Futility

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I had the opportunity to speak at a recent hospice and palliative care conference. The case under discussion was not unusual, but it raised some basic issues in health care ethics and in Christian values.

Briefly the details were as follows. Mr. P, a 75-year old who lives at home with his elderly wife, has advanced heart disease. A couple of months ago, Mr. P's doctor told him that "there's nothing more that can be done medically" and recommended that he consider hospice care. The hospice nurse visited Mr. and Mrs. P at home, made sure that Mr. P understood the nature of his illness, and explained the philosophy of palliative care. Mr. P wanted to be admitted to the hospice program because, in his own words, "I know I am terminally ill and almost without hope of recovering." But he did not want to agree to a "DNR"—a "Do not resuscitate" order. The resistance to a DNR has grown stronger since Mr. P consulted his children. Now the family is exerting a "powerful and inflexible influence" on Mr. P, in the view of the hospice team, and they have made it virtually impossible to talk about what should be done were Mr. P's heart to stop beating. The nurses are feeling deep ethical distress at the prospect of being obligated to try to resuscitate him.

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One way to describe the problem here is as a clash between patient autonomy and medical authority: Who has the right to make the decision about CPR (cardiopulmonary resuscitation)? An older style of medical practice said that the doctor knows best and the patient's responsibility was to be patient—and passive. That style has now been rejected. For good reason. Advances in medicine have meant that more treatment options are available, but also that it's less certain that the doctor can know which option is best for the patient. On top of that, it's just plain more respectful to treat adults as adults, and that means accepting them as active participants in the decisions about their own health care.

While doctors and nurses have accepted the patient autonomy movement by and large, we are now seeing something of a backlash. The term "medical futility" is appearing frequently in the medical journals. "Surely I have no moral obligation to provide a 'service' that will be useless," the argument goes. "And in patients with Mr. P's condition I can be certain that CPR will not work. Disease has ruined his heart; nothing can change that. And no one in his condition whose heart has stopped has had it sucessfully restarted."

Patients may be tempted to reply, "What makes you so certain? Are you God?" And in so replying to perpetuate an old-fashioned power struggle.

But I think there's another way to understand the ethical challenge in Mr. P's case. "Futile" is not an absolute term like "green," it's a relative term like "short." A procedure is not futile as such but relative to some goal or outcome. The doctors and nurses caring for Mr. P are doubtless right that CPR would not start his heart again after an arrest, and if that's the goal it would indeed be futile. But Mr. P and his family may have other goals.

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What do they hear when they hear "No CPR"? Do they hear a decision to simply withdraw? Dying people are concerned about not being abandoned, about not being regarded as worthless. And with that goal in mind an expectation of CPR can make sense.

The experts expected that "living wills" would be completed by patients in consultation with their physicians, and that medical treatment options would be the focus. But research has shown that in actual experience patients use living wills as an occasion to talk to their family about the meaning of life and death. Medical treatment options are relevant, but the patient's goals are broader, and one might say more spiritual, than the doctor's.

I am not so naïve as to think that simply reframing the issues will solve all the conflicts around care of the dying. But we all need to understand that death is more than a medical event. When people are searching for hope it's not necessarily hope of medical success they want. As The Salvation Army Position Statement says, death is a transition from this life to life eternal. Dying people need the opportunity to see matters that way, and I think they are ethically wronged if they are denied it. One would hope that the frustrated hospice nurse attending Mr. P would be able to communicate that her care for him is not only for his physical being, but for him as a whole person whose living and dying are sacred.

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