

Surrogates and Extra-Familial Interests

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ABSTRACT

A case is presented in which the therapeutic interests of the patient conflict with the safety of a community, and in which the surrogate decision maker has very limited knowledge of or concern for the patient's preferences. The substituted judgment and best interest (or rational patient) standards for surrogate decision making are problematic in this case. It is argued that the interests of even those outside the family ought to be taken seriously when making decisions about such cases, and it is proposed that clinical ethics committees could play a new role here. This case also illustrates the difficulties of making decisions regarding the treatment of a very unlikable patient.

INTRODUCTION

Surrogate decision makers are sometimes presented with situations in which the interests of the patient conflict with extra-familial interests (such as community interests). We do not currently have clear ethical frameworks or policy guidelines for addressing such cases, but this is an area in which

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hospital ethics committees may be well placed to assist in decision making.

CASE PRESENTATION

A neurosurgeon asked the ethics committee of a regional medical center to review the case of Mr. C. Details of the case have been altered to preserve the privacy of the patient and family. Mr. C is a late-middle-aged male, who, in his teenage years, had a brain tumor surgically removed and irradiated. Some years later he was incarcerated in a state correctional facility for sexually inappropriate behavior toward children. It is plausible that his sexual deviancy could be related to impaired inhibition from his brain tumor or its treatment.

After more than 20 years in prison, Mr. C was released in a physically debilitated and cognitively impaired state. He was incontinent, wheelchair bound, and functioning cognitively at or below a grade school level. His sister, the only family member officials could reach, agreed to look after his interests as best as she could; this included acting as the patient's surrogate decision maker for medical decisions. (She was so designated in Mr. C's durable power of attorney for healthcare form.) She reports sexually inappropriate advances toward her by the patient in the distant past.

When Mr. C was released from prison, he was admitted to a hospital near his sister's home and di-

agnosed with a blockage of spinal fluid flow, for which a shunt was placed. His recovery was such that he could not be cared for in his sister's home. His sister was also concerned that the patient's sexual behavior could pose a risk to her two young children. Upon discharge, the only facility in the state that would accept a patient with his history of predatory sexual behavior was a private, secure, long-term psychiatric nursing facility in the far corner of the state.

Soon thereafter, Mr. C became seriously ill with life-threatening sepsis and meningitis related to infection of the shunt. He was admitted to a regional medical center where the shunt was removed and the meningitis treated with a prolonged course of antibiotics; he recovered well from his infection. Despite being critically ill, he was observed to masturbate compulsively in the emergency department and hospital.

Imaging tests revealed evidence of the prior brain tumor surgery and a large tumor mass in his neck that was pressing on his spinal cord. The neck tumor was determined to be the likely cause of his worsening lower extremity weakness and incontinence. A psychiatrist evaluated the patient and found that he was not competent to make his own healthcare decisions.

The neurosurgeon determined that the tumor in Mr. C's neck would probably continue to grow slowly, cause progressive disability, and could shorten the patient's life. It was also his opinion that removal of the tumor, although associated with some surgical risk, would arrest the deterioration in Mr. C's physical function and probably improve his level of function. Tumor removal would probably allow for a lower level of care and a higher level of independence. Although clinical outcomes vary considerably in such cases, there is a good chance that this treatment would improve Mr. C's competence and ability to ambulate, increasing his opportunities to interact with others (inside and outside the facility); thus, treatment holds out the possibility of a marked improvement in the patient's quality of life. Surgery would not affect his cognitive functioning or his lack of impulse control, so this patient would require a higher level of supervision and could place other residents and the community at greater risk.

The neurosurgeon worried that improving Mr. C's mobility and functioning may lead to his no longer satisfying criteria for continued care at the secure psychiatric nursing facility. If he were to be released to a less restrictive facility, or onto the street, he would be less likely to receive appropriate care and might engage in his prior pattern of sexually

predatory behavior. His sister did not want him returning to her home because of her concerns for the safety of her own children. The ethics committee pondered whether the interests of the community (keeping a potential sexual predator off the streets) should play any role in their deliberations.

SUBSTITUTED JUDGMENT OR BEST INTEREST?

The surrogate in this case is the patient's sister, but she has had little or no contact with the patient since they were young adults. When they were in their teens, the surrogate was a target of the patient's inappropriate sexual behavior (although it was not reported at the time or punished). There are no other family members or close friends who could act as this patient's surrogate, and the sister's decisions are closely monitored by the attending physician (in consultation with the ethics committee) to ensure that she appropriately fulfills her responsibilities.

Although this patient has been autonomous (to some degree) in the past, the substituted judgment standard is not appropriate as a guide for surrogate decision making in this case.¹ The patient's period of autonomy was relatively brief and declined rather sharply (probably in his late teens) when his brain tumor was found and treated. The surrogate does not recall the patient's views from that period in any detail (and, in any case, who among us would want our medical decisions guided by views we held in our teens?). Therefore, the surrogate should probably be guided by the best interest standard (also known as the reasonable person standard).

The Best Interest Standard and Its Problems

The best interest standard has long been recognized as being problematic.² Many of these difficulties arise from the vagueness inherent in the concept of an incompetent patient's best interests; these will not be explored here.³ But difficulties also arise when the patient's interests conflict with those of family members (or others).

The Patient's Interests

Let us assume that patients generally want to have their preferences fulfilled in the absence of higher level preferences to the contrary (for example, a smoker who wants a cigarette, but who also wants to stop smoking). In this case, Mr. C might well want to be able to gratify his desires, and he seems to lack the cognitive capacity to reflect critically upon them. Thus, one might argue that the surrogate should

make treatment decisions to maximize the satisfaction of his desires. This would involve consenting to surgery and associated treatment for the tumor in his neck, probably resulting in a higher level of physical functioning. Unfortunately, this patient's most noticeable desires are sexual in nature and have previously led him to harm others. So, treatment decisions based on a simple desire-gratification view of interests would maximize the likelihood that he would return to his predatory ways. This simple preference fulfillment approach indicates that the patient's interests and those of the community would be in conflict.

DeGrazia has argued that not all desires are equal when it comes to determining one's interests; he says we should consider only the gratification of "informed" or "rational" desires.⁴ If a desire is "informed" only if the patient himself or herself is in possession of the relevant information and grasps its significance, or "rational" only if the patient has her- or himself arrived at it via reasoning (or could so reason, if prompted), then this patient's low cognitive functioning may prevent him from having any qualifying interests. But surely patients with very limited cognition still have interests, so perhaps we should be guided instead by those desires that would be held by a hypothetical informed and rational agent. It seems likely that this set of desires would include wanting to maintain health and a high level of functioning, experience satisfaction, and avoid pain, discomfort, indignity, and so forth.

Although these desires are very different from this patient's primitive sexual urges, treatment decisions guided by them will be much the same. As before, the surrogate would select treatment to remove the tumor in the patient's neck and restore physical function (but without improving cognition, changing the patient's urges, or giving him the capacity to govern his behavior). Given the problems with finding a suitable treatment facility or program, it seems likely that this patient would eventually be released into the community, where he would pose a hazard to others. Those involved in the ethics consultation were not aware of any other treatment alternative that would both address his declining function and yet maintain his eligibility for residency in the secure facility. So, the "rational desires" approach also involves a conflict between the patient's interests and those of the community.

Incorporating Family Interests

When decision-making guidelines such as the substituted judgment and best interest standards were first developed, surrogates were instructed to

focus on the patient, giving very little weight to the interests of others. The President's Commission argued that surrogates should take the family's interests into account only if the patient would have done so.⁵ Similarly, some commentators asserted that "the family's rights *vis à vis* the medical care of an adult are limited to ensuring that the wishes of the patient are fulfilled and to expressing their considered judgment regarding what is in the best interest of the patient, given their presumably more intimate knowledge of the patient and his life and values."⁶

It wasn't long, however, before ethicists challenged this narrow focus, arguing it was permissible and appropriate—perhaps even obligatory—for surrogates' decisions to be influenced by the family's interests. Hardwig, for instance, held that the interests of family members are legitimate and should be taken into account regardless of whether the patient (if competent) would have done so.⁷

Family relationships play several roles here. First, they make it likely that the patient's family members will have adequate knowledge of the incompetent patient to make judgments about which goals should be pursued, which risks are worth taking, and so forth.⁸ Second, these relationships provide a sort of authority to make these decisions.⁹ Third, and most importantly in this context, when the interests of the family or its members conflict with those of the patient, the family has a special claim to have those interests taken seriously. In some cases, the family may permissibly decide upon a treatment that is less than optimal for the patient in order that the interests of family members are not unduly thwarted. (It is worth noting that family relationships also make these tasks much more difficult in some ways. Surrogates are called upon to make complex decisions in the face of medical uncertainty, grief, financial stress, financial conflicts of interest, relational ambiguity, and so forth.)

There are, however, important boundaries to be observed when surrogates make these decisions. Kopelman argues that surrogates' decisions "must meet at least a minimum threshold of acceptable care,"¹⁰ and Kapp explains that treatment decisions must "serve a therapeutic interest of the patient."¹¹ The interests of family members may be taken into account, but not to the extent that the well-being of the patient is entirely overridden.

Extra-Familial Interests

In addressing these patient-family conflicts, the literature on surrogate decision making has tended to assume that family interests may be taken into account because they are *family* interests.¹² If the

treatment that is optimal for the patient would involve serious burdens for the family, this line of reasoning leads to the conclusion that families (acting as surrogates) are permitted to choose some suboptimal treatment, provided it meets certain minimum standards.¹³ But it is still assumed that if the patient's interests conflict with those of someone outside the family, the surrogate's role is to give them no consideration. For instance, if the patient would benefit from something that is in short supply (for example, a transplantable organ or a bed in a treatment program), family members acting as surrogates are permitted (and expected) to select them, despite the fact that doing so may conflict with the interests of the strangers competing for those resources. Similarly, Mr. C's sister would be permitted to choose a suboptimal treatment site if doing so would protect her children against this patient's behavior, but she would not be permitted to make that choice if her sole reason were to protect strangers.

It does not follow, however, that the interests of those outside the family should receive no consideration. The *surrogate* may not consider the interests of strangers when making treatment decisions, but this does not mean that those competing interests have no moral weight. Viewed from an ethical perspective, there is no sharp boundary between family members and others. Instead, we find ourselves in networks of relationships with family members, friends, neighbors, colleagues, community members, and so on. When a case can be made for incorporating the family's interests in a medical decision for an incompetent patient, a broadly parallel argument can generally be constructed for the conclusion that extra-familial interests ought to be considered as well.

For instance, consider Hardwig's discussion of surrogates and family interests:

Because medical treatment decisions often deeply affect more lives than one, proxy decision makers must consider the ramifications of treatment decisions on all those who will be importantly affected, including themselves. Everyone with important interests at stake has a morally legitimate claim to consideration; no one's interests can be ignored or left out of consideration. And this means nothing less than that the morally best treatment in many cases will not be the treatment that is best for the patient.¹⁴

Nothing in this argument relies on the nature of families. If justice requires that the family's interests be considered when making decisions for patients, then a parallel line of reasoning leads to the conclusion

that the interests of non-family members and broader social interests ought to be considered, too.¹⁵

The conflict about whether the interests of others should be taken into account when making the patient's treatment decisions may be rooted in a disagreement about which moral perspective to adopt. Consequentialism would support incorporating the interests of strangers in these treatment decisions, whereas a focus on respect for autonomy and the right to self-determination would tend to allow the (limited) consideration only of family interests (because of the role of the family in the formation and function of the individual).¹⁶ The consequentialist perspective conflicts with the patient-centered approach to practicing medicine, although it fits well with the population-focused approach to public health, and with distributive justice.

There are already familiar and established mechanisms for balancing the interests of patients against those of strangers. When allocating transplantable organs, for instance, we routinely balance patients' interests against one another—a process in which consequentialist ethical principles are far more prominent than autonomy or self-determination.¹⁷ When a surrogate's choice of a transplant is a poor use of those resources, that decision is rightly overridden.¹⁸

Consider the public health response to outbreaks of infectious disease when the disease is serious, easily spread, and we lack vaccines or other effective prophylaxis. In such circumstances, quarantine and other measures are commonly taken, even though they are designed to benefit others at the expense of those who have been exposed.¹⁹ Exposed individuals who want to move about freely would have that decision overridden; their individual interests would conflict with and be overridden by the community's interests. As with allocation decisions, public health utilizes consequentialist reasoning to balance competing interests in ways that have found broad support. There is no reason this model cannot be adapted for balancing patients' interests against those of people outside their families.

This has already found its way into the literature on surrogate decision making. For instance, these extra-familial interests are noted explicitly by Brody:

While the interests of the patient will often be the predominant factor to consider, in part because of obligations of promise keeping and fidelity to the patient and in part because the patient is the most affected, there will be cases in which the interests of others (family members, caregivers, society) take precedence, because

these are cases either in which the interests of others are affected far more than the interests of the patient or in which the caregivers have greater obligations to others.²⁰

Kopelman agrees that legitimate interests should be taken into account regardless of whether these arise within the patient's immediate family: "The best interests standard was introduced to give incompetent patients legally enforceable rights to a minimal level of care," but this "does *not* require ignoring all other duties, allocation plans for scarce resources, or others' interests in deciding what ought to be done for someone."²¹ There are legitimate worries, however, about having the *surrogate* try to balance the patient's and family's interests as well as extra-familial ones.

Who Should Balance Competing Interests?

If extra-familial interests are to be taken into account, who should do it and how? When the patient is incompetent, the surrogate has authority to make choices and consent to treatment, but she or he ought not to be responsible for weighing all the competing interests when they include (as in this case) factors beyond the family. The surrogate's role is chiefly to promote the patient's interests and secondarily to balance those against conflicting *family* interests. But when broader social concerns arise, the task of balancing these factors—and thus the final decision about what to do—should lie elsewhere. Brody both acknowledges the legitimacy of extra-familial interests and warns against having the surrogate try to resolve conflicts among these and the patient's interests: "The role of the proxy decision maker is to speak in place of the patient, to advocate what the patient would have advocated. That is the point of the substituted-judgment standard. It remains for others to decide whether to accept that advocacy. They usually will, for all the familiar reasons. But when the interests of others are more affected, or when other special obligations are present, they will not."²²

Unfortunately, there does not seem to be any body charged with this responsibility, any clear ethical guidelines, or any supporting policy or legislation for this sort of decision making. Public health agencies, policy, and legislation provide this structure for balancing competing interests during an outbreak of infectious disease.²³ For allocating such resources as transplantable organs, we have the federal government's contract with the United Network for Organ Sharing, with its scoring systems, waiting lists, and so forth. But for other kinds of circum-

stances, we do not yet have any mechanism or guidelines for balancing the interests of a patient against those of individual strangers or entire communities.

Public health and resource allocation systems provide a consequentialist framework balanced with the recognition of individuals' rights that would be suitable for this weighing of competing interests. In a case such as this, it seems likely that the interests of the community that are at stake would *not* override the patient's therapeutic interests; that is, a system for balancing the interests of the patient and the community would reach the conclusion that the surrogate's decision to proceed with surgery (to remove the tumor from the patient's neck) should be honored. After surgery, Mr. C may no longer be eligible for treatment in a secure facility, and he may once again pose a risk to others. But there is no certainty that others would be harmed, and the risks involved can probably be mitigated by means less drastic than withholding treatment (although those have yet to be determined). If there were greater certainty that the patient's release would result in harm to others, and if there were no less drastic means of avoiding that harm, then we could build a compelling ethical case that the surrogate's decision to proceed with surgery should be overridden.

The hospital ethics committee that considered the case presented above discussed the interests of the community, but did not want to undertake the responsibility for balancing those against the patient's interests. Even so, this may be where the balancing ought to take place. In the committee's deliberations, the physician could present the patient's "therapeutic interests"; the surrogate (if a close friend or family member) could provide more information about the patient's interests and balance those with other family interests; and one or more other committee members could present the case for extra-familial interests (for example, the health and safety of the public). (The ethics committee might play this role even if the case did not involve an incompetent patient represented by a surrogate decision maker.) This would be faster, less expensive, and less confrontational than trying to resolve these issues through the courts—provided these committees are provided with the appropriate legal and policy framework.

This process would be complicated in cases such as this by the fact that the patient is very unlikable. It is very tempting to withhold treatment to punish the patient for his past behavior or his perceived moral character, to overestimate the probability that he will cause harm, and so forth. The ethics committee worked hard to avoid these pitfalls, and tried

to focus on Mr. C's medical needs and on bringing about the best outcome from his perspective; the issue of protecting the community was left to (unspecified) others. In such cases, the surrogate or ethics committee should push aside any distaste or dislike for the patient, and focus on what is medically indicated and what would improve the patient's quality of life (as the patient sees it).

If hospital ethics committees are to be given the role of balancing the patient's interests against those of the community, important practical challenges will have to be overcome. This role is not among those traditionally assigned to hospital (or other) ethics committees.²⁴ It will be difficult to design a system that insulates the committee's deliberations from inappropriate influences such as the personalities of its members, the likability of the patient, the interests of the institution, and so forth. Nevertheless, this task should be undertaken; the alternative is to continue to neglect morally weighty considerations.

CONCLUSION

This case illustrates that when the interests of the patient conflict with those of the community, some means of balancing these interests is ethically required, but no practical structure currently exists to handle it. The functions of hospital ethics committees could be extended to address this need.

Cases such as this would probably become more common if political or economic factors lead to reductions in healthcare facilities and programs. We need to prepare our institutions and communities by developing the appropriate laws, policies, and the ethical analysis on which they should be founded.

NOTES

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