

Touched by Life - Then Touching Others

New Books, Videos, and Journals by Nurses in Ethics

Anita J. Catlin

This month's column will describe five new works for those interested in ethics and the lives of children and families. Described here will be three new videos, a journal edition, and a new book that all share a common thread: Each has been created (entirely or in part) by nurses who have worked with children. The work has inspired them with the desire to reach out and share their thoughts with professional and public audiences. Each piece describes an aspect of nursing care of value and further educates us in pediatric ethics.

Reviewed here will be the videos *America's Oncology Nurses: Fighting on the Front Lines in the War on Cancer*; *When a Child is Dying*; and *A Chance to Grow*; and written material *Journal of Clinical Ethics*; *Special Issue in Neonatology*, and text *Karma and Happiness: A Tibetan Odyssey in Ethics, Spirituality, and Healing*.

***America's Oncology Nurses: Fighting on the Front Lines in the War on Cancer* – Oncology Nursing Society (ONS)**

This new video, *America's Oncology Nurses: Fighting on the Front Lines in the War on Cancer*, is not to be missed. The pride in nursing that this film instills will bring tears to your eyes. ONS has created a vision of nursing, telling what nurses do, how they contribute, and the essential value of nursing in patient care. Produced in cooperation with U.S. Oncology, a Cancer Health Care Network, this film reaches out to government officials, funding agencies, and the public to speak about the work of outpatient nursing care for cancer. Physicians managing cancer therapy; nurses providing treatment, support and symptom management; and patients receiving care are all heard. It is a perfect video not only for oncology aspects, but for recruiting young men and women into the field of nursing.

This film, interestingly, was created to reach out to the public to make the contribution of nurses visible to the consumer. Instead, it also became a vehicle to educate the 2000 Congress when the Health Care Finance Authority decided

to lower Medicare reimbursement for outpatient chemotherapy administered by registered nurses in physicians' offices. After the film was shown in Congress and distributed to every Senator and Congressperson in Washington, DC, the Medicare decision was "placed on delay," and office chemotherapy (rather than inpatient hospitalization) was allowed to continue.

America's Oncology Nurses, filmed under the leadership of certified oncology nurse Kristine Hartigan and Luana Lamkin, MPH, is a celebration of all nurses. I recommend it be shown to every staff member for National Nurses Day.

***When a Child is Dying* – Erica Rothman and Beth Seyda**

This video, produced by Erika Rothman, Licensed Clinical Social Worker, and Beth Seyda, mother and ethics committee member, takes us through the lives of four children ranging from newborn through 18 years old who died after intense medical treatment failed. Rothman and Seyda worked with nurses Deborah Harper-Crespo and Karen Metzguer to create the film. Cardiac nurse Harper-Crespo is one of the mothers interviewed and neonatal nurse Metzguer served on the film's advisory council. Harper-Crespo speaks frequently about what parents need to help comfort them in the death of their child. "I had a son," she states. "He had a brain tumor. We had some good times, and we had some bad times. And it's OK to talk about." The purpose of the video is to educate physicians, colleagues, as well as nurses, social workers, and volunteers, about the needs of families whose children are dying. Parents and one sibling discuss how they felt and what might have helped them during these difficult days.

Highlighting the video is music, which sets a tone of beauty, and photos of the children in their bravery. As an ethicist who works for parental comfort, I found the most significant point of the film to be the diversity of the parents: A divorced mother who describes working closely with her ex-husband and his wife for the good of their 18-year-old son, a single mother from Trinidad with little money to care for her 9-year-old son in the U.S. who takes him back to Trinidad, a husband and wife who are both obstetricians with a dying newborn twin, and a couple who divorces over their differences in response to their dying 6-year-old son. And a teenage sibling describes what Sandra Faux (1993) has written about, the loneliness a sibling can experience when the family focus changes to center on the sick sibling. We learn from each. We see that even the physician parents are never allowed to hold their daughter during the days in the neonatal intensive care unit (NICU) until she is removed from the ventilator and dies in their arms. We see a family separate as a father tries to manage the unmanageable and control the uncontrollable. We see a single working mother (Harper-Crespo) receive no assisting services because she "makes too much money." And we see, even now (as Marcia Levetown [1996] has often described), that children are referred to hospice very late or not at all. This video may be obtained by contacting

Anita J. Catlin, DNSc, FNP, is Professor of Nursing at Napa Valley College and an ethics consultant in Napa, CA. She is Column Editor for the Pediatric Ethics, Issues & Commentary column of *Pediatric Nursing*. She can be reached at acatlin@napanet.net

Pediatric Ethics, Issues, & Commentary focuses on exploring the interface between ethics and issues in clinical practice. If you have suggested topics or cases for consideration in the column, please contact Anita J. Catlin, DNSc, FNP; P.O. Box 226, Pope Valley, CA 94567; (707) 965-2530.

WhenaChildisDying@mindspring.com or tel/fax (919) 960-3838.

***A Chance to Grow* – Claire Marie Panke**

Nurse Claire Marie Panke created a film in response to the recent advances in neonatal medicine. She has experienced working in neonatal units where attempts were made to save fetuses born as early as 5 months gestation and critiques media focus on the “miracles” created in neonatal intensive care without attention to the follow up. Eight years ago, Panke began to merge her experiences in the NICU with her background in writing, film, and photography to develop *A Chance to Grow*. Inspired by parents’ courage and insight, she wanted to make a film that allowed families’ voices to be heard, that focused on the human side of health care rather than the rising tide of technology, and that showed what may happen after discharge to home from the NICU.

Panke creates a video that shows the life of children and families in the NICU. She gives us a positive but candid presentation of the wonders of neonatal medicine. We view with amazement happy and healthy Jake, who began life critically ill with a severe congenital diaphragmatic hernia. We see him dancing and playing, but are also honestly reminded that he is now having problems succeeding in school with learning. Four other cases are offered that show the triumph of nurses’ work in the NICU, along with the heartache of uncertainty.

With her own belief in the film’s message, Panke worked to finance the making of this film herself, raising over \$80,000 from 215 individuals, foundations, and corporations. She wrote and received a grant from the New York State Council on the Arts and received fiscal sponsorship from the Center for Independent Documentary. In association with Gabriel Films, she entered into a co-production agreement with The Discovery Channel, where the film was aired in 2000 and garnered several film awards. For a candid view into neonatal nursing, this film can be ordered from www.fanlight.com.

***Journal of Clinical Ethics /Special Issue in Neonatology* (Fall, 2001) – Guest Editor Anita Catlin**

This special issue showcases the knowledge and talents of nurse ethicists and authors from the U.S. and abroad. Gladys White (American Nurses Association, on multiple births), Linda Franck (London) and Linda LeFrak (California, on neonatal pain), Karen Smith and Mary Ellen Uphoff (Omaha, on the separation of families from their acute and chronically ill children), Berit Brinchmann (on dilemmas in Norway), Mats Eriksson (on dilemmas in Sweden), and Hicran Cavusoglu (on dilemmas in Turkey) all contributed to this issue devoted in entirety to neonatal/pediatric ethics. The 17 articles, written by physicians, ethicists, economists, and nurses, describe the various ethical dilemmas of modern neonatal medicine. Smith and Uphoff contribute a groundbreaking article on children who can never leave the hospital. Eight sets of authors describe paradoxes in their countries, ranging from the need to experiment on babies in order to learn (Turkey) to the treatment of babies from countries in conflict (Israel). Clinical staff describe dilemmas in caring, policy makers prioritize cost issues, Helen Harrison describes the pain of mothers of impaired children, and mental health and clinical staff from Massachusetts General describe measures that can be taken to comfort all parties involved in neonatal medicine. This issue can be found in local medical libraries or requested from University Press at www.clinicalethics.com.

***Karma and Happiness: A Tibetan Odyssey in Ethics, Spirituality, and Healing* – Miriam Cameron**

Miriam (Mim) Cameron’s experience in providing care for children and their families led her to writing her new book. She worked as a nursing assistant, staff nurse, and nursing instructor on a pediatric unit in a large metropolitan medical center that treated children from diverse ethnic and social backgrounds. All of the children, ranging from newborns to 16-year-olds, had life-threatening health problems. Approximately one child died each week, usually after repeated and lengthy hospitalizations. Mim knew the children and their families well, felt attached to them, and grieved when they suffered and died.

As the daughter of a Lutheran minister, she spent much of her childhood accompanying her father when he visited parishioners and was accustomed to seeing suffering and death firsthand. Giving nursing care to children was different, though, because they were young and vulnerable. Excruciating ethical problems bombarded her. In the book, she describes laying awake at night worrying about whether to be honest with terminally ill children who asked if they were dying when their hopeful parents wanted the nurses to say that they were getting better. Often she felt like she was the only nurse on the unit to experience conflict about the right thing to do.

In the text, she attempts to answer universal questions. Why do bad things happen to good people, and good things happen to bad people? Is it possible to be happy? What can we do to heal ourselves and the world? Underlying these questions was the ultimate ethical problem confronting every human: How should I conduct my life, knowing that I will die? In her doctoral and postdoctoral studies, Mim studied the major wisdom traditions, religion, and nursing bioethics. Her ethical and spiritual quest led to travel in Tibet and exposure to traditional Tibetan medicine. She wrote *Karma and Happiness: A Tibetan Odyssey in Ethics, Spirituality, and Healing* to teach us the ancient, universal values taught by Tibetans. The text includes a foreword by His Holiness the Dalai Lama. In this text, Cameron describes her journey through Tibet as part adventure story and part ethical examination. Published by Fairview Press in collaboration with the University of Minnesota Center for Spirituality and Healing, it can be ordered directly from Fairview Press at (800) 544-8207.

Nurses helping children with cancer, assisting the families of dying children, focusing on neonatal intensive care, describing ethical dilemmas in neonatal medicine, and examining spiritual healing are the topics of these new resources. The creators are those who have been touched by their work with children, who were able to translate their thinking into media presentations, and who are reaching out with a message to others. Readers are encouraged to review these works, write responses, and suggest additional resources of their own for review. Direct comments and questions to the column editor at acatlin@napanet.net.

References

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