Futility as a Fluid Concept of Moral Judgment

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Futility is a patient centered decision-making process that takes into account medical effectiveness, patient preferences, and a shared understanding by the patient (or their surrogate) and their providers of the potential benefits and burdens of treatment that may incur. A decision to withhold or withdraw treatment is therefore a shared clinical judgment that doing so is the most prudent option available for the patient. Claims of futility may be made too soon or delayed too long, depending on the circumstances and the needs of the patient. When patients request that “everything be done” it does not necessarily equate that doing so is the most prudent decision, especially when medical futility truly exists. Any intervention offered, as always, should be evidence based as to having a reasonable likelihood of success, consistent with patient preferences and values, and not overly burdensome for the patient. Decisions about treatment and futility are a process, not a point in time, and require prudent review of the facts on a day to day basis. As new information is learned and as clinical circumstances change the variables used in the futility calculus may likewise change and thus modify the clinical decision as to whether or not to treat. Futility, therefore, is a proportionality equation taking into account the balancing of medical effectiveness (ME), benefit (Be) as determined by the patient in conjunction with their physician, and burden (Bu) as determined by the patient.

Substituted Judgment: Patients may or may not want others informed or involved in decisions about their care and treatment. Respecting patient autonomy (the right of self determination) requires that providers remain patient centered in the clinical decision making process and, if at all possible, allow the patient to decide what is in their best interest. This may be difficult if the patient is unresponsive or cognitively impaired, in which case a surrogate must step in to represent the patient. When patient’s demand that physicians “not involve the family” they may be seeking means to maintain control as illness progresses to a point where the patient is becoming more dependent and there is fear of loosing control, and thus their dignity. Family members are usually the surrogate decision-makers when no written health care directive is available and when patients can no longer speak for themselves, however several requirements must be met:

1. Families typically know their loved one’s preferences and values best and we traditionally defer to them as long as they remain appropriate in that role.
2. There should be no undue conflict of interest on their part.
3. They should be present, interested, and appropriately connected to the patient emotionally during and prior to this hospitalization.
4. The family may already actively participate in decisions with the patient.
5. The family should speak in a unified and consistent voice.
6. There may be no time to get a court appointed guardian (family being the most likely candidates anyway).

The patient has the right to refuse treatment and limit information about themselves being given to others, no matter how appropriate the others in question may seem to be or how close they are to the patient, as long as those others are not potentially and definably harmed by withholding said information from them (Re: Tarasoff). The obligation of confidentiality does not change when the patient becomes incapacitated. The family is typically brought in when the team needs help to decide (if the patient can no longer do so) and if it is unclear whether the patient would not want them involved.
Setting Treatment Goals: This is always challenging in end of life care because the health care team must set reasonable expectations and prevent unreasonable suffering while not encouraging undue hope. It’s important to know patients’ preferences as well as what reasonable options exist for treatment. The family in years past may have witnessed statements made by the patient indicating they “he would not want this kind of life” on life sustaining technology if there was no hope of recovery. On the other hand, the patient may now be requesting what can no longer realistically be provided. In any case, the patient’s last autonomous statement regarding a desire not to remain on life support if there is no hope of recovery may be very consistent with an ultimate clinical decision to limit further aggressive treatment. When there is a nil prognosis of surviving CPR (cardio pulmonary resuscitation attempts) writing a DNAR (do not attempt resuscitation) order is also reasonable. Physicians and other providers are not obligated to provide interventions that will not be successful.

Medical Futility—the ultimate claim: As noted, when patient’s have multiple severe medical conditions (brain injury, heart failure, respiratory failure, kidney failure, etc.) cardio-pulmonary resuscitation (CPR) has minimal chance of success, there being an extremely low probability of survival to discharge and a high probability of incurring further pain and suffering, should the patient survive the acute event. A grim prognosis in context with previously expressed values statements made by the patient regarding life support provide a reasonable assessment supporting a claim of futility, meaning that the likely burdens of further treatment far outweigh any slim possibility of benefit. Futility, balancing effectiveness, benefit and burden, is a fluid process and different for each patient; its determination may, and often does, change from day to day in the same patient, depending on the data at hand.

Bottom line:
Patients have a “limited” right to accept or refuse treatment.
Patients have a “limited” right to limit information being given out.
Providers’ obligation to protect these rights does not wax and wane with patients’ capacity.
Futility takes into account more than medical effectiveness and is a fluid, ongoing determination.
The team uses the best information available to determine what needs to be done.
Knowing what the patient really wants may be difficult to get at.

Finally, when the patient is incapacitated we must rely on trusted resources to represent the patient’s interests – finding out early from the patient about treatment goals and how they want to be represented will save much grief and confusion in the long run. Physicians and other providers should begin these discussions early with patients and their family… in clinic or when first admitted to the hospital; when patients become very ill or first take a turn for the worse it may be too late for patients to make a truly autonomous decision about end of life care.