

Andrew G. Shuman, Adam A. Khan, Jeffrey S. Moyer, Mark E. Prince, and Joseph J. Fins, "When Negative Rights Become Positive Entitlements: Complicity, Conscience, and Caregiving," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 308-15.

When Negative Rights Become Positive Entitlements: Complicity, Conscience, and Caregiving

*Andrew G. Shuman, Adam A. Khan,
Jeffrey S. Moyer, Mark E. Prince, and Joseph J. Fins*

ABSTRACT

Clinicians have an obligation to ensure that patients with adequate capacity can make autonomous decisions. Thus, patients who choose to forego treatment and leave hospitals "against medical advice" are typically allowed to do so. But what happens when they require clinicians' assistance to physically leave? Is it incumbent upon clinicians to not only respect and fulfill patients' requests with which they disagree, but to physically assist in their fulfillment?

Andrew G. Shuman, MD, is a Fellow in the Division of Medical Ethics, Weill Cornell Medical College, in New York City, shumana@mskcc.org.

Adam A. Khan, BA, is a Medical Student at University of Michigan Medical School in Ann Arbor, Michigan.

Jeffrey S. Moyer, MD, is an Associate Professor in the Department of Otolaryngology—Head and Neck Surgery, University of Michigan Medical School.

Mark E. Prince, MD, is an Associate Professor in the Department of Otolaryngology—Head and Neck Surgery, University of Michigan Medical School.

Joseph J. Fins, MD, MACP, is a Professor and Chief of the Division of Medical Ethics at Weill Cornell Medical College. ©2012 by *The Journal of Clinical Ethics*. All rights reserved.

We attempt to develop an ethical framework wherein clinicians can honor patients' wishes without necessarily sacrificing their own moral position.

INTRODUCTION

Autonomy is one of the *prima facie* principles of conventional medical ethics; at its core, clinicians have an obligation to respect patients' informed decisions, including preferences to forego care or leave the hospital against medical advice. A unique ethical dilemma arises when patients need to rely upon medical staff to facilitate such wishes. What is the scope of a patient's right to refuse care? To what extent, if any, do clinicians need to actively participate in facilitating requests that are not consonant with their own values or professional judgment?

To delve into these novel and difficult questions, we must consider the confluence of and conflict between multiple virtues: patients' safety, nonmaleficence, non-abandonment, equality, voluntariness, and the right of conscientious objection. Only once these competing forces are dissected may we formulate a nu-

anced approach to resolving problems that juxtaposition patients against professionals' obligations to service and professionals' own moral compass. Using a challenging case example, we seek to elucidate a working framework to address this impasse that relies upon existing ethical methodology, respects competing interests, and encourages cooperative mediation.

CASE PRESENTATION

A middle-aged man with extensively recurrent squamous cell carcinoma of the larynx was admitted to the hospital with a malignant fistula. Despite heroic interventions, his condition could not be stabilized, and he suffered a carotid rupture and subsequent stroke after hemostasis was achieved. Neurological deficits compounded his underlying weak and frail state, leaving him hemiparetic and bed-bound, requiring continuous nursing care. He is unable to speak due to his tumor, and communicates by writing and gestures. Despite remaining alert, awake, and cognitively intact, his prognosis is extremely poor.

The patient understands that his condition is terminal, and he expresses his desire to die at home. He has a do-not-resuscitate (DNR) order. He is partially estranged from his family and has limited financial resources. The patient's relatives are unable to provide the level of care he requires, and he has no insurance coverage for home hospice or other form of nursing care at his residence. He likewise refuses transfer to either inpatient hospice or a skilled nursing facility. His desire to die at home supersedes all other concerns; he understands that he may be left alone in that setting, and is willing to sign out against medical advice (AMA). Palliative care and ethics representatives have been consulted.

Given that his current medical condition precludes his physical ability to leave the hospital without assistance and that he will be unable to care for himself at home, his care-providers are uncomfortable honoring his wishes.

FRAMING THE DEBATE

This case example illustrates the limitations of utilizing a strictly principle-based approach to solve ethical dilemmas, as autonomy diametrically conflicts with nonmaleficence, which also emphasizes a clinician's obligation not to abandon a patient in need. To address these concerns, more information is needed. Why does the patient feel compelled to go

home? Is there something specific that he needs to obtain or accomplish in doing so that might otherwise be facilitated? What is the degree and etiology of the familial estrangement, and could it be mitigated in his time of need? Are other potential social support structures or individuals available? Is his emotional response to the dying process coloring his judgment? Might dedicated psychosocial support be helpful? What is preventing the patient from receiving care at home; might a financial and/or institutional compromise be reached? While these factors were each considered, unfortunately they could not be resolved in a manner that facilitated an easy or timely solution.

Principlism, casuistry, and virtue ethics, among other constructs, have proven to be trusted methods of resolving moral problems, and are by no means mutually exclusive. Both moral theory and clinical circumstances steer all morally weighty decisions, just as underlying cancer biology and the physical location of a tumor dictate choices among oncologists. As such, clinical pragmatism seems to provide a convenient way to consider this dilemma.¹ In this model, ethical principles are not fixed; rather, they are proportional to perceived risks and benefits and are heavily dependent upon clinical context, practical reality, and the overarching goals of care.² That said, pragmatism is an eclectic approach that is open to the contributions of other methods if they can contribute instrumentally to resolving this quandary. Thus, our focus will remain vested in the content, rather than the process, involved in considering this dilemma.

CLINICAL CONTEXT

Prior to engaging in discussion specifically regarding this ethical dilemma, components of the clinical picture deserve clarification. Patients with terminal cancer present formidable challenges to providing compassionate medical and nursing care. Our patient's fierce independence and challenging social situation created barriers to providing adequate care—which occurs with some frequency in this patient population.³

From a practical standpoint, the patient requires near-constant nursing attention for wound care, positioning, airway/secretion management, hygiene/toileting, and pain control. If he were allowed to return home without assistance, he physically could not manage any basic functions or even summon assistance, given his inability to speak. Thus, adequate palliation would not be possible without some form of assistance. Palliative care team involvement in managing patients with terminal head and neck cancer is beneficial.⁴ Data suggest that the end-of-life experience in head and neck cancer is improved when death occurs outside of the hospital.⁵ Thus, the importance and value of hospice services in this case cannot be overstated.⁶ That said, patients have the right to forego even interventions that have proven effective, and neither families nor clinicians should impose their values upon patients who are capable of making decisions.⁷

One distinguishing feature of this case is that the outcome is known; the patient has terminal cancer and will succumb to his disease in the very near future, regardless of his location or circumstance. This makes extrapolating other ethical discussions of “harm” challenging. What would make a situation unsafe or potentially injurious when death is already imminent? Of course, his demise may be a foregone inevitability, but its context is not. Palliation is the overriding goal, to facilitate a dying process in which pain is treated, other symptoms are addressed, dignity is maintained, and emotional support is provided. The patient and all other involved parties must then weigh competing interests with regard to this process in considering whether the preferred location of death might not override the sacrifices that it would require.

AUTONOMY AND CAPACITY IN CONTEXT

In accordance with the principle of autonomy, patients with decision-making capacity can refuse recommended treatments. Clinicians need only ensure that patients have adequate capacity, are sufficiently informed of the rationale for medical recommendations, and can

recognize the consequences of their choices; this is typically described as the right to informed refusal.⁸ This universal right applies equally to dying patients in intensive care units.⁹ That said, a patient’s preference is not absolute, and consideration of a patient’s welfare should not be ignored in an effort to preserve independence at all costs. Rather, Pellegrino and Thomasma argue that clinicians have an equal (or even greater) commitment to act virtuously to improve and maintain patients’ welfare, and they outline a new principle that they dub “beneficence in trust.”¹⁰ The obvious danger of such a construct is that it may degrade into paternalism, although this is mitigated by their concept of open communication and reciprocal conviction to a productive, professional relationship.

Autonomy is dependent upon a patient’s ability to effectively and clearly communicate his/her decision and its potential consequences. Our patient’s inability to speak may complicate effective dialogue and formal assessment of capacity, but it certainly does not obviate it.¹¹ In such situations, communication is paramount.¹² First and foremost, it is critical for the patient to understand his options, and to engage the multidisciplinary care team in efforts to attempt to provide adequate palliation while honoring his wishes. Thus, there is a need for forthright communication about what clinicians are worried about, and why it might be unwise for the patient to go home alone.¹³ With considerable deliberation and patience, he was able to clearly communicate his wishes by writing, augmented with facial expressions and hand signals. The repercussions of expected inadequate palliation at home were discussed openly and frankly, and he demonstrated understanding thereof.

The concept of a sliding scale of capacity deserves attention, as decision-making capacity is neither all-or-none, nor absolute. A higher standard for capacity is required when decisions are more critical and have potentially dire consequences.¹⁴ In the case at hand, in the opinion of his clinicians, the patient met the appropriate standard for decision-making capacity to leave the hospital. Given his condition, it is highly likely that he would lose capacity at some point, related to delirium.¹⁵ However, as-

suming his wishes had remained consistent to that point, his surrogate decision makers and caregivers would be obligated to honor his wishes in accordance with the concept of substituted judgment, even if he became incapacitated.

This patient defines vulnerability; he is dying, unable to speak, unable to ambulate, and is estranged from those who know him best. While the patient met strictly defined criteria for capacity, was he truly free to act autonomously? Probably not. Not only was he physically confined to bed, institutionally limited due to inadequate social services, and medically condemned by a terminal disease, he was also at the mercy of decisions made by his clinicians, who remained in a position of relative power, even when working under the rubric of his freedom of choice. Thus, every effort needs to be made to avoid paternalistic impulses, which requires engaging him in the decision-making process and empowering him to have some control over those decisions that remain potentially within his purview.

Patients at risk for self-harm may be not granted the right to make autonomous decisions, even if they otherwise demonstrate capacity. As discussed, “harm” is relative when considering the plight of a patient with terminal cancer, although unnecessary suffering certainly qualifies as such. However, physical suffering from inadequately managed symptoms may be judged as the lesser evil when compared to the patient’s anguish from not being able to die at home. As such, making a decision based upon the “lesser harm” remains contentious. Nevertheless, there is no doubt that there is a high likelihood for unintentional self-harm (or at least inadequate palliation), due to his inability to care for himself, assuming that he is able to go home. There also exists the possibility that the patient (and clinicians) may not be able to accurately anticipate his disease progression and the type or severity of symptoms he might experience on his own at home. Once he has been made aware of the risks, both direct and indirect, of leaving, as well as the potential for other unanticipated harms, his decision should be respected if he still decides to go.

AGAINST MEDICAL ADVICE: COMPLICITY VERSUS RESPECT

Is there a significant difference between passively respecting a patient’s autonomous decision and assisting in carrying it out? Typically, a person can make an autonomous decision to leave the hospital AMA, and medical practitioners are not actively involved in facilitating what they believe is not in the best interest of the patient. In this case, clinicians’ refusal to assist would be, by default, in conflict with the patient’s autonomous request. If the medical team assists the patient in carrying out his decision (in this case, by physically carrying him out), would that be tantamount to endorsing his decision?

Most discussions of the principle of non-maleficence revolve around potential harm from therapeutic interventions, and these conflicts often focus upon patients’ cultural, religious, or personal mores that lead them to forego recommended therapies.¹⁶ A clinician’s active involvement in achieving a potential harm differentiates this case. When direct action is needed—as opposed to passive acceptance—the burden is greater. Autonomous decisions are no longer independent, as the involvement of others complicates this privilege and merits re-examination.

We contend that in this particular case, the medical team’s assistance in carrying out a patient’s autonomous decision to forego further care would be acceptable. The patient’s decision to go home is an informed, capacitated choice, and facilitation thereof does not transfer the burden of its consequences upon his clinicians. Of course, while autonomy is an affirmative right, it does not erase a clinician’s affirmative obligation to help. As such, clinical professionals should respect patients’ choices to decline medical recommendations, but within a context in which the door remains open for future care. Once this door closes, we have essentially abandoned our patient, which is a development with dire professional and emotional consequences, to be explored in further detail shortly. In addition, it is difficult to define how far this obligation should extend.

Escorting a wheelchair-bound patient to an awaiting ambulance may be expected, but clinicians would not be obligated to drive this man home in their own personal vehicle and tuck him into bed. We admit that it is difficult to know where to draw this line.

In essence, just as ambulatory patients with sufficient capacity cannot be locked in a hospital ward over their objection, bed-bound patients cannot be kept against their will by refusal to physically assist them in leaving. While the latter action may not meet legal criteria for involuntary imprisonment, in our opinion, this line remains unacceptably thin.

ABANDONMENT

One of clinicians' fundamental obligations is to remain available to patients in need. As such, abandonment is perceived as an ultimate violation of professionalism. An early discussion of medical abandonment defines the practice as a physician-initiated, unilateral termination of the doctor-patient relationship with neither the patient's consent nor adequate opportunity to procure an alternate provider.¹⁷ Surely, our case does not meet these strict criteria. A more flexible concept in which patients and clinicians maintain an "open-ended, long-term, caring commitment to joint problem-solving" more aptly describes the principles behind the need to avoid perceived or actual abandonment.¹⁸

The need to support patients during the dying process is, arguably, as important as the maintenance of partnerships with curative intent; experiences at the end of life require both physical and emotional support provided by individuals with whom patients have an established relationship.¹⁹ As such, the need to avoid abandoning terminal patients is among the strongest imperatives in medicine. In a qualitative study of dying patients, their families, and doctors, the concept of non-abandonment comprised two distinct elements: providing continuity and facilitating closure of the therapeutic relationship.²⁰

In our case, the patient's desire to die at home would likely prevent his clinicians from

assisting him, and his inability to communicate verbally might potentially preclude him from summoning help even if he were to change his mind. Of course, consideration of practical solutions is warranted, such as a call button system that might alert emergency medical services, thereby keeping the proverbial door open for future care. However, the patient's request would nevertheless fundamentally limit his clinicians' availability. We must be mindful that patients' autonomy may supersede other conflicting professional obligations. Clinicians must then balance these incompatible values, preferably with some sort of compromise, to allow a patient's rights to be respected without sacrificing a major ethos of professional medical care.

CONSCIENTIOUS OBJECTION

While autonomy is an ethos of professionalism, it is not the only such factor. Since we have argued that autonomy is not a blanket that obscures all other considerations, physicians are not obligated to directly violate their own moral or professional values or existing laws when acquiescing to patients' requests.²¹ Patients' refusal to facilitate or allow routine (or "ordinary") nursing care seems fundamentally different than refusal of "extraordinary" measures, such as chemotherapy or resuscitation.²² Ignoring elemental human needs such as hygiene may be considered socially taboo, and caregivers may rightfully experience moral distress if they perceive that they are contributing to such "wrongs."²³ Failure to address such basic needs, particularly when considering vulnerable populations, may put clinicians at risk for accusations of professional or legal misconduct under the rubric of patient neglect.²⁴ As discussed, abandonment falls within the same moral purview.

Refusing to honor a patient's request on moral grounds requires professional diligence to ensure that the patient continues to receive care until another clinician who is willing to provide care is available. In addition, such cases require a critical reassessment of one's position to determine if there is truly an irreconcilable

disagreement, or whether cooperative mediation may yield a satisfactory answer.²⁵ Without such safeguards, the caregiver's conscience is satisfied only at the expense of the patient's.²⁶ Our case does not involve one caregiver's moral objection, but rather a collective (and admittedly paternalistic) professional opinion that honoring the patient's request would simply be a wrong that would be difficult to accept, even at the risk of shirking duties to preserve the patient's autonomy. The absolute categorization of this as a "wrong," we fully recognize, is as nebulous as knowledge of the "right" thing to do for this poor man.

In cases involving refusals of nursing care, another suggested solution involves "negotiated reliance," which "recognizes the reliance of the patient on her care providers . . . combines empowerment and dependence . . . presupposes a relationship of care and intimacy . . . [and] allows for more therapeutic and reciprocal responses."²⁷ This concept forces clinicians to do their best to avoid limiting patients' autonomy while encouraging patients to make concessions, and also asks clinicians to make allowances that may extend beyond standard professional practice. Essentially, it is based upon the principle that patients and clinicians "are in this together," and that mutual compromises and trade-offs are obligatory in pursuit of common goals. This idealized model allows clinicians and patients to shoulder the burden of their decisions together, in a partnership. The application of negotiated reliance to our case might involve discourse such as, "I know you want to go home, but I cannot abandon you . . . so let's see what we can arrange."

CONCLUSION

Members of the clinical team, ethics consultation service, and family discussed the case and their positions with the patient extensively. He remained adamant in his desire to go home, regardless of all other potential risks and clinical realities. Attempts were made to secure in-home assistance, including exploring options in which the cost of home services would be absorbed by the hospital. The next day, while

such arrangements were still in development, the patient suffered a recurrent stroke and died peacefully in the intensive care unit.

In some measure, the clinical outcome is reassuring. The patient died tranquilly with adequate palliation. His clinicians did not overtly violate his wishes by refusing transfer to his home, nor did they act in direct opposition to their own morals. However, this is also a tragedy. A dying man's wish to return home was not honored, at least partially due to clinicians' refusing to acquiesce to his request in a timely manner; he was in effect held against his will, on someone else's terms. In retrospect, deliberation and delay were in fact decisive.

This case also highlights the inherent inequalities within our healthcare delivery system, since the ideal solution for all involved parties would involve dedicated home hospice services, which are cost-effective, clinically proven, and frequently covered by both private and public health insurance plans. While clinicians are bound by institutional and financial practicalities, we cannot simply shrug our shoulders without encouraging political advocacy and fighting for our patients' rights not only at the bedside, but also on a meta-level.

If our patient had not died so quickly, we would have been obligated to honor to his wish to go home. While the hospital is not compelled to assume these costs, such institutional decisions are based upon a permutation of financial, practical, and moral reasoning. Ideally, a plan would have been implemented involving some form of in-house services, although discharge should have been facilitated even if such an arrangement proved impossible. In essence, morally weighty decisions should not be made in a different context based purely upon physical ability. Assuming that an ambulatory patient in a similar situation would not be physically prevented from leaving the hospital, it is problematic to refuse to allow a bed-bound individual to make the same choices. In other words, it is hard to distinguish between passively enabling medical decisions that we cannot condone from actively participating in equivalent processes. A similar argument has been employed in condemning physicians' complicity

with euthanasia.²⁸ In such cases, the onus rests with the clinical team to achieve a workable solution that merges competing interests with clinical realities.

Healthcare providers have a fundamental, fiduciary responsibility to respect patients' autonomous decisions. That said, it is challenging to do so when a decision is perceived to be "wrong." Assuming that an informed choice is made by a capacitated individual, clinicians' disagreement with a decision should not adversely affect their willingness to assist their patient. In most cases, cooperative mediation will facilitate outcomes that honor patients' autonomy, but also provide safeguards that address clinicians' concerns. That said, the clinical obligation to respect "bad" decisions, both in word and action, remains a fundamental part of our professional duty.

MASKING OF THE CASE

The identity of the patient in this case has been masked to protect his/her privacy.

DISCLOSURE

The authors have no financial interests, disclosures, sources of funding, or conflicts of interest regarding the content of this original article.

NOTES

1. T.L. Beauchamp, "Principlism and its alleged competitors," *Kennedy Institute of Ethics Journal* 5, no. 3 (1995): 181-98.
2. J.J. Fins, M.D. Bacchetta, and F.G. Miller, "Clinical pragmatism: a method of moral problem solving," *Kennedy Institute of Ethics Journal* 7, no. 2 (1997): 129-45.
3. J.L. Penner, "Psychosocial care of patients with head and neck cancer," *Seminars in Oncology Nursing* 25, no. 3 (2009): 231-41.
4. Y.P. Talmi et al., "Home and inpatient hospice care of terminal head and neck cancer patients," *Journal of Palliative Care* 13, no. 1 (Spring 1997): 9-14.
5. A.G. Shuman, Y. Yang, J.M. Taylor, and M.E. Prince, "End-of-life care among head and neck cancer patients," *Otolaryngology-Head/Neck Surgery* 144, no. 5 (2011): 733-9.
6. I.G. Finlay et al., "Palliative care in hospital,

hospice, at home: Results from a systematic review," *Annals of Oncology* 13, supp. 4 (2002): 257-64.

7. H. Kuhse, "Some reflections on the problem of advance directives, personhood, and personal identity," *Kennedy Institute of Ethics Journal* 9, no. 4 (1999): 347-64.

8. D.T. Ridley, "Informed consent, informed refusal, informed choice—what is it that makes a patient's medical treatment decisions informed?" *Medicine and Law* 20, no. 2 (2001): 205-14.

9. K. Faber-Langendoen and P.N. Lancken, "Dying patients in the intensive care unit: forgoing treatment, maintaining care," *Annals of Internal Medicine* 133, no. 11 (2000): 886-93.

10. E.D. Pellegrino and D.C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (New York: Oxford University Press, 1988).

11. C.S. Rodriguez and D.M. Blischak, "Communication needs of nonspeaking hospitalized postoperative patients with head and neck cancer," *Applied Nursing Research* 23, no. 2 (2010): 110-5.

12. Y.L. Lin, I.C. Lin, and J.C. Liou, "Symptom patterns of patients with head and neck cancer in a palliative care unit," *Journal of Palliative Medicine* 14, no. 5 (2011): 556-9.

13. M.C. Beach, P.S. Duggan, C.K. Cassel, and G. Geller, "What does 'respect' mean? Exploring the moral obligation of health professionals to respect patients," *Journal of General Internal Medicine* 22, no. 5(2007): 692-5.

14. A. Buchanan, "Mental capacity, legal competence and consent to treatment," *Journal of the Royal Society of Medicine* 97, no. 9 (2004): 415-20.

15. E. Fan et al., "Informed consent in the critically ill: A two-step approach incorporating delirium screening," *Critical Care Medicine* 36, no. 1 (2008): 94-9.

16. W. Gaylin, L.R. Kass, E.D. Pellegrino, and M. Siegler, "Doctors must not kill," *Journal of the American Medical Association* 259, no. 14 (8 April 1988): 2139-40.

17. N.L. Chayet, "Abandonment of the Patient," *New England Journal of Medicine* 272, no. 22 (3 June 1965): 1172-1173.

18. T.E. Quill and C.K. Cassel, "Nonabandonment: A central obligation for physicians," *Annals of Internal Medicine* 122, no. 5 (1995): 368-374.

19. P.K. Han and R.M. Arnold, "Palliative care services, patient abandonment, and the scope of physicians' responsibilities in end-of-life care," *Journal of Palliative Medicine* 8, no. 6 (2005): 1238-45.

20. A.L. Back et al., "Abandonment at the end of life from patient, caregiver, nurse, and physician

perspectives: Loss of continuity and lack of closure,” *Archives of Internal Medicine* 169, no. 5 (2009): 474-9.

21. American Medical Association Council on Ethical and Judicial Affairs, *Code of Medical Ethics: Current Opinions with Annotations* (Chicago: American Medical Association, 2002).

22. D.M. Dudzinski and S.E. Shannon, “Competent patients’ refusal of nursing care,” *Nursing Ethics* 13, no. 6 (2006): 608-21.

23. D.M. Dudzinski, S.E. Shannon, and R. Tong, “Competent refusal of nursing care,” *Hastings Center Report* 36, no. 2 (2006): 14; discussion, 14-15.

24. D.G. Stevenson and D. M. Studdert, “The rise of nursing home litigation: Findings from a national survey of attorneys,” *Health Affairs* 22, no. 2 (2003): 219-29.

25. J.A. Carrese, “Refusal of care: Patients’ well-being and physicians’ ethical obligations: ‘But doctor, I want to go home,’” *Journal of the American Medical Association* 296, no. 6 (9 August 2006): 691-5.

26. R.A. Charo, “The celestial fire of conscience—refusing to deliver medical care,” *New England Journal of Medicine* 352, no. 24 (16 June 2005): 2471-3.

27. Dudzinski and Shannon, see note 22 above.

28. D. Callahan, “When self-determination runs amok,” *Hastings Center Report* 22, no. 2 (1992): 52-5.