



ATTENTION and INTENTION

AN INVITATION TO REFLECT ON LANGUAGE

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Palliative and hospice clinicians are practicing and evolving in a period of unprecedented flux and uncertainty, where policy and politics, finance, and social justice issues permeate practice both with bludgeoning force and in subtle, quiet ways. At the same time, we are experiencing expanding interest in palliative care, a proliferation of new programs, and the pervasive desire across all disciplines to serve persons living with serious illness and their families with expertise, authenticity, and fidelity.

The intent of this article is to provide an oasis where we stop and reflect on our language: the words we choose, the many metaphors and shorthand communications that encompass a kaleidoscope of meanings, beliefs, and values that are unspoken day to day but creep like mist into our everyday parlance, writing, and teaching.

This lexicon of words and phrases has permeated our field over time. Hospice has come to be called an “industry,” patients “consumers,” and clinicians “providers.” Palliative care is frequently described as “comfort care,” branding that may minimize the expertise of clinicians and complexity of the work. In some settings, a referral for “goals of care” has become a metaphor solely for discussions about resuscitation and limiting life-sustaining therapies. The emphasis on withdrawing or forgoing treatments requires that we continue to be articulate and direct in explaining the range of services provided to patients, families, and institutions, and that we be clear that withdrawing certain treatments is not withdrawing care.

This is an exciting time because palliative care is integrating into many practice settings. This provides ongoing opportunities for seasoned clinicians and emerging leaders to pause and bring further clarity and precision to the words that describe the shared and separate experiences of clinicians, patients, and families.

It may be the ideal time to direct renewed attention to the language of a specialty that embraces science, humanity, and mystery, as we continue to dispel myth and innuendo and clearly articulate the thoughtfulness, compassion, and expertise that are the foundations of palliative care.

Although words and language are shared across disciplines, each profession has a unique education and brings distinct contributions both as generalist and specialist clinicians and as team members. Therefore, this topic is of mutual interest and responsibility. At the same time, our tasks, liabilities, and respective distress emanate from different roles, codes of ethics, and expectations, and from self, society, and institutions. Those who focus intently on process may be troubled by influencing an outcome, even when the outcome is deemed by all disciplines as the most appropriate. It is at this intersection where perspectives meet and sometimes collide that reflection in a setting of safety is most challenging. It is with this goal that we pause for a few moments to consider words.

WHO BRINGS WHAT LANGUAGE TO THE TABLE?

Those who work to achieve comfort with listening and silence often find patients and families “know” what we expect to have to tell them. Asking what they see, know, hope for, or have experienced in the evolution of an illness can begin a process of mutual discovery wherein the work of the clinician is not only to inform, but, perhaps more importantly, to affirm or impart meaning to their observations as we elicit and share the emotional and spiritual aspects of their experience.

When clinicians introduce words and phrases different from the words and phrases used by persons who are ill and their families, we risk creating distance. When patients speak of “passing, crossing over, or traveling”

as metaphors for dying, they invite us to join in their representation of a dying process. This is quite different from clinicians who are unable to speak of dying or who use language that may be heard as insensitive, purely clinical, or poorly aligned with the families' culture and experience.

When solicited, a family's descriptions and observations may inform their understanding that treatments intended for positive outcomes have become more burdensome, without benefit, and actually prolong a dying process. This realization may substantially change a family's perceptions and hopes through a process of reflection. This differs from a conversation wherein either families or clinicians find themselves labeling these same treatments as "inhumane" or "torturous" and perhaps are left to bear the responsibility for having offered or accepted them. When we begin with an awareness of and curiosity about the meaning that words may have for self and others, there is an opportunity, as participant observer, to consider the potential for our language, in all its complexity and richness, to either harm or enhance the experience of patients and families in the present and future as the memory of illness integrates into family legacy.

When we stop to consider the language healthcare providers often bring to an encounter, it is no wonder patients and families can be perplexed and are sometimes described as being "in denial" or "just not getting it." Medical phrasing is unique and can be confusing and depersonalizing. For example, in the nonmedical world, positive denotes something affirmative or encouraging, but in the world of healthcare, a positive scan or pathology report often is just the opposite. Our language frequently identifies a person with a diagnosis or category. Patients who decline resuscitation can be identified as "a DNR," a shorthand label that represents a consent process and confuses a person with a singular aspect of a care plan. Those with the disease of addiction might be called "addicts" or people with sickle cell disease "sicklers." Patients living with cancer are said to be "progressing through treatment" when it is the disease that progresses.

Perhaps it is the aligning of person with disease that allows and invites references to failure. Persons with cancer are described as "failing treatment" and those who cannot be weaned from a ventilator "fail weaning"—attributions that compound emotional distress and may contribute to a climate that invites blaming patients or encourages them to blame themselves.

"Brain death" is another term that can be confounding for families at a time of crisis and intense emotion. To describe ventilator support as life support while at the same time asking families to integrate the meaning of brain death has the potential to provoke a range of emotions and confusion. Phrases such as "harvesting organs" and "persistent vegetative state" may be heard by family as descriptors diminishing the humanity of the person regardless of the state of their physical self.

COGNITIVE CONSTRUCTS

Cognitive therapies have the potential to bring unique and applicable constructs to a discussion of language. Dichotomous thinking and attributed meaning are two such ideas that may be useful.

The Lure of Dichotomous Thinking

In the cognitive therapy world, often we listen for "black and white" thinking, in which there appear to be no grays. All or nothing language is often intended to reflect perceived predictability and order and bring simplicity to a world replete with uncertainty and complexity. We see this represented in the phrase "Do you want everything done?" as if the choice is between nothing and everything. There is no specificity, just as there is no specificity in the dichotomy of "aggressive care or comfort care," which implies there can be no concurrent consideration of comfort when the choice is active disease-modifying therapies or when patients and families choose to extend life as long as technologically and medically possible. "There is nothing more I can do for you" may be spoken less often as specialists begin to integrate the idea that palliative interventions might enhance the care of their patients and provide a continuity of care over time no matter the disease outcomes.



Words not only convey something, but are something; that words have color, depth, texture of their own, and the power to evoke vastly more than they mean; that words can be used not merely to make things clear, make things vivid, make things interesting...but to make things happen inside the one...who hears them."

—Frederick Buechner



Clinicians moving from resuscitate/do not resuscitate discussions to a do not attempt resuscitation framework are replacing a dichotomous structure with a message of possibility and uncertainty—perhaps a more accurate reflection of the circumstances and the reality of a death we are attempting to reverse. Some integrate the phrase “allow natural death,” implying we will not impede the process of dying, although some sense presumption in the phrase and suggest a need for specificity regarding the care and services that may be essential as death approaches.

The burden of dichotomous thinking for patients frequently is reflected in war and sports metaphors defining disease as a battle to be won or lost. Especially prevalent in the oncology literature, this theme is more subtle in circumstances where palliative care is added on the heels of a lost battle and the recognition that treatments have failed. Consider the following scenario:

A family meeting is organized to discuss treatments and goals for a 78-year-old woman with multiorgan system failure receiving hemodialysis and a complement of medications to control blood pressure and treat infections.

“We have been doing everything we can, including hemodialysis and giving medications for your mother’s low blood pressure, heart failure, and infections, but she is not responding and her organs are shutting down. What we are doing is not working and there are no medical indications to continue. We recommend withdrawing care—stopping all this and just letting her be in peace. That is why palliative care is here, they can tell you about comfort care and hospice”

Alternative: “As we have been discussing, we have used all the interventions available to help your mother in the hope that we could control and improve multiple issues, including organ failure and low blood pressure. We wish these interventions were working but they are not. She is not responding to them or improving. Because they have not produced the results we hoped for, we want to consider stopping treatments that do not have a benefit, including hemodialysis and blood pressure medications, and focus on how we can insure her comfort as she comes to the end of her life. We have asked the palliative care team to join in her care.”

Transitions to palliative care or the addition of palliative clinicians to the lives of patients and families can create opportunities to reinforce the threads of continuity that can be essential not only to quality medical care but also to the emotional and spiritual life of families. Reinforcing what and who continue to be parts of the care plan can potentially diminish threats of abandonment in the setting of evolving illness and challenges the perception that adding palliative interventions equates not only with changing goals, but also with loss of that what is familiar.

Attributed Meanings

There is often a gap between what clinicians intend and say and what is heard by patients and families, whose interpretations are colored by their experience and infused with history, emotion, culture, spirituality, values, and beliefs. The following is a sampling of words, the intent of which may be significantly different from the message heard.



There is often a gap between what clinicians intend and say and what is heard by patients and families, whose interpretations are colored by their experience and infused with history, emotion, culture, spirituality, values, and beliefs.”

- The art of delivering bad news is a core, empathic skill of palliative physicians. The assumption implicit in this description is that patients and families will receive news as “bad” rather than creating an environment where patients and families attach meaning to the information provided. It is interesting to consider that in some situations important news, although negative, might be a relief or welcome affirmation of suspicions and worries.
- Clinicians speak of ceasing disease-modifying therapies that are no longer producing a benefit, but sometimes what is heard is giving up, doing nothing, or losing hope. Patients may interpret this as having failed or disappointed their physician and sometimes may equate the cessation of therapies with abandonment.
- Prognostication is an essential contribution of skilled palliative clinicians. Patients and families sometimes hear prognostic confidence as a challenge to the will of a higher power, potentially diminishing credibility in the clinician and the information provided.
- Patients and families may be asked about a “feeding tube” when speaking of artificial hydration and nutrition and the placement of a percutaneous endoscopic gastrostomy tube. Outside of medicine, feeding implies choice, socialization, and the pleasures of taste, all of which may be completely eliminated in the process of receiving artificial hydration and nutrition, but which may be somewhat recoverable with pleasure feeding when that is an option.
- At the end of life, clinicians may suggest or hear phrases that imply cause and effect around a reality that is mysterious and essentially unknowable. Families may talk about a dying person “giving up,” as if, had they chosen to fight, they may have overcome death. Clinicians sometimes invite families to “give permission to die” and patients are encouraged “to let go.” We may interpret an extended or agitated death as the result of “unfinished business.” Although families may assign meaning to what they experience and see, clinicians who volunteer ascribed meaning are tasked to consider both the intended and unintended consequences of their suggestions.

The following table highlights some additional words and phrases that may warrant attention.

Words/phrases	Possible attribution/considerations
Hang a morphine drip	Separates an order for infusion from the symptom it is expected to treat; this phrase might link to fears that death is being hastened
Pulling the plug	Invites clinicians to explore the thoughts and assumptions underlying the phrase
Narcotics	Law enforcement’s infiltration of medical practice; this term may reflect an identification perhaps in return for an illusion of safety
Futile treatments	Sometimes heard as descriptor not of treatments or their impact but of the worth of the patient

This article is a collaborative effort and was written by a seasoned social worker, a social work fellow, and a physician fellow who represent the emerging generation who will carry this work forward. Its design is not to engender agreement but rather to invite intention and attention to the words we choose to represent our work and its scope and values. 🍷

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