



Dealing with intractable conflict about treatments at the end of life: A harm reduction strategy
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Case: The patient is an 85-year-old man with hypertension, diabetes, chronic renal insufficiency and COPD who was admitted to the MICU after an episode of atrial fibrillation and a left brain stroke three weeks ago. In the ICU his course has been complicated by aspiration pneumonia, urosepsis, hypotension and worsening renal failure. He is currently intubated and receiving dialysis (which requires the use of low-dose pressors) and has been delirious for over two weeks. The patient has a Stage 2 decubitus and grimaces and moans when moved or touched. The health care team believes that he will never recover and will be ventilator and dialysis dependent and institutionalized. Despite numerous conversations with the patient's children, they have continued to request that "everything be done" to prolong his life. They explained that he told them not to give up because he wanted to live to 100 (his parents died in their mid-90s). He has been told at least twice previously that he was going to die (once when he had prostate cancer and once when he had sepsis due to pneumonia), and he pulled through both times. They view him as a survivor - he was one of the few soldiers in his troop who survived the Battle of the Bulge, and he survived a boat ride to America in which half the passengers died. Understanding that he is very sick, they are hoping for a miracle so that he can get better.

Recently, the family has expressed some frustration with the constant conversations regarding forgoing life-sustaining treatment. They wonder why nobody in the hospital seems to focus on helping their dad to get better. What should you do?

Discussion: Informed decision making about forgoing life-sustaining treatment means that sometimes the patient or family will make decisions with which you disagree. In the above case, the surrogates are making a well-informed decision that they believe represents their dad's expressed values. The treatment is not biologically futile as it helps him live longer. However, from the health care provider point of view continued life-prolonging treatment only inflicts pain and is unlikely to do more than prolong biologic life. Hence, the conflict.

In these situations, continued conversations about limit-setting are unlikely to be productive. Recurring attempts may lead the family to feel bullied and undermine their trust in the health care provider team. Instead of talking about forgoing treatment, it may be better to think of how one can minimize harm to the patient, to the family and to the health care team. The major components of a harm reduction strategy are as follows:

Acknowledge the patient's values so that the patient and family feel heard and respected. In this case, the patient's sons are trying to respect what they believe their dad would want. Even if you do not agree with their decision, you can let them know that you appreciate their struggle. (*I see how hard you are trying to respect your Dad's values*). Acknowledging the family's decision making has been shown to promote family satisfaction.

Parenthetically, these families are often described to be in "denial." In our experience, families who are hoping for miracles are aware that the health care team does not believe the patient is going to get better (the traditional definition of denial). They understand that the patient is very sick and that our medical technology is unlikely, on its own, to result in the patient getting better. That is exactly why they are invoking a supernatural act - a miracle. Therefore, comments such as "*I know you are hoping for a miracle, but it is very unlikely to happen*" or "*I know you are hoping for a miracle, but there is nothing more we can do*" are unlikely to promote understanding. Acknowledging the family's hope for a miracle (*I see how much you want a miracle*) allows them to feel that you understand their view and may let them talk about their fears about what if a miracle does not occur. (It is even more powerful if you joined with them by saying that you would be thrilled if a miracle did occur, and the patient got better.)

Stop regularly discussing resuscitation preferences unless the issue is raised by the patient or the family or there is a significant unexpected deterioration in the patient's condition. If there is a significant deterioration in the patient's condition, present that as a fact, and see what the family's response to that fact is rather than using it to ask yet again about "what they want."

Talk to the family about the things that you are doing (e.g., the treatments and diagnostic tests). When conversations focus on forgoing life-sustaining treatment, families may feel abandoned. It is, therefore, important in your daily conversations to stress the treatments that you are instituting to help their loved one.

Continue to meet with the family on a regular basis. Sometimes, when we are in conflict with others, we avoid them because the conversations are difficult - both for us and for the family. In some ways, this is exactly the wrong thing to do. By withdrawing, you increase the chance the family will feel abandoned. The family needs to see you as an active and involved participant in their loved one's care. Even if you do not agree on the goals or all of the things that are being done, this does not diminish the family's need for information about what is happening. Regular meetings allow you to build and maintain trust with the family.

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, 623-3008, beeper 263-9041, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644-1724, Interventional Pain 784-4000, Magee Women's Hospital, 641-2108, beeper 917-9276, VA Palliative Care Program, 688-6178, beeper 296. 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.

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See if you can find patient-centered goals that both you and the family can agree are important to work on. This may involve focusing on symptoms (the patient's pain), helping the family with a social problem or treating a defined medical problem (the decubitus). Finding a shared goal with the family helps build a positive, more trusting, relationship. In addition, it allows the health care team to feel that they are accomplishing a positive task that is consistent with their values.

Address the entire healthcare team's discomfort, disapproval or distress about providing care that they do not believe is appropriate. These cases are often very hard for the entire team. It is important that the team have an opportunity to vent about their discomfort, and that they are provided with information about the reason for the family's decision. Without the clear and open discussion, it is often the case that rumors or innuendoes about the family's reasoning are spread. These rumors often magnify conflict with the family and lead to further communication breakdown.

Continue to exercise clinical judgment. The family made the patient's values clear. He would want any therapy which has a chance of prolonging his life, regardless of its burden or the quality that would result from that. This does not require, however, that you offer or proceed with therapies for which there is no data or reasonable expectation that it will achieve this goal. If there is no evidence or expectation that adding a fourth pressor, for example, would achieve a life prolongation, the family can be told that you have, in fact, "tried everything," and that it is not working. Offering experimental or untried or unproven therapies is not necessary.

Take CPR as a specific example. Rather than repeatedly badgering the patient and family to consider a DNR decision, initiating CPR when the patient has a cardiac arrest is appropriate. But, also stopping after one cycle if there is no response and it is extremely unlikely to be successful from the onset, is an example of exercising clinical judgment. It is different from a show code or slow code, in that there is a genuine, albeit brief, attempt at CPR before stopping. This allows the family to know that everything possible was done but

avoids having the staff go through the ordeal of prolonged CPR with no prospect or evidence for recovery. We acknowledge that the difficulty of this approach is that there is often no empirical data to guide physicians in determining how much is enough. These determinations are often best made by a consensus of thoughtful physicians reviewing the data and the patient's case.

We realize that it is sometimes hard to define ineffectual care when the only goal is prolonging existence. How can one be sure that a third vasopressor will not, at least briefly, help the patient who is hypotensive and on two drugs?

There is no simple answer to this question: requiring either that the treatment is not logically possible or that randomized control data about the treatment's effectiveness will not work. The decision requires clinical judgment, preferably by a team of experienced clinicians who reflect current consensus about the treatment's effectiveness.

The goal of this strategy is harm reduction – psychological harm to the family who is struggling with their loved-one's death, the psychological harm to the health care providers who are providing treatment that they believe is ineffectual and may be causing physical harm to the patient. The strategy reflects the fact that regardless of how good one's communication skills are and how much everyone tries, there are going to be cases in which there are irresolvable disagreements. The above plan attempts to minimize the harm caused by those disagreements.

References:

1. Back AL, Arnold RM, Tulsky JA. Mastering communication with seriously ill patients: Balancing honesty with empathy and hope. Cambridge University Press. 2009
2. Quill T, Arnold RM, Back AL. Discussing Resuscitation Preferences With Patients Who Want "everything" "Tell Me What You Mean By 'everything'?" *Ann Int Med.* 2009; 151; 345-9.
3. Stone D, Patton, B, Heen S. *Difficult Conversation: How to discuss what matters most.* New York: Penguin Books. 200.

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The Institute's 5th Amdur Social Work Fellow

The Institute's Fifth Amdur Social Work Fellow has completed her fellowship this summer and is preparing to present her final project based on her fellowship experience. Katie Guardino is a graduate student at the University of Pittsburgh School of Social Work. Prior to University of Pittsburgh, Katie attended Slippery Rock University of PA where she received her Bachelor of Science in Psychology. "I applied for the Evelyn Amdur Fellowship because I wanted to expand my knowledge base about hospice and palliative care. This fellowship gave me the opportunity to work with other professionals in the field and to learn how the role of social work impacts end of life care."

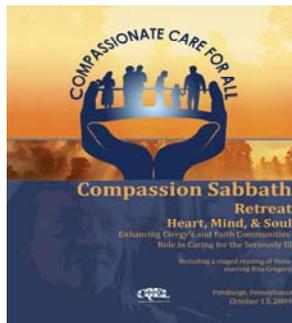


Katie Guardino, 5th Amdur
Hospice and Palliative are
Social Work Fellow September 2009

Her project included research on compiling a resource tab on long-term care and skilled nursing facilities for CQEL (Coalition for Quality at the End of Life) and for the Institute's upcoming Palliative Care Resource website for Southwestern PA which is due to soon launch. Katie is committed to specializing in geriatrics and in the issues facing the terminally ill and their families and believes in the importance of incorporating palliative and hospice care into treatment of the terminally ill.

The Institute and The Coalition for Quality at the End of Life (CQEL) Present Compassion Sabbath Pittsburgh's First Production

The Coalition for Quality at the End of Life (CQEL) in cooperation with the Institute to Enhance Palliative Care, is bringing Compassion Sabbath to the Pittsburgh area for the first time on October 13, 2009 from 12:30 - 8:00 pm at the Family Hospice and Palliative Care in Mt. Lebanon. Compassion Sabbath is a program that offers resources and support to clergy of all faiths, lay leaders and others, who wish to increase awareness about end-of-life care and also improve the spiritual care of the seriously ill and dying.



A special feature will be a staged reading of *Vesta*, a remarkable play that captures with humor, poignancy, and honesty one family's struggles with the challenges of aging, sickness, and loss. *Vesta* is staged in cooperation with Rita Gregory & Company and produced by the Coalition for Quality at the End of Life. **For more information, please contact:**

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Institute Student Researcher Wins Award for Outstanding Clinical Research

A student researcher from the Institute has been awarded the Arthur Mirsky Award for outstanding clinical research and is preparing to present the results of her research project focusing on the availability of opioids for HIV-positive palliative care patients in South Africa.

Wynne Lundblad is a second year medical student at the University of Pittsburgh School of Medicine. Prior to University of Pittsburgh, she attended



Wynne Lundblad
Mirsky Research Awardee
September 2009

Wellesley College where she earned a Bachelor of Arts in American Studies. Wynne's research was supported by the Institute's Alan Gleitsman Student Research Fund in Palliative Care, which provides financial support of \$3,000 for a medical student's summer learning in the Palliative Care Program. Students may work with faculty of the Institute on a research project, and/or see hospital patients with the Palliative Care Team in the hospital to gain a better understanding of the nature of palliative care, the therapies associated with it, and the benefits it can provide to patients and families. Wynne is interested in expanding access to palliative care both here and abroad, and in the promotion of health as an essential human right.

For more information on The Alan Gleitsman Student Research Fund or to request an application, please contact: Monica Ceraso at iepctemp@pitt.edu or Amy Slade at aes72@pitt.edu

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