

Decision Making in Palliative Care

A Guide to Approaching Care Choices

Palliative Care is a comfort-focused approach to life-limiting or life-threatening illness, whose overarching goal is to maximize quality of life. A “good death”, while a desired outcome of quality end-of-life care, may be considered as good quality of life, albeit the final phase.

The concept of “quality” in describing an individual’s day-to-day life is subjective and experiential, and as such requires the input of that individual if possible, or failing that the input of surrogate decision makers who can speak to the person’s values and goals.

Not uncommonly, the concept of “futility” is raised by members of the health care team as a consideration in limiting options for investigations and interventions in the care of the dying. However, futility can only be considered with regards to the possibility of achieving goals; a distinction must be made between experiential goals (requiring the input of patient and/or family) and physiologic goals, which are those defined by objective, measurable, physiologic parameters (such as laboratory results, vital signs, body weight, etc.). An intervention that cannot possibly achieve its physiologic goals may be considered as “medically futile”, such as attempted cardiopulmonary resuscitation following death due to overwhelming multisystem failure in the context of a terminal illness such as widely metastatic cancer.

However, even in palliative care there are not as many circumstances of medical futility as one might think; there often remains the possibility of achieving physiologic goals from an intervention. An intervention might be incorrectly deemed by the health care team as “futile”, when the actual concern may be:

- ***This is an inappropriate use of a limited resource***, such as:
 - providing frequent blood product transfusions with no possibility of changing the underlying problem requiring transfusions, for example bone marrow failure or ongoing bleeding
 - providing hemodialysis in a terminally ill individual, for example in a cancer patient with ureteral obstruction

In such situations, the physiologic goals of care (maintaining hemoglobin and hemodynamic stability with transfusions, or metabolic homeostasis with dialysis) may well be achievable; the pertinent issue is the principle of justice in the allocation of limited health care resources. While this is a valid concern, it cannot with honesty be couched in terms of medical futility.

- ***There will be no benefit from the intervention, or perhaps it will be excessively burdensome or result in no improvement in quality of life.***

The concepts of benefit/burden and quality of life are subjective, experiential considerations requiring the input of the patient and/or family. As health care providers, we can describe the positive effects or the adverse effects of an intervention, however we require the person experiencing them to translate these into benefits and burdens.

An intervention may be futile if it cannot possibly achieve the stated experiential goals, however whether or not such goals are being reached require input from the person experiencing them. Concepts such as energy, well-being, comfort, symptom distress, all require the interpretation of the patient.

- ***If I (the health care provider) were this patient, I would not want this done.***

Health care providers must remain self-aware about their own feelings and biases around end-of-life care. Most people have considered their own mortality at some point, and providers of health care may have developed strong beliefs about how they would wish to be treated if they were dying... perhaps even more so than around other health care scenarios. Projection of one's own wishes should not bias the discussion around treatment options for the terminally ill.

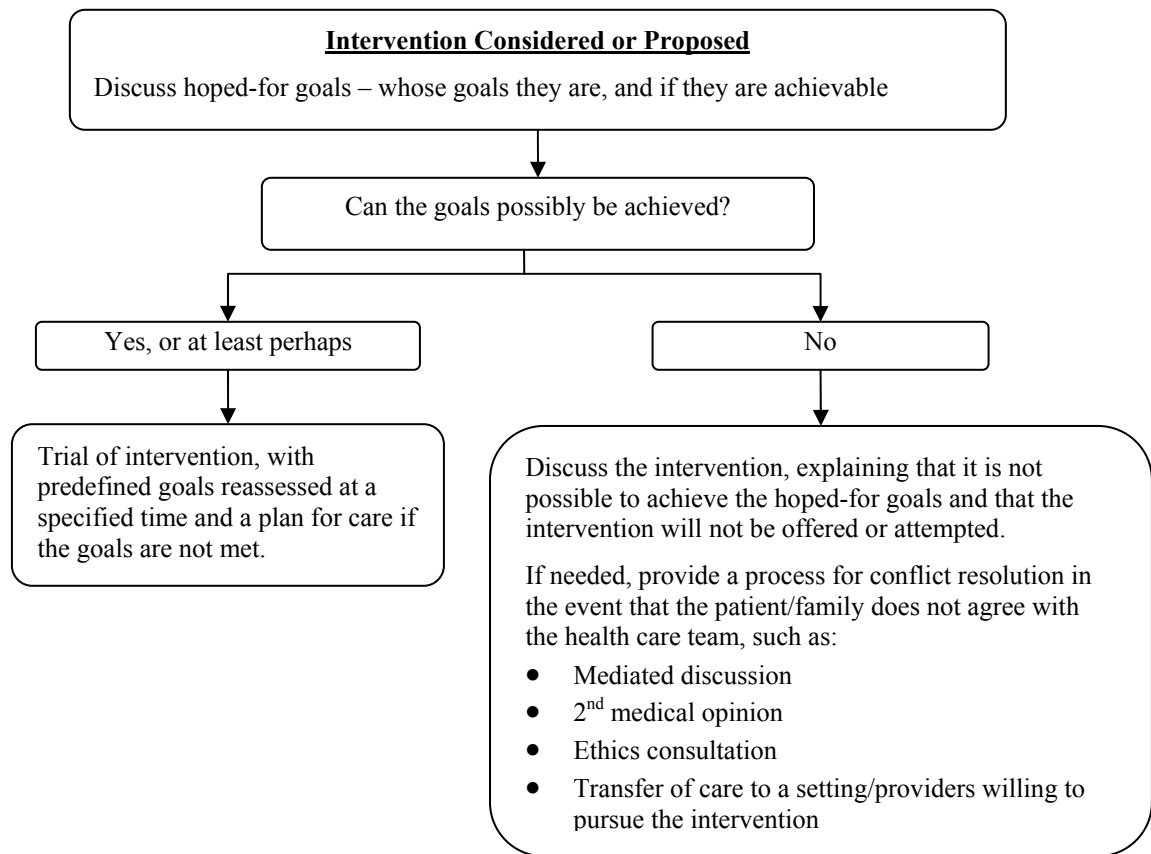
The decline in overall strength/energy/functional status in terminal illness is usually marked by what appear to be potentially reversible complications, such as infections, bleeding, or metabolic disturbances such as hypercalcemia. It can be very challenging to develop an approach to such circumstances, as the desire will often be to “fix the fixable”, without means of knowing if or how this will influence the course of illness.

The first step in considering an intervention in palliative care— such as antibiotics, hydration, enteral feeding, radiation therapy, physiotherapy – involves defining its hoped-for goals and evaluating the possibility of those goals being achieved. Impossible goals should not be pursued – not even with the misguided intention of “providing hope”; honest and open discussion of health care options does not include misrepresenting potential benefits in an effort to avoid unpleasant discussions around death and dying.

In circumstances where it is unclear whether experiential goals might be achieved with an intervention, a time-limited trial may be the most appropriate approach. Through dialogue with the patient and/or family, the duration of the trial and the parameters defining success or failure of the intervention are decided in advance. A clear plan outlining an approach to a failed trial of an intervention must be developed.

There should be a process for addressing conflict about care options, such as the provision of second medical opinions, ethics consultations, or arranging for transfer to an alternate care setting or provider.

The following flowchart outlines a simple approach:



Specific situations/questions in palliative care:

• **When do you stop transfusions of blood or blood products?**

Simply put, transfusions are discontinued when the goals are no longer being met. The physiologic or medical parameters which will dictate the end-point of transfusing blood products include:

- Blood loss exceeding possible replacement (such as a carotid artery erosion from tumour)
- Inability to obtain venous access
- Inability to match the blood product due to antibodies

Subjective or experiential parameters determining the futility of ongoing transfusions include:

- Failure of the transfusion to achieve the hoped-for goals of improved energy, strength, dyspnea

• **Discussing “Do Not Attempt Resuscitation” in situations where it is not a possible option.**

The approach commonly taken in discussing CPR with those for whom CPR cannot possibly restore cardiac or respiratory function (the basic physiologic goals of CPR) is intriguing, if not disturbing. The discussion usually unfolds in a manner such as:

“If your heart stops, do you want us to try to get it started again?”

The person may have no idea that what is being discussed pertains to efforts to reverse what is essentially a natural death, often in the context of a relentless terminal condition. The response to

such a question is usually “sure”, and what follows is an awkward process of trying to explain what was really meant by the question, and in fact that CPR wouldn’t work in any case.

There is no other health care circumstance where a non-option is offered, only to be withdrawn if accepted. A surgeon would not ask if the patient would want surgery, only to state when the patient says “Yes” that it will not be possible. A teenager with a painful throat related to acute mononucleosis is not asked whether he or she would like penicillin, only to be told that it will not be prescribed as it is not effective for the viral illness

However, many “non-options”, such as curative surgical removal of a primary tumour that has widely metastasized, or antibiotics for a viral pharyngitis, are still expected by reasonable people who are simply exploring all options. Such interventions *should* be discussed, in a manner that explains that they cannot effectively achieve the hoped-for goals, and will not be attempted. Ideally, such discussions will be preemptive, such as:

“You might be wondering about whether ...”

An example of an approach to letting someone know that CPR will not be attempted might be:

“I’d like to talk with you about how things are going with this illness, and about what we can do for you in order to help.

As you know, there have been some changes that tell us that your body isn’t as strong as it was a short while ago, and that the impact of the illness on your strength and energy has worsened. With time, we expect that to continue, and we can make sure that whatever comes up, you are comfortable.

There will be a time at the end of this illness when your body systems gradually shut down, and your heart will not be able to keep functioning. At that point, your heart will stop... this is the way that your body shuts down and dies from this condition. It is not possible to restart the heart in such situations, as it stops beating due to the general weakness of the rest of the body, which cannot be changed. We won’t be trying to restart your heart at that time.

Do you have any questions about that?

Of course, with the variety of illnesses people may have and the uniqueness of each individual, it is not possible to provide a universal template for such discussions. The main point is to refrain from offering an intervention which you have no intention of providing, but to discuss such “non-options” that most reasonable people would nonetheless expect. Ideally, such discussions should be preemptive, raised by the involved health care providers.