

PHYSICIANS FOR COMPASSIONATE CARE NEWS

Affirming An Ethic That All Human Life is Inherently Valuable

Vol.2, No.3, Fall 1999

Beyond Symptom Management: Human Development at the End of Life

At the third annual Compassionate Care Conference, Ira Byock, MD, encouraged doctors, nurses and other health care professionals to “foster the opportunities” at the end of life. “We must preserve the ability of society’s members to develop through their entire life, including through the dying process,” Byock said. Byock believes dying is more than a series of medical problems and symptoms, and he also contended that when a patient’s symptoms are not addressed, medical problems will be the patients’ focus. So, first and foremost, the patient’s symptoms must be addressed and well managed. Then, patients may become ready to go on with the issue of living out the rest of their life. That is when the clinician’s focus must also shift. “It is at this time that caring for the seriously ill requires another lens through which to see the patient. Then the provider can validate the process of growth and development and reframe the experience of dying,” Byock said.

This reframing is sometimes difficult since doctors, nurses, and other health care professionals have been trained to use problem solving models with their patients. In these models, the focus is only on symptoms to manage, pains to treat, problems to fix. According to Byock, “Dying is not a problem to be solved, but a part of life to be lived,” a developmental phase that is “as important and valuable as any other experience in a person’s life.”

Byock used the analogy of the pediatrician who monitors the infant patient closely, not because of a particular problem, but because of the dynamic and tumultuous developmental phase of the infant, during which things change rapidly. The same model fits with the seriously ill. Byock explained, “There is a tendency within contemporary culture and reflected in medical practice to assume that on receipt of a terminal diagnosis, meaningful life has ended. Within this perspective the person is constrained to wait for death, being reduced to hope only for some measure of comfort and to avoid being a burden to others. This attitude is incongruous with the basic philosophy of modern palliative care for it inappropriately devalues and separates the human life-cycle, comparable to infancy, childhood, adolescent, adulthood and advanced age” (Byock, I (1996). “Suffering and Opportunity at the End of Life.” *Clinics in Geriatric Medicine* 12: 237-252).

So, how do clinicians foster growth at the end of life? Byock suggested we do this by “facilitating the developmental landmarks and tasks for the end of life.” Some examples of these task works include: the sense of completion with worldly affairs (the transfer of fiscal, legal and formal social responsibility) and the sense of completion in relationships with family and friends (reconciliation, fullness of communication and closure in each of one’s important relationships). Component tasks might include, expression of regret, expressions of forgiveness and acceptance, expression of gratitude, and saying goodbye. Patients can be told about “The Five Important Things” to say for relationship finishing: “Forgive me,” “I forgive you,” “Thank you,” “I love you,” “Goodbye.” Knowledge and use of these tasks, rather than a set of requirements, is intended to serve the patient and enable the clinician to anticipate issues that may arise for patients who are seriously ill.

Doctor Byock gave the example of a male patient who asked him to write down “The Five Important Things.” This was a man who didn’t usually express himself. The man read the five things his doctor had written on the back of a prescription pad to his family around the dinner table. Even this awkward expression of love and concern triggered tremendous closeness for the family and the dying man.

Another tool Dr. Byock and his staff use to facilitate the reframing of this life phase is a treatment self-report inventory [(MVQ-oLI) is available on the web at: www.dyingwell.org]. The inventory becomes a springboard from which the patient and family can seize opportunities for growth and development. The doctor may also simply ask after the physical exam; “And how are you within yourself?” Such a simple question from a doctor willing to listen can make all the difference.

In the midst of the suffering that can occur, many think growth unimaginable, but “Positive growth experience at the end of life is not a fiction. It is a reality,” Byock said.

Fluctuation in Will to Live

Chochinov et al. reported findings that demonstrate emotional and other correctable factors predict fluctuations in will to live among patients with life threatening illness (Chochinov et al. (1999) “Will to Live in the Terminally Ill” *The Lancet* 354: 816-819). 168 cancer patients in inpatient palliative care, ranging in age from 31 to 89 were participates in the project. Twice daily from the time they were admitted, until they died or were discharged, each patient completed an assessment that measured pain, nausea, shortness of breath, appetite, drowsiness, depression, sense of well-being, anxiety, activity, and will to live. The median length of time in the study was

12 days (mean 21.6 days). In order to breakdown possible relationships between “will to live” and the various symptoms of distress, multiple regression models examined cross-sectional data at 12-hours, 24-hours, 1 week, 2 weeks, 3 weeks and 4 weeks.

In the 12-hour model, anxiety entered first, followed by dyspnea and activity as a predictor of decreased will to live. In the 24-hour sector, anxiety was the only predicting variable of will to live. In 1 week, depression was the variable most often accounting for diminishment of the patients’ will to live. Depression was also the major predictor for 2 weeks. On weeks 3 and 4, a time-frame often approaching death, dyspnea became the variable most predictive of fluctuation in will to live. The study shows that, over all, during the 12-hour period, the patients will to live could fluctuate by 30 percent, and over a longer period, the fluctuation was an average of 60 to 70 percent.

These findings demonstrate significant variation in will to live, over even the shortest time period, among cancer patients. “Our study shows that patients with little will to live are often in distress. It also provides information about how that distress might be relieved. Once we understand why people are suffering, we can attempt to do something about it,” Dr. Chochinov told Canada NewsWire Ltd. (September 1, 1999).

The study highlights the crucial importance of identification and treatment of factors that account for the most significant predictors of a decrease in will to live, that is anxiety and depression. And as life nears an end, physical distress, such as shortness of breath, becomes an important predictor and must be addressed and managed. The diagnosis and treatment of all symptoms of distress and illness at the end of life remain paramount, especially when the patient’s will to live wanes. “Doctors must act responsibly and compassionately,” says Chochinov.

When seriously ill patients voice suicidal wishes, it is important to know that the symptoms leading to suicidal thinking can be alleviated through treatment, that loss of will to live is a symptom of distress, and that it has been shown to fluctuate substantially over short periods of time.

Recent Publications:

Petty, W.M. (1999). “Pain Relief Legislation Advances Comfort Care.” *The Scribe* 18:14.

Special Thanks

PCC extends special thanks to those who made the Third Annual Compassionate Care Conference such a great success. This year, once again Dr. Chuck Bentz of Providence and PCC did a wonderful job with the thousands of details that makes a conference happen. Dr. William Petty, vice-president of PCC, and PCC coordinator of the yearly conference also played a key role in this year's conference. Thanks to the Sisters of Providence and to John Lee for his support of our educational mission. Thanks to John Fletcher for administrative support. Thanks to Dr. Woody English and Fr. Touhey for collaborating on this years conference. Again, we would like to thank our guest speakers, Ira Byock, MD, Mark Kallgren, MD, Ann Soule, MSW, LCSW, and Susanne Hartung, SP, and those who lead workshops and breakout sessions, Stuart Rosenblum, MD, Greg Hamilton, MD, Fr. Touhey, PhD, Miles Edwards, MD, Susan Hedlund, MSW, Barry Egner, MD, Michele Sakurai, MA, Rev Sandy Walker, Steve Gordon, MD, Adrienne Simmons and Bill Toffler, MD.

National Director

PCC National Director, William Toffler, has been extensively called upon to share his experience and expertise recently. For example, he gave lectures in three states in September alone, Arkansas, North Dakota, and Colorado. His topics included: Enhancing Communication at the End-of-Life, Physician as Healer, and The Compassionate Response to an Assisted Suicide Request. Doctor Toffler is the co-founder of Physicians for Compassionate Care. He is Professor of Family Practice at Oregon Health Sciences University.

PAIN RELIEF PROMOTION ACT VICTORY IN THE HOUSE

Wednesday, October the 28th, 1999, in an overwhelming win, the US House of Representatives passed the Pain Relief Promotion Act of 1999 in a bipartisan vote. The bill passed 271 to 156. Senator Don Nickles, who sponsors a companion bill in the Senate, told PCC news, "The House today took a huge step toward improving the quality of life for thousands of Americans. Numerous federally-controlled substances will relieve pain for patients who are near the end of life or in chronic pain. Unfortunately many of these substances are under prescribed because doctors fear investigation if use of these substances inadvertently accelerates death. The Pain Relief Promotion Act will for the first time confirm and promote the use of federally-

controlled substances for alleviating pain. At the same time, it will re-affirm current law and Congress' view that these federally-controlled substances cannot be used for physician-assisted suicide." Senator Nickles went on to say, "I am hopeful the Senate will act as expeditiously to send this important legislation to the President for his signature."

If passed, the bill, which enjoys bipartisan support in the Senate, would then be handed to President for his signature. The President is on record condemning assisted suicide when he signed a bill in 1997 that banned the use of federal funds for assisted suicides. After the Supreme Court decision that there is no constitutional right to assisted suicide Clinton said, "The risks and consequences of doctor-assisted suicide are simply too great," Clinton said.

"The Pain Relief Promotion Act protects doctors, nurses, and patients through legitimizing the aggressive use of controlled substances for the treatment of pain and by sponsoring education concerning the wonderful pain treatments now available," said Dr. Hamilton, President of Physicians of Compassionate Care. "This education is urgently needed. In the 'Oregon Report Card' (June 30, 1999), it was demonstrated that too many patients still die in pain in Oregon alone; this tragedy can largely be remedied with intensive education of health care professionals. Additionally, September's Lancet documents that patients' will-to-live fluctuates dramatically, and arises from treatable problems such as anxiety, depression, or physical discomfort that can be addressed and managed by knowledgeable physicians," he said.

A broad base of support from the largest medical groups in the nation rally behind the bipartisan bill including the American Medical Association, the National Hospice Organization, the American Academy of Pain Management, Americans for Integrity in Palliative care, Physicians for Compassionate Care, and others.

CONSULT CORNER

What might be happening when morphine has been an effective pain drug for my seriously ill cancer patient, and suddenly it's not working? And what do I do?

Consultant response by: Mark A. Kallgren, MD Legacy Emanuel Pain Medicine Clinic (503) 299-9906

Consider a new disease state---Rule out infection, new mets, or development of a treatment related pain problem (e.g. radiation neuritis, chemotherapy induced neuropathies), or other disease process.

Consider tolerance---This is the most common reason for decreased effectiveness of morphine---try increasing the dose or consider changing to a different opioid.

In unusual cases---Consider decreased clearance of morphine metabolites and possible development of a paradoxical pain state. Treatment of this might be to change the route of administration of drug used (i.e. to decrease the systemic morphine level).

PCC Officers

N. Gregory Hamilton, MD

President

William M. Petty, MD

Vice President

Mark Kummer, MD

Treasurer

Miles J. Edwards, MD

Secretary

William L. Toffler, MD

National Director

Board Members

Pamela J. Edwards, MD

Thomas Pitre, MD

Kenneth R. Stevens, MD

Paul D. Stull, MD

Regional Directors

Gerald B. Ahmann, MD

Medford

Thomas Comerford, MD

Bend

Carl R. Jenson, MD

Coos Bay

Marvin M. John, MD

Hermiston

Robert DuPriest, MD

Eugene

Richard M. Thorne, MD

Salem

George Middlekauf, MD

Roseburg

PCC ADDRESS:

P.O. Box 6042

Portland, Oregon 97228

503-533-8154 Phone

503-533-0429 Fax

www.pccef.org

PCC News Editor: Catherine Hamilton