June 2010 Article of the Month

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

Boyd, E. A., Lo, B., Evans, L. R., Malvar, G., Apatira, L., Luce, J. M. and White, D. B. "**'It's not just what the doctor tells me': factors that influence surrogate decision-makers' perceptions of prognosis**." *Critical Care Medicine* 38, no. 5 (May 2010): 1270-1275.

SUMMARY and COMMENT: This month's article deals with situations in which hospital chaplains regularly find themselves: caring for family members who have their own ideas about a critically ill loved one's prognosis, often in tension with the physician's assessment. The study -- supported by a grant from the National Institutes of Health -- identifies five "sources of 'knowing'" [p. 1274] used by surrogate decision-makers apart from the prognostic estimate of a physician. One of these five other sources deals with religion/spirituality, but this research as a whole should be of interest to chaplains who work with families and medical staff in the midst of uncertainty and differences of opinion about a patient's chances for survival of grave illness.

The authors postulate, out of their own experience, that dissonance between physicians and surrogate decision-makers over prognosis is more complicated than merely poor communication --that physicians and surrogates may actually "systematically differ in how they formulate prognostic estimates" [p. 1270]. They conducted semistructured interviews at the University of California, San Francisco Medical Center, with 179 surrogates associated with 142 Intensive Care Unit patients 3-5 days after those patients were placed on mechanical ventilation. Participants were first asked in a questionnaire for "a percentage estimate of their loved one's chances of surviving the hospitalization" [pp. 1271], then followed up with private, audio-taped interviews that opening with: "I see that you've noted here that you think your loved one has a(n) __% chance of surviving the hospitalization. Can you tell me a little bit about what has made you think this is his/her prognosis?" [p. 1271].

Only 3 of the 179 surrogates -- less than 2% -- said that they based their sense of the patient's prognosis solely on the physician's estimate, and only 47% indicated that the physician's estimate contributed at least in part to their thinking. The other "sources of 'knowing'" [p. 1274] identified were:

> **The patient's intrinsic qualities and will to live** -- 27% of participants seemed to focus on their understanding of such qualities as "[h]aving a 'stubborn' or 'determined' disposition and being stronger than most people" or being a "fighter" [p. 1272].
>
> **The patient's physical appearance or status** -- 64% relied upon their own observation and interpretation of such things as "facial expression, hue of the skin, apparent comfort or discomfort, and degree of synchrony with the ventilator" [p. 1272], or, for 37%, the patient's "previous physical fitness and age" (e.g.: "She's only 57") [p. 1273].

The patient's history of illness and/or survival -- 28% talked of how they relied upon knowledge of whether the patient had been sick in the past and/or had survived serious health crises, with this theme being especially important for surrogates "who perceived an optimistic outcome for their loved one" [p. 1273].

The power of bedside presence -- 13% expressed a belief that "one's presence and support" [p. 1273] at the bedside could affect outcomes, while 5% reported the effect of "rallying the community of family and friends" [p, 1273], including church groups (e.g.: "I mean, the nuns came over here, with the priest, and they anointed the sick. And a couple of days later, she was okay" [p. 1273]).

Optimism, intuition, and faith-based beliefs -- 36% told of how they "used their own intrinsic optimism or pessimism," and 19% "cited reliance on intuition or 'gut feeling'" [p. 1273]. More specifically, regarding religion/spirituality:

> For 20% (35 of 179) of surrogates, a faith in God overrode any other source of prognostic information, allowing the person to believe, against all odds, that their patient was going to survive. This faith was expressed as a belief in the power of prayer, in the power of prayer circles and community support for the patient, or as the presence of God working through the actions of the doctors, nurses, and hospital staff. Some surrogates believed that it was not only their faith but also the patient's faith that would carry them toward recovery and health. As one parent described, "My daughter is very, very sick, but I believe her faith in God and her faith in being cured of this rare disease she has will--has given her strength to survive and to--to live."
>
> Two percent (4 of 179) reported a belief in the power of reciprocity, believing that their loved ones' good behavior, kind actions, or helpful life work would result in a "favor" being given back from the universe. Some reported that their loved ones gave freely of their time to other sick people, that they used their humor or abilities to help others, and that this would somehow return to help them through their own struggles. As one family member said, "Good things come to good people so I'm gonna hope that--you know, call in some markers for his good behavior."
>
> Finally, in light of terrible odds and the realization that the patient was not going to recover, this expression of faith was termed as a belief in--or hope for--miracles. When they had little else on which to base an optimistic prognosis, 4% (7 of 179) of surrogates said they resorted to hoping for a miracle. "So the only thing we have left is a miracle. And before this, I really do not think I would have believed in miracles." [pp. 1273-1274].

Clearly, it is helpful for chaplains to understand what various *sources of "knowing"* are at play among family members (as well as clinical staff and patients themselves), in order to work effectively both with interpersonal tensions around prognostic estimates and with pastoral issues like hopefulness or anticipatory grief. In this study's sample, fully one fifth of surrogates said that their religious faith "overrode any other source of prognostic information" [p. 1273]. A chaplain is in a good position to address religious/spiritual concerns, but, more than that, to observe closely how family members generally may be coming to their own understanding of their loved one's medical condition and outlook and then to aid in the facilitation of collaborative communication -- what our authors call "bidirectional discussion aimed at achieving a shared understanding" [p. 1274] -- between families and clinicians. For this to be the case, chaplaincy research might focus on the development of strategies for assessing families' *sources of "knowing"* in critical care circumstances and upon how religious/spiritual worldviews might influence even those factors identified here that are not explicitly religious/spiritual.

One final note: The present study found that the surrogate decision-makers in the sample were correct an average of 69% about their own estimates of their loved one surviving to discharge from the hospital (with a

standard deviation of 29.6; range of 2%-100%).

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

This month's article is relative brief and very well written, and so it should be usable with a wide variety of CPE groups, even those with limited exposure to research. There is a somewhat detailed methodology section [pp. 1270-1271], but it is set apart in smaller type for only those readers interested. The authors have illustrated their findings with quotes from the interviews, and these should evoke real-life circumstances that students could connect with their own clinical experience. The findings regarding religious beliefs will surely catch students' attention, but discussion could also consider how religion/spirituality might pertain to the other identified *sources of "knowing."* For instance, how might a family's religious culture affect a surrogate's sense of the patient's "will to live"? How might religious or cultural modesty issues affect how a family is able to perceive the patient's physical appearance in contrast to how the clinical team is able to observe the patient's body? What are the theological assumptions or implications of beliefs in the power of bedside presence? Finally, what tend to be chaplains' own *sources of "knowing"* about a patient's prognosis, and how might this lead to tensions between a chaplain and family members or clinicians?

Related Items of Interest:

I. For more on the perspectives of surrogate decision-makers, see the following recent studies:

> Apatira, L., Boyd, E. A., Malvar, G., Evans, L. R., Luce, J. M., Lo, B. and White, D. B. "**Hope, truth, and preparing for death: perspectives of surrogate decision makers**." *Annals of Internal Medicine* 149, no. 12 (December 16, 2008): 861-868. [Among the findings of this study of 179 surrogate decision-makers: "Seventeen percent (30 of 179) of surrogates felt that hope came from sources other than the physician. One explained, 'Hope has to come from me.' For others, it came from 'God,' 'faith,' 'belief in miracles,' the patient's 'will to live,' or the family's ability to 'hold each other up.' Some surrogates felt that hope came from prognostic uncertainty. Another surrogate made it clear that being informed provided an important context for hope." (p. 864). Also (from the abstract:) Overall, 93% (166 of 179) of surrogates felt that avoiding discussions about prognosis is an unacceptable way to maintain hope. The main explanatory theme was that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death. …A few surrogates (6 of 179) felt that physicians should withhold prognostic information because of a belief that discussing death could be emotionally damaging to the family or could negatively affect the patient's health.]

> Ford, D., Zapka, J., Gebregziabher, M., Yang, C. and Sterba, K. "**Factors associated with illness perception among critically ill patients and surrogates**." *Chest* 138, no. 1 (July 2010): 59-67. [This study involving 23 patients and 77 surrogate decision-makers used the Illness Perception Questionnaire-Revised (IPQ-R), measuring 6 domains: timeline-acute/chronic, consequences, emotional impact, personal control, treatment efficacy, and illness comprehension. Among the findings (from the abstract:) Faith/religion was associated with positive illness perceptions including less concern regarding consequences ($p=0.02$); less emotional impact ($p=0.03$); and more confidence in treatment efficacy ($p<0.01$). Lower patient pre-critical illness quality-of-life (QOL) was associated with negative perceptions including greater concern about illness duration and consequences as well as perception of less personal control and less confidence in treatment efficacy ($p<0.01$ for each).]

Zier, L. S., Burack, J. H., Micco, G., Chipman, A. K., Frank, J. A. and White, D. B. "**Surrogate decision makers' responses to physicians' predictions of medical futility**." *Chest* 136, no. 1 (July 2009): 110-117. [Among the findings of this multicenter study employing semistructured interviews with surrogate decision-makers for 50 critically ill and incapacitated patients: "Based on religious grounds, roughly one third of surrogates (n = 18) doubted physicians' ability to predict futility. These individuals believed that God was capable of miraculously healing patients regardless of the severity of their illness. (p. 114). ...Surrogates who doubted physicians' futility predictions on religious grounds were more likely to request continued life support in the face of a very poor prognosis…, whereas those whose doubt was based on secular concerns were not. (p. 115)." The authors suggest the help of a chaplain (--see p. 116).]

II. For insight into factors that make the *process* of decision-making harder or easier for surrogates, see:

Braun, U. K., Beyth, R. J., Ford, M. E. and McCullough, L. B. "**Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making**." *Journal of General Internal Medicine* 23, no. 3 (March 2008): 267-274. [This focus group study of 44 surrogate decision-makers sought to describe perspectives along racial/cultural lines, and the authors do analyze and illustrate their findings accordingly. See especially the sections on religion and spirituality on pp. 271-272. Also, one particularly valuable element of this article is a general table of major themes from the focus groups, indicating the dynamics of decision-making and factors that increased or decreased a sense of burden on the surrogates. Unfortunately, that table is poorly printed, but a clearer version is available by clicking HERE.]

[Added 10/14/17:] Schenker, Y., Crowley-Matoka, M., Dohan, D., Tiver, G. A., Arnold, R. M. and White, D. B. "**I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU.**." *Journal of General Internal Medicine* 27, no. 12 (December 2012): 1657-1665. [This study used in-depth, semi-structured interviews with 30 surrogates from five ICUs at two hospitals in Pittsburgh, Pennsylvania, who were actively involved in making life-sustaining treatment decisions for a critically ill loved one. Among the findings were these regarding spirituality: "The majority of family members spoke about prayer as a source of hope, solace and community when facing difficult decisions. A minority described asking God to make decisions for them. One wife described the role she was asked to play as 'Real scary. 'cause I don't want to be the one saying, you know, 'we should just let him die', or just, 'so he doesn't have to suffer any longer' ...like I said, I want the Lord to take care of that one, you know?' For these participants, involving God in decision making relieved the weight of responsibility they bore and helped them to feel less alone." (p. 1663)]

III. This month's featured article is paired in the journal issue with an editorial: Siegel, M. D. "**Do you see what I see? Families, physicians, and prognostic dissonance in the intensive care unit**." *Critical Care Medicine* 38, no. 5 (May 2010): 1381-1382.
