Case 14—To Treat…or Not to Treat?

14

CB was a 45-year-old man who was admitted to the head and neck cancer service of a large, tertiary care hospital immediately upon presentation to the emergency department (ED) where he complained of severe head pain. He reported a 9-month history of pain on the left side of his head behind his left eye, with slight diplopia (double vision) and left otalgia (ear pain). He had a long history of tobacco and alcohol use, and it was evident that he had been drinking when he arrived at the hospital. The physical exam revealed a large mass in the left neck underneath the sternocleidomastoid muscle from the angle of the mandible to the level of the clavicle; a CT scan revealed this mass to be approximately 5.3 cm × 6.4 cm in size and to extend from the clavicle inferiorly to the skull base superiorly. The carotid sheath was completely surrounded by the tumor, which also abutted the left optic nerve; the scan also indicated the tumor was beginning to erode the skull base.[1] The clinical exam further revealed bilateral neck adenopathy[2]; a fine needle aspiration (FNA) of one of the large nodes came back positive for squamous cell carcinoma.[3]

CB's case was discussed in the weekly interdisciplinary tumor board conference.[4] Based upon the clinical findings, the scans and the lab report of the FNA, the attending head and neck surgeon diagnosed this as Stage IV disease and judged the tumor to be inoperable because of its size, location and extensive nature.[5] She also felt that chemotherapy would be ineffective in this particular case and estimated CB's likelihood of survival at five years to be less than 10%. She stated her opinion that the patient would survive perhaps no more than two months without treatment, but that surgery to "debulk" the primary tumor and neck nodes could possibly extend his life by three to four more months. The radiation oncologists pointed out that radiation therapy could be expected to shrink the size of the mass and nodes, thus also extending his life a few extra months while adding the benefit of pain relief from tumor shrinkage; the surgeons and medical oncologists concurred with this view. All physicians present agreed, however, that CB would eventually succumb to his disease.

Nevertheless, the medical team was divided on the appropriate course of action in this case. Even in situations where patients are seen by physicians to have little

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chance of survival, it is customary to offer them either (a) a choice of indicated treatments, or (b) no treatment for the disease itself, but at least palliative care to address symptoms and improve quality of life for the patient. There were those in the tumor board meeting who felt strongly that CB should be offered precisely that, which is to say that he should have carefully laid out for him the pros and cons of the three options discussed in tumor board: (1) debulking surgery, (2) radiation therapy (XRT), or (3) no treatment except for palliative pain and comfort measures only. It would then be left up to him, in further consultation with the attending physician, to make an informed choice. However, there were complicating factors.

CB's only home was a room above a bar loaned to him by the owner in exchange for maintenance work. Given that fact, along with his history of tobacco and alcohol use over many years, there were those who felt he was not likely to follow his complicated pre-operative care instructions as well as the post-operative self-care that would be required were surgery to be at all successful. Team members espousing this view also expressed concern that the proposed surgery could last as long as twelve hours, that this would mean dedicating an entire day of one operating room to one case only, and that such valuable OR time could otherwise be shared among several other needy patients who might be more likely to do well post-operatively than CB. These team members also pointed out that were he to be offered radiation therapy instead of surgery, the advanced nature of his disease would probably require placing him ahead of other patients in the queue, and that those waiting their turn in line would now have their treatments delayed. Consequently, these team members believed it inappropriate to offer CB all three options but thought that the palliative care option would be best.

The attending head and neck surgeon happened to be one of those in this second group. She argued strongly for her position, but she also listened carefully to the views of the other group, the group that felt CB should be offered all three options, with the choice then left to him. In the end, she indicated she would review all that had been discussed before deciding what to present to her patient.

Discussion Questions

1. Before reading either of the two following responses, formulate your own position on the option(s) that should be offered to CB.
2. *Autonomy* is often viewed as the overriding principle in bioethics, which is to say that it is viewed as the equivalent of saying that if one is medically competent one has the right to decide freely for oneself. Do you agree that this should always be the case? Could there be valid exceptions?

A Bioethicist Responds

It is not difficult to imagine the give and take that took place during the discussion of this case in tumor board:

"You just want to deny him the difficult, time-consuming, costly surgery because he's a charity case, he's an alcoholic and he's never taken care of himself! Well, he's a human being and worthy of our care just like anyone else!"

"Look, I've spent countless hours in the OR on poor, indigent folks who had no financial means and who may have done it to themselves (i.e., caused or aggravated their disease through excessive alcohol and tobacco use), and I'd do it again, but I believed they had a chance because I felt they'd be able to follow through after surgery with what they'd need to do to help heal themselves. But in this case I have no confidence he'll do that, and so I'm really afraid all the work we'll do will be for naught!"

"Yeah, but you don't know that, so we have to give him the same chance as anybody should have. Besides, if you don't offer him all the options, you're not holding true to the rules of informed consent!"

"Well, what's more important, sticking to some formal rule, or doing what is best for the patient in the long term? This patient has no way of knowing or understanding what will happen to him, what he will truly experience, what kind of suffering he will go through if he should choose the wrong option, and I do know. I don't want to be paternalistic, play God, or say I know what's good for him, but in this case I do know what is best for him because of my experience with patients who lack sufficient social support."

The primary ethical issues that quickly surface here are patient autonomy and justice. Autonomy in this case includes questions related to informed consent and paternalism; justice here must account for both fairness and proper use of scarce resources.

We turn first to a quick review of the essential elements of informed consent, which are: 1—the patient must possess the medical *competence* to understand and follow the standard consent process; 2—the patient acts completely *voluntarily*; 3—the consent form and process must include complete *disclosure* of all aspects related to the procedure (surgery, etc.) to which the patient is consenting; 4—the physician must make a *recommendation* as to what he/she honestly believes is the best treatment option (including no treatment) for this specific patient; 5—the patient must ideally have an *understanding* of what has been disclosed and recommended; 6—the patient makes a free and unfettered *decision*; and finally, 7—the patient, or patient's legally authorized representative, formalizes the decision by means of an *authorization* (written or oral).[6]

In view of the preceding it is easy to see that were the attending physician not to consent CB properly, he could not possibly make a truly *informed* decision about any option she might propose to him. Were she not to let him know that there existed three typical therapeutic options for dealing with his particular disease, carefully explain the pros and cons of each, tell him what she thinks is his best option based on her knowledge and experience, and then let him choose which seemed right for him after reflective discussion with her, he could not possibly be fully and fairly informed before making his decision. In fact, if she were to do as she had first suggested and simply offer him palliative care, she would be acting paternalistically.

Most persons today are strongly averse to paternalism practiced by either men or women unless they believe that a specific situation is so unique that the intentional overriding of a person's autonomy may be justified by the goal of beneficence they hope to attain in taking that action. This is risky, however, and there must be very compelling reasons for doing so. Perhaps one such compelling reason in this case could be the very fact of limited resources, combined with the attending physician's conviction that her long hours of work in the OR would likely go for naught when her patient found himself unable to care for himself post-operatively, with no adequate support system to care for him either, including the likelihood of an early death anyway. The challenge then would be to demonstrate that a fair allocation of resources would permit overriding this patient's autonomy to the extent suggested here where strong paternalism comes into play and any informed consent process that may ensue virtually takes on a whole new meaning.

The whole question of consent remains an interesting if not challenging one. Debate continues as to whether truly informed consent is ever really obtained from a patient. Then there is the question of whether it really matters if true informed consent is obtained, or whether what really is at stake is doing the best one can and making sure that a record of the process has been made. Moreover, some studies have shown that what may really matter in the final analysis, at least to patients, is not the more formal or legalistic elements physicians and bioethicists generally think of with regard to informed consent, but rather such things as enhancement of trust through the referral process, the idealization of the doctor, the belief in the doctor's expertise rather than the medical information he or she might be able to provide, and that when a patient accepts the doctor's recommendation for a treatment he or she is, in effect, thereby giving his or her consent (McKneally et al. 2009). Yet while this may offer some perspective, it may not provide much practical guidance ethically.

Full disclosure is in order at this point. The present writer was a member of the tumor board in question and was one of those who advocated, along with the attending head and neck surgeon, in favor of recommending only palliative care to CB. It genuinely appeared that this would be in the best interest of this patient; that the co-morbidities associated with a long surgery would do far more harm than good; that he could not possibly care for himself afterward; that there was little likelihood of anyone else providing care for him post-operatively; that there would be a good chance of his being lost to follow-up; that if he went for XRT and jumped ahead of others in the queue it would be grossly unfair to them; that the amount of extra time afforded him through surgery or XRT would be so little (several months at best) as to be relatively negligible since there would have to be trade-offs for discomfort; there might be the possibility of getting him into hospice care, with nurses and other allied health professionals who could be assured of visiting him at his current residence or in a skilled nursing or rehabilitation facility if it came to that. He was surely going to die within the foreseeable future. It seemed that helping him to do that as quickly and comfortably as humanly possible was the most beneficent and ethical choice; this option would also ensure the best use of the scarce human and material resources available to the institution while concomitantly observing issues of fairness and beneficence regarding other patients for whom the institution was responsible.

Without further consultation with anyone, however, the attending physician decided to play it "by the book." She presented CB with the standard three options; explained to him that he was not a realistic candidate for chemotherapy and why; laid out the seriousness and challenges of a very long, possibly twelve-hour operation; carefully presented the pros and cons of the surgery; told him what he would be required to do for himself on a daily basis, and for how long, after the operation; explained that he would definitely also need a caregiver for some weeks right after surgery; explained all that would be involved with XRT and what he could expect with that; told him approximately how many additional months of life he might expect with either surgery or XRT, but that these additional months would come at a cost of additional discomfort; told him what was meant by hospice and palliative care, approximately how many months of life he might expect if he chose that route, and told him this would be the most pain-free choice and why. She stressed that no matter which choice he made, she and the rest of the medical team would be with him until the end and that they would ensure that he would be kept as free of pain and as comfortable as possible. Lastly, she told him what she would choose if she were in his place and why—that enrolling in hospice and taking a palliative care approach would most be most likely to maintain his comfort, reduce suffering, and enhance his quality of life. She reported several days later that after listening carefully to all that she had said, CB merely smiled gently at her and said, "Thanks, doc. Glad to hear you agree with me. Truth is, I'd pretty much made up my mind that's what I wanted anyway. I just wanted to hear you say it first!"

A Health Communication Scholar Responds

Communication about end-of-life care is increasingly recognized as a core clinical skill, but some doctors, unlike the attending physician in this case, are not well prepared to have these conversations. This case is an example of the ways in which honest, personal, face-to-face communication between a seriously ill person and a physician can and should occur. The attending physician in this case likely had strong feelings about the correct medical course of action, and equally strong feelings about the correct ethical course of action. There was a chance, of course, that doing the right thing ethically might complicate doing the right thing medically. Physicians often find themselves in situations where they have presented the options available to the patient, some of which have very limited likelihood to improve the patient's life expectancy, functional status, or quality of life, only to have the patient and his or her family declare that "everything" must be done! Even though that was not the case with CB, allow me to speculate on what the attending physician in this case likely feared was at stake when she made the choice she did to fully inform CB of his choices for treatment.

Crisis situations at the end of life, such as when a patient with a poor prognosis requests that "everything" be done, pose serious communicative challenges (Roscoe and Tullis 2015). Surely this was one scenario that crossed the mind of the attending physician in CB's case. Decisions on the part of a patient or family to do "everything" are often seen as a demand for care that may be burdensome or even harmful, rather than the start of an important conversation about values and goals. We can surmise from the skillful communication demonstrated in this case, that rather than defer to a demand that "everything" be done, the attending physician would have continued the conversation about what "everything" meant to CB. This is how it should be. Informed consent, as presented in the *Bioethicist's Response*, requires information, but it also requires an engaged, conversational exchange to allow each individual's motivations, concerns, and convictions to emerge and be addressed.

Situations where so-called "bad news"[7] must be conveyed to patients have prompted the development of prescriptive approaches to communicating. Such scripted approaches are better than ignoring the need for such a conversation, but they have limitations since they focus more on the physician's message ("this is how sick you are and these are the decisions you need to make") than on developing a relationship with the patient so as to elicit the meaning of the illness and its treatment, identify the patient's values and goals, and jointly agree on a way forward. Whereas older models of the communication process focused on message transmission, more current models of communication are less about delivering messages and more about the ways in which meaning is co-constructed in relationships. The words a physician uses, his or her body language and tone of voice, the time and care taken—all contribute to and shape the illness experience and context for decision making for the patient. In this case we have an example of a physician who entered the world of her patient, and explained in detail how CB's limited life expectancy would likely play out under various treatment scenarios. This is difficult and brave work. There are such obvious chasms to transcend—the physician is healthy, the patient is not; the physician is well- educated, the patient is not; the physician is well-off financially, the patient lives in a room above a bar; the physician has detailed knowledge of treatments and their outcomes, the patient has limited health literacy; and the list could go on. Despite these obstacles, the attending physician in this case did bridge those gaps, and managed to develop a relationship with a very sick man who had a difficult, high-stakes choice to make.

I wish to encourage every physician reading this case to accept the inherent risks inconveniences and spend the time necessary to forge a relationship with his or her patients when important treatment decisions must be made. Unfortunately, not all physicians (or any of us, really) have the communication skills that allow us to do so. For physicians, communication training most often takes the form of tools and scripts, which do not fit the nuances inherent in any difficult patient situation. I want to encourage physicians to do what the attending physician did in this case—engage the patient in an honest dialogue, and do not stop until a real "meeting of the minds" has taken place. It involves more than making eye contact, or following a series of steps to effectively "deliver the bad news." All of us need human relationships in order to thrive (and to die with dignity), and seriously ill people desperately need such a connection to and conversation with their physicians in order to make the decisions they need to make. Especially in the case of CB, who is alone, the doctor's role in providing a communicative space is all-important.

All patients deserve such engaged care, but head and neck cancer patients face specific communicative challenges. Patients with head and neck cancer, whose disease processes and surgical treatments are often disfiguring and limit their ability to communicate, may be at higher risk of having insufficient information about end-of-life care (Roscoe et al. 2013; Schenck 2002). Since their oncologists (including surgeons, and medical and radiation oncologists) and other specialized clinical health professionals (nurses, psychologists, and social workers) are often the only ones who really understand the nature of this disease, its potentially disfiguring treatments, the outcomes of various treatment modalities, and often their patients' disadvantaged access to health care resources over their lifetimes, they have a heightened responsibility to ensure that their patients understand their prognoses and have the information necessary to make informed decisions about end-of-life care.

The question remains whether such "empathetic witnessing" as described by Broyard (1993) and others and the compassionate communication accompanying it can be taught to physicians and other medical practitioners. Perhaps medical students should be admitted based on their emotional intelligence along with their MCAT scores. More pedagogical research can be conducted to try to discern when and in what ways the medical school curriculum can best accommodate communication skills training and practice. It has been documented that empathy declines over the course of one's medical education, but are there ways that can be changed? These are open questions, subject to much debate among medical school faculties and curriculum committees.[8]

Most of us feel that we are good communicators, but as this case demonstrates, what really matters is that our conversational partner is satisfied with our exchange. CB's comment about "wanting to hear it from you first" is a good indication that this communicative exchange was beneficial to his decision making and peace of mind. We can be fairly sure that he grasped not only the information about his disease and treatment options, but also the warmth and empathy of the attending physician. Most of us are quite cavalier about this important aspect of good communication—we rarely check for grasping. If we were passing a physical object—picture runners in a relay race passing a baton—we would not let go until we felt the reassuring pressure that indicated that our receiver had a firm grasp. We do this with important information all the time, and physicians are no less culpable: We put the information in the vicinity of the other person, and hope they get it. What is clear is that when such good communication does occur, the dignity and personhood of the patient is affirmed, the moral distress of physicians and other health care providers is lessened, and scarce resources are justly managed.

Notes

[1] The anatomical area of the head outlined in these two sentences corresponds roughly to what is known as the *infratemporal fossa* (for detailed drawings, see: Netter, Frank H. 2014. *Atlas of Human Anatomy*, 6th ed. Philadelphia., PA: Saunders/Elsevier). Two things should be noted at this point. The first is that the tumor appears to be eroding the skull base, which means that the brain may soon be invaded by cancer. The second is that the indication of tumor completely surrounding the internal carotid artery sheath suggests it is only a matter of time before the cancer weakens the wall of the artery itself sufficiently to cause what is known as a "carotid blow-out." This would mean virtually instant death, or death within relatively few seconds. The patient could be rendered unconscious almost immediately, but the event would doubtless be horrifying for others alongside, especially loved-ones, for the weakened vessel is often near the surface of the skin when this occurs, causing blood from the ruptured artery to continue spurting until sufficient blood volume is lost and/or the heart begins to slow.

[2] *Adenopathy* indicates the presence of enlarged lymph nodes or nodal disease. Nodes are usually first noticed on physical exam in clinic, but only if they are large enough to be palpated. They are more easily seen on CT, MRI or PET scans. Not all enlarged nodes are necessarily malignant, however. There are a great many lymph nodes in the head and neck, located along "chains," and their main purpose is to serve as filters to collect waste products, invading germs or other foreign "poisons" in the body. They will also pick up errant cancer cells from adjacent tumors, or cancer cells released from distant sites in the body.

[3] This chapter contains greater medical detail and terminology than most of the other parts of this book, which in itself reflects the complex nature of the surgical subspecialty known as *otolaryngology-head and neck surgery*. The anatomy of the head and neck is highly complex; cancer terminology can be confusing; cancer staging of the head and neck is complicated; and, the field of cancer therapeutics is a lexicographer's dream.

[4] These conferences ("tumor boards," for short) generally consist of a team of head and neck surgeons, radiation oncologists, medical oncologists, a radiologist, a pathologist, residents and/or fellows, the nurses who work with each of the clinical medical specialists, speech-language pathologists, nutritionists and social workers involved in the care of head and neck cancer patients. Depending upon the institution, the tumor board may also be attended by students (e.g., medical, nursing), pastoral care personnel and a bioethicist. Everyone present is bound by HIPAA regulations. The purpose of the tumor board is to review cases, to seek input primarily from physician members of the team and to develop a treatment plan. In all cases, however, the final decision on a treatment plan is the responsibility of the attending together with her/his patient.

[5] For staging in head and neck cancer, see: Deschler, Daniel G., Michael G. Moore, and Richard V. Smith (eds). 2014. *Quick reference guide to TNM staging of head*

and neck cancer and neck dissection classification, 4th ed. Alexandria, VA: American Academy of Otolaryngology-Head and Neck Surgery Foundation.

[6] The best overall treatment of informed consent is still to be found in Faden, Ruth R., and Tom L. Beauchamp. 1986. *A history and theory of informed consent*. New York: Oxford University Press. See also Beauchamp, Tom L. and James F. Childress. 2013. *Principles of biomedical ethics*. 7th ed. New York: Oxford University Press.

[7] For more information about scripted communication models for giving "bad news" to patients, see:
Arnold Back, R. M. Arnold, W. F. Baile, James A. Tulsky, and K. Fryer-Edwards. 2005. Approaching difficult communication tasks in oncology. *CA: A Cancer Journal for Clinicians 55*: 164–177; and Eggly, S. S., Terrence L. Albrecht, K. Kelly, H. G. Prigerson, L. K. Sheldon, and J. Studts. 2009. The role of the clinician in cancer communication. *Journal of Health Communication, 14*: 66–75.

[8] For more information on preserving empathy in medical students and physicians in training, see:
M. Hoja, M. J. Vergare, K. Maxwell, et al. 2009. The devil is in the third year: A longitudinal study of erosion of empathy in medical school. *Academic Medicine, 84*:1182–1191.
B. W. Newton, I. Barber, J. Clardy, E. Cleveland, and P. O'Sullivan. 2008. Is there a hardening of the heart during medical school? *Academic Medicine, 83:*244–249.
S. Rosentha, B. Howard, Y. R. Schlussel. D. Herrigel, G. Smolarz, B. Gable, J. Vasques, H. Grigo, and M. Kaufman M. 2011. Humanism at heart: Preserving empathy in third-year medical students. *Academic Medicine, 86*:350–358.

References

Broyard, Anatole. 1993. Intoxicated by my illness and other writings on life and death. New York: Ballantine Books.

McKneally, Martin F., Douglas K. Martin, Esther Ignagni, and Jason D'Cruz. 2009. Responding to trust: Surgeons' perspective on informed consent. *World of Surgery* 33: 1341–1347.

Roscoe, Lori A., and Jillian A. Tullis. 2015. The meaning of everything: Communication at the end of life. *Journal of Medicine & the Person* 13: 75–81.

Roscoe, Lori A., Jillian A. Tullis, Richard R. Reich, and Judith C. McCaffrey. 2013. Beyond good intentions and patient perceptions: Competing definitions of effective communication in head and neck cancer care at the end of life. *Health Communication* 28: 183–192.

Schenck, David P. 2002. Ethical considerations in the treatment of head and neck cancer. *Cancer Control* 9: 410–419.