

## PHYSICIANS FOR COMPASSIONATE CARE NEWS

Affirming An Ethic That All Human Life is Inherently Valuable

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### DOCTOR'S REACTION TO HELPLESSNESS IN PATIENTS

Many doctors cope with emotions by holding them at arm's length; they are more comfortable with facts than feelings, Dr. Greg Hamilton told Compassionate Care Conference participants. It comes as no surprise, then, that feelings of helplessness in the face of treating the seriously ill patient can be extremely difficult for physicians to tolerate. Dr. Glen Gabbard has pointed out "... a grand paradox on which to reflect is that those individuals who are so vulnerable to feelings of helplessness choose a profession where they are repeatedly reminded of their inherent impotence in the face of disease and death." It is, however, this profound paradox that can lead physicians to recognize and understand their own feelings of helplessness and thus come to their patients prepared with an increased ability to assist the seriously ill or suicidal patient who may feel helpless.

Modern medical practice puts increasing pressures on physicians, binding them by time and money conflicts that threaten to compromise ethical practice. The compassionate physician, having a high personal need to engage in caring activities, feels all the more trapped; so, the wish to avoid feelings of helplessness may be multiplied. Intense emotions and a need to escape from this problem of helplessness can interfere with compassionate care of the patient at a time when the patient needs it most. It can lead to instances of clinician burnout and emotional distancing. Being aware of these potential emotional reactions is the first step in coping with such pressures. The physician's human emotional vulnerability contains within it the key to solving clinical dilemmas compassionately.

Doctors often have an unconscious belief that their worth as a person is defined by task accomplishment. When the doctor thinks, "There's nothing I can do, no task I can accomplish," he may feel more and more frustrated whenever patients come in who have illness that can't be cured. They may even say to themselves, "There is nothing I can do, except get through the appointment." But there are things doctors can do.

For example, one day Dr. A. found he was troubled after the clinic visit of a patient who had a life-threatening illness. He had skillfully and carefully managed his patient's complex pain, but the patient remained discouraged and complained

hopelessly about immobility. She even said she was thinking about assisted suicide, which was receiving considerable press. Dr. A. didn't think physicians should offer lethal prescriptions, but he felt helpless and discouraged in himself when he faced this patient. Instead of talking about her suicidal thoughts he changed the subject. Later, he talked with a colleague about transferring the case. While talking with his colleague, he remembered how, when he was a boy, his mother would get intoxicated and complain to him about his father. He remembered how inadequate and guilty he felt back then, sitting, helplessly listening. It was then that he realized that he was avoiding his old feelings of helplessness by avoiding the patient. With this understanding, he resolved to master the old problem and also to try to help his patient. During the next clinic visit, he listened with active and interactive empathy through paraphrasing and empathizing, instead of helplessly avoiding what the patient was telling him. The patient then opened up and talked about how powerless she and her family felt about the progression of her illness. She felt relieved and understood by her doctor; and paradoxically, with having her helplessness understood, she no longer felt suicidal.

Recognizing his own feelings of helplessness and his tendency to throw up his arms, as if to say, "It's useless and I'm useless and then feeling guilty in the face of powerlessness," Dr. A. accepted his own vulnerability. Then, instead of feeling worthlessly hopeless, he could accept the patient's plight and respond by a compassionate action of understanding and listening.

Of course, the doctor isn't the only one that brings a past into the current emotional equation. Patients have emotional styles that can cause complications, too. While some patients describe their feelings clearly, without needing to overwhelm their doctors in order to be sure they have been completely understood, there are others who seem to elicit powerful emotions from their caregivers as a style of communicating their own feelings. This process of communicating emotions to a doctor or caregiver by behaving in such a way that the patient actually elicits the feeling in the clinician is called projective identification.

One way to deal with such feelings elicited by our patients is called containment. Using this technique, the doctor accepts the feelings being thrust upon him or her by the patient, reflects upon them and upon what the patient must be experiencing and offers understanding back to the patient in words that make his or her own intolerable emotional experience more tolerable.

Over the past twenty years, psychotherapists have learned to use these feelings that patients engender in the clinician as an effective therapeutic tool. Physicians in the medical setting are also beginning to use them. Doctors have always talked with their

patients about their feelings; it can be done spontaneously and is appropriate in the doctor-patient relationship within primary care or specialist settings.

While the personal backgrounds of doctors may pose challenges when they are faced with helplessness in the seriously ill, those very factors, if understood and accepted, can allow the clinician to more deeply understand and help the patient. When the patient requires the physician to overcome a tendency to take distance from emotions and listen with active understanding, it is an opportunity for the doctor to grow as well.

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Living with a life-threatening illness  
People talk about their experience

Doctor Sylvia McSkimming, PhD, RN, of Supportive Care of the Dying: A Coalition for Compassionate Care, told PCC NEWS, following the Compassionate Care Conference, that much of what happens in the health care setting is based on a set of provider assumptions. Unfortunately, these assumptions may not take into account the needs and experiences of the people receiving the care. “We wanted to understand more fully the experiences of people living with and around life-threatening illnesses. We talked to patients, family, caregivers, community members, bereaved caregivers and healthcare professionals,” McSkimming explained in an interview about the group’s recent study.

McSkimming described the project as ‘needs assessment research’ involving 400 subjects from around the nation. Subjects participated in 1 of 5 focus groups containing 3 to 10 participants and a project coordinator. All participants were asked to respond verbally to the following:

1. Tell me about your experience, or the experiences of someone you know, from the time the illness appeared to be life-threatening or fatal.
2. How were you prepared for this? (cues: How did health care providers assist you? How did your prior life experiences assist you?)
3. What were your concerns or fears?
4. What were the problems or barriers you faced? (Cues: In meeting the problems and barriers, what was helpful and what was not helpful?)

5. Any experience can impact our attitude and values. How has your experience changed your attitudes or values?

6. Is there anything else you would like us to know?

The participant audio tapes were transcribed and the transcripts were analyzed using a qualitative methodology. The study has been submitted for publication.

Dr. McSkimming reports that themes emerged from the data which could enhance patients', doctors', health care providers' and health care systems' ability to cope with life-threatening illnesses. "One of the primary themes that emerged was that seriously ill people want to be seen as living persons, not as a class categorized as terminally ill. 'I am a person not an illness,' said one patient. They want to be treated as living persons, not dying ones," McSkimming added. She observed that use of the term "terminally ill" may stigmatize patients and focus everyone on the dying instead of on the living until they die. The patients described themselves as "well," spiritually and emotionally in relationship to others, even though physically their illness was not cured.

Patients also want to learn about their illness and the dying process. They want their questions answered--so they can get on with living. One participant put it this way: "I don't focus on the dying part all of the time. I might have a month or two where I just kind of really feel drawn to education, to learn, and kind of really get into it. Then I pull out and live. I work just as hard at living."

Patients weren't the only focus of the study, the experience of the provider was also explored. Doctors and other health care participants agreed that today's health care organizations tend to emphasize reimbursement and productivity quotas, both of which interfere with a professional's ability to respond to the needs of patients and families. "...It's a scarce resource we're dealing with in medicine these days...Even though my boss knows better, she counts productivity based on numbers that I turn in..." Many health care professionals, however, seek to provide truly supportive care, even when demands for productivity and compassionate care seem irreconcilable; these clinicians have learned from experience that for the patient with a life-threatening illness, the hierarchy of needs reverses. According to the investigators, when the body can't be made well, spiritual, emotional and relational growth take priority.

The researchers also report that when it comes to the personal caregivers of the seriously ill, they want to be included in treatment team discussions, before decisions are made. Health systems are in the habit of treating a patient and an illness and the caregiver can be inadvertently left out of the loop. "Additionally, the entire system

needs to see that the caregiver is living with this life-threatening illness, too,” said McSkimming. Doctors, other health care professionals, friends and relatives can help the caregiver of a seriously ill person by asking questions like: How are you doing with your mother’s illness? Instead of always asking: how is your mother?

The bereaved family members presented one of the most challenging themes. “They feel abandoned,” said Dr. McSkimming. “Because the care is for the patient, when the patient dies the care stops. The challenge is not just for the doctors; it’s for the health care systems.” The bereaved families said they would like the doctor who cared for their family member at the end-of-life to call and ask if they have any questions or just ask how they are doing. However, in order to meet such challenges, systems of health care must advocate for this type of bereavement follow-up contact, consider it part of standard care, and support it, in order to better serve those with end-of-life needs.

To review the executive summary of this project, see the WEB @ [www.chausa.org](http://www.chausa.org) -- mission services--supportive care of the dying. Co-authors: Sylvia McSkimming PhD, RN; Alicia Super, RN; Marie Driever, PhD, RN; Mary Schoessler, EdD, RN; Stephen Franey; Edwin Fonner, DrPH. For more information call Sylvia McSkimming, Executive Director 503-215-5053; E-mail: [smskimming@providence.org](mailto:smskimming@providence.org).

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PCC anticipates Kevorkian killing broadcast  
Call for boycott

PCC president urged CBS affiliates to boycott the airing of “60 Minutes,” which televised Kevorkian killing. “By manipulation of the legitimate news media, Kevorkian seeks to validate the killing of innocent victims and make illegal killings seem like a debatable medical issue,” said Dr. Greg Hamilton, who refused to watch the program re-aired by a local Portland station, KOIN TV. “The only place this tape should be played is in a court of law.”

PCC asked all Oregon CBS affiliates not to show the segment of tape which reportedly displayed the actual killing of a man, asserting that such a segment could serve as a suggestion of suicide. Although the Oregon stations aired the killing, a number of stations around the nation refused to run the segment because of policies against broadcasting the taking of a life or the moment of death over the air. Six stations owned by AH Belo Corp. with stations in Houston; San Antonio; St. Louis; New Orleans; Tulsa, Okla.; and Spokane, Wash., refused to air the apparent murder of Thomas Youk, a man with Lou Gehrig’s disease.

This CBS production, is the third instance PCC has noted in recent months in which ALS patients have appeared to be a specific patient population targeted by right-to-die activists and their media campaigns. Used to “justify” the necessity of assisted suicide and euthanasia, this category of citizens are being stigmatized, as are other seriously ill; they are being depicted as those most deserving of death by suicide or euthanasia. PCC called for the media to stop such indiscriminate public dehumanization of individuals who are sick and vulnerable.

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“Not Dead Yet” Protests funding of assisted suicide  
State okays cheap suicides

“It’s not about cost; it’s about savings,” said Ellie Jenny, President of the Oregon Chapter of Not Dead Yet, an advocacy group for disabled individuals. It will only cost the state between \$63 and \$200, according to estimates by state health officials, for Oregon Health Plan recipients to commit assisted suicide through the government funded HMO. The health plan didn’t report the estimated amount that they would save if even one of their patients with a life-threatening illness committed suicide instead of living and receiving medical care. “It’s one more layer of discrimination,” claims Jenny, “They tell us to come and let them know what we need and then they ignore us when we say it.”

Despite the fact that a roomful of consumers appeared at the hearing opposing state funded assisted suicide, the Oregon Medical Assistance Program director reportedly dismissed the groups’ testimony as not being germane to the question. “Basically the health plan says: we know better than you,” Jenny said of the pro forma hearing. “Hersh Crawford pushed through what Governor Kitzhaber wanted. Wherever and however they can, they want to save a buck. A dozen cheap suicides could save the state health plan a fortune,” Jenny said.

Cutbacks on needed medical services run rampant in the financially strapped health plan. Rick Burger, President of the Oregon chapter of American Disabled for Attendant Programs Today (ADAPT) and member of Not Dead Yet, who testified at the OMAP hearing, cited this example: “...people who want to live in the community are facing a shrinking supply of service providers (due to state cutbacks on compensation for services providers), and will eventually be forced into institutional settings. The fact that the state of Oregon will not properly fund our Personal Attendant Services, yet will pay for us to die, amounts to nothing less than cultural genocide.” Burger went on to say in his written testimony, “I believe that greedy health maintenance organizations will place pressure on us to end our lives...The proponents of physician induced death refer to this as a quality of life issue. I ask

them, if you are concerned about our quality of life, why aren't you advocating for increased funding for attendant services? Why is your so-called compassion limited to allowing us to die?"

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## Second Annual Compassionate Care Conference

Enhancing Life at the End of Life, the Second Annual Compassionate Care Conference, co-sponsored by PCC and Providence Health Systems gave doctors, nurses, social workers, and clergy new techniques for and insights into caring for the seriously ill. Topics discussed included advanced pain management, strategies for creating health care systems that are more responsive to the needs of the dying and their families, overcoming barriers to hospice, and caring for the caregivers of those with life-threatening illness.

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