

Patient Informed Choice for Altruism

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Abstract: Respect for persons protects patients regarding their own healthcare decisions. Patient informed choice for altruism (PICA) is a proposed means for a fully autonomous patient with decisionmaking capacity to limit his or her own treatment for altruistic reasons. An altruistic decision could bond the patient with others at the end of life. We contend that PICA can also be an advance directive option. The proxy, family, and physicians must be reminded that a patient's altruistic treatment refusal should be respected.

Keywords: informed consent; altruism; advance directive; autonomy; medical ethics

Case Study

A 78-year-old terminally ill woman with end-stage congestive heart failure, diabetes, and chronic obstructive pulmonary disease asked her team of ICU physicians, "Why are you doing all this for me? Just let me die . . ." Her physicians were distressed, fearing that the patient lacked self-respect or a sense of her own worth or was depressed. The patient had a do not resuscitate order and was apparently comfortable. Her physicians thought, "What could be done to impart a stronger sense of her worth and greater hope?"

In contrast to what her doctors inferred, this patient felt that her value was completely independent of the amount of healthcare resources devoted to her, whether in quantity, intensity of environment, or dollars spent. To this patient, the use of resources in her own case represented a tremendous waste, but not because she was not worth treating. She believed that using these resources made no real difference in the achievement of her life goals as she now lay dying, and those resources could be instead devoted to others.

If this woman had simply decided to stop her therapies based on her self-regarding desire for a shorter dying process and her right to refuse treatments, her doctors would likely understand and respect this request. But her request went beyond the refusal of treatments for herself, as she objected to the use of so many resources, and the sheer wastefulness of it all appalled her. She did not want her life to end with an expensive bill that would be left on someone else's doorstep. The patient wanted all treatment to stop now to save her family, and society, the resources that she believed were being unduly and unjustly spent on her.

Altruism in Patient Care

Refusal of treatment is an essential part of informed consent doctrine.¹ Following this doctrine, we allow not only consent to therapies but also refusal of them. We allow adult patients with capacity not to initiate or continue those therapies that *they* do not want to have visited on their bodies. We hold this doctrine as an essential part of our liberty-based interests: "I will tell you what I do not want, and you will not impose it on me." However, there is a missing ingredient in this informed refusal mix—the concept of the "other." We tend not to investigate altruistic

motives in clinical medicine, but they do exist, such as for patients who refuse proposed end-of-life treatments when they are concerned about the physical and financial stress it would place on their loved ones.^{2,3}

Actions that benefit others have very high moral standing in theory, and we recognize their social importance. Altruistic decisions are typically suspect in clinical settings, as clinicians can be deeply suspicious.⁴ This altruism can even be viewed by physicians as a symptom of some psychological malady due to poor self-image or lack of self-worth. Such patients would have to convince physicians that one of their goals is a virtuous desire to help others.

Nevertheless, there are two contexts in which altruistic decisions are routinely accepted in clinical medicine. The first is clinical trials. Although we take great pains to get an appropriate cost-benefit ratio for experimental subjects, we also recognize—and take advantage of the fact—that many patients participate in experiments for essentially altruistic motives. These patients enroll—sometimes at considerable (nonfinancial) cost to themselves—in the hope that doctors will be able to learn something from them that will help future patients. The second context in which we accept altruistic decisions is in circumstances of undirected organ donation, in which a donor wants to donate a kidney to help an anonymous recipient. Although this occurs more often today, it was greeted with suspicion when first proposed and is not now a universally accepted practice. We believe that respect for genuine, informed altruistic decisions should play a much wider role in clinical medicine. Although altruism and restraint are admirable virtues in decisions about medical care throughout life, for present purposes we limit our discussion to decisions at the end of life.

Care for others is a laudable goal in life in many religions and philosophies. In clinical ethics, the virtue of self-effacement is quite different from a focus on self-interest aimed at getting everything one might want for oneself.⁵ Although data suggest that some patients do want more time or therapy and are willing to suffer the burdens of those treatments, other patients do not want such therapy when life's quality is low and its cost high.^{6,7,8,9} Consider a few possibilities of how persons may arrive at these other-regarding, altruistic values:

- 1) Some patients embrace a religious view that holds that we are fulfilled by giving rather than getting, believing that self-effacement is the path to peace and fulfillment.
- 2) Some patients' self-identity includes a strong allegiance to fairness and even generosity to others. For those who live that way, refusing life-prolonging therapy reaffirms lifelong commitments to extend these values to their dying.
- 3) Some patients have a strong desire to atone for a life misspent, perhaps due to its extravagant self-centeredness.
- 4) Some patients are deeply disturbed by the sheer wastefulness of maximal life-prolonging treatments when the benefits produced are so minimal.
- 5) Some patients carry vivid memories of what it was like to be uninsured and unable to get medical care, or to be afraid that medical treatment would result in economic catastrophe. They strongly desire that other sick people never face that same horrific predicament.

Physicians do not normally even inquire about the values of altruism or self-effacement. If a patient expresses any of the values or outlooks described previously,

physicians tend to suspect (rather than respect) her values. Many physicians may openly wonder why such a patient would not want all available medical treatments for her illnesses and to prolong her life. This perspective that one should treat oneself first and consider others later could actively *disrespect* a patient's values as a person, leading physicians to view her concern for others as a form of pathology.

Our social/medical context is a system of pooled healthcare resources (either within one's own family or for other members of society) that is almost always insufficient to deliver needed medical care to all patients. Some would also contend that we need to look outside our own national perspective to a global perspective of health for all.¹⁰ Yet even in this context, doctors routinely encourage patients to make exclusively self-regarding decisions concerning their treatment. When obtaining informed consent, normally the only question considered relevant is, "What do you want?"—as if the patient's self-regarding desires and preferences regarding treatment were the only relevant issues. This question does not address how the patient's decisions will affect the lives of anyone else, and how the patient considers this aspect of his or her own care. This approach to treatment decisions ignores the impact that such decisions have on the pooled resources of the insurance plan, on the other enrollees in that plan, and on those who pay for that health insurance—or even the emotional and financial burdens on family and other loved ones.^{11,12}

The triumph of the patient autonomy movement empowered patients to make decisions about their own healthcare. However, responsibility follows from autonomy. The power to make decisions calls for those aspects of character and wisdom required to make responsible decisions. Without this responsibility, the right to decide can result in self-indulgent decisions. Unbridled decisionmaking based on self-interest can also easily result in a power struggle in which the autonomy of the more powerful (e.g., the wealthy and well-insured) is served and the autonomy of the less powerful (e.g., the uninsured and working poor) is systematically ignored.

Almost all major medical treatment decisions do affect the lives of others. The patient's ethical responsibility in making an autonomous decision therefore needs to examine these factors beyond a self-regarding vacuum. Medical decisionmaking, then, should couple consideration of the interests of the decider herself and the interests of others (i.e., family, loved ones, other sick people, and society). We all recognize this in many aspects of our lives. We recognize that some people already embody active concern for others in their lives. And for some, these concerns are highlighted, not negated, by a chronic or terminal illness. What we call for here is overt institutional support for those who want to make balanced, responsible decisions about their medical care.

We believe it is time to reintroduce physician recognition of the *patient* virtues of altruism, prudence, and wisdom into patient decisionmaking. We need to appeal to patients, too, to consider the fact that healthcare resources are not unlimited and must be used judiciously. We propose here a method that would allow patients to make medical treatment decisions that take into consideration the impact of their decisions on others. We propose *patient informed choice for altruism* as an important step in that direction.

Patient Informed Choice for Altruism in Medical Decisionmaking

Patient informed choice for altruism (PICA) is a decision by a patient with decisionmaking capacity to limit his or her own treatment for autonomous and

altruistic reasons. PICA decisions must be fully autonomous, of course. They must be made only after the treatment options, and their risks and benefits, have been carefully weighed by the patient. PICA is a means to carry out altruistic decisions for the good of others in either a concrete (e.g., for one's spouse or family) or an abstract sense (e.g., for the good of unknown others). We believe PICA is a treatment option that patients should be informed of when addressing treatment options for end-of-life care.

PICA would be a deliberately and freely chosen decision to forego any or all medical treatments at the end of life so that other patients in need can have more healthcare. For a patient to make a responsible decision, he or she must weigh the potential benefits and harms, given his or her medical condition and the options available. One relevant concern is the cost of the use of medical resources and the benefits that others could accrue if this treatment were foregone. It goes without saying that PICA should not ever be used as a coercive measure or be imposed on patients reasoning through their informed choices. However, PICA should be available to anyone with a terminal illness or a chronic and progressive illness, as well as to frail adult patients when treatments no longer sufficiently benefit the patient (as determined by him or her) and when there is no evident psychological reason, such as depression, driving the foregoing of treatment. Verification of a lack of depression, psychosis, and possible external coercive factors would need to be made by the physician, and, as appropriate, by a mental health professional, in conjunction with a known debilitating condition or terminal illness that has been diagnosed and is not amenable to treatment to the patient's satisfaction. To allay potential concerns that physicians could too rapidly accept PICA (in such cases as depression, coercion, and lack of understanding), a second opinion by an independent physician should be advocated for inclusion in policies developed in healthcare facilities.

It is important to emphasize that by "the end of life" we mean something much more comprehensive than the hospice requirement of "less than six months to live." Many chronically infirm patients, we believe, recognize that their lives have already been lived as fully as they wish them to be. They have accomplished what they could—roads not taken and experiences not had are now beyond reach. Some of these patients are quite comfortable with the fact that their lives are now complete. Sometimes they have already said their good-byes, perhaps many times. Now they are just waiting for the end to come. If they have reasoned sensibly that medical resources would be better devoted to those whose lives are still largely in front of them, we should respect and honor those sentiments. We should allow their competent, autonomous, and altruistic values to be actualized, and PICA would help to do so.

A PICA decision would also serve to connect the patient with others through their other-regarding decision. A sense of connection is critical at the end of one's life. As our lives draw to a close, the struggle to find meaning in our existence requires identification with someone (or something) that will go on after we are gone. To many infirm patients, this sense of meaning and connection is much more important than treatments that will enable them to linger on for a few more weeks, months, or even years. Some patients may even be waiting for the opportunity to say, "Let others benefit from the resources that I do not want."

PICA Advance Directives

There is currently no institutional recognition of the virtues of altruism, prudence, and wisdom involved in autonomous patients exercising restraint in utilizing medical resources that are available to them in end-of-life-care. There is certainly no mechanism for patients to integrate PICA into contemporary advance care planning, to signal their desire that restraint should be used in their care after they become unable to speak for themselves. True, patients can decline medical interventions in their advance directives, just as they would if they didn't want those interventions. The problem lies in a lack of means for patients to discuss their altruistic motives and then authorize proxies to make PICA-based decisions for them at life's end. We advocate that PICA is not only useful for contemporaneous medical decisions but also a feasible addition to advance directives.

A PICA amendment to an advance directive would articulate those future circumstances in which an act of sharing through effacing one's own interest is requested in order to benefit others. Almost all states allow for advance directives to have written amendments that will have the same power as the advance directive it amends. PICA could thereby be a noble and wise practical advance directive amendment about what the patient thinks will be appropriate and what will not, based on the patient's values and preferences—and should be recognized as such. Without such an advance directive, considerations like "she doesn't seem to be in any discomfort" are often sufficient to launch expensive life-prolonging treatments.

An advance directive PICA amendment would be applicable when the patient has lost decisionmaking capacity, and circumstances would describe when treatment should cease because there is insufficient benefit from the patient's perspective in light of the patient's articulated altruistic values. The loss of decisionmaking capacity would have to be, in the judgment of physicians, permanent or, if temporary, accompanied by irreversible illness and/or a terminal illness.

The directions given to surrogate decisionmakers would require modification in light of advance directives involving PICA. Obviously, a proxy decider cannot choose PICA without clearly expressed and documented directions from the patient. (Self-denial, charity, or generosity is *impossible* without consent.) PICA is an advance directive decision that only the patient can make. But proxies and physicians need to be told that they must respect directives containing the PICA amendment and are responsible to choose as the patient would have chosen. Some proxies and physicians may be uncomfortable with PICA and may resist it. Some proxies may need support in honoring the wishes expressed in PICA—love naturally wants to hold on to the beloved. Some physicians likewise may claim that their obligation to help the patient is greater than the patient's values about helping others. Also, the old idea is still strong that we show love and beneficence by keeping our parents, partners, and patients alive as long as possible if they are not in pain. When the patient has chosen medical altruism, the proxy and physicians must be reminded that treatment choices should reflect the patient's PICA-based values.

Concluding Considerations

Voluntary, competent decisions that reflect altruistic values are not pathological, or products of deception or coercion. Just as with any patient decision to limit

life-prolonging medical treatment, we would need to be prudent about employing medical self-denial. PICA decisions must not be cajoled, coerced, or misinformed. Just as with any other patient decision to limit treatment, we would need to be very careful that the decision was not motivated by depression; by feelings of lack of value, worth, or dignity; by false views about the patient's future; by conflicts of interest with or among proxies; or by exaggerated estimations of the negative impact of one's prolonged existence on the lives of others. Genuinely altruistic decisions by patients at the end of their lives should be honored and respected. PICA represents an institutional mechanism for upholding these decisions in end-of-life care.

Notes

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