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July 2017 Article of the Month

This month's article selection is highlighted by John Ehman,
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Donohue, P. K., Norvell, M., Boss, R. D., Shepard, J., Frank, K., Patron, C. and Crowe, T. Y. 2nd. **"Hospital chaplains: through the eyes of parents of hospitalized children."** *Journal of Palliative Medicine* (June 26, 2017): published [online ahead of print](#) by the journal.

[Editor's Note: Because this article is available ahead of print, no final page numbers can be cited. Quotations noted below are referenced by manuscript [MS] page numbers.]

SUMMARY and COMMENT: This month's study continues the theme of perceptions of the chaplain's role, which was the subject in [last month's](#) feature. Here, investigators from Johns Hopkins Medicine (Baltimore, MD) "wondered whether parents [of hospitalized children] perceive the hospital chaplain to be separate from or part of the medical team, their understanding of the role of the chaplain, and their experience of solicited versus unsolicited interactions with hospital chaplains"; with a "goal...to help guide the hospital chaplain practice" [MS p. 1]. The researchers "hypothesized that most families view a chaplain's visit as supportive, but those without religious affiliation might find it intrusive, and some might find it frightening if perceived as associated with end-of-life care" [MS p. 1]. While this article focuses on the context of the care of children, it is data rich and may help chaplains in other health care contexts think about how they are perceived.

Data were collected in 2013 at the researchers' tertiary care institution, from 74 parents of children whose medical records indicated had been visited by staff chaplains or CPE residents (29% of the total sample of 257 visited families for whom there was contact information). Telephone interviews covered a 40-item questionnaire developed for the current purpose. "All respondents reported that they were the primary person with the child during the hospitalization" [MS p. 2]. A majority indicated that they were spiritual/religious, three quarters "considered their child very sick during the hospitalization" [MS p. 2], and 81% had received more than one visit from a chaplain.

Among the many particular findings detailed in the text and tables:

About half of the parents (59.6%) knew a hospital chaplain was available to them; 42.3% of parents requested a chaplain visit. Sixty-two percent of parents understood that the role of a hospital chaplain included providing religious and secular services: prayer and sacraments, family support, and comfort. The remaining 38% of parents reported that chaplains help patients/parents with decision making, medical terminology, advocacy, and by just being there. [MS p. 2]

...[M]ore than 50% of parents reported that hospital chaplains helped them explore the meaning of

their child's illness, and more than 80% reported that chaplains helped them maintain hope during the hospitalization. [MS p. 5]

...More than half (54%) of the respondents receiving an unsolicited visit reported being grateful and appreciative of the sincerity and caring behavior demonstrated to the whole family. Only five respondents would have preferred giving prior approval before the chaplain visit. For three of these respondents, the unsolicited visit was viewed as surprising, awkward, or frightening. Two parents reported that they feared the staff called the chaplain because bad news was going to be delivered or that doctors had been withholding information about the seriousness of the child's condition. In all five of these cases, respondents reported that once they understood the purpose of the chaplain's visit, they appreciated the support and welcomed additional visits. [MS p. 2]

...About 75% of parents agreed with the statement, "during the hospital stay, I viewed the chaplain as part of my child's health care team," and 38% reported that chaplains helped healthcare providers understand parents' preferences for care at least some of the time. Just over half of the parents reported some conflict or tension with the healthcare team; for 21.6% of these parents, a chaplain helped resolve the conflict. [MS p. 2]

Also, 50 of the 74 parents offered additional comments, and some illustrative quotes are provided here. For instance, regarding a finding that "nonreligious respondents were overwhelmingly positive about the role of the hospital chaplain," one parent stated,

Even though we are not religious, the chaplain was very supportive during a long hospitalization. If asked, we would have turned down a chaplain visit... [but] chaplains should visit all patients and families. [MS p. 4]

Analysis regarding patient satisfaction is highlighted by the authors: "Remarkably, 66% of parents reported that as few as one or two visits from a hospital chaplain positively influenced their satisfaction with hospital care" [MS pp. 4-5]. However, a regression model showed that the number of chaplain visits was not an independent predictor of a chaplain visit influencing satisfaction with hospital care [--see MS p. 3]. A table gives a quantitative summary of responses to seven questions relating to satisfaction [--see MS p. 4].

Overall, the data suggest that chaplains are perceived as contributing positively to the overall hospital experience. For a significant majority of the parents, chaplains were seen as part of the care team (though one of the limits noted for this research is that "about 80% of the children in our sample spent some time in intensive care," where chaplains are "preferentially staffed" [MS p. 6]). Regarding this key point the authors' interestingly note the possible downside of such a view of an integrated role, in the risk that the sense of chaplains as patient advocates might be diminished:

As a bona fide member of the medical team, patients and families may view chaplains as representing the medical system or hospital, which could adversely affect trust for some. Chaplains' vision of themselves as apart may also facilitate their effectiveness in mediating physician -- family conflict, which could be lost if they are an integrated member of the team. [MS p. 6]

For this chaplain reader, who does *not* work in a pediatric setting, the article is valuable in at least four ways: first, by enriching the picture of how families may understand (or come to understand) the broad role of the chaplain; second, by bolstering the idea that a chaplain can help people experience the whole of their hospitalization as more caring; and third, by demonstrating the very feasibility of a 40-item telephone interview about chaplaincy care (which might have been too fatiguing an exercise). Also striking is one particular item in the questionnaire: "The chaplain asked me about my child's pain and responded to my concerns" --to which 40.8% responded "*always*" and another 14.1% responded "*usually*." That item (while it is a compound question and therefore involves some ambiguity) raises the issue of a chaplain explicitly asking about pain.

The bibliography is fairly extensive, with 43 references, though all but six (including three internet references) are over five years old.

Special comments to the Network from authors, [Matt Norvell](#), Pediatric Chaplain, Johns Hopkins Children's Center; and [Thomas Y. \(Ty\) Crowe, II](#), Director, Department of Spiritual Care & Chaplaincy, The Johns Hopkins Hospital, Baltimore, MD:

Our research team here at Hopkins was excited about this project from the beginning because it gave us the opportunity to receive direct feedback from families of our pediatric patients specifically about the spiritual support they received. Most of the time our assessment of outcomes is based in the chaplain's experience of the encounter immediately after it has happened. This study gave us the chance to understand the actual experience that parents had of our chaplains and the spiritual support interaction.

We are grateful to have this published in *JPM* because it highlights the work and value of chaplains for the greater medicine community. We think this type of work is important because it helps bring greater awareness of the value of spiritual support to families and the ways it influences their perception of the care they received. Of particular interest was the experience of the unsolicited visit from parents who may not be spiritual or religious.

This work investigated the specific specialty of pediatric chaplaincy, which is unique because of the consistent presence of other family members as a part of the spiritual support encounter. Thus, our study offers some contribution to the area of patient and family centered care as we all continue to explore the ways pediatric chaplains have been, and can be, involved in providing the best possible hospital experience to each uniquely comprised family system.

Suggestions for Use of the Article for Student Discussion:

If students have read [last month's](#) article, which touched on similar themes, then the current article could provide an opportunity both to continue conversation about the role of the chaplain and to think about how the two articles provide different methodological approaches to exploring their topics. What, for instance, might be the advantages of the specificity of a 40-item questionnaire used here (rather than focus groups or generally guided interviews)? Disadvantages? Note the step in the data collection process: "Any parent considered by the interviewer to be distressed by the survey was referred, with permission, to a hospital social worker for evaluation and referral to mental health services if warranted" [MS p. 2]. What do students make of the need for this kind of protection for study participants? Turning to the results of the study, students at pediatric hospitals or serving pediatric units might discuss how the findings reflect their own sense of working as a chaplain. For students not in a pediatric setting, how do the results here compare and contrast to their experience? How do they believe that patients or families gain a sense of the role of the chaplain? Is there a widely held perception that a chaplain is part of the care team? Does the article help students to think about the value of unsolicited visits and visits with non-religious individuals? What about the position of chaplains in conflict resolution? Do students think of themselves as being able to influence patient/family satisfaction with the care team? Finally, do they believe that the pediatric setting brings into play special dynamics regarding patient/family needs and perspectives?

Related Items of Interest:

I. The origin of the research partnership between the Johns Hopkins Department of Spiritual Care & Chaplaincy and lead author Pamela K. Donohue, M.S., Sc.D., has been noted in our [Winter 2010 Newsletter](#) [-- see that issue's item #3]. Other research of special interest to chaplains by Dr. Donohue include:

Boss, R. D., Hutton, N., Sulpar, L. J., West, A. M. and Donohue, P. K. "**Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns.**" *Pediatrics* 122, no. 3 (September 2008): 583-589. [Among the results of this qualitative multicenter study involving interviews with 26 mothers of infants who died as a result of extreme prematurity or lethal congenital anomalies in 1999-2005: "Religion, spirituality, and hope guided most parents' decision-making. Regardless of the medical information, parents maintained hope that everything would be fine. They were encouraged by friends and family members to pray for miracles, to transfer to a hospital thought capable of miracles, or to trust that a miracle would happen despite the physicians. Some parents felt that there were no decisions to make regarding delivery room resuscitation; they wanted the physicians to do everything they could, and the rest was 'in God's hands.' (See p. 585.) The authors propose "addressing parents' religious and spiritual concerns early, as they relate to decisions regarding delivery room resuscitation, may enhance communication and understanding between parents and physicians." (See p. 586.)]

Donohue, P. K., Boss, R. D., Aucott, S. W., Keene, E. A. and Teague, P. "**The impact of neonatologists' religiosity and spirituality on health care delivery for high-risk neonates.**" *Journal of Palliative Medicine* 13, no. 10 (October 2010): 1219-1224. [(Abstract:)
BACKGROUND: Ethical decision-making regarding life-sustaining therapies (LST) for high-risk neonates can be challenging for both neonatologists and parents. Parents depend on neonatologists to interpret complex information, identify critical opportunities for decision-making, and present options for care. How neonatologists' belief systems affect care delivery for critically ill newborns is unexplored. OBJECTIVE: To characterize the relationship between neonatologists' religiosity or spirituality and the provision of intensive care services for high-risk newborns. METHODS: Neonatologists practicing at an American Academy of Pediatrics Neonatal-Perinatal Training Program were surveyed about their religious/spiritual beliefs, provision of LST for critically ill neonates, and communication with families. RESULTS: Two hundred ninety-eight neonatologists responded to the survey; 66.4% consider themselves very or moderately spiritual, 40.8% very or moderately religious. In response to a hypothetical prenatal consultation for a fetus at 23 1/7 weeks gestation, 96.3% agreed that the physician has a moral obligation to present all options to parents, including the provision of comfort care. More than 95% had no objection to withholding or withdrawing LST, with religion playing almost no part in these decisions. 38% of participants reported no objection to resuscitating an infant with trisomy 13 or 18; 40% of these neonatologists considered themselves very/moderately religious, 60% slightly/not at all religious. Eighty-nine neonatologists reported that their religious beliefs influence their medical practice. These physicians had similar responses as those not influenced by religion. CONCLUSION: For the majority of neonatologists participating in this study, differences in critical care practice cannot be attributed to personal religious or spiritual views.]

II. For insights into the perspective of pediatric physicians and palliative care teams on the chaplain's role, plus the perspective of chaplains on their own role in the pediatric setting, see the [July 2011 Articles-of-the-Month](#), featuring:

Cadge, W., Calle, K. and Dillinger, J. "**What do chaplains contribute to large academic hospitals? The perspectives of pediatric physicians and chaplains.**" *Journal of Religion and Health* 50, no. 2 (June 2011): 300-312. [(Abstract:) This article analyzes interviews with pediatric physicians (N = 30) and chaplains (N = 22) who work at the same large academic medical centers (N = 13). We ask how pediatric physicians understand and work with chaplains and how chaplains describe their own work. We find that physicians see chaplains as part of interdisciplinary medical teams where they perform rituals and support patients and families, especially around death.

Chaplains agree but frame their contributions in terms of the perspectives related to wholeness, presence, and healing they bring. Chaplains have a broader sense of what they contribute to patient care than do physicians.] [Available on line from www.wendycadge.com.]

Fitchett, G., Lyndes, K. A., Cadge, W., Berlinger, N., Flanagan, E. and Misasi, J. "**The role of professional chaplains on pediatric palliative care teams: perspectives from physicians and chaplains.**" *Journal of Palliative Medicine* 14, no. 6 (June 2011): 704-707. [(Abstract:)
CONTEXT: Pediatric palliative care (PPC) specialists recognize spiritual care as integral to the services offered to seriously ill children and their families. Little is known about how PPC programs deliver spiritual care. OBJECTIVE: The goal of this pilot study was to begin to describe the role of professional chaplains in established PPC programs in children's hospitals in the United States. METHODS: In 2009 we surveyed 28 PPC programs to ascertain how spiritual care was provided. Of the 19 programs with staff chaplains who met additional study criteria, we randomly selected eight to study in detail. Based on interviews with the medical director and staff chaplain in these eight programs, we qualitatively delineated chaplains' roles in PPC. RESULTS: Twenty-four of the 28 surveyed programs (86%) reported having a staff chaplain on their clinical team. Among the 8 interviewed programs, there was considerable variation in how chaplains functioned as members of interdisciplinary teams. Despite these variations, physicians and chaplains agreed that chaplains address patients' and families' spiritual suffering, improve family-team communication, and provide rituals valued by patients, families, and staff. CONCLUSIONS: Our survey of these PPC programs found that spiritual care was typically provided by staff chaplains, and our interviews indicated that chaplains appeared to be well-integrated members of these teams. Further research is needed to evaluate how well the spiritual needs of patients, families, and staff are being met, and the organizational factors that support the delivery of spiritual care in children's hospitals.]

III. For a recent study of how parents of children in Pediatric ICUs may draw on spiritual sources of support for decision-making, see:

Madrigal, V. N., Carroll, K. W., Faerber, J. A., Walter, J. K., Morrison, W. E. and Feudtner, C. "**Parental sources of support and guidance when making difficult decisions in the Pediatric Intensive Care Unit.**" *Journal of Pediatrics* 169 (February 2016): 221-6.e4. [(Abstract:)
OBJECTIVE: To assess sources of support and guidance on which parents rely when making difficult decisions in the pediatric intensive care unit and to evaluate associations of sources of support and guidance to anxiety, depression, and positive and negative affect. STUDY DESIGN: This was a prospective cohort study of 86 English-speaking parents of 75 children in the pediatric intensive care unit at The Children's Hospital of Philadelphia who were hospitalized greater than 72 hours. Parents completed standardized instruments and a novel sources of support and guidance assessment. RESULTS: Most parents chose physicians, nurses, friends, and extended family as their main sources of support and guidance when making a difficult decision. Descriptive analysis revealed a broad distribution for the sources of support and guidance items related to spirituality. Parents tended to fall into 1 of 2 groups when we used latent class analysis: the more-spiritual group (n = 47; 55%) highly ranked "what my child wants" (P = .023), spouses (P = .002), support groups (P = .003), church community (P < .001), spiritual leader (P < .001), higher power (P < .001), and prayer (P < .001) compared with the less-spiritual group (n = 39; 45%). The more-spiritual parents had greater positive affect scores (P = .005). Less-spiritual parents had greater depression scores (P = .043). CONCLUSIONS: Parents rely most on physicians, nurses, and friends and extended family when making difficult decisions for their critically ill child. Respondents tended to fall into 1 of 2 groups where the more-spiritual respondents were associated with greater positive affect and may be more resistant to depression.]

IV. Recent studies about parents' interest in spiritual support from the care team:

Arutyunyan, T., Odetola, F., Swieringa, R. and Niedner, M. "**Religion and spiritual care in Pediatric Intensive Care Unit: parental attitudes regarding physician spiritual and religious inquiry.**" *American Journal of Hospice & Palliative Medicine* (2016): published online ahead of print by the journal, January 1, 2016. [(Abstract:) OBJECTIVE: Parents of seriously ill children require attention to their spiritual needs, especially during end-of-life care. The objective of this study was to characterize parental attitudes regarding physician inquiry into their belief system. Materials and Main Results: A total of 162 surveys from parents of children hospitalized for >48 hours in pediatric intensive care unit in a tertiary academic medical center were analyzed. Forty-nine percent of all respondents and 62% of those who identified themselves as moderate to very spiritual or religious stated that their beliefs influenced the decisions they made about their child's medical care. Although 34% of all respondents would like their physician to ask about their spiritual or religious beliefs, 48% would desire such enquiry if their child was seriously ill. Those who identified themselves as moderate to very spiritual or religious were most likely to welcome the discussion ($P < .001$). Two-thirds of the respondents would feel comforted to know that their child's physician prayed for their child. One-third of all respondents would feel very comfortable discussing their beliefs with a physician, whereas 62% would feel very comfortable having such discussions with a chaplain. CONCLUSION: The study findings suggest parental ambivalence when it comes to discussing their spiritual or religious beliefs with their child's physicians. Given that improved understanding of parental spiritual and religious beliefs may be important in the decision-making process, incorporation of the expertise of professional spiritual care providers may provide the optimal context for enhanced parent-physician collaboration in the care of the critically ill child.]

Kelly, J. A., May, C. S. and Maurer, S. H. "**Assessment of the spiritual needs of primary caregivers of children with life-limiting illnesses is valuable yet inconsistently performed in the hospital.**" *Journal of Palliative Medicine* 19, no. 7 (July 2016): 763-766. [(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.]

V. The **Pediatric Chaplains Network** (<http://pediatricchaplains.org>) formed as an independent organization in 1999, after developing through the Association for the Care of Children's Health. Research is one of its three mission components (along with education and support), and while the website does not currently offer content regarding research, it notes the following ways that the organization seeks to be involved with research:

- to PROVIDE resources that educate pediatric chaplains and interested disciplines in research literacy;

- to PROMOTE active research projects in pediatric chaplaincy by supporting PCN members and their collaborators as they do so;
- and to ADVOCATE for research in chaplaincy and spirituality in healthcare that are specifically oriented to the pediatric setting.

The site also includes a "members-only section that offers templates for specific kinds of research, how-to guides for getting started, networking opportunities for those interested in specific research topics, and valuable resources to support our members." Interested chaplains may [contact](#) the PCN for further information.

VI. The Centre for Paediatric Spiritual Care (www.bch.nhs.uk/cpsc) at Birmingham Children's Hospital (UK) "exists to support and encourage the research and resourcing of multi-disciplinary spiritual care of sick children and young people of all ages and conditions, their families and to support staff who work with them" [-from the website]. See the [research section](#) for a listing of published studies. The site also links to a **Paediatric Chaplaincy Network** (www.paediatric-chaplaincy-network.org) -- *not to be confused with the Pediatric Chaplains Network noted in our Item V, directly above*. That site includes its own [page on research](#).

VII. The Grosseohme Lab at Cincinnati Children's Hospital is an excellent source for research into the needs of parents especially of children with cystic fibrosis (in addition to research about young patients themselves). A sample of studies from Dr. Grosseohme and colleagues:

Grosseohme, D. H., Cotton, S. and McPhail, G. "**Use and sanctification of complementary and alternative medicine by parents of children with cystic fibrosis.**" *Journal of Health Care Chaplaincy* 19, no. 1 (2013): 22-32. [(Abstract:) Complementary and alternative medicine (CAM) use, including spiritual modalities, is common in pediatric chronic diseases. However, few users discuss CAM treatments with their child's physician. Semi-structured interviews of 25 parents of children who have cystic fibrosis (CF) were completed. Primary themes were identified by thematic analyses. Most parents (19/25) used at least one CAM modality with their child. Only two reported discussing CAM use with their child's pulmonologist. Most reported prayer as helpful (81%) and multi-faceted, including individual and group prayer; using aromatherapy or scented candles as an adjunct for relaxation; and the child's sleeping with a blessed prayer. Parents ascribed sacred significance to natural oral supplements. CAM use is relevant to the majority of participating parents of children under age 13 with CF. Chaplains can play a significant role by reframing prayer's integration into chronic disease care, co-creating rituals with pediatric patients, and mediating conversations between parents and providers.]

Grosseohme, D. H., Cotton, S., Ragsdale, J., Quittner, A. L., McPhail, G. and Seid, M. "**I honestly believe God keeps me healthy so I can take care of my child': parental use of faith related to treatment adherence.**" *Journal of Health Care Chaplaincy* 19, no. 2 (2013): 66-78. [A limited number of studies address parental faith and its relationship to their children's health. Using cystic fibrosis as a disease exemplar in which religion/spirituality have been shown to play a role and parental health behaviors (adherence to their child's daily recommended home treatments) are important, this study explored whether parents with different levels of adherence would describe use of faith differently. Twenty-five interviews were completed and analyzed using grounded theory methodology. Some parents described no relationship between faith and treatment adherence. However, of those who did, higher-adherence parents believed God empowered them to care for their child and they used prayer to change themselves, while lower-adherence parents described trusting God to care for their child and used prayer to change God. Clinical implications for chaplains' differential engagement with parents are presented.]

Grosseohme, D. H., Opiari-Arrigan, L., VanDyke, R., Thurmond, S. and Seid, M. "**Relationship of adherence determinants and parental spirituality in cystic fibrosis.**" *Pediatric Pulmonology*

47, no. 6 (June 2012): 558-566. [(Abstract:) The course of cystic fibrosis (CF) progression in children is affected by parent adherence to treatment plans. The Theory of Reasoned Action (TRA) posits that intentions are the best behavioral predictors and that intentions reasonably follow from beliefs ("determinants"). Determinants are affected by multiple "background factors," including spirituality. This study's purpose was to understand whether two parental adherence determinants (attitude towards treatment and self-efficacy) were associated with spirituality (religious coping and sanctification of the body). We hypothesized that parents' attitudes toward treatment adherence are associated with these spiritual constructs. A convenience sample of parents of children with CF aged 3-12 years (n=28) participated by completing surveys of adherence and spirituality during a regular outpatient clinic visit. Type and degree of religious coping was examined using principal component analysis. Adherence measures were compared based on religious coping styles and sanctification of the body using unpaired t-tests. Collaborative religious coping was associated with higher self-efficacy for completing airway clearance (M=1070.8; SD=35.8; P=0.012), for completing aerosolized medication administration (M=1077.1; SD=37.4; P=0.018), and for attitude towards treatment utility (M=38.8; SD=2.36; P=0.038). Parents who attributed sacred qualities to their child's body (e.g., "blessed" or "miraculous") had higher mean scores for self-efficacy (airway clearance, M=1058.6; SD=37.7; P=0.023; aerosols M=1070.8; SD=41.6; P=0.020). Parents for whom God was manifested in their child's body (e.g., "My child's body is created in God's image") had higher mean scores for self-efficacy for airway clearance (M=1056.4; SD=59.0; P=0.039), aerosolized medications (M=1068.8; SD=42.6; P=0.033) and treatment utility (M=38.8; SD=2.4; P=0.025). Spiritual constructs show promising significance and are currently undervalued in chronic disease management.]

Grossoehme, D. H., Ragsdale, J., Cotton, S., Wooldridge, J. L., Grimes, L. and Seid, M. "**Parents' religious coping styles in the first year after their child's cystic fibrosis diagnosis.**" *Journal of Health Care Chaplaincy* 16, nos. 3-4 (2010): 109-122. [(Abstract:) Parents of children diagnosed with cystic fibrosis described it as "devastating." Given religion's importance to many Americans, parents may utilize religious coping. Relatively little is known about parents' use of religious coping to handle their child's illness. Interviews with 15 parents about their use of religion in the year following their child's cystic fibrosis diagnosis were coded for religious coping styles. Sixteen styles were identified. Positive religious coping styles were more frequent than negative styles (previously associated with poorer health outcomes), and occurred more frequently than in other studies. Religious coping styles used to make meaning, gain control, or seek comfort/intimacy with God were equally prevalent. The most common styles were: Pleading, Collaboration, Benevolent Religious Reappraisals, and Seeking Spiritual Support. Parents described active rather than passive coping styles. Religious coping involving religious others was rare. Clinical attention to negative religious coping may prevent it becoming chronic and negatively affecting health.

Grossoehme, D. H., Ragsdale, J. R., Snow, A. and Seid, M. "**We were chosen as a family: parents' evolving use of religion when their child has cystic fibrosis.**" *Journal of Religion & Health* 51, no. 4 (December 2012): 1347-1358. [(Abstract:) Parental coping with new CF diagnoses often includes religion; however, little is known about how the use of religion changes over time. Longitudinal grounded theory method, in which parents were interviewed twice the 2 years after their child's diagnosis, was used. Parents constructed the meaning that parenting a child with CF is their vocation, in accordance with "God's plan." A shift from isolation to an outward focus and reentry into the community was clear. The use of faith evolved over time and continues to be a source of support and hope for parents. Clinical implications of parental religion are discussed.

Grossoehme, D. H., Ragsdale, J., Wooldridge, J. L., Cotton, S. and Seid, M. "**'We can handle this': parents' use of religion in the first year following their child's diagnosis with cystic fibrosis.**" *Journal of Health Care Chaplaincy* 16, nos. 3-4 (2010): 95-108. [(Abstract:) The diagnosis of a child's life-shortening disease leads many American parents to utilize religious beliefs. Models relating religious constructs to health have been proposed. Still lacking are inductive models based on parent experience. The specific aims of this study were: 1. develop a

grounded theory of parental use of religion in the year after diagnosis; 2. describe whether parents understand a relationship between their religious beliefs and their follow-through with their child's at-home treatment regimen. Fifteen parent interviews were analyzed using grounded theory method. Parents used religion to make meaning of their child's cystic fibrosis (CF) diagnosis. Parents imagined God as active, benevolent, and interventionist; found hope in their beliefs; felt supported by God; and related religion to their motivation to adhere to their child's treatment plan. Religious beliefs are clinically significant in working with many parents of children recently diagnosed with CF. Interventions that improve adherence to treatment may be enhanced by including religious aspects.

Grossoehme, D. H., Szczesniak, R. D., Britton, L. L., Siracusa, C. M., Quittner, A. L., Chini, B. A., Dimitriou, S. M and Seid, M. "**Adherence determinants in cystic fibrosis: cluster analysis of parental psychosocial, religious, and/or spiritual factors.**" *Annals of the American Thoracic Society* 12, no. 6 (Jun 2015): 838-846. [(Abstract:) RATIONALE: Cystic fibrosis is a progressive disease requiring a complex, time-consuming treatment regimen. Nonadherence may contribute to an acceleration of the disease process. Spirituality influences some parental healthcare behaviors and medical decision-making. OBJECTIVES: We hypothesized that parents of children with cystic fibrosis, when classified into groups based on adherence rates, would share certain psychosocial and religious and/or spiritual variables distinguishing them from other adherence groups. METHODS: We conducted a multisite, prospective, observational study focused on parents of children younger than 13 years old at two cystic fibrosis center sites (Site 1, n= 83; Site 2, n = 59). Religious and/or spiritual constructs, depression, and marital adjustment were measured by using previously validated questionnaires. Determinants of adherence included parental attitude toward treatment, perceived behavioral norms, motivation, and self-efficacy. Adherence patterns were measured with the Daily Phone Diary, a validated instrument used to collect adherence data. Cluster analysis identified discrete adherence patterns, including parents' completion of more treatments than prescribed. MEASUREMENTS AND MAIN RESULTS: For airway clearance therapy, four adherence groups were identified: median adherence rates of 23%, 52%, 77%, and 120%. These four groups differed significantly for parental depression, sanctification of their child's body, and self-efficacy. Three adherence groups were identified for nebulized medications: median adherence rates of 35%, 82%, and 130%. These three groups differed significantly for sanctification of their child's body and self-efficacy. CONCLUSIONS: Our results indicated that parents in each group shared psychosocial and religious and/or spiritual factors that differentiated them. Therefore, conversations about adherence likely should be tailored to baseline adherence patterns. Development of efficacious religious and/or spiritual interventions that promote adherence by caregivers of children with cystic fibrosis may be useful.]

Grossoehme, D. H., Szczesniak, R., Dodd, C. and Opiari-Arrigan, L. "**Dyadic adjustment and spiritual activities in parents of children with cystic fibrosis.**" *Religions* 5, no. 2 (2014): 385-401. [(Abstract:) Children's diseases can negatively impact marital adjustment and contribute to poorer child health outcomes. To cope with increased marital stress and childhood diseases severity, many people turn to spirituality. While most studies show a positive relationship between spirituality and marital adjustment, spirituality has typically been measured only in terms of individual behaviors. Using the Dyadic Adjustment Scale (DAS) and Daily Phone Diary data from a sample of 126 parents of children with cystic fibrosis as a context for increased marital stress, spiritual behavior of mother-father dyads and of whole families were used as predictors of marital adjustment. Frequency and duration of individual, dyadic and familial spiritual activities correlated positively with dyadic adjustment. Significant differences in spiritual activities existed between couples with marital adjustment scores above and below the cutoff for distress. The only significant factors in regressions of spiritual activities on marital adjustment scores were number of pulmonary exacerbations and parent age. Higher odds of maintaining a marital adjustment score greater than 100 were significantly associated with spending approximately twelve minutes per day in individual, but not conjugal or familial, spiritual activities. The Daily Phone Diary is a feasible tool

to study conjugal and familial activities and their relationships with beliefs and attitudes, including spirituality.]

Chaplain researcher Daniel Grossoehme has also authored several pieces to help chaplains envision their own path into original research, including an "**Overview of qualitative research**" [*Journal of Health Care Chaplaincy* 20, no. 3 (2014): 109-122], which was featured as our [August 2014 Article-of-the-Month](#), and a chapter on "**Identifying the research question**" in [An Invitation to Chaplaincy Research: Entering the Process](#), ed. by Myers, G. E with Roberts, S. [John Templeton Foundation, 2014], pp. 40-50.

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 .

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