

Will I Receive Competent Care?

B.O.A.T.I.N.G.©

Before Offering Another Treatment, Identify New Goals is a powerful, one-act play that provides insight into the benefits and burdens of treatment at the end of life.

Ramona is diagnosed with metastatic cancer and is treated with aggressive chemotherapy and procedures. Each new treatment option is dramatized by Ramona taking on a new piece of scuba gear until she ultimately is unable to move or find comfort. Her physician words, "There is nothing more we can do for you!" are repeated over and over again, demonstrating the many ways this phrase can be heard.

However, a whispered voice says, "There is plenty we can do for you." The care given Ramona will now reflect her goals. As the invasive treatments are discontinued and replaced with comfort care, Ramona is made more comfortable and allowed to die peacefully, on her own terms.

Using these metaphors, B.O.A.T.I.N.G.© is able to address this issue clearly and with greater impact that a didactic presentation could ever hope to do. This play speaks to everyone at a deeply personal level about a subject that has or will impact each of us.

The author, Jill Bixby, was inspired by a vivid dream. She had been wrestling with a way to educate physicians and other medical professionals on the importance of recognizing the point at which aggressive, curative treatment might no longer be consistent with the patient's goals. When is the right time to refer to palliative care and hospice—to determine what the patient really wants?

Highlights from the focus group

Increase . . .

- understanding of the Medicare hospice benefit
- education
- hospice referrals
- education regarding the dying process

Address . . .

- regulatory environment
- licensure requirements
- communication barriers
- law enforcement issues
- accountability issues
- elements of Last Acts State Ranking Report
- institutional barriers

Develop competencies
Utilize interdisciplinary approach
Respect/honor patient wishes
Empower consumers
Educate third-party payers
Promote ELNEC and EPEC training
Involve print and broadcast media in outreach

Ben Rich

"The question 'will I receive competent care' can be answered with another question -- 'what do you define as competent care?'. Competent Care, in the medical community, is defined by what is usual and customary, and this definition has already been described as 'mediocre at best'. Is this the level of 'competent care' we want at the end-of-life? What happens if I don't get competent care? Will there be consequences, not just for the patient, but for the provider giving less than competent care? How do you break the bad news without using the 'D' word? The 'D' word has been replaced with the term 'multi-organ system failure'. How are we going to provide care which is consistent with the patient's goals and values if we have cultivated our ignorance of what they are, or acted as though our sublime indifference to them is competent medical care."

Lauren Michalakes

"Maine was one of two states which received a failing grade from Last Acts with regards to the utilization of Medicare hospice benefit. We have wonderful hospice providers in Maine -- some of the most skilled, most compassionate, most dedicated. But when the hospice model is complicated with issues of reimbursement and regulation, it changes from this wonderful community-driven, born-in-our hearts, type of entity, into something less than it should be."

Jill Bixby

"'Will you receive competent care? It depends on who's on.' As a result of a multi-million dollar law suit, California physicians are required to take continuing education on pain management and end-of-life care. The problem is cultural. In some countries, people look forward to death, in others, death is honored. In the US, we look at death as an option. The first step is to acknowledge and accept that a patient is dying. Once this is real to the caregiver and patient, steps can be taken to provide appropriate care."

Thomas Keating

"The likelihood of someone receiving competent care is much better now than it was 10 years ago. It wasn't very long ago that shared decision making was not heard of. The general public is much more sophisticated and physicians are realizing this. Mainstream medicine is finally getting the message. Reimbursement is a big key. Physicians want to do the right thing, and they will respond to what is valued in society. We need to value the time spent by a physician speaking with the patient about patient wishes and care options -- time to develop a relationship which will be needed to answer the difficult questions."

From the facilitated discussion group

The group identified the following list of issues as concerns and barriers: self-advocacy, physician training, DEA concerns on prescribing, absence of interdisciplinary approach, current licensing requirements, reimbursement levels, and Maine's low grades in the Last Acts State Ranking report.

Education: There is a lack of educational competencies for end-of-life health care professionals. The medical and nursing schools need core curricula regarding hospice and palliative care. Consumers need more information — often, they do not know what they do not know. Informed consumers drive social change.

- Continuing education could be tied to license renewal. For example, refer to laws in California.
- Medical and nursing school curricula need to include end-of-life care modules.
- Consumers need a process to obtain information on the competency of health care professionals.

Policy and regulation: The climate surrounding the prescribing of opioids is difficult, at best. Physician prescribing practices have been under increased scrutiny because of the concern for opioid abuse. More and more prescribers have decided to drop their DEA licenses, or they simply shy away from prescribing these drugs for legitimate purposes. As recently as last October, the State of Maine adopted a monitoring system to track physicians' prescribing practices for Schedule II drugs. There needs to be a balance between providing appropriate pain management and addressing issues of diversion.

Communication: This requires the coordination and cooperation of everyone involved. It is important to identify where communication breaks down. Communication breakdown creates problems and interferes with competent care. The need for honest, open communication is critical. An interdisciplinary approach has been proven to be the most cost effective resource in obtaining better outcome. However, it is not always the standard of care.