

Retrospective Review of Medical Futility and Ethics Consultations at MD Anderson Cancer Center

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Abstract

Ethics consultations, conducted over an 11-year span at a major cancer center, were reviewed and medical futility emerged as the most identified ethical issue. Medical futility is commonly understood as treatment that would not provide any meaningful benefit for the patient. While medical facts help determine what is medically appropriate, it is often difficult for patients, families, surrogate decision-makers and healthcare providers to navigate these complex and immensely challenging situations. This paper presents some of the common and confounding issues that have been brought to the attention of a Clinical Ethics Service and delineates some effective methods for physicians to address medical futility at the end of life.

Keywords: Medical futility; Ethics consultation; End of life; Beneficial and non-beneficial treatment

Introduction

At The University of Texas MD Anderson Cancer Center, our Core Value of 'Discovery' states, "We embrace creativity and seek new knowledge" and specifically delineates that, "We help each other to identify and solve problems, ...seek personal growth and enable others to do so, ...[and] encourage learning, creativity, and new ideas." Our purpose in conducting a review of ethics consultations at MD Anderson was to identify trends of the types of ethical issues to which our ethicists were devoting the greatest expenditure of time and effort, as well as to determine what recommendations resulted in positive resolution. Learning from our ethics consultation experiences would then enable us to provide a greater level of ethics support and education to enhance physicians' ability to address such patient issues.

Medical Futility is defined in multiple ways [1-4], by many different individuals. The definition of medical futility most often cited is that of Schneiderman et al. in their June 1990 article in the *Annals of Internal Medicine*. Schneiderman and his colleagues note that "futility refers to the objective quality of an action." Ultimately, they define futility as "...any effort to achieve a result that is possible but the reasoning or experience suggests is highly improbable and that cannot be systematically produced [5]." Medical futility is commonly understood as treatment that would not provide any meaningful benefit for the patient. It could present in a variety of forms. Some examples include continuing to provide respiration for a patient in a terminal condition or providing dialysis for a patient with kidneys destroyed by disease. While the medical facts help determine what is medically appropriate, facts are not always as clear as they could be and determining the outcome of patients who are perceived to be treated with futile measures could be complex. Further, it is often difficult for families, surrogate decision-makers and healthcare providers to navigate these difficult situations. The goal of this article is to share information regarding an active Clinical Ethics Service in a large specialty hospital.

The University of Texas MD Anderson Cancer Center is one of the world's largest and most recognized cancer centers, with more than one million outpatient clinic visits, treatments or procedures provided annually. In 2009, there were 23,277 hospital admissions. MD Anderson services range from cancer prevention to survivorship.

MD Anderson Cancer Center is also a major research institution and has more than 1,000 open clinical research protocols to support the care of patients and learn more about future prevention and treatment methods [6].

In an attempt to establish trends among what we observed in terms of patients, healthcare providers, and our own clinical ethics service, a review of our existing clinical ethics practice was conducted. We determined that, while there were few unique elements among the patients or healthcare providers, there were definite commonalities in related issues as well. Moreover, trends emerged within our own recommendations for addressing medical futility. The commonalities identified do not delineate an exhaustive list, nor are they meant to represent stereotypical patients or situations. Rather, we offer the identified commonalities as a reflection of our practice and as points for consideration for healthcare providers faced with issues of medical futility.

Methods

In order to get an assessment of our practice, we conducted a broad-spectrum analysis of our ethics consultation database, which contains records of ethics consultations that have taken place over the last 11 years. Information collected in the database was transferred from a standardized form used at the time of the consultation and completed by the ethicist or individual serving in that capacity as part of an ethics team consultation. Database notes for each case were categorized and

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those related to medical futility were considered, and from those, we attempted to identify any recurring trends. We also reviewed how well our recommendations were received by participants at the time of consultation to get a sense of whether our process was useful in dealing with situations of medical futility. Further, we investigated the socio-demographic information of each patient involved in an ethics consult with the particular ethical issue of medical futility, and then compared them with the patients seen in other types of ethical issues.

We concluded that our advisory-only recommendations are often followed and that, while the patients and their families or caregivers enmeshed in these issues are not terribly unique, compared to those involved in other ethical issues in cancer care, there were a few noteworthy differences.

We categorized each consultation in terms of the three most common ethical issues presented. There are 16 identified ethical issues from which the ethicist selected at the time of the consultation. Of the 1,080 consults done over an 11-year span, 196 consultations identified medical futility as one of the most cited ethical issues. Of these 196, 80 ethics consultations identified medical futility as the primary issue, 73 identified it as the second major issue (resuscitation code status was most listed as first issue for 62 of these), and 42 identified it as the third major issue. While this set does not represent a large percentage of our consultations, it does represent a significant 18% of the total ethics consults brought to the ethics service for guidance and resolution.

Results

Overall, recommendations by the Clinical Ethics Service were well received by requestors and participants. Recommendations were followed in 68% of all ethics consultations, and another 12% were partially followed. Adherence to the recommendations of the ethics service did not significantly vary by issue, though recommendations were followed slightly more where medical futility was the primary issue compared to those where it was the third most important issue. While there was not a significant discrepancy, outcomes of the study suggest that when futility is seen as an important element to patient care, those involved seek greater levels of ethical guidance.

Physicians were more likely to initiate ethics consults than any other type of care provider, representing 43% of those requesting an ethics consultation. When combined, clinical nurse specialists and registered nurses represented the next largest group and comprised 27% of those initiating requests. The remaining consultation requests were made by: patient advocates at 20%, patients or family members at 6%, chaplains at 3%, and administrators at 1%.

Ethics consultations related to medical futility were sought primarily while the patient was in the Intensive Care Unit (ICU) and had been there for more than 10 days. This was the case for 83% of the consultations. An additional 4% were sought in the ICU prior to a ten-day mark. The remaining consults were sought while the patient was on a different inpatient floor.

Interestingly, in ethics consultations involving medical futility, the ages of the patients ranged from two to 90 years, with a mean age of 51.

We did not look at specific cancer diagnoses because there were so many that no statistical significance would exist due to the specificity. However, patients with leukemia (combining several specific cancer diagnoses) were the largest in number at 42%. It must be noted that MD Anderson serves a large number of leukemia patients and the Leukemia Service is among the largest at the institution. The socio-demographics

of the patient population with medical futility issues were very similar to other patients who have been subjects of ethics consultations with issues other than medical futility. There were, however, two notable differences in these patients when compared to the typical patient seen by the ethics service. In terms of religious preference, patients who are Muslim typically represent five percent of those patients seen in ethics consultation. In the case of medical futility questions, however, Muslim patients represented a significant 9.5% of the patients in comparison with ethics consult cases for other religious groups. Though still only representing a small percent of those patients consulted regarding medical futility, this increase suggests that this issue may be particularly difficult for families and surrogate decision-makers of Muslim patients. When looking further into these consultations, it was found that 56% of patients from the Muslim tradition actually came to MD Anderson through our International Center and were predominantly from countries in the Middle East. This gives rise to questions which we could not answer directly such as: 1) did governmental issues related to travel back to the homeland effect the need for consultation, and 2) were communication difficulties due to cultural differences a factor adding to the challenge in making medical decisions?

Notably, 69% of the patients, who were the subject of ethics consultations involving medical futility, were male. Contrastingly, 55% of the patients involved in all other ethics consultations were male. We did not find any definitive explanation within our database to account for this difference. However, we did note that the majority of male patients did have female caregivers/decision-makers, most often a spouse or a daughter who provided care over a span of several months or more.

Confounding concerns: common issues that come with futility

As Gabbay et al. noted in their July 2010 article, "...the concept of futility has proven to be very difficult to define and apply [7]." Thus, medical futility is not well defined in any of the literature, in part because it has multiple meanings and incorporates many aspects of care [1-3,8]. Equally problematic are the confounding concerns that often accompany these situations. In addition to medical futility, our study revealed a number of other issues driving requests for ethics consultation during the course of cancer care including: withdrawing or withholding life-sustaining procedures; questions about appropriate levels of treatment, particularly whether to shift from curative to palliative care or the patient's resuscitation status; and issues of quality of life and pain control. While each of these clearly relate to the issue of medical futility, concerns ranging from current care to issues of future care can compound to create a cacophony of similar voices that are challenging to separate, let alone orchestrate.

As Gabbay and colleagues note, "Applying empirical outcome data to decisions about limiting treatment in critically ill patients is fraught with statistical and methodological problems [7]." The fluid definition of medical futility lends itself to disagreement about the assessment of the patient, the interventions provided, and the eventual prognosis. This can be particularly challenging when such disagreement is between physicians. In these cases, consensus about what is being done and what ought to be done can be difficult to achieve [9]. However, one of the keys to resolving issues of futility is achieving this elusive consensus. Thus, the very nature of the medical futility situations can create a fundamental problem in attempting a solution. Disagreement among physicians regarding the beneficial aspects of treatment or futility was present in 7% of the ethics consultations entered in our database.

Family dynamics can also play a very large role in these situations. For some families or surrogate decision-makers, making decisions about the health care of a loved one can elevate underlying turmoil [10]. Some family members may see the patient as a foundational member of the family and, as such, may have a difficult time letting go. Others may simply struggle with the perceived weight of deciding the fate of the patient. Still other dynamics may arise in which family members find themselves pitted against each other based upon long standing roles or conflicts. It is important for healthcare providers to acknowledge these roles with the understanding that they will likely not resolve themselves in a brief period of time. In cases of appointed decision makers, it may be easier to connect them with social resources within the institution. In our ethics consultations, disagreements among family members were present 53% of the time and disagreements among patient and family members were recorded 11% of the time. As noted previously, patients having ethics consults involving medical futility ranged in age from two - 90, with a mean of 51 years. Patients' ages could impact how patients, families and/or caregivers make healthcare decisions and the level of aggressive care that they seek in cases where interventions are considered medically futile.

Religious and cultural considerations did not appear to stand out in our ethics consultations, but patients of the Muslim faith were more prevalent in situations of medical futility than in other ethical issues. In patients of the Muslim culture, there appears to be a tendency at MD Anderson Cancer Center to seek and accept all available treatments. Further, it is generally not acceptable to request withdrawal of life-sustaining procedures. As such, it would be unusual for a family member or surrogate decision-maker of the Muslim culture to affirmatively assert that interventions should be withdrawn. While there is acceptance of death as part of the natural process, any perception of hastening this death must be avoided [11]. People who follow a Muslim religious or cultural tradition are not alone in this belief and are not uniform in this subscription, but their prevalence in our data indicates that issues of medical futility are challenging. It is important for healthcare providers to be aware of these tendencies when facing this situation. It is our recommendation to physicians that they inform decision makers regarding having done all that is appropriate and beneficial for the patient, in their best medical judgment, and state that they believe further aggressive treatment is no longer beneficial, and that they will offer support and comfort care when medically futile situations occur.

Another challenge in handling this concern is the lack of knowledge about the patient's wishes. Advance directives are not common with most patients, and patients involved with this issue are no exception. Advance Directives are completed and placed in the medical record for only 23% of patients for whom an ethics consultation related to medical futility is sought. Of those, less than half have living wills or directives to physicians that declare a patient's wishes at the end of life. While this cannot be rectified at this point in a patient's care, it is important to be aware that family members or surrogate decision-makers may not have a clear picture as to the wishes of the patient. It is an important consideration when working with those involved in a patient's care.

One of the major confounding factors in the Clinical Ethics Service's response to this problem is that we are alerted late in the process 62% of the time. In most cases, patients died within one to two weeks of the involvement of the Clinical Ethics Service, many within five days (56%) of the initial request for ethics consultation. When accessed at this late stage, the Clinical Ethics Service generally can provide assistance only to the physician in mediating a conflict with family or surrogate

decision-makers. While mediating conflict is a necessary element of care, an earlier intervention could alleviate tension surrounding an already sensitive situation. Part of the challenge for physicians and other healthcare providers is assessing when the concern of medical futility has escalated to the point of great conflict and is in need of facilitated resolution.

Practice: Commonalities at MD Anderson Cancer Center

As has been noted above, ethics consults centered in futility are uncommon, even at a major cancer center where very sick individuals come to seek specialized, intensive treatment. However, there is a certain amount of common practice when these situations do arise, particularly within communication models similar to those seen elsewhere [12].

The most utilized ethics recommendation and practice generally focuses on giving a patient or family members' opportunity to express their understanding of the medical situation/prognosis and ensuring that they are adequately informed of the physicians' perspective of the patient's medical condition. At MD Anderson, this often occurs in a care-conference setting, offering the patient or family members a chance to hear the multidisciplinary medical opinions. Family conferences, with medical futility issues, were called by the Clinical Ethics Service in 88% of the ethics consults. The remaining 12% were in-person discussions between healthcare providers and an individual ethicist.

Investigators found the following to be most helpful when approaching family members or decision-makers regarding such challenging situations.

1. Clarifying goals of care
2. Assessing whether all reasonable options have been attempted
3. Not offering options that are not medically appropriate
4. Establishing guidelines and limits for interventions in place
5. Seeking to address emotional needs of the caregiver [13].

Taking time to allow family members to comprehend and accept medically futile situations, in which there is little chance of recovery, is perhaps one of the more critical aspects of patient care as it allows for the continuation of trust in the relationship between provider and patient or family. Obviously, the amount of time that can be allotted will vary in each case. Occasionally, the ethicist involved with the case will need to establish a time frame for the family or caregivers, should decision-making be time sensitive. Such time frames may be necessary for decisions about life-sustaining interventions, or may simply reflect the need for an outcome in an already protracted situation. In cases such as these, family members may be adhering to unrealistic expectations for long periods of time such that the only foreseeable resolution is to set a hard deadline for those involved.

Limitations

This is a data review of ethics consultations involving medical futility in only one cancer center. The population studied is limited to inpatients at a cancer center thus limiting generalizability to only similar situations. A similar study of multiple cancer centers and their experiences might produce additional information about distinctions among a population of patients with cancer, their family members, and their healthcare providers. Further, such information from multiple cancer sites would enable investigators to contrast findings to general hospital populations. This retrospective study limited us to considering

what information people had recorded at the time the consultations occurred. Other than through the original consultation process, it did not incorporate information gathered directly from participants, most especially the patients and their family members as to their reasoning for requesting continuing aggressive treatments.

Subjectivity of the ethicist who documented the ethics consultation is a limitation as well as the fact that eight individuals served as ethicist/recorder. The database form has been changed twice during the 11 years, each with additional delineations for the type of issues being addressed and cancer diagnosis changed from general to specific, thus the challenges for those two particular questions.

Conclusion

Ethics consultations related to medical futility accounted for 18% of the consultations at The University of Texas MD Anderson Cancer Center over an 11-year span. More than half of the consults were sought in the late-stage of the patient's care and only after healthcare providers had struggled with patients and/or family members about care decisions at the end of the patient's life. In 68% of the situations, the full recommendations of the Clinical Ethics Service were followed, and in another 12%, the recommendations were partially followed. This resulted in 80% concurrence with ethics consultation recommendations being successful in resolving the conflicts related to medical futility. Earlier requests to the ethics service are strongly recommended to enhance expeditious conflict resolution. Family conferences called and led by the trained ethicists had the most successful outcomes.

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