" hospitals, as designated by *US News and World Report*, with data from the General Social Survey. Results (--see the Abstract, p. 736): "Eighty-five percent of pediatric oncology faculty described themselves as spiritual. In all, 24.3% reported attending religious services 2 to 3 times a month or more in the past year. Twenty-seven percent of pediatric oncologists believed in God with no doubts. In all, 52.7% believed their spiritual or religious beliefs influence interactions with patients and colleagues. Among the general public 40.1% reported attending religious services 2 to 3 times a month or more in the past year ($P<0.01$) and 60.4% believed in God with no doubts ($P<0.001$). Conclusions: Although many have no traditional religious identity, large fractions of pediatric oncology faculty described themselves as spiritual. This may have implications for the education of pediatric oncologists and the spiritual care of seriously ill children and their families." (The article is preceded by a commentary: Walco, G. A., "Religion, spirituality, and the practice of pediatric oncology," on pp. 733-735.)]

Freyer, D. R., Kuperberg, A., Sterken, D. J., Pastyrnak, S. L., Hudson, D. and Richards, T. "**Multidisciplinary care of the dying adolescent**." *Child and Adolescent Psychiatric Clinics of North America* 15, no. 3 (July 2006): 693-715. [The authors, from DeVos Children's Hospital in Grand Rapids, MI, review issues of end-of-life care for adolescents and how care may be provided by an interdisciplinary team (that includes a chaplain). Special attention is paid to the issue of the adolescent's involvement in medical decision making.]

Gudmundsdottir, M. and Chesla, C. A. "**Building a new world: habits and practices of healing following the death of a child**." *Journal of Family Nursing* 12, no. 2 (May 2006): 143-164. [This study from the School of Nursing at the University of California in San Francisco uses interpretive phenomenological methodology to identify themes from multiple interviews with members of seven families who had suffered a sudden death of a child. Analysis focuses on rituals, often with explicit or implicit spiritual elements, to memorialize the deceased children and to connect with the child's spirit. There is a good bibliography.]

Himelstein, B. P. "**Palliative care in pediatrics**." *Anesthesiology Clinics of North America* 23, no. 4 (December 2005): 837-856, xi. [This is a broad overview of the subject. See especially the section on Psychological and Spiritual Concerns (p. 839ff) and specifically the sub-section on Spiritual Care (p. 842), and the assessment planning chart (figure 1, p. 843).]

Kang, T., Hoehn, K. S., Licht, D. J., Mayer, O. H., Santucci, G., Carroll, J. M., Long, C. M., Hill, M. A., Lemisch, J., Rourke, M. T. and Feudtner, C. "**Pediatric palliative, end-of-life, and bereavement care**." *Pediatric Clinics of North America* 52, no. 4 (August 2005): 1029-1046, viii. [This article, from The Children's Hospital of Philadelphia in Philadelphia, PA, addresses palliative, end-of-life, and bereavement care from the perspective of physicians but in the context of an interdisciplinary team. See especially the section on Psychosocial and Spiritual Needs (pp. 1033-1035) and table 5 regarding a Framework for Assessing and Improving Quality of Care (p. 1044). The presence of chaplains is also twice noted (pp. 1033 and 1044). This article is useful background reading on the role of the physician, particularly the hospitalist.]

Meert, K. L., Thurston, C. S. and Briller, S. H. "**The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study**." *Pediatric Critical Care Medicine* 6, no. 4 (July 2005): 420-427. [The study interviewed 26 parents whose children who died in the pediatric intensive care unit at a university-affiliated children's hospital between January 1, 1999, and August 31, 2000. (From the abstract:) The main spiritual need described by parents was that of maintaining connection with their child. Parents maintained connection at the time of death by physical presence. …Other spiritual needs included the need for truth; compassion; prayer, ritual, and sacred texts; connection with others; bereavement support; gratitude; meaning and purpose; trust; anger and blame; and dignity….]

Nottage, S. L. "**Parents' use of nonmedical support services in the neonatal intensive care unit**." *Issues in Comprehensive Pediatric Nursing* 28, no. 4 (October-December 2005): 257-273. [This study from the Oregon Health and Science University, Child Development and Rehabilitation Center in Portland found evidence of an "inverse relationship between social support and the use of supportive services," like chaplains, and that parents "appear to use support services less often than would be anticipated based on their reports of utility" (--from the abstract). See especially the sections on Chaplains/Religious Counselors (p. 239) and the various tables under Results that give data pertaining to the use of chaplains (pp. 265-266).]

Schneider, M. A. and Mannell, R. C "**Beacon in the storm: an exploration of the spirituality and faith of parents whose children have cancer**." *Issues in Comprehensive Pediatric Nursing* 29, no. 1 (January-March 2006): 3-24. [In this phenomenological study out of Canada, interviewed were conducted with 12 parents. In the analysis, religious and secular views of spirituality were identified. Religious themes included: faith as a source of comfort, the power and importance of prayer, the deeply personal nature of faith, and faltering faith. The secular view of spirituality was found to revolve around nature. The article is aimed at nurses. Chaplains are not mentioned, though there is passing reference to referral to clergy.]

Tan, G. H., Totapally, B. R., Torbati, D. and Wolfsdorf, J. "**End-of-life decisions and palliative care in a children's hospital**." *Journal of Palliative Medicine* 9, no. 2 (April 2006): 332-342. [This article from the Division of Critical Care Medicine at Miami (FL) Children's Hospital presents a complex analysis of the charts of 236 deceased children. The study looked for documentation of end-of-life care discussions and spiritual support, the nature of those end-of-life care decisions, and the degree of opioid analgesics and the use of sedatives. End-of-life care discussion was associated with (among other things) spiritual support, and spiritual support was associated with higher use of opiod analgesics and sedative administration. The article would likely be of interest to researchers more than to a general readership.]

II. In January 2004, *Child and Adolescent Psychiatric Clinics of North America* published a special theme issue (vol. 13, no. 1) on religion and spirituality in pediatrics. This may be of interest to chaplains in general, and to researchers looking for background material on the dynamics pediatric spiritual care. See, for instance, Margaret L. Stuber and Beth M. Housekamp's "**Spirituality in children confronting death**" (pp. 127-136), and the following articles on religious/cultural diversity issues:

Al-Mateen, C. S. and Afzal, A. "**The Muslim child, adolescent, and family**." Pp. 183-200.

Black, N. "**Hindu and Buddhist children, adolescents, and families**." Pp. 210-220.

Mercer, J. A. "**The Protestant child, adolescent, and family**." Pp. 161-182.

Murrell, K. "**The Catholic child, adolescent, and family**." Pp. 149-160.

Rube, D. M. and Kibel, N. "**The Jewish child, adolescent, and family**." Pp. 137-148.

If you have suggestions about the form and/or content of the site, e-mail Chaplain John Ehman (Network Convener) at john.ehman@uphs.upenn.edu .
Copyright © 2006
The ACPE Research Network. All rights reserved.