



Patient preference for learning survival estimates: Balancing hope with realism.
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Case: AB is a 52 year old woman with poorly differentiated pelvic sarcoma. She underwent a debulking surgery at the time of diagnosis and was then treated with chemotherapy. After four months of chemotherapy her disease progressed and a new agent was started. Several weeks later she was admitted to the hospital with nausea and anorexia felt to be secondary to the new drug. The drug intolerance was severe enough that the treating physician felt it should be stopped, leaving her with no other treatment options for her cancer. A palliative care consult was requested to discuss goals of care.

We met with AB and asked her what she understood of her disease. She told us that she knew there was no further treatment available for her cancer. She explained that she had already asked her daughter to be her health care power of attorney. They had discussed her wishes and she was clear that she would not want to undergo CPR and would not want to be on prolonged life support. She and her daughter had also discussed funeral arrangements. The only thing that they had left to decide was where she would like to have her ashes scattered. She felt comfortable about her decisions thus far and grateful to have had the opportunity to prepare her family for the eventuality of her death.

When we asked what she understood about her prognosis, she stated that she knew she was going to die, but had no idea how or when it would happen. When we further explored her wishes for information she said, "I know that I'm dying ... I just don't want to have an expiration date tattooed on my foot." She explained that having an exact time frame would take away her hope and her enjoyment of the time she had left. She preferred to make all of her arrangements, and then live her life as best she could without looking at the calendar each day to count how many days she had left. Despite the seriousness of her illness and many psychosocial stressors, AB was coping well with her illness and screened negative for depression at the time of our visit.

Discussion: Our encounter with AB was interesting in that she had a clear understanding of the terminal nature of her disease and had been very proactive in her advance care planning while desiring no specific information about expected survival. It was obvious in her case that knowing she had a terminal illness was very important because it

allowed her to make arrangements and prepare her family. However, knowing more specific information about how much time she had would be distressing to her.

In a study about patient preference regarding prognosis, Clayton, et al conducted focus groups of terminally ill patients, their carers and treating health professionals. They found that patients demonstrated a wide variation of responses with regard to prognostic information. Some wanted to learn no time frame at all while others wanted very specific probabilities of survival.

However, like AB, patients from both ends of the spectrum felt strongly that they needed to know that life was limited so that they could get their affairs in order. In this study, carers more often than patients wanted a time frame. Most of them cited reasons such as planning to take time off from work to care for the patient. One carer stated that after his terminally ill wife was given specific prognostic information; she began "counting the weeks away" until the time that she would die. Some patients even marked a date on the calendar for when they were going to die.

In another study of patients' preferences and prognosis, Hagerty et al surveyed patients with a recent diagnosis of metastatic cancer while also measuring levels of depression and anxiety. Most patients desired some prognostic information at the time of diagnosis. Interestingly, the patients in whom testing revealed higher levels of depression and anxiety were more likely to want survival estimates and detailed information about prognosis. In a later analysis, the same authors explored patients' definitions of hope. For most patients, hope was linked to being able to maintain a quality of life and to fulfill goals, rather than to a cure for their illness.

Through her choices regarding information sharing, AB was trying to strike a balance between realism and hope. She wished to be realistic enough to get her affairs in order and make sure that someone whom she trusted would make decisions for her. By knowing the terminal nature of her illness, she was able to fulfill a goal of preparing herself and her family. However, she felt that too much information about survival would adversely affect her quality of life, and thus her hope. By living her life on a day to day basis, rather than focusing on when death would happen, she was able to maintain a quality of life that was acceptable to her.

For palliative care consultations please contact the Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, beeper 412-647-7243 pager # 8513 or call 412-623-3008, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644-1724, Interventional Pain 784-4000, Magee Women's Hospital, beeper 412-647-7243 pager #: 8510, VA Palliative Care Program, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore, and Children's page 958-3844. With comments about "Case of the Month" call David Barnard at 647-5701.



It is clear that patients have various and often very specific needs when learning their prognosis. It seems that giving patients the type of information they desire, while withholding other information at their request, may play an important role in allowing them to achieve good quality of life. Clinicians should be sensitive to individual patient preference when discussing prognosis and follow their lead with regard to how much or how little information to deliver. In this way, we might help them find the balance that AB was able to achieve.

References:

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Compassion Sabbath Retreat with *Vesta* Performance Well Attended by Clergy and Healthcare Professionals

The Institute and the Coalition for Quality at the End of Life (CQEL) held Compassion Sabbath: Heart, Mind & Soul. *Enhancing Clergy's and Faith Community's Role in Caring for the Seriously Ill*, on October 13, at Family Hospice and Palliative Care (FHPC) in Mt. Lebanon. Compassion Sabbath was well attended by local clergy and health care professionals and received extremely positive feedback.



Keynote Speaker
Rev. Dr. Thomas Long
Candler School of Theology

Compassion Sabbath began with a warm welcome from Rafael Sciuolo, CEO of FHPC, followed by keynote speaker Rev. Dr. Thomas Long. Rev. Long's lecture presentation focused on the



Family Hospice and Palliative Care Medical Director Dr. Susan Hunt (far left) conducts a breakout session

messages in his newly published book: *Accompany Them with Singing – the Christian Funeral*, which provides a theological and cultural critique of today's Christian funeral and thoughtful guidance for planning and preaching funerals. Simultaneous workshops



Dr. David Barnard
Director of the Institute
To Enhance Palliative
Care

were held with Dr. Susan Hunt presenting "The Dying Experience," while Dr. David Barnard discussed "Ethical and legal context for patient and family decision making." Rev. Leonard Sponaugle, Spiritual Care Specialist/Chaplain at Family Hospice and Palliative Care and Rev. B. De Neice Welch, pastor of Bidwell Presbyterian Church, led open discussions related to the application and practice of the information from the workshops and keynote presentation.

After dinner, as a special part of Compassion Sabbath, *Vesta* was performed as a staged reading by Rita Gregory & Company, with Rita playing the lead role of *Vesta*. This nationally renowned drama of aging, love and loss, led the audience through a variety of emotions in dealing with one family's struggle in coming to terms with the fact that their matriarch, *Vesta*, is nearing the end of her life.



Rita Gregory as *Vesta* (left)
Vesta's daughter Carol
played by Brenda Marks

The Institute and CQEL Are Set to Launch Palliative Care Resource Website for Southwestern PA

The long anticipated palliative care resource website, compassionatecareforall.org, will be launched before the New Year. The website will be a regional resource for Southwestern PA focusing on helping people with serious illnesses and their loved ones.

Institute Researcher Wins Funding Award

Dr. Mamta Bhatnagar, an assistant professor of medicine in the Section of Palliative Care and Medical Ethics at the University of Pittsburgh has been awarded funding for her research entitled, "Falls in Hospice: Examining Risk Factors in the Hospice Population: A Hospice Provider Study" and is preparing to present the results of her research project.

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Prior to the University of Pittsburgh, Dr. Bhatnagar received her medical education at Lady Hardinge Medical College in Delhi, India and completed an internal medicine residency at Case Western University in Ohio. Dr Bhatnagar subsequently completed a fellowship in Geriatrics from the Cleveland Clinic and a Palliative Medicine fellowship from Summa Hospital Health System in Ohio and is



Dr. Mamta Bhatnagar
Assistant Professor of
Medicine Palliative
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Ethics

currently pursuing a Masters in Clinical Research at the University of Pittsburgh. Through her research she hopes to enhance understanding of

nature and risks of falls among hospice patients leading to assessment and prevention.

Institute Researcher Presents Findings on the Quality at the End of Life as a Public Health Concern

The Institute's Dr. Steven Albert recently presented his research "The End of Life as a Public Health Issue." His research centers on the assessment of health outcomes in aging and chronic disease, including physical and cognitive function, health service use and the cost of care, quality of life, and clinical decision making. His current efforts include a study of worksite health promotion, modeling of vaccine refusal across the lifespan, and public health surveillance of the end of life. Some of Dr. Albert's broader interests involve international aging and a life-span approach to health in old age. Dr. Albert's research focuses on neurological deficits and the relationships of these deficits to health outcomes, levels of functioning, and overall quality of life. He is also



Dr. Steven M. Albert,
Professor
Associate Chair for
Research and Science

heavily involved in studies examining patient and family decision making in palliative care and end-of-life issues. Dr. Albert is a Professor of Behavioral and Community Health Sciences at the University of Pittsburgh's Graduate School of Public. He also directs the Department's Public Health Gerontology Program. Prior to the University, Dr. Albert was an Associate Professor at the Mailman School of Public Health at Columbia University, and the Director of the Outcomes Division of the Sergiesky Center. At Columbia he also was Co-Director of the MPH Program in Aging and Public Health. Based on his research, Dr. Albert is recognized as an expert in the measurement of function and health-related quality of life, and is known for his efforts to link his neurological research to public health initiatives.

The Institute Welcomes Interim Manager of Programs and Communication

The Institute welcomes Monica Ceraso as the Interim Manager of Programs and Communication. Monica is filling in for Paige Hepple while on maternity leave and is working on launching the Compassionate Care for All website along with many of the day-to-day coordination of Institute activities and programs.

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