
Case 10—Please Stop Torturing Me! (Unless My Wife Is in the Room)

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LA was a 55-year-old man who until recently had been in excellent health. He was active in many community business and philanthropic organizations. His first wife died of cancer several years earlier, which was traumatic for both LA and his adult son. LA remarried five years ago. Over the Christmas holidays he began experiencing drenching night sweats, unexplained weight loss, and shortness of breath and was diagnosed with Diffuse Large B-cell Lymphoma (DLBCL) shortly after New Year's Day. His oncologist was part of a community cancer practice with admitting privileges and patient care responsibilities at a large urban hospital. On January 19, one week after his diagnosis, LA presented to the Emergency Department, as directed by his oncologists, with severe abdominal pain. At that time he was hypotensive (low blood pressure), tachycardic (rapid heartbeat), and anemic (low red blood cells or hemoglobin) and had a large hemoperitoneum (blood in the peritoneal cavity) from a ruptured spleen, which is generally classified as a surgical emergency. LA was a very sick man.

LA was taken to Interventional Radiology for embolization of his spleen and was then admitted to the Intensive Care Unit (ICU) where he received large doses of blood products. He developed ischemic hepatitis, also called shock liver, which is characterized by sudden elevation—sometimes to as much as 20 times the upper limit of normal—of liver enzymes. In addition to systemic hypotension, a common accompaniment to shock liver, LA developed acute renal failure and elevated bilirubin, a possible sign of hepatitis or cirrhosis. His increasingly severe respiratory failure now meant he required ventilator support.

Over the next several days, LA was successfully weaned from the ventilator and was transferred to the Oncology Unit. He had his first course of chemotherapy on January 24. His wife and adult son were frequent visitors, and they closely monitored his treatment and well being. LA had pancytopenia (a reduction in the number of red and white blood cells), and he continued to be anemic and in need of frequent blood transfusions. LA received a second round of chemotherapy in early February. Shortly after, he was transferred back to the ICU so his altered mental status and recurrent respiratory failure could be addressed, and he was started on the

antibiotic Cefipime due to the presence of gram-negative rods. Gram-negative bacteria are resistant to multiple antibiotics, and are more typical in health care settings; they can cause infections such as pneumonia, bloodstream infections, wound or surgical site infections, and meningitis.

LA's altered mental status worsened, which may have been exacerbated by the administration of Cefepime in the context of renal failure. LA was then diagnosed as having myoclonic encephalopathy, an epilepsy syndrome that is resistant to treatment. He also developed a subdural hematoma with a midline shift, which is a collection of blood below the inner layer of the dura but external to the brain and the most common type of traumatic intracranial mass lesion. Mortality and morbidity rates are high, even with the best medical and neurosurgical care, especially when accompanied by midline shift. Midline shift is a shift of the brain past its center line, evident on neuroimaging such as CT scanning, and is considered ominous because it is commonly associated with a distortion of the brain stem that can cause serious dysfunction such as abnormal posturing and failure of the pupils to respond to light. Midline shift is also associated with high intracranial pressure, which can be deadly.

LA's wife and son were extremely concerned about his worsening condition. Since his initial admission was for DLBCL, the oncology group who had diagnosed his cancer oversaw his care in the hospital. His wife had become close to these oncologists, who were optimistic about their ability to cure LA's cancer, and who repeatedly reassured his wife and son that he would recover despite his increasingly serious complications. LA was also seen by the neurology and neurosurgery services, as well as by the intensive care team, while he was in the ICU. His wife was suspicious of these other physicians, however, and "fired" the first group of intensivists because she felt they were not hopeful enough about her husband's chances for recovery. They had encouraged her to talk with her husband about his treatment preferences, and even to consider a Do-Not-Resuscitate (DNR) order, since they had come to believe that continued aggressive treatment would be of unlikely benefit to LA. The information she received from the intensivists focused on LA's worsening, serious multiple organ failure rather than on the chances of his cancer going into remission, and this stood in conflict with the information provided by the oncology team. LA's wife refused to discuss the matter further and consequently refused to have the intensivists involved in her husband's care.

During this time LA's oncologists ordered a bone marrow biopsy, the results of which indicated that he was now free of lymphoma. His oncology team determined LA's cancer to be headed toward remission (which usually means being cancer-free for five years), his organ failure possibly reversible, and they recommended continued aggressive treatment for the other medical complications that had developed. All of this was good news to LA and his family, and as a result his wife became determined that no other conflicting information would spoil that view of things for her, her husband, or her step-son.

LA did not have an advance directive and at no time was he under a DNR order. In the presence of his wife and son, LA put on a brave face and reassured them that he was doing fine, that he was recovering slowly, and that he was greatly encouraged

about his cancer's "remission." However, during the few times that his wife or son were not with him, LA told the nurses "I know I'm dying, please stop this torture!" When the nurses brought these comments to the attention of the oncology team, the oncologists interpreted this as evidence that, because of his neurological issues, LA was not competent to make his own medical care decisions. They relied solely on his wife for direction, who continued to demand aggressive treatment. The oncology team did not request either a psychiatric or neurological consult, which would have either confirmed or contradicted their opinion about LA's mental capacity.

LA's wife and son told the oncologists that they could not bear to lose him and that all available treatments must be tried. His wife provided consent to start LA on total parenteral nutrition, which dripped nutrition and hydration through a needle for 10–12 h each day. LA then developed a bowel obstruction, which caused extreme pain. His wife demanded that his pain medication be reduced when she was there so he could be awake and could interact with her; LA requested and received more aggressive pain medication when his wife was not visiting.

LA remained in the ICU, and even though the intensivists provided daily care, the oncologists, as admitting physicians of record, refused to collaborate with the ICU team about LA's care plan. The new intensive care team requested consults from the palliative care team, psychiatry, and the ethics committee. They were concerned that LA was not able to direct his own care, and that he may, in fact, be competent to do so. They also increasingly felt that continuing aggressive care was not in LA's best interest, especially since he had said on several occasions that his treatment was "torture." Nonetheless, the oncologists continued to direct his care, and they refused to allow any of the consultations to proceed. According to them, LA's cancer was in remission, and their patient and his wife had agreed to a plan of aggressive care to address his other medical issues. They documented that his bone marrow was clear of disease and that treatment should continue. The oncology team felt that some of the messages being conveyed to LA and his wife by the intensivists and ICU nursing staff were too negative, unhelpful, and not professional.

The chaplain from the palliative care team was able to visit with LA during the few times when his wife was not present, and talked with him about what he perceived as his impending death. The chaplain's notes of March 9 read: "Pt is tired of fighting and says he wants to pass peacefully and no longer wants to go on living if this means going through all these medical procedures." The chaplain tried on many occasions to meet with LA's family, but they rejected pastoral support and refused to meet with anyone but the oncologists. On March 16, the chaplain again met with LA who said, "I wish I could close my eyes and this would all be over." The next day LA and his wife were together, and on March 17 LA stated that he had hopes for a full recovery and would never make any decisions that would run counter to his wife's or son's wishes. "I just want to sit in a chair and hold my wife," LA said, "and I will do anything if it makes this easier for her." Over the course of that month, LA was transferred back and forth between the ICU and the oncology unit. He was once again transferred back to the ICU on the evening of April 3 to treat rapid atrial fibrillation. A few hours later the nursing staff found him unresponsive and called a full code, which involved chest compressions, electric

shocks, and the administration of emergency medications. Despite these efforts, LA did not survive and was declared dead on April 4 at 12:30 am.

Discussion Questions

1. How can hospitals ensure that consistent messages are conveyed to patients and families when several medical services are involved in a patient's care?
2. How should medical professionals react when ethics and other consults are rejected by family members or by other health care providers?
3. How might this patient and family have been counseled to understand that while the primary cancer diagnosis was responding to treatment, the patient's condition remained extremely poor?

A Bioethicist Responds

Those who care for patients in ICUs, those who care for the terminally ill, and even family members or friends of those who have died after long illnesses in hospitals or long-term care facilities may not find this case all that extraordinary. The particular circumstances may well seem egregious, yet the general situation presented in the foregoing narrative might also remind one of similar cases wherein patient capacity appears never to have been clearly determined, if at all, and where in the absence of such determination family members and/or attending physicians have decided that patients lacked capacity to make their own medical decisions. LA's story is certainly not unfamiliar to the present writer, who has served on a number of hospital ethics committees over a period of twenty-five years.

The narrative is clear that LA had no advance directive. It may also be presumed that at some point during his hospital admission, and allowing only for the possible failure of Admissions Office personnel to observe the requirements of federal law, either he or his proxy would have been asked if he had an advance directive or would like to prepare one at that time (Vollandes 2015). But, we do not know for sure what may or may not have transpired with regard to this issue at time of admission. Still, it is curious that LA apparently never asked that anything be put in writing regarding his wishes concerning medical treatment, despite his apparent clarity of mind when speaking with the nurses and hospital chaplain. Perhaps the fact that LA never committed anything to writing, never prepared a Living Will or Advance Directive, never signed a Durable Power of Attorney or designated a health care surrogate, speaks to his age and relatively good health heretofore. He is undoubtedly like many, if not most, persons his age who have yet to encounter serious illness: "young," at least from a medical point of view, which is to say, still in the prime of his life, well and, therefore, unlikely to be particularly concerned about end-of-life issues; he was still active in business and the community; and, having remarried only five years prior, he must surely have been thinking of a second life plan. The health crisis that apparently beset him quite suddenly, with little or no warning, could have only had the effect of turning his world completely on its head. Few persons in this situation are likely then to pause, take stock of who

and where they are, and to begin the careful, reflective process of planning for their future with family, physician(s) and friends, a process that ideally would include discussion of advance health care planning, living wills, durable powers of attorney, surrogacy, as well as the drafting and filing of appropriate documents. Moreover, it is certainly understandable that a sick, very vulnerable patient would entrust his care and well being to his closest family member and physician at this critical time. At least in the beginning.

The dynamics of this case are complex, though, again, not all that unusual. LA's wife seemed genuinely interested in her husband's welfare, determined as she was to share his oncologists' optimism that he could be cured, even to the point of "firing" the first group of intensivists who encouraged a different treatment approach, yet she quickly began driving the action and directing treatment decisions. The oncologists in turn seemed only too willing to take their cues from her to the point of refusing to collaborate with the intensive care team and refusing to allow any requested consults to go forward. Meanwhile, LA acquiesced to the decisions made for him by his wife, all the while complaining privately to his nurses and the chaplain about how he was being treated. It is unlikely that LA was simply "giving in" to his wife or that he really was so incapacitated that he was incapable of speaking rationally and competently for himself. The testimony of the chaplain should be sufficient evidence to the latter. Furthermore, LA's apparent acquiescence before his wife is most likely explained as the terminal patient's desire to be the strong one, the one to hold out hope for those around him who are undergoing their own suffering and who must struggle with their own anxieties and fears about death and loss. LA made it clear that he knew he was dying and that he wanted his suffering to be over, yet at the same time he had stated unequivocally that he would never have made any decisions counter to his wife's or his son's wishes and had stated, "I will do anything if it makes this easier for her." Were this the complete picture of LA and the dynamic in which he is found at the end of his life, he might almost be seen as a rather noble figure of a man.

Yet this is not the complete picture, which is made infinitely more complex by the behavior of the oncologists, such that in the final analysis LA appears largely as victim, the unfortunate subject unjustly deprived of his rights, autonomy and freedom so that the world according to his wife and those physicians earning her approval may proceed with their own narrative. This is more than a simple deprivation of rights, autonomy and freedom, however; the violation of at least one state law, or statute, appears to occur as well.

The oncology team relied solely on LA's wife for guidance in terms of treatment decisions and chose unilaterally not to seek confirmative consults for their determination that LA had lost medical decision making capacity. While attending physicians are not required by Florida state law to obtain confirmatory consults in situations regarding capacity, seeking one in this case would certainly have been the most prudent approach. LA's oncology team chose to interpret the nurses' report of LA's wish to die as evidence of medical incapacity. If there is any truth to this, it is evidence only of strong paternalism requiring justification, and begs for confirmation upon the general assumption that not everyone would possibly draw the

same conclusion to a patient's expressed wish for his suffering to end. Florida's end-of-life statute, F.S.765.204, states: "If the evaluating physician has a question as to whether the principal lacks capacity, another physician shall also evaluate the principal's capacity, ..." ¹ It might be argued that LA's physicians had no question whatsoever concerning his capacity, but whether this argument could be made in total candor seems open to doubt given the exclusive relationship that developed between them and the patient's wife. The fact that the attending physicians chose not to ask for confirmation of their assessment of the patient's capacity demonstrates at least a violation of the spirit of this statute.

Regrettably, LA's wife also violated one of the fundamental principles of biomedical ethics in demanding that his pain medication be reduced when she visited him in the hospital, the principle of nonmaleficence. ² Her behavior in this regard, while understandable from a certain perspective given the stresses upon her, is primarily egocentric and self-serving.

LA suffered needlessly. This is not to say that anyone wished him harm or wanted him to experience pain or discomfort. His family had difficulty seeing themselves and their own suffering over LA's impending death as different from his, while at the same time the oncology team seemed to have difficulty relating to LA in caring, patient-centered ways. It would have been unlikely that a resolution to this situation could have developed out of the patient-physician-family triad. Where it might have been found, however, is from within that other group of persons privileged to have a close relationship with LA, that is the nurses and the chaplain. These persons can typically be real patient advocates. The only problem is that all too often they are not empowered to speak up or to be the advocates they have a legitimate right to be for the patients they serve. A team effort is required to serve patients properly, especially in complex hospital settings today, and all members of the team should feel comfortable playing their roles in responsible ways. All do not have equal responsibilities here, but none should feel so disenfranchised that they must remain silent when genuine concerns of real value to patient care and well being are at stake. And above all, it must be remembered that no one, nor any group of persons, should ever have the power simply to veto or forestall legitimate processes, such as determinations of patient decision-making capacity and ethics committee consults, designed to promote beneficence.

A Health Communication Scholar Responds

It can be bewildering for patients and their families when a formerly healthy person is diagnosed with a serious illness, especially when the outcomes of treatment are ambiguous. In LA's case, he was in the unenviable position of being cancer-free, but in multi-system organ failure. The extent to which his cancer treatment caused or contributed to the complications he experienced is an open question. Cancer treatment by its very nature is destructive; our hope is that we are increasingly able to target its destructive power to cancer cells alone, sparing healthy tissue and function.

It is quite easy to become frustrated with LA's wife and her insistence on continued aggressive treatment and her inability to hear information contrary to her wishes. It is natural for patients and their families to cling to good news and to those who convey it, and to shun those who provide information that complicates or nullifies the "good news" they think they have received. One must try to be sympathetic to the plight of LA's wife as she tries to come to terms with her husband's increasingly dire medical condition. It is possible that she did not understand the ways in which various medical services attempted to engage her in discussions about her husband's care, and believable that she would prefer to let the oncologists and their hopeful message of recovery guide her decisions. This case reads like an exaggerated version of a familiar, albeit misleading scenario, in which a health care provider comments on a subtle improvement in a patient's blood chemistry, for example, while failing to emphasize that the patient's overall condition and prognosis remain dire. No one likes to be the bearer of bad news and no health care provider wants to believe the treatments they ordered for their possible benefits might ultimately prove futile or even harmful.

When a patient has a serious and complicated diagnosis, the ways in which information is provided to the patient and family becomes an even more crucial element in formulating a treatment plan. Good communication practices can also help facilitate coordination between medical services, and can help patients voice their own treatment preferences even if they do not align perfectly with family members' hopes or expectations. We have all likely heard stories that highlight the lack of coordination between medical services, and about the fragmentation that continues to characterize the American health care system. The lack of communication and coordination between the intensive care service and the oncologists involved in LA's case reached epic levels. Physicians of various specialties are generally courteous to one another and generally hesitant to call one another out for bad behavior, but it appears clear from the case description that the oncology team overstepped their boundaries in excluding the expertise of the intensivists, the psychiatrists, the neurologists, the palliative care team, and the ethics committee. It is unrealistic to think that LA's wife would be capable or willing to attempt to untangle the roots of what must have been a long standing series of conflicts between the medical services involved in her husband's care.

At times LA and his wife appear to be in agreement that aggressive treatment should continue, and at other times, LA made it clear to the health care team that he knew he was dying and hoped they would stop "torturing" him with continued treatment. Had LA's wife allowed the palliative care team to become involved, perhaps they would have been able to facilitate a conversation between husband and wife to resolve their contradictory preferences and expectations. While we tend to regard autonomy as pertaining to an individual, some accommodations need to be made in order to honor and respect an individual patient's treatment preferences and also acknowledge that the patient wants also to honor his or her spouse's or family members' preferences too. Palliative care team members are experts in helping patients and families negotiate and decide on a course of action, even when all the available choices appear to be bad. Unfortunately, "palliative" is associated

with dying; maybe another name could be given to the palliative care service to make it easier for patients and families to take advantage of their expertise. Euphemisms do not always work, of course, and it is likely in this case that LA's wife would not have allowed anyone in her husband's hospital room who thought talking about death or a change in the course of treatment was necessary, or even more effective pain management.

Recent changes to Florida's statute directing end-of-life care in some ways further confound the issues in LA's complicated case. A new provision in the law allows a person to choose to have their designated health care surrogate make all medical decisions for them even if they retain capacity.³ Given LA's acquiescence to his wife's demands for aggressive treatment, it seems likely that he would have chosen the option of allowing her to make medical decisions for him even if he was competent to do so himself. The language in the statute still privileges any decisions made explicitly by the patient, even if the surrogate disagrees, but provides little guidance in a situation such as this where the patient refuses to express treatment preferences unambiguously.

This case took a tremendous toll on the ICU team. The ICU team members—the second team after the first group was “fired” by LA's wife—were very supportive of the family but predictably did not react well when the family began dictating care, which was particularly problematic since the health care team members were aware of the discrepancies between LA and his wife. LA's wife was constantly critical of the ICU team, and at one point demanded that his blood be redrawn three times because she “disagreed” with the results and felt the nurses must have done something wrong. The ICU team members were concerned that the oncologists had not helped the patient or family understand the gravity of LA's medical condition overall. The cancer diagnosis may be responding to treatment, but the rest of LA's body was rapidly failing. The ICU staff truly felt they were torturing their patient, and several nurses were in tears over what they were required to do to LA to comply with medical orders.

At some point, LA's cancer diagnosis became the least of his problems, but organizational procedures kept the oncology team as his treating physicians, and the cancer diagnosis in the forefront of his wife's consciousness and decision making. It is completely understandable that patients and families prefer good news, but the extent to which LA's wife and the oncology team were able to silence competing opinions about his condition is unconscionable. All medical professionals want to claim victory, but in LA's case, the “win” over his cancer was far overshadowed by the extreme and ultimately fatal complications he endured.

The reality of current day hospital administration is that specialist medical services are often contract employees, and the institution responsible for patient care is sometimes held hostage to the demands and dictates of physician practices who are free to take their expertise and patient caseloads elsewhere. The communication challenge is obvious: Consistent messages should be conveyed to the patient and family to allow decision making to proceed in accord with new information, but there are not always organizational mandates that require all those involved to meet and agree on the patient's status, recommended treatment plan, or the language chosen to describe both.

Another serious difficulty here is the extent to which the oncology group directing LA's care was able to shield their patient and his family from competing concerns about his care and treatment goals. In theory, anyone can call an ethics consult, but this freedom is severely curtailed if the patient's treating physicians can forbid new information from being considered. LA's own voice was also silenced. How are we to manage patients who tell us one thing in private, and then publicly acquiesce to the treatment preferences of their family members? LA's wife essentially trampled over his preferences for treatment and the information from the intensivists as well as the other relevant services—chaplains, palliative care, ethics, psychiatry—that had contributions to make that would have ameliorated LA's distress, as well as that of the nursing staff in the ICU (and probably of LA's wife and son). We cannot fault LA's wife for wanting to believe only hopeful messages, but we can fault the organizational structures that allowed her to only hear what she wanted to hear.

The moral distress experienced by the nurses and intensivists in the ICU is a real issue that needs to be addressed (Corley et al. 2005; Elpern et al. 2005; Hamric and Blackhall 2007). State law pertaining to this case allows physicians to withhold care they believe to be futile, but since futility is always a value judgment, it is extremely rare for a physician to withhold treatment on this basis (Schneiderman et al. 1990). Treatments that were keeping LA alive at great burden to him and enormous distress to some members of the medical staff were not futile in the opinion of his wife (or of the oncologists). Medical staff members, particularly nurses, bear a high emotional toll when compelled to do procedures they feel are more burdensome and harmful than beneficial. And having to navigate a patient care situation where the patient says one thing alone and another in the presence of his wife is especially taxing.

The other long-lasting outcome of LA's case is the continuing animosity between the intensivists and the oncologists at this large urban hospital. It is an understatement to say that the inability of these physicians to meet, talk, and agree on a course of action is disappointing. The ICU team felt that they were thrown under the bus by the oncologists, who wanted to celebrate their short-lived victory over LA's cancer. The absolute power of the admitting physicians to dictate a patient's course of treatment merits reexamination, especially since it is very likely that these physicians will be involved together in other complicated patient care situations in the future.

Notes

¹Florida State Statutes, Chapter 765.

http://www.flsenate.gov/Laws/Statues/2013/Chapter765/Part_I

²In the authors' opinions, the best treatment of the well-known "principles" of biomedical ethics is to be found in: Beauchamp, T.L. & Childress, J.F. (2013) *Principles of Biomedical Ethics*, 7th ed. New York: Oxford University Press.

³The new language states: “My health care surrogate’s authority becomes effective when my primary physician determines that I am unable to make my own health care decisions **UNLESS** I check and initial one or both of the following boxes: If I initial this box, [] my health care surrogate’s authority to receive my health information takes effect immediately.

If I initial this box, [] my health care surrogate’s authority to make health care decisions for me takes effect immediately, pursuant to section 765.204(3), Florida statutes, any instructions or health care decisions I make, either verbally or in writing, while I possess capacity shall supersede any instructions or health care decisions made by my surrogate that are in material conflict with those made by me.”

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