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**Case Commentaries**

# “Respect for Persons,” Not “Respect for Citizens”

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Imagine for a moment that this case were about a medically and socioeconomically identical American citizen. He has limited English proficiency and requires an interpreter. He has siblings in the United States and abroad. He is uninsured, perhaps because he falls into the coverage gap created when his state chose not to expand Medicaid. Would this citizen’s care team inform him of a potentially life-extending clinical trial? If the answer to this question in the analogous case is yes, then the correct course of action for the original patient should be obvious. Respect for patient autonomy requires that the team inform him about all of his treatment options, including the clinical trial. I argue that respect for patient autonomy is not a duty owed solely to compatriots, but rather to all humans, regardless of their immigration status. Although the case does not explicitly state that the palliative care team’s primary concern is the patient’s immigration status, consideration of the case with that variable removed could yield clear guidance. Immigration status is morally irrelevant, and the medical team should consider only the morally relevant facts in deciding whether or not to inform the patient about the clinical trial.

## DUTY TO RESPECT AUTONOMY TRANSCENDS IMMIGRATION STATUS

The principle of respect for autonomy can be derived from the Kantian categorical imperative that we treat each person as an end in himself, and never merely as a means (Beauchamp and Childress 2009). It calls on us to recognize the unconditional worth of individual persons, and to respect their capacity to decide for themselves those ends that they find most valuable and worthy of pursuit. Kant does not restrict the application of the categorical imperative only to those persons with whom we share a nationality. Indeed, Kant does not even restrict the categorical imperative to humans, but claims that it applies to all rational beings (Kant, Gregor, and Timmermann 2012).

Non-Kantians might base a duty to respect autonomy on John Stuart Mill’s harm principle, which requires that society “should permit individuals to develop according to their own convictions, as long as they do not interfere with a like expression of freedom by others or unjustifiably harm others” (Beauchamp and Childress 2009). Like Kant, Mill makes no distinction between citizens and noncitizens in his theory; noninterference in the pursuit of projects is owed to all.

We need not focus only on the theoretical roots of respect for autonomy in determining to whom it is owed. Modern ethical guidelines for physicians similarly reject any differential duties on the basis of citizenship or immigration status. The 1964 update to the Hippocratic Oath contains the promise, “I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm” (Lasagna 1964). When new physicians swear this oath, they acknowledge that their obligations extend to all their fellow human beings; citizenship is not a precondition for the fulfillment of their duties.

## PHYSICIAN DUTY TO DISCLOSE

Having established that the duty to respect patient autonomy is not dependent on citizenship or legal status, we can dive into the details of this case to determine whether its morally relevant characteristics entail a duty to disclose the option of the clinical trial. For the purposes of this analysis, we examine the morally (rather than legally) relevant considerations from the consent literature that might override the requirement that patients be fully informed of all potential treatment options. These include diminished capacity to consent, the futility of the treatment option, and medical contraindication of disclosure (Beauchamp and Childress 2009). I examine each of these in the context of this case, and evaluate whether any are legitimate reasons for the care team to withhold treatment information from the patient.

First, the patient’s capacity to understand and consent should be considered. From the case description, it is clear that the patient retains full capacity. He is alert and compliant with treatment, and is able to communicate through

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interpreters. Although he is unable to describe his condition beyond recognition that he has "blood cancer," it seems unlikely that even many fluent English speakers could describe myelofibrosis with more detail or medically relevant information than that it is a cancer of the blood. Capacity to consent is therefore not at issue in this case.

The second consideration that might allow the medical team to withhold information about a treatment option would be the futility of the option. Although determinations of medical futility can be subjective and can vary from patient to patient, a physician is not morally required to provide treatment that is "highly unlikely to be efficacious," and "may not even be required to discuss the treatment" (Beauchamp and Childress 2013). While the BMT trial in this case is experimental, the facts of the case do not indicate that that enrolling in this trial would be prima facie futile. Indeed, there seems to be a good chance that bone-marrow transplant (BMT) could be a viable option for this patient; siblings typically experience a one-in-four chance of being a human leukocyte antigen (HLA) match, and with three siblings, our undocumented patient has a decent chance of finding a match among his siblings (Be the Match 2016). If a sibling match could be identified, a 30 percent 5-year survival rate after BMT could yield a strong positive benefit for the patient. Thus, while the benefits of enrolling in the trial are uncertain, it cannot be argued that it would be futile for this patient.

Finally, it might, under very specific circumstances, be ethical for a medical team to withhold information about a treatment option if informing the patient about it is medically contraindicated. This idea, known as the therapeutic privilege, applies when the disclosure itself could cause harm to the patient's health (Beauchamp and Childress 2009). Although this patient may find it distressing to hear of the potentially expensive long-term costs associated with the BMT procedure, the disclosure itself would likely not cause any deterioration of the patient's condition, especially given his stable status. The emotional and psychological burden this choice could place on an uninsured and vulnerable patient may be heavy, but the existence of such a trade-off should not outweigh the duty to allow him to make his own choices.

## CONCLUSION

Immigration status is not morally relevant to this decision, and the criteria that are morally relevant suggest that the medical team has an obligation to inform their patient of the potentially life-extending clinical trial for which he is eligible. They must review, through the interpreter, all of the risks, benefits, and costs associated with each option, including the trial and the palliative care at home, and do their utmost to ensure that he comprehends them. A patient's noncitizenship does not absolve the medical team of their duty to respect autonomy. If anything, the patient's status as a member of a vulnerable population only strengthens the obligations of the medical team to ensure that he is able to choose the best option for his own life. Furthermore, as the physicians with whom he has an established relationship, they have a duty to facilitate his exercise of that choice, or to transfer his care to someone else who will. ■

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# The Potentially High Cost of a Free Clinical Trial

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Despite the rarity of the disease in question and the patient's status as an undocumented immigrant, the primary ethical challenges in this case reflect complex phenomena that affect most medical care and clinical research in the United States. For the research ethics consultant, the most pressing of these issues are the financial

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