Clinical and ethical judgment

A profound dilemma

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After 16 years of postgraduate medical education, which included a PhD and postdoctoral research, 3 residencies, and a clinical fellowship, I felt thoroughly prepared for the challenges of the neurocritical care unit. Then I met Ms. G.

Ms. G. was an 80-year-old woman with a history of atrial fibrillation, diabetes mellitus, chronic obstructive pulmonary disease, and orthostatic hypotension. She had fallen and sustained an odontoid fracture that required surgical repair. She had no myelopathy. After surgery, she developed pneumonia and respiratory failure. She improved clinically but remained intubated 1 week after her admission. Bilateral upper extremity deep venous thromboses developed. Yet her overall prognosis seemed excellent once her pulmonary problems were resolved.

Through it all, Ms. G. remained mentally intact and required minimal sedation. Ms. G. was able to write on a board and communicate with her family and the medical team. She comprehended her clinical status and excellent prognosis for she had worked as a nurse for 30 years. Our conversations provided me a window into her inquisitive mind and pragmatic (utilitarian) view of the world.¹⁻⁴ Ms. G. started by expressing her wish to not be treated for deep venous thrombosis. She then stated that she did not want further ventilatory support. Her relatives were at the bedside daily and confirmed that she seemed to be her “usual self.” Moreover, they believed that her thought process was in alignment with her normal beliefs and upbringing. Family members expressed their sorrow, yet respected and supported Ms. G.’s wishes. I believed she remained fully oriented and had the cognitive capacity to make this

type of decision.^{5,6} Our psychiatry team confirmed that she was not depressed.^{5,6} We were fortunate that in contrast to more common contentious situations in which clinicians disagree about capacity, or in which there are no family members to help support the patient, there was consensus among us regarding her clinical status. Nonetheless, the perfect ethical storm was developing before my eyes.

According to Aristotelian and Socratic tradition,⁷ and following my Hippocratic Oath, I invoked the principle of beneficence, the duty to provide good care and minimize harm.⁸ I expressed my view that Ms. G.’s functional prognosis was excellent. She had no spinal cord lesions, and her quality of life should largely remain unchanged. She did not share my opinion and reflected on how she dreaded becoming a burden on her relatives. She had required progressively more help with activities of daily living, such as shopping and transportation, during the past year and did not want to risk losing even more independence. I found myself torn between duties of beneficence and the principle of autonomy.²

Obligations of beneficence have slowly given way in Western bioethics to the demands of respect for autonomy, the liberty right of competent individuals to make their own decisions, unimpeded by the wishes or control of others. Reflecting the strength of this principle, classic deontologists, such as Immanuel Kant, and classic utilitarians, such as John Stuart Mill, argue for the liberty right of autonomy as fundamental to morality, albeit for different reasons.¹⁻³

With the move away from the paternalistic days of “the doctor knows best” to a more patient-centric model of respect for patient preferences, the priority of the patient’s decision,

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made freely without influence, has become almost sacrosanct. If taken to the extreme, however, the unquestioned default to the patient's choice could entail a transformation of medical care into a medical service industry. I am a

physician, not just a provider of technology. I believed there needed to be a balance between Ms. G.'s right to autonomy and my duties of beneficence, sensitive to the specific sociocultural/religious context of this patient. Although the right to refuse life-sustaining treatment in the setting of a very poor prognosis has been affirmed since the Karen Ann Quinlan decision in 1976,⁹ Ms. G. had a good prognosis.

Thus, I requested further consultation from our ethics team. After 24 hours, Ms. G. remained firm in her decision. Our expert ethicist confirmed that, given consensus about her cognitive capacity, confirmation by her family of the authenticity of her values, and the consistency of her expressed decision, the principle of autonomy held precedence. Accordingly, and after further conversations at the bedside with Ms. G. and her family, she was extubated and died 8 hours later. It still troubles me.

Is there a best approach? Although the principle of autonomy, both in clinical care and research, is now recognized as central to the practice of medicine, the tension between the duty to serve the patient's best interest and the duty to respect choice remains. Physicians seem to appreciate the gravitas the principle of autonomy bears, and by no means do they oppose it.¹⁰ A shared approach between the physician and patient or their relatives is favored by the medical community.¹¹ However, the primacy of self-rule has been advocated as the ethical nexus in an increasingly multicultural society, where there are a wide variety of deeply held value systems.¹²

Was I too removed from Ms. G.'s experience to aid her in her decision?¹³ That is, influenced by my conviction that she could recover and feeling compelled to fight for her survival, was I unable to appreciate, in the fullest sense, the basis of her decision? I was not certain that was the case. Therefore, I advocated for my patient during a period that I perceived as a time of need, because her emotions and physical constraints might have been overwhelming.¹⁴ In my tribulation, I am convinced the patient's and family's wishes, as well as the pertinent ethical concerns, were properly addressed. I found my conversations with our ethics director and further appraising the literature enriching. But was I emotionally ready to discontinue treatment? Will

Comment: Autonomy vs beneficence

The dialogue between autonomy and beneficence is ages old. Doing what the patient wants is not always consonant with doing what one believes is good and right for the patient. Inner conflict for the physician lies on both sides of this issue. As illustrated by the articles by Ronan¹ and Daly et al.,² it is just as hard to live with giving the judgmentally competent patient the right not to be treated when the outcome of treatment is likely to be good as with doing everything possible for a patient, predicting or even promising a good outcome, only to have the actual outcome make one question the quality of that saved life. Part of physician discomfort with both of these situations derives from the notion that the medical community can correctly and unambiguously identify what is or is not good and right for a given patient. Several recent studies have generated results that fly in the face of that notion and the long-held concept that there is a core set of moral and ethical values that are independent of context.^{3–6} Given that culture, environment, professional domain, and personal and family history can influence that ethical core, it is perhaps not surprising that what their nonphysician patients chose to do or have done sometimes makes physicians feel uneasy in not having done what is in keeping with their own moral and ethical code.

Although the debate between patient autonomy and health care team beneficence or paternalism is perhaps most frequent in intensive care settings and situations, it has fostered controversy in such things as decision-making around prenatal testing, informed consent before surgical procedures, and palliative care.^{7,8} Most of the literature in this area portrays autonomy vs beneficence as a debate between patient and care team, respectively. But the essays by Daly et al. and Ronan demonstrate that often this debate rages within individual care team members. Some studies suggest that interdisciplinary discussion of moral and ethical issues among care team members might contribute to avoidance of burnout in these individuals.^{9,10} It is interesting that neither piece addresses how we do or might support one another through such situations and validate one another's conflictedness born of commitment to doing the right thing for every patient.

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I ever be? Should I ever be? Indeed, emotional and professional development remains a process throughout our careers and lives. As this ethical debate ensues, health care professionals accommodate their personal beliefs and professional standards to a moving societal ethical target. Toward this end, further formal ethics training and physician coping strategies will continue to be necessary not only during residency and fellowship, but as part of our professional and academic lives.

AUTHOR CONTRIBUTIONS

Dr. Daly: drafting/revising the manuscript, accepts responsibility for conduct of research and final approval, acquisition of data. Dr. Gokhale: drafting/revising the manuscript, study concept or design, accepts responsibility for conduct of research and final approval. Dr. Ramos-Estebanez: drafting/revising the manuscript, study concept or design, accepts responsibility for conduct of research and final approval, acquisition of data, study supervision.

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This podcast begins and closes with Dr. Robert Gross, Editor-in-Chief, briefly discussing highlighted articles from the October 7, 2014, issue of *Neurology*. In the second segment, Dr. Dan Larriviere talks with Dr. Ciro Ramos-Estebanez about his paper on clinical and ethical judgment. Dr. Adam Numis then reads the e-Pearl of the week about Brun nystagmus. In the next part of the podcast, Dr. Chenjie Xia focuses her interview with Dr. Justin McArthur on the salient and clinically relevant features of HIV and its neurologic complications.

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