BEREAVEMENT DEBRIEFING SESSIONS FOR HEALTHCARE PROFESSIONALS

“Bereavement Debriefing Sessions: An Intervention to Support Health Care Professionals in Managing Their Grief After the Death of a Patient” appears in the July/August issue of *Pediatric Nursing*. Harriet Lane Compassionate Care, the pediatric palliative care program of Johns Hopkins Children's Center, created a support program for their staff. One facet of that program is the bereavement debriefing session. Other parts of the program include “palliative care educational forums for information support, patient care conferences for clinical support, bereavement debriefing sessions for emotional support, and rituals of remembrance as opportunities for meaning-making.”

The bereavement debriefing sessions are always offered after a patient death. Staff members are not required to attend, and there are occasions when no one attends. The two main reasons offered for not attending are “we did not know the patient” or “the death was expected and everything went well.” There may be more than one session per patient if multiple services or units were involved in care.

Sessions are scheduled and invitations are issued by the bereavement coordinator, who also facilitates the discussions. The structure of the sessions borrows from the Critical Incident Stress Debriefing (CISD) sessions developed for trauma workers, but focuses on the emotional responses of the staff rather than any critical incident. Unlike CISD sessions, which are often held within hours of an incident, the bereavement debriefing sessions may occur as much as a week later, and are often held after the funeral.

The facilitator welcomes participants to the sessions, and participants answer “How were you involved in care for this patient/family?” as a way of introducing themselves. Then the circumstances of the death are reviewed. Questions such as “What was it like taking care of this patient?” and “What have you experienced since the death?” allow personnel to express both positive and negative emotions and experiences regarding the patient. Asking what participants have experienced since the death is an opening for discussing “emotional, behavioral and spiritual” responses.

The portion of the session devoted to “What will you remember most about this patient and family?” is “often the most emotionally vulnerable segment.” After memories are shared, the discussion shifts to coping strategies and a more “cognitive level.” The last question to be discussed is “What lessons did we learn from caring for this patient and family?”
Data on the sessions collected between 2002 and 2005 revealed strong interdisciplinary participation (54% nurses, 15% physicians, 8% child life specialists, 5% social workers, plus chaplains, allied health therapists, nutritionists, clerical associates, foreign language interpreters and even the librarian.)

Sessions were most often requested by the oncology service, and the most frequent reason cited was professional distress. The second most frequent reason was a sudden or unexpected death. Respondents said the most distressing aspects of care were the emotional impact of the death, witnessing the parents’ pain, sudden and unexpected deaths, and providing aggressive treatment while the patient was dying. The most satisfying aspects of care were “team collaboration, end-of-life care, and the relationship with the family.”

The evaluations of the sessions indicated that participants found them “helpful (98.4%), informative (97.8%), and meaningful (97.8%).” Many participants noted that it was helpful to see how other disciplines viewed the events.

The authors emphasize the importance of the role of the facilitator, saying, “It is important that the person leading the session has training in group process and grief and loss to recognize potential complications of grief or help foster healthy therapeutic relationships. If the facilitator can offer a quality of presence that creates a safe and trustworthy environment, the staff will have a level of comfort that allows them to participate fitly and honestly in vulnerable conversations.” Another key factor in the success of the groups is the support of nursing leadership. Both at Johns Hopkins and elsewhere the “provision of opportunities for nurses to share or reduce emotional distress have led to decreases in staff turnover.” (Pediatric Nursing, 2010,36(4):185-189, www.pediatricnursing.net/ce/2012/article36185189.pdf)

**DISABILITIES AND END-OF-LIFE PLANNING**

“Disability Perspectives on Health Care Planning and Decision-Making,” in the Journal of Palliative Medicine, is a review of the literature on the significance of disability on health care decision-making, advance care planning, and end-of-life care.” The authors paid particular attention to “assessing the life values or preferences of persons with intellectual disability with limited decisional capacity.”

Persons with disabilities have “similar experiences of stigma, isolation, rejection, and discrimination” which create a “minority … community whose unique concerns should be considered, addressed, and included in policy analyses of end-of-life decision-making and advance care planning.” But in spite of their needs for planning for serious illnesses in order to get good end-of-life care, “this community has often been overlooked in the extensive research, programs, and policies regarding advance care planning and end-of-life care. Following a history of societal abuse, neglect, and prejudice, it is necessary to ensure that people with disabilities participate in planning their care, services, and supports, as well as in societal dialogue about care near the end of life.”

One significant finding is that healthcare professions often hold negative attitudes toward people with disabilities, perhaps even more than the general public. “More specifically, health professionals significantly underestimate the quality of life of persons with disabilities compared with the actual assessments made by persons with disabilities.
themselves. … Such pessimistic professional views of life with disability are implicitly conveyed to patients and their families while they are in the midst of decision making about new disabilities … [and] are related to professionals’ views about whether or not to offer life-sustaining treatment options to persons with disabilities.” One commonly expressed concern is, “Doctors need to realize that I have a real life and it’s a valuable life.”

Another area for exploration is the difference in viewpoint of persons with and without disabilities regarding some life-supporting interventions. “People with no significant history of disability may clearly indicate in their advance directives preferences to forgo life-sustaining measures, such as ventilators or artificial feeding and hydration. However, for some people with disabilities, these interventions may represent routine care that supports everyday life.”

The authors cite a study which says that patients with intellectual disabilities “have historically been excluded from various spheres of decision-making about their lives, on the presumption that they are incapable of making informed decisions.” All those around such patients have “commonly assumed a protective stance toward people with intellectual disabilities, even when decision-specific capacity may have existed.”

Three reasons are given for questioning such a paternalistic approach. One, medical advances allow people with intellectual disabilities to live longer. Second, the cultural changes surrounding end-of-life care and medical decision making have “evolved from a paternalistic to an autonomy-based approach.” And third, providers and advocates have brought the concerns of those with intellectual disabilities to the table when discussing health care and advance planning.

The authors recommend the 1996 guidelines issued by the Center for Practical Bioethics for facilitating “individual decision-making and more accurate professional assessments of decisional capacity.” The guidelines help assess “whether patients meet a minimum level of understanding (for example, nature of the health problem, treatment options, including nontreatment, and their consequences).”

Another useful document is the position statement on “Caring at the End of Life, issued by the American Association on Intellectual and Developmental Disabilities in 2005. It advocates discovering and honoring the treatment wishes of persons with intellectual disabilities through observing and interacting with individuals over time to understand what is important to them; encouraging expressions of preferences regarding end-of-life care ‘before situations requiring decision-making occur’; and for capable individuals, documenting preferences through ‘living vision statements, health care proxy instructions, and other indicators of one’s wishes.’”

In conclusion, the authors say, “Advance directives guiding care toward the end of life are irrelevant when one’s concern is the denial of care: unwanted interventions at the end of life are not the central issue (although individuals could specify in their directives a preference for continuing with aggressive, curative care). There is a need for more information on access to and quality of end-of-life care for people with disabilities, and how this may be different or the same from nondisabled individuals generally.

“In addition, for people with intellectual disability, there is a need to replace paternalistic attitudes and stereotypes about cognitive limitations with skilled, careful assessments of decisional capacity and abilities, strategies for assisted and shared decision-making and life-planning, and more thoughtful communication about medical options.” (Journal of Palliative Medicine, 2010,13(9), dx.doi.org/10.1089/jpm.2010.0159)
Columnist Jesse Kornbluth’s review of *Intimate Death*, by Marie de Hennezel, says, “These 182 pages are loving and wise. Even more, they are thrilling…” In a personal interview with de Hennezel, Kornbluth writes, “What I really got: that her book helps me to learn to help others die and it helps others to help their loved ones move into position for their final passage. No wonder the readers of *Intimate Death* feel mostly... gratitude.” ([The Huffington Post](http://www.huffingtonpost.com/jesse-kornbluth/before-someone-you-love-d_b_714686.html), 9/13)

“A Systematic Review of Postgraduate Palliative Care Curricula” examines 28 studies to determine the most effective palliative care components in a family medical education program. The authors conclude that an “effective palliative care curriculum will need to use a multifaceted approach, incorporating a variety of intentional strategies to address the multiple competencies required.” ([Journal of Palliative Medicine](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2249315&tool=pmcentrez&rendertype=abstract), 2010,13(9):1091-1108, dx.doi.org/10.1089/jpm.2010.0034)

“Consider the Conversation,” a documentary about the way Americans live at the end of life, was produced by Terry Kaldushal and Mike Bernhagen and will be released in early 2011. Bernhagen lost his mother to congestive heart failure in 2003, and not a single medical professional mentioned hospice to him. Kaldushal’s brother died of pancreatic cancer. Both men’s experiences led them to help others through the end-of-life process, and the film is the result. See [www.considertheconversation.org](http://www.considertheconversation.org). ([The Journal-Sentinel](http://www.jsonline.com/news/opinion/103171044.html), 9/18)

“Opioid Use at the End of Life and Survival in a Hospital at Home Unit” reports on a Spanish study of whether high or increasing doses of opioids affect survival of terminal cancer patients being treated at home. Results showed slightly longer lifespans for patients who received increasing or higher doses of opioids. Researchers concluded that opioid use at home is not associated with reduced survival. ([Journal of Palliative Medicine](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2249315&tool=pmcentrez&rendertype=abstract), 2010,13(9):1079-1083, dx.doi.org/10.1089/jpm.2010.0031)

A study of whether the religiosity and spirituality of neonatologists affects health care delivery of high-risk neonates found that “for the majority of neonatologists participating in this study, differences in critical care practice cannot be attributed to personal religious or spiritual views.” Two-thirds considered themselves very or moderately spiritual, about 40% very or moderately religious. “More than 95% had no objection to withholding or withdrawing LST, with religion playing almost no part in these decisions.” **The eighty-nine physicians who reported that their beliefs influenced their medical practice had “similar responses as those not influenced by religion.”** ([Journal of Palliative Medicine](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2249315&tool=pmcentrez&rendertype=abstract), 9/11, dx.doi.org/10.1089/jpm.2010.0049)

North Dakota’s Medcenter One College of Nursing uses a computerized manikin to teach nursing students about end-of-life care. Nursing student Amanda Schmidt found the process helpful, because the students get experience in a safe setting. After the simulated death, oncology
nurses talk with the students, answering questions and suggesting ways of dealing with issues such as physical symptoms and talking with families. (*The Bismarck Tribune, 9/16, www.bismarcktribune.com/news/national/article_c142dc64-c145-11df-b629-001cc4e03286.html*)

* Many New York doctors support the new law that requires them to have conversations with patients with terminal illnesses about all treatment options, including end-of-life care. Dr. Mary Ellen King, geriatrician at Orange Regional Medical Center, says, “It is ingrained in our hearts and our minds that we can't face death, that we shouldn't talk about it," she said. “It's quite uncomfortable and it's not easy, but not talking about it is not fair to the person facing their death. They are facing it, whether we are talking about it or not.” *The Medical Society of the State of New York opposes the law.* (*Times Herald-Record, 9/15, www.recordonline.com/apps/pbcs.dll/article?AID=/20100915/HEALTH/9150316/-1/NEWS*)

* Dr. Sarah Friebert, of Akron Children's Hospital, says that kids “have a particular courage and resilience” when faced with a terminal illness. She thinks that “most children are very aware of what’s going to happen to them.” As director of pediatric palliative care at the hospital, she “aims to reduce the suffering of these children and their families through an approach that includes pain management, psychological counseling, spiritual guidance, and education about navigating the health care system. The program visits seriously ill children in their homes, advocates on behalf of them at school and addresses other quality of life issues.” (*CNN, 9/15, pagingdrgupta.blogs.cnn.com/2010/09/15/children-palliative-care-hospice*)

* The World Health Organization will address the issue of “old age” as a cause of death at its meeting next year. Physicians specify both immediate and underlying causes of death, but in the very old, the underlying cause may be difficult to identify, or choose, when the patient has several illnesses. Unless causes of death are accurately defined, statisticians must guess at how many deaths were preventable. Good mortality data “can identify overlooked problems and help public health agencies decide where to direct effort and money.” (*The Washington Post, 9/17, www.washingtonpost.com/wp-dyn/content/article/2010/09/17/AR2010091703823.html*)

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