

ETHICS AND PALLIATIVE MEDICINE: AN UMBRELLA EFFECT

Communication in Complex Situations

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Abstract

Many of the most common ethics consults are rendered at the end of life: A family cannot consent to withdrawal. A patient cannot give up hope and pushes for futile, inappropriate and burdensome treatment. A patient is suffering unnecessarily because a family does not want their loved one sedated. The question presents itself: are these dilemmas purely ethical, or is there another discipline that may seem more appropriate?

Many systems draw a clear, differentiating line between palliative care and ethics. I propose using palliative medicine to practice proactive ethics. Tools exist that can serve to address both disciplines. These tools embrace the common denominator, the crossover element in most end-of-life issues, the quality of life factor. And though this phrase may be subjective, subjectivity depends upon understanding.

In the United States, palliative care is not embraced with the open arms that it offers a hospital and its' patients. Some administrators view it as a money pit, unnecessary, and a trend that will pass. But the reality is that as a Neurologist treats the brain and Nephrologists treat the kidneys, a Palliative Physician treats the symptoms. That is their organ. And it is our responsibility, as ethicists and advocates, to open the healthcare umbrella up to this realm of medicine. Our consults may benefit and our patients will benefit.

Introduction

The patient was a young man with three young children and a young wife who loved him with all the power of her being. When his cough started, they did not think that it was anything too serious; He was given a myriad of antibiotics. It was not until his lab work showed an iron deficiency that they connected the two and admitted him for tests. Everything after that was like a bad dream. Once further tests showed the growths, the cancer diagnosis came like a slap across the face. His wife kept her focus on the "when" for chemo, the "when" for the next test (Srivastava, 2007).

"He knows he is dying. We know he is dying But we are reluctant to acknowledge it, instead finding distractions that will carry us into another day....We sidestep the conversation

about prognosis, so much more at ease discussing the various reasons his liver could be failing... Each time he edges towards closure, our conversations introduce new and confusing avenues of hope, hope that may be sustained at least until the next ward round (Srivasta, 2007, p. 4).

Doctor after doctor came in the room and offered the same glimmer of hope, but what was the reality? What was not communicated? He had days, maybe a week to live. But they kept him in the hospital as an inpatient, weak, with blown veins and all. They kept him for more moot tests. And the only time in all those weeks that his face shined was when one physician mentioned that maybe he should just go home, just be with his loved ones. That MD never said why, but everyone new with each conversation what was being hinted at, and no one said the words, ever. On the day before he passed away, an order was written for a liver biopsy. They wondered why his liver was failing. Was it because of the cancer or because of the antibiotics during a previous diagnosis? Fortunately, the doctor who would perform the biopsy refused such a procedure on someone so fragile. The absurdity of such an order was evident; these tests were moot and an absolutely futile and an almost abusive play of the not-so-strategic plan towards end-of-life treatment. And then it was over. And everyone, even the experts seemed shocked- they never let them know; they never let him go (Srivasta).

Overview

This paper will examine the communication skills, or lack of, pertaining to patients, their families and the communication by health care professionals regarding complex, medical situations and end-of-life. Based on evidence, as collected through the methodology of literature review, this paper will take the stance that a disconnect exists in end-of-life communication, probably caused by the inability of health care professionals to accept and to face the death of a patient. Many of these miscommunications result in ethical consults that may be proactively addressed in another way, through palliative medicine.

Communication within the healthcare team can make or break the conversation about mortality with the patient and family (Kirchoff & Faas, 2007). If the professionals do not have the same understanding of where the patient is in the digression of illness, then the family cannot be expected to understand. And therefore may consequently be demanding medically inappropriate and ineffective care.

The purpose of this study is to highlight the unfulfilled need for better communication regarding treatment wishes at the end of life. The overall hope is that with this improved dialogue, patients will experience better quality of life throughout an illness. By addressing the not-talked about, taboo area of death, the doors of communication may be opened to discuss side-effects of treatment and how to handle this as well. The end goal is to avoid ethical dilemmas that may emerge through initial, proactive work. With more open communication, the

disease, whether imminently terminal or chronic, will be discussed with no reservation and the patient and families' frustration level will be lightened and likewise the tensions and ethical questions that may arise within the minds of healthcare professionals in anticipation of a battle lost will be more easily handled.

Limitations

This paper did encounter some limitations, ironically because the area of end-of-life has not been studied to the extent that some other areas have within health. This is probably because it is not a subject many like to embrace within communication or research. The initial subject focus of this paper was meant to be contained within the realm of United States healthcare so that specific cultural norms could be highlighted and so that deviations within healthcare systems did not skew the theory focused on end-of-life communication. However, not surprisingly, there is not much research in the U.S on communication about death or end-of-life and therefore, the focus, on communication in this paper, has been extended to an international level.

Another limitation is the specificity of disease when using literature review as the methodology for research. The majority of articles found were specific to a single disease instead of including terminal/chronic patients in general. This created some barriers in the overall analysis. Specifically, it is difficult to write on the general population with regard to these conversations when so much of the literature focuses on cancer, for example.

Lastly, there exists an age limitation in that communication must be analyzed disparately dependent upon the age of the terminal patient. However, once again the lack of research available did not allow the researcher to concentrate on only one age group and therefore some specific references are included pertaining to age limiting the overall analysis of this topic. For example, it is quite obvious that approaching a parent and child about the potential death of a five-year-old would require different skill-base from that of approaching the children of a geriatric patient. All of these factors must be considered by the reader when digesting overall content as applied to the thesis.

Literature Review

Problems

According to Cartwright et al. (2007), "a major issue in the care provided to terminally ill patients is that of communication and information provision, in particular about the illness and its expected sequel" (p. 295). When physicians diagnose, they may not necessarily want to include a prognosis because, if it is a terminal prognosis it defeats their goal of healing. It is evidenced that end-of-life discussions are probably one of the most difficult of all tasks

required of the physician. Much of the reason for this is proven to be because of the negative attitudes towards dying in this global society (Cartwright et al.). Studies show that the ongoing barriers to end of life conversations include the fear of death, issues with trust in surrogate decision making, family dynamics and general unknowing of what a patient really wants (Glass & Nahapetyan, 2008). If surrogate decision making is not for example addressed preemptively, a non-responsive patient may be left with no patient advocate, which could result in a complex ethical issue.

Studies have shown that dying patients value symptom management, good relationships and truly desire to prepare for death, not to prolong it; they do not want to burden their loved ones (Ganzini, Johnston, & Silveria, 2002). In a study done by Ganzini et al., on ALS patients, it was found that physicians did not refer to Hospice 1/3 of the time and 12% of the time end-of-life goals were not honored by practitioners. "Physician communication with patients and their family caregivers is of central importance to quality end-of-life care;" in a study by Biola et al., physicians were found to be the named initiator of the most and least favorable conversations at the end (Biola, Sloane, Williams, Daalman, Williams, Zimmerman, 2007, p. 846.). The study went on to say that family perception of physician was improved, not as a result of treatment but rather based on how the physician listened to the needs of the family and patient. Some of the problems with the specifics of end-of-life conversations dealt with the initial communication of prognosis, what to expect during the process of dying, how clear the physician was with medical lingo, over-estimation of expected life-span for false hope, the physicians friendliness when rounding in the hospital and continuing full family and physician communication throughout the illness through face-face meetings (Biola et al.).

A vital part of communication encompasses the education of how to communicate. In a study by Basem and Usta fourth-year medical students were surveyed looking at how and what to do when "breaking bad news," defining hope, explaining palliative care and "empowering a dying patient" (2006, p.18). In Basem and Usta's study it was determined that 64% of medical students finish school without ever having watched a senior physician give a patient a terminal prognosis. Instead, a bright picture of hope was given without including the reality of death (2006). The best communication that can be aimed for is finding a balance between hope and reality of the progression of the illness (Cartwright et al).

Glass & Nahapetyan describe end-of-life care in the United States as sub-par and a major concern. It is in fact, according to above researchers so awkward to discuss death in this country that studies on such are difficult to conduct. "America has a death denying culture" (p. 4). One may see how in a culture that does not embrace death, it may be difficult for conversations to be facilitated. Subsequently, if a conversation is not initiated, a family cannot know what their loved one's wishes are. Hence, as in present study, 30% of surrogates were wrong in guessing what the patients' wishes may be (Glass).

"Because technology has become so effective at extending life, it is difficult to determine

when it is appropriate to accept that a patient is dying" (Reynolds, Cooper, & McKneally, 2005, p.469). According to Reynolds et al. many issues contribute to this dilemma. One includes the distinction between withholding support and withdrawing support. Once treatment has begun, especially if the decision to begin the treatment was made by the patient, caregivers and clinicians may feel a moral obligation to continue the treatment. Withdrawal decisions usually are a means to the end of life and are therefore usually made by a surrogate when the patient is at the point of unconsciousness. Clinicians do not make it easier for caregivers, in that, when they feel uncertainty about prognosis, they will err on the side of maximizing any "potential benefit" (Reynolds et al., p. 471). There is much literature on the inability of physicians to communicate at this point of care; during family conferences, doctors do 70% of the talking and do not listen to families. Families may experience communication overload and be unwilling or unable to offer feedback. At this point many communication barriers are likely. The power of influence and intimidation that a physician may warrant may close further gaps for understanding. When these factors exist, selective perception may create a further disconnect from reality of prognosis and family comprehension. Emotions may factor into this issue (Tompkins & Wanca-Thibault). These conversations take skill base that physicians may not have, such as establishing trust, empathy, using particular opportune moments to discuss issues, and changing the physician and family into a more deliberative relationship. (Reynolds et al.). We are at a place in society where "everything" can mean consenting to allow a patient to exist on machines: life vs. quality of life. "Everything" can constitute life on a ventilator, hydrated and fed artificially for an unknown amount of time. Quality of life constitutes the definite overlap between pursuant ethical dilemmas and good palliative medicine.

"Despite all of the advances made in critical care, not all patients can be saved" (Kirchhoff). The service of a critical care unit has changed so much over the years and the responsibility of the family for the patient in critical care has increased. Removing this paternalism piece may be the avenue out that healthcare professionals take at end-of-life. Families may be asked, "What do you want me to do?" "Do you want me to turn the vent off and let your loved one die?" "Should I do everything?" Somehow the MD's expertise is taken out of the discussion and responsibility for decisions regarding future treatments, even those that will not improve prognosis are handed-off to the loved ones. The emotional output resulting from these changes may contribute to the taboo accompanying death.

70% of the deaths that occur in a critical care unit involve withholding and withdrawing, and of course consent for such has to come from the authorized party, not the healthcare team (Kirchhoff). When a decision such as the aforementioned have to be made, studies show a major role strain for the caregiver, decision maker. Emotions such as guilt, anger and regret, and even the anticipation of these potential emotions act as barriers to letting go. The role of conversation starter and the healthcare professionals' ability or inability to embrace the social

and emotional influences of the person/s consenting to withdraw or withhold may make a strong difference in outcome. If, for example a Do Not Resuscitate (DNR) is discussed before the attending has had a lengthy and clear dialogue about poor prognosis, the family and patient may be resistant and unable to accept the inevitable. Health professionals in general tend to hold off until all therapeutic resources have been exhausted. Their negative approach surrounding ineffective treatment may trump any positive attempt at conversation about palliative care that might be received with a more positive acceptance. (Kirchhoff).

Resolution Analysis

It is helpful to families and patients to communicate about end of life before the end is too near. In 1991, Congress passed the Patient-Self Determination Act that included verbiage about living will and power of attorney, important factors in making these decisions. These documents were recognized as advance directives, and the importance of asking patients if they have one and the education on such was highlighted. However, though the idea is statistically supported by 90% of patients and physicians, only 5-15% of patients have these documents (Grimaldo, Kronish, Jurson, Shaughnessy, Curtis and Liu, 2001). "Advance directives can help patients control healthcare decisions in cases where they may be unable to speak for themselves" (Tierny, Dexter, Gramelspacher, Perkins, Zhou, & Wolinsky, 2001, p. 32). When a patient cannot speak for himself or herself and a surrogate is not involved or a surrogate refuses to uphold patient wishes, an obvious disconnect exists. Ethics is needed. However, in the study done by Tierny et al. it was noted that confusion within communication has much to do with the physicians' beliefs that the patient should initiate the discussion and the patients' belief of the reverse. A palliative conversation may avert this dilemma. Both parties seem to experience anxiety when discussing the area. Tierny et al. studied 686 patients for which only 2% had experienced this discussion with their physician; after the study 110 had the discussion. In the post physician visit rating, 51% rated excellent when the discussion took place. This study reasoned that it is important that this conversation take place while in a healthy state, or at least not acutely ill so that it may be received better and without fear from the patient (Tierny et al.). However, all studies do not support this evidence-base.

According to Menkin, tools have been developed to aid professionals with end-of-life care and decision making: ethical or palliative. Most popular is the go wish card set. The cards are used to prompt conversation. The study conversation began with the recognition that doctors have been focused in past months on the kidney, the heart, and the lungs and now it is time to focus on the soul and the mind's desire: "the rest of what makes him who he is" (Menkin, 2007, p. 299). The four packs of cards list important elements of meaning in life and the patient and family are asked to place the cards in order of importance; the cards provide opportunity for in-depth conversations on what quality of life may mean for that person

(Menkin). And meaning in communication is of course the self's interpretation, and should be understood to be subjective (Tompkins).

Surprisingly, semantics can also make or break these sensitive conversations according to research done by Venneman, Harris, Perish and Hamilton (2008). These proactive semantic pieces can be aligned with proactive ethics. This particular research revolves around DNR (Do Not Resuscitate) versus AND (Allow a Natural Death). This may be result of the serial transmission effect which constitutes "changes of meaning due to filtering and distortion" (Tompkins, p. xix). Families have increasing difficulty understanding DNR and are much more receptive of AND. DNR produces much greater anxieties for families who may correlate this with giving up, a negative connotation. The rationale for this is that emotional state defines so much of what a person comprehends and in a state of grief, it may be easier for a loved one to positively allow nature to take its course (Venneman et al.). The endorsement for this end-of-life order not only improved amongst family members in this study but also amongst the medical team providing the care when phrased, AND. The overall message was that positive terminology helps understanding when explaining a poor prognosis (Venneman et al.). And some situations are more sensitive than others at end of life. These conversations, though skill-based must still be dealt with on a case-by-case basis.

Discussion and Analysis

If dignity is the ability to engage in relationships with another human being, do we always honor this dignity at the end of life? Quality of life is, agreeably an awkward, subjective, and therefore, un-definable term, but few would argue that one does not need dignity and personal integrity in order to have quality of life. Dignity is defined by Webster as a feeling of worth or esteem. As human communicators, what gives us more worth than communicating (Leung, 2007)? Dying with dignity has a different meaning to each based on culture, history and personhood. When an otherwise healthy person loses their total health to a disease, the fundamental self changes immediately and this new self mutates, possibly digresses throughout the disease. Illness diminishes the person and as the person is lost to the dependency on the caregiver, Leung suggests that the obligation of the clinician changes from maintaining breath and healing to maintaining dignity. "Indeed, God did not want us to wish for a long life," a quote spoken by a wise professor from Boston College who maintains that death is truly a beautiful thing and nothing more than a reward. This professor is quite obviously in the minority. (Fr. Himes, PhD, personal communication, February 29, 2008).

Our American society does not accept death, and poor communication can worsen an already negative experience. This is why it remains vital for all healthcare professionals to stay diligent in their know-how to communicate. Though physicians are a major part of a patient's care, when a patient's becomes in-house, other roles may become just as important,

particularly to the end-of-life conversations. Social workers are trained to do family and patient therapy and have excellent skill base to facilitate these conversations and advocate for patients. Social Workers are able to divulge a value base by spending quality time with dying patients and encouraging families, increasing the trust levels the family develops on the medical team.

In the case of a brain death patient, a mother notes, "on one occasion, a doctor had noticed Tara was breathing over the ventilator on her own" (Simmons, 2008). This is a very typical example of an unnecessary, non-factual conversation that may prevent the decision maker from making the humane withdrawal choice for a very obviously deceased patient. This has now become an ethics consult because a dead patient is now being treated. However, if there was a stronger understanding of end-of-life and it was addressed proactively with palliative team support, healthcare professionals could replace some of the disheartened feelings that accompany these trials.

It is hoped that someone involved with the patient will come to terms with the reality. Nurses say that a common response when asking about end-of-life decisions is to revert to a spouse or family member, "my husband [or] my daughter/son knows what my wishes are" (S.W, RN, personal communication, February, 6 2008). This is not sufficient. Healthcare professionals are ethically charged with bringing this palliative conversation to the next level, possibly by suggesting that if a loved one knows, maybe a conversation to reiterate wishes may be helpful. One such suggestion to make this less of a negative conversation may be for the healthcare professional to fill out their own advance directive so that they may articulate to their patients how important it is to state these wishes, for the healthy and the ill. The end of a patient's life can last days, weeks, even months. With advancing technology, society has reached a point where death has phases dependent upon how much treatment is given and how long a person/family wants to hold on. End-of-life is too big an area to only hope that someone in the family knows a patient's wishes.

The Resolve

"Patients, families and health care professionals all recognize the need for better communication in palliative and end-of-life care" (Fineberg, 2005, p. 857). What kind of practice in medicine is responsible for handling end-of-life when several specialists are already involved? Who is charged with having this discussion when the attending is no longer the primary care physician? Is it the cardiologist if it is a heart matter or the neurologist perhaps when there is brain damage? Is it the ethicist when the situation's complexities increase? The specialty of palliative care is a relatively new one and these professional teams, including that of the physician are trained in pain management, quality of life and end-of life.

"Palliative care is interdisciplinary care to relieve suffering and improve quality of life for

patients and families... they need not be imminently dying or even certain to die of the illness, for this care to be appropriate and beneficial. Nor is palliative care a mutually exclusive alternative to curative care” (Griffin, Koch, Nelson, Cooley, 2007, p. 405).

Discussion of care goals and an increased focus on the patient’s understanding of the illness are both important parts of palliative care. Because the negativity that is death and failure may not be embraced in discussion, so too may the side effects and barriers of illness and treatment. Because physicians have a tendency to underestimate symptoms at the end of life, palliation has almost become a necessity, rather than an additive. Palliative care aims to put all of these issues in the forefront, along with symptom and soul management (Griffin et al.).

Focus must be balanced on patient and family because patient may not be a participant eventually in care. The patient must be treated as a whole person from the get-go, rather than as a kidney, a heart or a brain. Family conferences are recognized as one of the best resolves to the struggles of communicating at the end of life. However, if healthcare professionals are not taught how to facilitate these conferences, they can change from benefit to burden. Conferences provide a place for problem-solving and working towards a common goal (Fineberg). Families are so absolutely vital to communication and support at end-of-life. Health care professionals must note that, despite years of medical schooling the family knows the patient best and if he/she cannot speak for themselves the family is best prepared to do so.

Elizabeth Kubler Ross, a well known physician and researcher of death and dying clearly notes the five stages of death. These emotions, denial, anger, bargaining, despair, and acceptance must be considered, beyond simply the clinical facts. Death and end-of-life has the potential to be a beautiful part of life, not an ethical dilemma. If we learn how to embrace it as a healthcare profession, the lay world may learn to let go as well.

References

- Basem, R., &Usta, J. (2006). Communicating with Terminal Patients: Lessons From “Wit” and Students. *Family Medicine*, 38(1), 18-20.
- Biola, H., Sloane, P., Williams, C., Daalman, T., Williams, S., & Zimmermann, S. (2007). Physician Communication with Family Caregivers of Long-Term Care Residents at the End of Life. *The American Geriatrics Society*, 55, 846-856.
- Cartwright, C., Bregje D. O., Williams, G., Faisst, K., Mortier, F., Nilstun, T., et al. (2007). Physicians discussions with terminally ill patients: a cross national Comparison. *Palliative Medicine*, 21, 295-303.
- Clayton, J., Hancock, K., Butow, P., Tattersall, M., & Currow, C. Clinical practice Guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical*

- Journal of Australia*, 186 (12), pp. S77-S107.
- Fineberg, I., (2005). Preparing Professional for Family Conferences in Palliative Care: Evaluation Results of an Interdisciplinary Approach. *Journal of Palliative Medicine*, 8(4), pp. 857-866.
- Ganzini, L., Johnston, W., & Silveria, M., (2002). The final month of life in patients with ALS. *Neurology*. 59.
- Glass, A., & Nahapetyan, L. (2008) Discussions by Elders and Adult Children About End-Of-Life Preparation and Preferences. *Public Health Research, practice and Policy*, 5(1), 1-8.
- Griffin, P., Koch, K., Nelson, J., & Cooley, M. (2007). Palliative Care Consultation, Quality-of -Life Care in Patients With Lung Cancer. *ACCP Evidence Based Clinical Practice Guidelines* (2nd edition) (pp. 404-422). Memphis TN: American College of Chest Physicians.
- Grimaldo, D., Kronish, J., Jurson, T., Shaughnessy, T., Curtis, J., & Liu, L. (2001). A Randomized, Controlled Trial of Advance Care Planning Discussions during Preoperative Evaluations. *Anesthesiology*, 95, 45-50.
- Hordern, A., & Street, A. (2007) Communicating about patient sexuality and intimacy after Cancer: mismatched expectations and unmet needs. *MJA*, 186(5), 224-227.
- Hsiao, J., Evan, E., Zeltzer, L. (2007) Parent and child perspectives on physician Communication in pediatric palliative care. Cambridge University Press (Eds.), *Palliative and Supportive Care* (pp. 355-365). Cambridge, MA
- Kirchhoff, K.T., & Faas, A.I. (2007). Family Support at End of Life. *AACN Advanced Critical Care*, 18(4), 426-435.
- Leung, D., (2007). Granting death with dignity: patient, family, and professional Perspectives. *International Journal of Palliative Medicine*, 13(4), 170-174.
- Menkin, E., (2007). Go Wish: A Tool for End-of-Life Care Conversations. *Journal Of Palliative Medicine*, 10(2), 297-303.
- Milstein, J., & Raingruber, B. (2007). Choreographing the End of Life in a Neonate. *American Journal of Hospice and Palliative Medicine*, 24(5), 343-349.
- Reynolds, S., Cooper, A., & McKneally, M. (2005). Withdrawing Life-Sustaining Treatment: Ethical Considerations. *Thoracic Surgery Clinics*, 15, 469-480.
- Simmons, A. (2008, February 10). Doctors have final say on brain-dead patients. *The Atlanta Journal Constitution*. Retrieved February 11, 2008, from <http://ajc.com/metro/printedition/2008/02/10/lifesupport0210g.html>
- Srivastava, Ranjana. (2007). The Art of Letting Go. *The New England Journal of Medicine*, 357(1), 3-5.
- Tierny, W., Dexter, P., Gramelspacher, G., Perkins, A., Zhou, X., & Wolinsky, D. (2001). *The Effect of Discussions About Advance Directives on Patients'*

Satisfaction with Primary Care. Indianapolis, IN: Indiana University.

Tompkins, P., & Wanka-Thibault, M. (2001). Organizational Communication, Prelude and Prospects. F. Jablin., & L. Putnam (Eds.), *The New Handbook of Organizational Communication* (pp. xvii-xxx). Thousand Oaks, CA: Sage Publications.

Vennerman, S., Harris, N., Perish, M., & Hamilton, M. "Allow Natural Death" versus "do not resuscitate": three words that can change a life. *Clinical Ethics*, 34, 2-6.

* Please note four references are personal communications which based on APA guidelines should not be included on the reference page, rather within the paper only.

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