A FAMILY SYSTEMS THERAPY APPROACH TO PALLIATIVE CARE

“A Novel Approach to Hospital Palliative Care: An Expanded Role for Counselors” discusses the Transitions and Palliative Care Therapy Model, developed by the Medical Center of Central Georgia (MCCG), uses a strong counseling base. The Center uses counselors with master’s degrees, rather than advance practice nurses or palliative physicians, for much of the work of the team.

The model developed by the counselors is called the “Transitions and Palliative Care Therapy Model” (TPCT), and focuses on “7 Core Components of Communication & Decision Making.” The article discusses the components (preparation, assessment of the situation, identifying roles, managing conflict, provision of information, essentials of processing) in detail, and offers many examples, barriers encountered, questions to ask, and suggested interventions.

The article, online ahead of print in the Journal of Palliative Care, says that the counseling model keeps “the communication open and flowing,” and “consistently diminishes potential for conflict, communication deficits, time constraints, and knowledge gaps.” The researchers write, “The specialized training that the counselors receive is based on a systemic approach where all parts of the interdisciplinary team and the patients’ families and support systems are collaborating to make the difficult decisions involved at the end of life.

This TPCT model appears to be a cost-effective way to provide palliative services, using counselors who are hired at a much lower cost than clinical staff. This model has attracted interest from other hospitals and is now being replicated at various sites. “The Transitions and Palliative Care Model has become an accepted standard of practice at MCCG and continues to be a successful means of managing the most complex cases in the hospital.”

There are three components of the Center for Palliative Care at MCCG – a palliative care consult service, a 5-bed inpatient palliative care unit, and transitions counselors. The consult service is a typical palliative care team that responds to consult orders written by attending physicians. The inpatient unit, according to the article, provides “a more suitable environment for end-of-life care/inpatient hospice or a transition from curative to comfort based care,” and focuses on acute pain management and symptom control.

The staff of the Transitions Counselors unit makes initial contact with persons with terminal or severe chronic disease. Referrals can come from anyone in the hospital; most come from physicians and nurses, but some from family members. The counselors are “trained to provide critical services in a medical facility helping families navigate complex systems,” and attend weekly interdisciplinary palliative rounds “to increase their knowledge of
medical issues related to the palliative patients.” Counselors are also “integrated into the intensive care units (ICUs) and medical–surgical units through rounds where they receive pertinent information on specific disease processes and treatment options.”

At MCCG, the counselors handle the complex cases, working through the interrelated subsystems with their individual rules and regulations. The article says, “Physicians and nurses often have neither the time nor training to navigate this complex emotional, cultural, and spiritual system. The TPCT model of patient-centered care enhances interactions among providers, departments, and health care settings.”

The Center to Advance Palliative Care has a way of estimating palliative care program volume “that takes into account the hospital’s average length of stay, frequency of deaths and patient mix.” At MCCG, the CAPC algorithm estimated 338 potential referrals to the CPC in the first year -- the Center actually received 751 referrals in that time. (Journal of Palliative Medicine, 3/16, www.liebertonline.com/doi/abs/10.1089/jpm.2010.0432)

RESEARCH & RESOURCE NOTES

Resources for National HealthCare Decisions Day (NHDD), April 16, are available on the NHDD site listed below. The site provides information about advance directives, an event map for the activities held on that day, suggested outreach activities, media kits, a blog, and facts about NHDD. You can follow NHDD on Twitter at @NHDD, or on Facebook at www.facebook.com/nationalhealthcaredecisionsday. (National HealthCare Decisions Day Website, www.nhdd.org/)

“The Hospice Caregiver Support Project: Providing Support to Reduce Caregiver Stress” reports on a study in which “hospice social workers referred caregivers identified as needing additional support into a special project that funded services not covered by hospice and that the family could not afford to purchase.” Researchers used the Pearlin role overload measure of caregiver stress, and families chose a service provider from a list of agencies. Results of the study showed that “offering such services relieved caregiver stress, reduced use of respite, and reduced the number of respite days used.” (Journal of Palliative Medicine, 3/25, www.liebertonline.com/doi/abs/10.1089/jpm.2010.0520)

A survey of the families of deceased Oregon residents compared the quality of the dying experience, from the viewpoint of family members, of 52 persons who took a lethal prescription, 34 who requested the prescription but did not ingest it, and 63 who did not request a prescription. Family members completed a 33-item tool, the Quality of Death and Dying Questionnaire. “Few significant differences were noted in items that measured domains of connectedness, transcendence, and overall quality of death. Those receiving PAD [physician-assisted death] prescriptions had higher quality ratings on items measuring symptom control (e.g., control over surroundings and control of bowels/bladder) and higher ratings on items related to preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or, in some cases, those who requested but did not receive a lethal prescription.” The researchers concluded, “The quality of death experienced by those who received lethal prescriptions is no worse than those not pursuing PAD, and in some areas it is rated by family members as better.” (Journal of Palliative Medicine, 3/18, www.liebertonline.com/doi/abs/10.1089/jpm.2010.0425)
“Palliative Dialysis in End-Stage Renal Disease” recommends a review of the Medicare policy of denying hospice benefits to dialysis patients unless they forego dialysis. The abstract says, “Many of those patients might benefit from as-needed dialysis treatments to palliate symptoms of uremia, fluid overload, etc. The current Medicare payment system precludes this ‘palliative dialysis’ except in those few cases where the terminal diagnosis is unrelated to renal failure.” The authors suggest a new “palliative dialysis” category allowing terminal patients to receive less frequent dialysis without adversely affecting the quality statistics of the dialysis center. (American Journal of Hospice & Palliative Medicine, 3/10, www.ncbi.nlm.nih.gov/pubmed/21398269)

“Racial Differences in Location Before Hospice Enrollment and Association with Hospice Length of Stay,” in the current Journal of the American Geriatrics Society, says that knowledge of race and location on hospice enrollment and length of stay “may inform the development of interventions to increase timely access to hospice care.” Just before hospice enrollment (1-2 days), African Americans were more likely than whites to be in the hospital. “Regardless of race, those whose preadmission location was the hospital were more likely than those from other locations to die 7 days or less after hospice enrollment. Initiatives to improve end-of-life care should focus on increasing timely access to hospice referrals in settings outside of the hospital.” (Journal of the American Geriatrics Society, 3/15, onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03326.x/abstract)

The current Hastings Center Report discusses “Ethical and Religious Directives for Catholic Health Care Services,” which was issued by the US Conference of Catholic Bishops in 2009. Directive 58, which required that “all patients—including those in the so-called persistent vegetative state—be provided with artificial hydration and nutrition if such care could extend life indefinitely,” caused confusion in hospital ethics committees, and objections from death-with-dignity movements. The directives raised questions about how much authority bishops have over Roman Catholic health are institutions, and whether they are a departure from traditional Catholic teaching. (Hastings Center Report, 3-4/2011)

“Care Goals and Decisions for Children Referred to a Pediatric Palliative Care Program” reports on a study to describe goals of care for children with life-limiting conditions and to determine which variables influence these goals. Goals of care were grouped into four domains: physical health and independence, psychological and spiritual, social, and environment. The parents and children verbalized goals relating to health maintenance and independence. The researchers say, “Anticipating this expectation may foster communication and improve patient care.” (Journal of Palliative Medicine, 3/25, www.liebertonline.com/doi/abs/10.1089/jpm.2010.0450)

PUBLIC POLICY NOTES

Representatives of several organizations (AARP, AHA, AMA, American Case Management Association, American Medical Directors Association, Center for Medicare Advocacy, National Association for Home Care and Hospice, Society of Hospital Medicine and the Visiting Nurse Associations of America) recently met with CMS to express concerns about the home health face-to-face requirement. CMS is studying the group’s concerns, and will respond within the next few days. (American Case Management Association, 3/23, www.acmaweb.org/legislative_detail.asp?ID=173)
The National Conference of State Legislatures has established a free database for tracking state legislation that relates to the Patient Protection and Affordable Care Act. The database is searchable by state, topic, keyword, status and sponsor. Included topics are Medicaid, health insurance exchanges, health insurance reform, health information technology, prevention and wellness, providers and workforce and challenges and alternatives. The last topic “covers policies that differ from the federal provisions.” (National Conference of State Legislatures, www.ncsl.org/?TabId=22122)

Recently, the Delaware Senate Health and Social Services Committee passed legislation that would legalize medical marijuana in the state. Senate Bill 17 “would allow residents 21 years of age or older with debilitating conditions to get certified by their physician to purchase medical marijuana at one of three state-licensed dispensaries. Qualifying conditions include cancer, multiple sclerosis, HIV/AIDS, hepatitis C, PTSD, glaucoma, Crohn's disease, Lou Gehrig’s disease or other chronic wasting diseases.” (The News Journal, 3/23, www.delawareonline.com/article/20110324/NEWS02/103240344/-1/updates/Medical-marijuana-proposal-advances)

Washington State is implementing a comprehensive effort to prevent excessive narcotics prescriptions. Doctors will be required to consult pain specialists if a patient's opioid dose exceeds a certain level, use a prescription monitoring program to prevent doctor shopping, maintain screening and treatment records, and enter patient progress information into a statewide database. The new regulations will not apply to “cancer pain, end-of-life care or acute pain after an injury or surgery.” Instead, they reflect the growing array of state, federal and medical industry actions to grapple with an epidemic of addictions, overdoses and deaths arising from more liberal use of prescription narcotics for chronic ailments other than cancer, such as back pain.” (The Buffalo News, 3/23, www.buffalonews.com/city/special-reports/rx-for-danger/article373743.ece)

OTHER NOTES

The Rev. Dr. Martha R. Jacobs, author of A Clergy Guide to End of Life Issues, is starting a new blog on end-of-life issues from a Christian perspective on The Huffington Post. Jacobs says she will be using the column to encourage end-of-life discussions while people are still healthy. She plans to include theological, sociological and biblical ways to talk about sickness and the end of life, “hot button issues,” the dying process, DNR orders, and end-of-life documents. (The Huffington Post, 3/21, www.huffingtonpost.com/rev-martha-r-jacobs/a-clergy-guide-to-end-of-_b_836865.html)

Lily Rapaport is sharing the memories of 100 years of living with StoryCorps, which recently affiliated with Riverdale’s MJHS Hospice, where Rapaport is a patient. Rapaport and her family escaped the Jewish pogroms in the Ukraine in the early 1900s, and came to America a few years later. She learned to bellydance in her 70s, and can still demonstrate the moves for visitors. StoryCorps is “a nationally renowned nonprofit, for the new Legacy Initiative program, designed to preserve the stories of people with life-limiting condition,” and MJHS is the first hospice to partner with the organization. See the link below for more information. (New York Daily News, 3/27, www.nydailynews.com/ny_local/2011/03/27/2011-03-27_stories_immortalized.html; http://storycorps.org/initiatives/legacy/)
Dr. Bob’s Place, a new hospice for children in Baltimore, will open in June but began home-based services recently. Charlotte Hawtin, executive director of the Joseph Richey Hospice, of which Dr. Bob’s Place is a part, says, “Most hospices provide care for well-insured suburbanites. We were founded for people who are alone and lack an able caregiver. Most of our patients come from the city, but we are licensed in seven Maryland counties.” “The mission of the Joseph Richey House,” according to Hawtin, “is to serve those most in need, regardless of insurance or personal finances.” (The Baltimore Sun, 3/18, articles.baltimoresun.com/2011-03-18/health/bs-md-children-hospice-20110318_1_charlotte-hawtin-second-hospice-joseph-richey-house/2)

“Baby Joseph,” the Canadian toddler whose parents brought him to St. Louis for treatment, has received a tracheotomy (see HNN, 3/15). The goal is for him to go home in about two weeks. Doctors at London (Ontario) Health Sciences Center had determined that a tracheotomy was not recommended because they considered it invasive and not advised for long-term treatment. The St. Louis team deemed the procedure “medically appropriate.” Joseph suffers from Leigh Syndrome, a rare neurometabolic disease. (CNN, 3/21, www.cnn.com/2011/HEALTH/03/21/baby.joseph/index.html)

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