DISCLOSING INFORMATION TO PEDIATRIC PATIENTS

In “The Need to Know: Disclosure of Information to Pediatric Patients,” the summer issue of *Ethics & Medicine* explores issues surrounding a nine-year-old girl dying of AIDS. While the medical team wanted full disclosure, the child’s guardian (her grandmother) did not want her to know she had AIDS. An ethics consultation was called.

The author, Dr. Wayne R. Waz, says the case was a “battle of good intent vs. good intent,” with everyone having the child’s best interests at heart and sharing the desire to minimize her suffering. The American Academy of Pediatrics has listed guidelines for parents in such cases:

* Children should be allowed to participate in decision-making “commensurate with their development.”
* Minor patients should be encouraged to “assent to their care” when possible.
* Adolescents should not be discouraged from decision-making “without persuasive reasons.”

The guidelines have their own problems, which include requiring the determination of what level of decision-making is appropriate for the child’s age and development, when assent is reasonable, and which reasons are persuasive. There may be differences of opinion over whether the health care professionals or the parents/guardians are the best party to answer those questions.

The consultation laid out four possible medical-ethical pathways and the possible effects of each on the child.

1) **Keep the information from her where this results in a good outcome.** This was the grandmother’s wish – that the child be allowed to live out her life without physical or emotional suffering.

2) **Keep the information from her but a bad outcome ensues.** This was the fear of the medical team – a curious child who was afraid to ask questions, wondering why no one addressed her concerns, failing to understand why people were whispering outside her hospital room. Or worse, they feared, would be the child learning her diagnosis accidentally and losing trust in the people who were closest to her.

3) **Inform the child with the result of a good outcome.** The medical team hoped for this approach. Even a dying child “might have very specific things she would choose to do with her life,” and being able to discuss death and say her goodbyes is viewed by many as a good outcome.

4) **Inform the child, with a resulting bad outcome.** The grandmother feared this. The child’s mother had been the source of the AIDS, and the child might feel angry and isolated to know that her parent was the reason for her suffering and death.
In this specific case, the committee recommended that “all reasonable efforts” be made to follow the grandmother’s wishes. However, if directly asked by the patient about her condition or prognosis, the team would not lie or withhold information. With the grandmother or other support person(s) present, her questions would be answered. This course was followed, and the child died at home several weeks later, never having asked or been told about her diagnosis. “Several months later, one of the attending physicians met with the grandmother, and she stated that her granddaughter died peacefully at home - a ‘good’ death.”

The article cites another ethicist, J.Y. Song, as saying that confidentiality rests on four characteristics of the medical situation: 1) How much harm can be done? 2) How likely it is that harm will occur? 3) Does a real or hypothetical third party exist? 4) How effective are medical interventions for this condition? Consideration of these characteristics will give direction to the team in deciding whether a patient should know the full diagnosis. (Ethics & Medicine, Summer/2010)

ARTICLE EXAMINES LENGTH OF HOSPICE STAYS IN NURSING HOMES

“Long and Short Hospice Stays among Nursing Home Residents at the End of Life,” in the Journal of Palliative Medicine, reports on a study of the characteristics of nursing homes and residents that were associated with very long (more than 180 days) or very short (three days or less) hospice stays.

The study found no statistically significant predictors of long stays in the characteristics of the facilities. As the number of beds increased, the probability of a long hospice stay slightly decreased, but not significantly. The prospects of having a stay less than or equal to three days increased as the nurse staffing ratio increased, and slightly decreased with the percentage of residents with Medicaid coverage.

There were a number of significant characteristics of residents affecting the length of stay of more than 180 days.
* Men were less likely than women to have long stays.
* Those aged 81-90 were less likely to have long stays than were those 70 or younger.
* White residents were more likely than black residents to have long stays.
* Residents with dementia were more likely to have long stays than those with any other diagnosis.
* Of borderline statistical significance were the facts that Medicaid residents and married residents (vs. unmarried) were less likely to have long stays.
* Fourteen percent of residents were discharged by hospice before their deaths because they were no longer eligible for the hospice benefit, and this group had a much longer length of stay in hospice than all other groups.

Residents’ characteristics associated with a very short stay included the following:
* Those 70 or younger were less likely than those over 80 to have a short stay.
* More men had short stays than women.
* White residents had more short stays than blacks or Asians.
* Catholic residents were less likely than Protestant or religiously unidentified residents to have short stays.
* Those diagnosed with cancer, cardiovascular disease, pulmonary diseases, terminal debility, CVA, and other non dementia diagnoses were more likely to have short stays than those with dementia.

The researchers concluded that nursing home characteristics had little effect on the time of enrollment. But, they say, “Our findings call into question whether eligibility criteria based on prognosis are appropriate for the nursing home setting, where a large proportion of terminally ill residents suffer from a terminal condition with a less-predictable life trajectory relative to many types of cancer.” The study also points “to the need to reassess the structure of the Medicare hospice benefit for the nursing home population to ensure that palliative care needs of this group are adequately addressed. Also, further studies aimed at understanding the process by which nursing home physicians and other providers decide to refer residents to hospice are needed.” (Journal of Palliative Medicine, 2010,13(8), www.liebertonline.com/doi/pdf/10.1089/jpm.2009.0387)

RESEARCH & RESOURCE NOTES

* “The Development and Evaluation of an Inpatient Palliative Care Admission Triage Tool” reports on a study of the development, implementation and outcomes of a tool for triaging inpatient palliative care admissions. The authors note that this study is the first effort to define waiting list priorities for palliative care units, and report that several participants found it useful as a means of educating staff who were less experienced in assessing the needs of palliative care patients. It also functioned “as a useful decision-making device in times of uncertainty and particularly when there was high demand for beds.” The tool scores closely agreed with clinician’s assessments. (Journal of Palliative Medicine, 2010,13(8), www.liebertonline.com/doi/pdf/10.1089/jpm.2009.0374)

* “The New Grief,” in The Huffington Post, says that the nature of grief has changed as “modern medicine …is getting better and better at staving off death.” Death has become “less and less a sudden and unexpected event,” and more a “process that begins with a diagnosis, proceeds through a period of treatment (or treatments), and ends eventually in death.” Patient and family must “live with death” for a longer period of time. This new grief means dealing with changing relationships, coping with setbacks and remissions, talking about death, dealing with grief in the midst of busy lifestyles, and “confronting family issues that may have been dormant – but unresolved – for many years.” The new grief also “means moving forward together, potentially as a stronger and more resilient family, after a loved one passes.” (The Huffington Post, 8/14, www.huffingtonpost.com/joseph-nowinski-phd/the-new-grief-how-modern_b_677508.html)

* Dr. Stefan J. Friedrichsdorf, director of pain and palliative care at Children’s Hospital and Clinics of Minnesota, says that children are regularly undertreated for pain. Speaking at the Pediatric Hospital Medicine 2010 meeting, he said, “Even among children, a 10-year-old is likely to get better analgesia than a 10-day-old for exactly the same procedure.” Friedrichsdorf cites fear of addiction as one of the reasons for “abysmal” pain management in children, but says that it’s more likely that the staff confuses tolerance with addiction, or administers morphine in such small doses that the child frequently asks for more. Friedrichsdorf recommends reading “Principles
of Pediatric Acute Pain Management” in the 1988 WHO report, Cancer Pain Relief and Palliative Care in Children. (Elsevier Global Medical News, 8/9)

* In “Pediatric Palliative Care,” which reports on new research in the field, the authors say, “Rather than defining pediatric palliative care in terms of a patient base, severity of disease, or even a general philosophy of care, palliative care can best be understood as a specific set of tasks directed at mitigating suffering. By understanding these tasks; learning to identify predictable times and settings of suffering; and learning to collaborate with multidisciplinary specialists, use communication skills, and identify clinical resources, the pediatrician can more effectively support children with life-threatening illnesses and their families.” (Pediatrics Week, 8/14; Current Problems In Pediatric and Adolescent Health Care, 2010;40(6):120-51)

PUBLIC POLICY NOTES

* In JAMA, “Simplifying Drug Disposal” notes that Wisconsin Senator Herb Kohl (D) is urging that the federal government create a single guideline for drug disposal. Kohl says that conflicting rules issued by several agencies make it difficult “to remove potentially dangerous medications from their homes.” To read more about the hearing, go to aging.senate.gov/hearing_detail.cfm?id=326079&. (JAMA, 2010, 304(6):628, dx.doi.org/10.1001/jama.2010.1078)

* The Florida Society of Pain Management Providers (FSPMP) has issued a press release in response to the state’s Office of Drug Control’s assertion that it needs about a half million dollars to make the Prescription Drug Monitoring Program (PDMP) fully operational. The legislature failed to adequately fund the program. The FSPMP and the National Pain Institute have recommended two solutions for funding: a half-cent surcharge on all prescriptions filled in Florida, or requiring all registered pain clinics to pay an annual PDMP fee of $1000. Either would completely fund the annual budget. (The Earth Times, 8/10, www.earthtimes.org/articles/press/theres-not-enough-funding,1417470.html)

* Connecticut Hospice Inc. is getting a $1 million grant from the state to help reduce its debt. Governor M. Jodi Rell (R) said, “For people in the final stages of terminal illness — and for their families — Connecticut Hospice is quite simply a godsend. … Unlike other acute-care hospitals in our state, Connecticut Hospice relies largely on donations. This state funding will help ensure that this incredibly important institution will continue to serve the people of Connecticut.” (The Middletown Press, 8/8)

OTHER NOTES


* On “Morning Edition,” Steve Inskeep and Renee Montagne interviewed personnel from Pitney Bowes about the company’s efforts to accommodate its employees who are serving
as caregivers. The company offers legal and financial resources, hospice and palliative care counseling, support groups, and flexible working arrangements. The National Business Group on Health, along with Pitney Bowes, GE, Pepsico and IBM, is working on an end-of-life toolkit for employers. (NPR’s Morning Edition, 8/10)

* Hospice nurse Elissa Al-Chokhachy has written Miraculous Moments: True Stories Affirming Life Goes On. Al-Chokhachy said, “Originally, I thought it was really rare that people had these experiences of loved ones after they die. I can now say it’s quite common, but very few people talk about it. They don’t want people to think they’re crazy, and they’re not even sure it’s real or not.” She adds, “The more I work with the dying, the more I believe in life after death. I know there is life after death because there are so many affirmations.” (The Patriot Ledger, 8/10, www.patriotledger.com/lifestyle/health_and_beauty/x721123030/Hospice-nurse-comforts-the-dying-and-bereaved-through-her-work-and-new-book)

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