

Nathan Scheiner and Joan Liaschenko, “‘Buying-In’ and ‘Cashing-Out’: Patients’ Experience and the Refusal of Life-Prolonging Treatment,” *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 15-9.

## Features

# “Buying-In” and “Cashing-Out”: Patients’ Experience and the Refusal of Life-Prolonging Treatment

*Nathan Scheiner and Joan Liaschenko*

### ABSTRACT

Surgical “buy-in” is an “informal contract between surgeon and patient in which the patient not only consents to the operative procedure but commits to the post-operative surgical care anticipated by the surgeon.”<sup>1</sup> Surgeons routinely assume that patients wish to undergo treatment for operative complications so that the overall treatment course is “successful,” as in the treatment of a post-operative infection. This article examines occasions when patients buy-in to a treatment course that carries risk of complication, yet refuse treatment when complications arise. We coin this counter-phenomenon “cashing-out.” Cashing-out may elicit negative feelings among careproviders. We question why patients or families may wish to cash-out. One reason may be the changing epistemological position of patients as they experience a complication. The shift from the hypothetical discussion of complications during the initial informed-consent process to the experience of having a complication represents new knowledge. Patients and families may use this knowledge as the basis to revoke consent for some or all of the remaining treatment course. This article seeks to understand cashing-out in terms of the patients’ experiences.

**Nathan S. Scheiner, BA**, is a Candidate for Master of Arts at the University of Minnesota Center for Bioethics, and is a Medical Student at the University of Minnesota Medical School in Minneapolis, Minnesota. [schei184@umn.edu](mailto:schei184@umn.edu)

**Joan Liaschenko, PhD, RN, FAAN**, is a Professor at the Center for Bioethics and the School of Nursing at the University of Minnesota. [jliasch@umn.edu](mailto:jliasch@umn.edu)

©2018 by *The Journal of Clinical Ethics*. All rights reserved.

We hope to prompt recognition of this phenomenon across medical contexts and to provide impetus for further work to understand why patients may wish to cash-out.

### INTRODUCTION

Patients occasionally consent to surgical or medical treatment yet refuse care when complications of the primary treatment arise. This may lead to conflict among patients, family members, and clinicians. This conflict is best understood through Schwarze and colleagues’ observation of surgical “buy-in,” an implicit understanding many surgeons hold that when patients consent to surgery, they consent to both the procedure and any follow-up care the surgeons anticipate.<sup>2</sup> We term the unanticipated refusal of medical care for a complication of treatment by patients or their advocates “cashing-out.” We illustrate the concept by examining the complicated case of a patient who underwent liver transplantation.

### CASE

A middle-age family physician became cognitively impaired from central pontine myelinolysis (CPM—a neurological disorder characterized by damage to the brain stem, which may result in changes to mental status, acute paralysis, difficulty swallowing, or speaking) one month after receiving

a liver transplant. The patient was also bacteremic and had possibly aspirated. The transplant team recommended aggressive antibiotic treatment and endotracheal intubation to the family. Neurology consultants wrote that the patient's CPM might resolve over weeks to months, and that, if it did resolve, it would require intense physical therapy without guarantee of return to baseline function.

This patient had do-not-resuscitate/do-not-intubate (DNR/DNI) orders prior to transplantation. These had been suspended for the procedure and had not been re-ordered. The patient's family, which consisted of the physician's spouse and three adult children—one of whom was a nurse and the spokesperson for the group—doubted the wisdom of intubation to treat aspiration pneumonia given the patient's grave, unanticipated, and uncertain neurologic condition. Citing the patient's values and advance directive, they requested the reinstatement of the DNR/DNI orders, which was done.

The transplant team disagreed with the family. The DNR/DNI orders were revoked by the treatment team, and clinical ethics was consulted after the family requested DNR/DNI orders once again. The DNR/DNI statuses were reinstated after a family conference determined that this was in accordance with the patient's advance directive, which stated that he wished to refuse aggressive care—including resuscitation and intubation—if it was “reasonably certain” he would not recover his ability to know who he was. The patient was made comfort-care-only, and his antirejection medications were stopped.

The transplant team had several strong reactions to this limitation of care, which they reported to the authors: “Transplant patients are considered ‘full code’ for a year” regardless of earlier DNR/DNI orders. Maintaining full-code status “would be difficult to enforce, though we talk about it behind closed doors.” The patient had an obligation to the donor: “someone died so they could live.” The staff has an obligation to the system: “We have to protect the organ.” One reason that treatment should continue is that “survival is measured at one year.” The patient reported to the authors that the transplant team told him: “I don't like those [advance] directives,” and “you never would have gotten this liver—it's way too valuable. . . .”

Two days later, the patient spontaneously became alert and oriented to his medical condition. He stated that he wished to restart antirejection medications and would agree to one week of intubation and ventilator-assisted respiration should it become necessary. The next day he shortened his prospective consent to ventilation to two days. His

DNR status was retained. He repeatedly said that his physicians should withdraw his care if it became clear that treatment would no longer allow him to interact with his grandchildren.

### **Understanding Surgeons' Expectations and Cashing-Out**

This disagreement may be best understood using the concept of “surgical buy-in.” Surgical buy-in is defined as “an informal contract between surgeon and patient in which the patient not only consents to the operative procedure, but commits to the post-operative surgical care anticipated by the surgeon.”<sup>3</sup> A recent survey suggests that up to 62 percent of surgeons across surgical subspecialties would create such an informal contract with patients.<sup>4</sup> Patients may buy-in to post-surgical treatment because they understand that some surgeries may have grave, but reversible, complications. Patients also trust their surgeons to decide on clinical decisions that are in accordance with their quality-of-life values.<sup>5</sup>

However, how such contracts are created and their form are unclear. These agreements often go undocumented in the medical record, and the degree to which surgeons expect buy-in to post-operative treatment depends heavily on several factors, including surgeons' belief in the acceptability of withdrawing life-sustaining treatment within the first two weeks of a major surgery, the degree of surgical risk, and whether morbidity and mortality outcomes must be reported.<sup>6</sup> Of the surgeons surveyed, 60 percent said that they would sometimes or always refuse to operate if a patient expressed preferences to limit life-supportive treatments such as mechanical ventilation or dialysis in the post-operative period.<sup>7</sup>

Furthermore, patients express a wide variety of preferences regarding the degree to which they are willing to give up decision-making authority in the post-operative period. In a recent survey, Nabozny and colleagues found that patients' preferences for autonomy in the peri-operative period exist over a wide range.<sup>8</sup> Some patients believe that decisions to correct peri-operative complications are matters of technical, not moral, expertise to be determined by physicians. Others believe such decisions should be made based on advance directives or by health-care agents. Importantly, the majority of patients surveyed reported they had no explicit discussions about the limits of life-sustaining treatment in the case of major, life-changing complications with burdensome corrective interventions.

Our experience reflects the concern expressed by Schwarze and colleagues that patients may find

the burdens of life-supportive treatment to outweigh the benefits, and that informally contracting the limits of post-operative treatment may be overly paternalistic. In such instances, patients or their families may wish to refuse treatments. We term this refusal “cashing-out”: the expressed refusal of medical or surgical treatment, in response to a change in values or medical status, when an agreement to continue treatment was previously understood to exist. We believe explicit recognition of this phenomenon is important because it highlights both the ethical question of what precisely patients consent to when agreeing to surgical procedures, and the practical concern that cashing-out can elicit “feelings of betrayal, unhappiness, disappointment, and even culpability” among careproviders,<sup>9</sup> possibly to the detriment of their relationship with patients.

### Ways of Knowing and Cashing-Out

One of several ways to understand cashing-out is through focus on the embodied experience of patients as their illness develops. One aspect of informed consent regards the knowing of medical facts related to oneself and one’s treatment options, then deciding which option best aligns with one’s values. The body is central to knowing one’s status in the world. Knowing one’s status in the world is achieved through sensory perception: sight, hearing, touch, olfaction, and gustation.

The embodied way of knowing is important because it concerns first-person knowledge, which is to say “people have first-personal access to some of their bodily states, yielding direct knowledge . . . about what it is like to be in those states.”<sup>10</sup> Personal experience is rich or “thick” with the sensations of daily life, and interpretation or judgment of events depends on how sensations are filtered through values and emotions. First-person knowing can be contrasted with third-person knowing, the primary method by which we construct the experience of others via imagination, interpretation of externalized signs, or listening to their narrative.

We maintain that patients may cash-out on a first-person, or embodied, basis as a matter of their changing epistemological position. Direct knowledge of what it is like to be sick may be why patients elect to forgo treatment for post-surgical complications. Although possible complications may be explained in great detail in the process of informed consent, we believe patients cannot have direct knowledge of these experiences unless they have experienced these complications previously. Patients may be able to imagine the experience of a complication, but this does not translate to embod-

ied knowing of the experience. For example, most people have embodied knowledge of the experience of nausea from routine illnesses, but can only imagine the experience of nausea secondary to chemotherapy. Yet even embodied knowledge of a potential complication may not prevent cashing-out, since values may change over time, and a recurrent complication may be judged intolerable the second or third time around.

The first-person perspective may account for the difference between having a disease and experiencing illness. Disease may be taken to mean those physical changes that lead to systemic dysfunction.<sup>11</sup> It is “an organic phenomenon (physiological events) independent of subjective experience and social conventions.”<sup>12</sup> Whereas “disease” is objective, “illness” is subjective. It is “a situation where a person’s ‘being-in-the-world’<sup>[13]</sup> is characterized by that lack of the rhythm, balance, and tune of everyday living that characterizes not ‘being-at-home.’”<sup>14</sup> More simply, illness is a disruption of the flow of one’s daily life. Patients may become accustomed to living with a disease in a certain rhythm, balance, and tune in their life, and experience an acceptable quality of life. However, a complication or a corrective medical or surgical procedure may disrupt that pattern of living, and introduce a new illness. This new set of embodied sensations, filtered through patients’ goals and values, may be the basis for patients’ cashing-out.

Of course, in this case, the patient’s family members refused treatments on the patient’s behalf. Following the feminist recognition that social situation is important to the formation of knowledge,<sup>15</sup> we argue that families have an additional way of knowing the life and values of others. We informally term this “third-person-intimate” knowing, which is based on the observation that “People behave differently towards others, and others interpret their behavior differently, depending on their personal relationships. . . .”<sup>16</sup> Families have particular knowledge of members’ lives and values as a matter of the intimate relationships they maintain with one another. They simultaneously construct and hold the identities of individual members, as well as define and instill values as a family unit, among other functions, throughout life.<sup>17</sup> This makes family members particularly well suited to describing the values and preferences of patients.

Refusal of treatment by family members is sometimes a substituted judgment on the basis of explicit conversations they have had with the patient. However, families often acknowledge they have not had explicit conversations regarding specific interven-

tions, or even the patient's values regarding end-of-life care. In these instances, families often make statements such as, "I just know he would not want this." Although the basis for the refusal by this patient's family may not be as strong as a first-person refusal or substituted judgment, an ambiguously defined refusal of treatment by a family member should be taken as greater than simple guesswork. On the basis of the above feminist and experiential considerations, a refusal by a family member likely represents an understanding of the "textured life" of the patient's normal rhythm, balance, and tune of being-in-the-world, which are defined by the patient's normal behaviors and values.

The third-person viewpoint of the clinician is not based on an intimate understanding of the daily life of patients and their values, as clinicians rarely see patients leading their normal lives. Instead, the clinical viewpoint is based on an understanding of anatomy, physiology, pathology, and prognosis, which is, in turn, based on a clinician's experience of disease as it is located within the bounds of patients' bodies. It is a disembodied way of knowing. To be clear, we do not mean to imply that the clinical viewpoint is without value: after all, patients seek out the clinical viewpoint precisely because they desire recommendations for medical treatment. However, defining the limitations of the clinician's viewpoint in medical decision making brings into relief the conflict of first-person and third-person experiences. It offers an explanation of why ethical and practical problems arise when patients cash-out, even when clinicians are tempted to say, "Just stick through this with me, I promise I can get you feeling good again."

### Implications

There are many ethical facets to this case. Readers will note we have not addressed the complex notions of the assignment of responsibility and obligation, the clash between autonomy and justice, and the potential conflict of interest that were introduced by the transplant team as they made objections. This is because we wish to focus on the clinical question at hand, as opposed to grand questions of rights, duties, and principles. How will we proceed now that we have met an impasse of values regarding whether a patient has prospectively consented to the treatment of post-operative complications?

First, in our experience, while analysis of ethical principles can occasionally provide a resolution to a conflict between clinician and patient, there are many times in which it will not be useful. In this

case, the analysis of principles will ultimately lead us to systemic versus individualistic concerns. This is to consider whether the demands of justice to the organ sharing system will trump the individual right of the patient to decide what treatments are acceptable. Such considerations are not useful in resolving the conflict in this case because there are perfectly good reasons to prioritize either systemic or individual concerns. These may simply be meta-ethical preferences. Additionally, such a consideration of principles often pits stakeholders against one another, losing sight of the common understanding that all involved are working towards their understanding of the most acceptable outcome for this particular patient.

Second, a focus on the analysis of principles unnecessarily restricts our discussion to the particular ethical problems of transplantation. This case rings true because we ask patients to buy-in to many kinds of burdensome medical treatments, not just surgical treatments. Consequently, cashing-out occurs in many sorts of medical decision making, from the post-surgical patient experiencing a complication to the patient who decides to stop taking a medication due to intolerable side-effects. Clinical ethics consultants should be aware that while formal discussion of buying-in within the literature has focused on the surgical context, we suspect they will find it in all aspects of medical care.

That the patient awoke to consent to a short trial of intubation in this case is a *deus ex machina*. In many instances patients do not awaken to voice their consent or refusal, or, if they do, then they often lack full capacity to decide such monumental questions. These circumstances are tragic for all involved, particularly families who are asked to make difficult decisions regarding the life of their loved one. We believe that when an impasse of values is reached with a patient or family members in circumstances such as this, the practical question of how to proceed can be reframed based on the patient's experience. Then, patients and family members become best suited to determine what treatments are acceptable. We are committed to this position because it is ultimately patients and their families who will have to bear the burden (or benefit) of continuing treatment for post-procedural complications.

Clinical ethicists might proceed in consultations such as this one by asking what has changed, in values or medical facts, and how the patient or family is experiencing that change. Shocking statements made by the clinical team might prompt ethicists to ask about the clinicians' expectations and experiences as well. Interpreting the values of both pa-

tient and careprovider can help consultants build empathy among all stakeholders. Explicitly acknowledging feelings of frustration and bewilderment may help balance the emotional tenor on all sides of a disagreement. Furthermore, building a narrative of the patient's illness, as a story of changing facts and understandings, can help shepherd the patient, the family, and the clinical team to the most acceptable conclusion of the story, whether treatment is continued or not.

Finally, we will pose a question to prompt further conversation and research: When and why do patients wish to end an informal contract such as the surgical buy-in? We have suggested that one possible reason is when the embodied experience of the procedure or complication becomes too much to bear. Empiric work to determine patients' and careproviders' values surrounding this phenomenon should clearly be undertaken. We hope this case provides impetus for further work to better understand the phenomenon of cashing-out.

#### CONFLICT OF INTEREST, PRIVACY, AND INFORMED CONSENT

The authors have no conflicts of interest to disclose. The names, ages, and genders of all of the individuals involved in this case have been altered to protect their privacy. Only the details essential to the patient's medical condition and the narrative of this case as it unfolded have been included. All statements in the case were made directly to the authors, except for those specifically noted to have been told to the patient and reported to the authors by the patient. The patient provided written informed consent to publish this case.

#### ACKNOWLEDGMENTS

Special thanks to the patient and their family for allowing us to write and publish this case. Thanks to Steve Miles for his consultation on this case and commentary during the conception of this article, and to Debra DeBruin, Susan Craddock, and Andrew Jameton for their very helpful comments on an earlier draft.

#### NOTES

1. M.L. Schwarze, C.D. Bradley, and K.J. Brasel, "Surgical 'buy-in': The contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy," *Critical Care Medicine* 38, no. 3 (2010): 843-8.

2. Ibid.

3. Ibid., 844.

4. M.L. Schwarze, A.J. Redmann, G.C. Alexander, and K.J. Brasel, "Surgeons expect patients to buy-in to postoperative life support preoperatively: Results of a national survey," *Critical Care Medicine* 41, no. 1 (2013): 1-8.

5. M.J. Nabozny et al., "Patient-reported limitations to surgical buy-in: A qualitative study of patients facing high-risk surgery," *Annals of Surgery* 265, no. 1 (2017): 97-102.

6. Schwarze, Redmann, Alexander, and Brasel, "Surgeons expect patients to buy-in," see note 4 above.

7. Ibid.

8. Nabozny et al., "Patient-reported limitations," see note 5 above, pp. 97-102.

9. Schwarze, Bradley, and Brasel, "Surgical 'buy-in,'" see note 1 above, p. 845.

10. E. Anderson, "Feminist epistemology and the philosophy of science," *The Stanford Encyclopedia of Philosophy*, 5 August 2015, <https://plato.stanford.edu/entries/feminism-epistemology/>.

11. C. Boorse, "On the distinction between disease and illness," *Philosophy & Public Affairs* 5, no. 1 (Autumn 1975): 49-68.

12. B. Hofmann, "On the triad disease, illness and sickness," *Journal of Medicine & Philosophy* 27, no. 6 (2002): 652.

13. Taken to mean both physical and mental position.

14. R. Ahlzen, "Illness as unhomelike being-in-the-world? Phenomenology and medical practice," *Medicine, Health Care and Philosophy* no. 14 (2011): 323-31.

See also J. Liaschenko, "At home with illness: Moral understandings and moral geographies," *Ethica* 15, no. 2 (2003): 71-82.

15. Anderson, "Feminist epistemology," see note 10 above.

16. Ibid.

17. H. Lindemann, "Why families matter," *Pediatrics* 134, supp. 2 (October, 2014): S97-103.