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What Families Say about Surrogacy: A Response to "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions"

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The authors of "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions" (hereafter "Autonomy and the Family") have conducted a small qualitative study of terminally ill patients to arrive at what would seem to be common-sense results: different patients and members of their families have different understandings of the nature, scope, and justification of families' roles in the decision to perform cardiopulmonary resuscitation (CPR) in the event of an in-hospital cardiac arrest. The differences that emerge, however, say the authors of the study, tend to draw on similar normative notions about familial responsibilities, familial strengths, and familial weaknesses.

These results are taken to support a policy of diversity in approaches to medical decision making. Different patients and different families should be allowed to play different roles in decision making, patients should not be forced to make decisions they do not wish to make, and family members should not be forced to participate in making decisions for their ill relatives if they don't want to. The authors view these results as a challenge to clinicians and policy makers, although why they're a challenge isn't clear. Is the idea that research results of any kind constitute a challenge as long as they support a change from current practice or policy? Or is the particular change advocated here supposed to be especially difficult to bring about in some respect(s)? If so, the cause of the difficulty might be confusions about autonomy that are so tenacious they even influence the conduct and interpretation of this study.

A strength of "Autonomy and the Family" is that it allows us to hear the voices of some patients and family members discussing very difficult issues among themselves. The article conveys an immediate sense of how bioethicists' abstractly characterized norms and procedures (autonomy, proxy decision making, decision-making standards) appear to, and are thought about by, those whom they most directly affect. It seems to us that the article's conclusions ought to be endorsed, as far as they go. If they were absorbed into Austra-

lian medical practice, that would constitute progress — at least, to the extent to which current routine inflexibly assigns DNR decisions to competent patients or to families of incompetent patients, regardless of what the parties themselves want.

We believe, however, that the road to these unsurprising results and the ensuing reasonable recommendations is bumpier than it needs to be, and that the authors miss the chance to address some of the most interesting ethical issues lurking within the subject matter of the article — issues surrounding families, decision making, and end-of-life care that, if better understood, could improve how we die in hospitals. We'll argue that the question the authors use to locate their examination of the role of the family in end-of-life decision making, while very much taken for granted by healthcare professionals and bioethicists alike, is seriously misplaced. We'll then explore some of the distortions and misinterpretations that arise from too single-minded a focus on autonomy at this location. And finally, we'll reflect on the oddity of regarding families as though their primary role in the care of the dying is to make treatment decisions — let alone decisions that conform to professional caregivers' code of ethics.

THE DNR QUESTION

We begin with our concerns about the conceptual site of the interviews. The patients, all suffering from cancer and none with a life expectancy of more than three months, are asked something (it isn't clear exactly what) about the degree to which their families either do or should (this isn't clear either) participate in the decision not to receive CPR if they suffer a cardiac arrest. The authors explain that, just as in the U.S., "CPR is the default option for patients who experience a cardiac arrest within an Australian medical institution."

But *why* is it the default option? A number of retrospective studies report that patients receiving CPR after in-hospital arrest seldom survive to hospital discharge, and this is particularly true if they suffer from cancer, vascular disease, chronic liver disease, end-stage renal disease, or other serious long-term conditions.¹ In one study, a mere one out of 29 resuscitated patients whose underlying disease was malignancy survived, only to die within one year (the study is silent regarding whether this patient was in the final stages of cancer at the time of the resuscitation).² Given these grim statistics, why are cancer patients with fewer than three months to live being presented with a DNR decision at all? And *how* is it presented to them? A Medline search and review of the literature conducted in 2004 indicates that conventional CPR in adults produces an incidence of rib fractures ranging from 13 to 97 percent and sternal fractures from 1 up to 43 percent, depending on the age and general condition of the patient.³ Were the patients in the current study made aware of these data?

They should have been, if the public's general ignorance is anything to go by. A 2006 survey of 100 patients aged 70 years or older, randomly selected from the general medical, internal medicine, and emergency departments at an urban medical center in the U.S., revealed that 81 percent of the respondents "believed that their chance of surviving inpatient CPR and leaving the hospital was 50 percent or better"; 23 percent of the respondents thought it was 90 percent or better.⁴ If, as is likely, the cancer patients labored under a similar misconception, did anyone explain to them how slim the chances really are and how physically traumatic the procedure? This is not the impression received from the interviews.

Let's suppose, though, that the study subjects had been carefully informed that for end-stage cancer patients, CPR is a punishing ritual with virtually zero odds of meaningful success — that there is almost no chance that resuscitation could prolong their lives past the three-month mark of their current prognosis. Because almost no chance is not the same as no chance at all, some patients might nevertheless consider the resuscitation option to be a reasonable object of deliberation. But then the question arises as to whether they would reason about a similar option in similar ways if they were at home. How much burden would they accept outside the hospital context for an equally tiny chance of extending their lives by at most a few weeks? Would they, for example, take seriously the possibility of not traveling by car for a month for an infinitesimal reduction in their odds of dying? Maybe some of them would. But the point we want to press here is that, as peculiar as it would be for families to sit around the dinner table helping Dad decide whether

to undergo a Ford-free February, it's no more peculiar, if one stops to think about it, than sitting around the hospital bed helping Mom in the end stages of cancer decide about CPR.

AUTONOMY: GOOD SERVANT, BAD MASTER

The authors of "Autonomy and the Family" vaguely characterize patients' autonomy in two ways: as "holding that patients have a right to make decisions about their healthcare" and as "relational," locating individuals "within a network of social relationships and moral obligations" and emphasizing "the presence and effect of emotions in decision making." More precisely, autonomy as properly understood in healthcare contexts is the source of the right to exercise an effective veto over unwanted treatment, expressed in practice by informed consent policies. The individuals who consent to or decline treatment are certainly nested within a network of social relationships (more about this later) and may or may not include emotions in their deliberations, but these matters, we think, are better understood if they are not subsumed under the concept of autonomy.

While respect for autonomy is surely an important value in any healthcare context, a single-minded focus on it is apt to produce moral astigmatism, creating blind spots or visual distortions where clarity of sight is particularly needed. So, for example, as we've just suggested, a fixation on autonomy can distract attention away from the context in which it's exercised, allowing a DNR decision for end-stage cancer patients to be passed over as unproblematic. Equally, this fixation allows other moral values to be absorbed under the respect-for-autonomy rubric even though they are conceptually quite distinct: in "Autonomy and the Family," the best-interests standard for proxy decision making is mistakenly characterized as an autonomy-motivated standard, although it's actually a beneficence-based standard to be used when a patient's values and desires are unknown (or determined not to be authoritative, as with children or the mentally ill). Best interests is a generic standard, in which the interests in question are determined from the perspective of a "reasonable person."⁵ It's invoked in precisely those cases when no autonomy exists.

Focusing solely on autonomy also produces the hammer-and-nail problem. If to a hammer everything looks like a nail, so to researchers fixated on patient self-determination all study data look like exercises of, infringements on, or threats to autonomy. For instance, here is what one study participant, Sally, says about her family:

I said I wasn't going to give my opinion at first. And they all gave their opinions on it. And they were all heartily agreeable that I should fight on. Do take the necessary precautions, the treatment that was being offered to me, and that. That they were behind me. And they spoke so nicely about it that I didn't answer them straight away, but I thought about it, and I thought, "I cannot refuse them that, try, try it."

The researchers interpret these data as Sally's expressing "an implied ultimate right to accept or decline [her family's] preferences," although they worry "whether Sally's actions might represent some degree of family coercion or simply Sally's autonomous decision to engage and accept family viewpoints." But to look at it this way is to miss a more plausible interpretation of what Sally is actually saying, which is that she wants to continue treatment because her family will go through it with her. She's not standing on her rights or concerned about being browbeaten: she's undertaking a venture that requires family participation. To pit Sally against the family is to miss that Sally is a *part* of the family. There is an "us" here that has deliberated together and come to a decision about the best thing to do, against the backdrop of a shared understanding that (a) Sally is a necessary part of "us" and (b) the rest of "us" will take care of her.

Of the number of interesting issues raised by Sally's comment, patient self-determination is pretty far down the list. We see what she describes as having much less to do with autonomy than with agency, and in particular, with shared agency. To judge by how they are acting, Sally and her family may well constitute what Carol Rovane calls a "group person" — a person composed of many single human beings who share a "single rational point of view" from which they can engage in distinctively interpersonal relations.⁶ Michael Bratman calls this kind of collective action "shared cooperative activity," and argues that it is characterized

by mutual responsiveness, commitment to the joint activity, and commitment to mutual support — all of which are clearly visible in the interchange that Sally reports to the interviewers.⁷ Margaret Gilbert too has argued that groups have a capacity for collective agency that can't be reduced to that of the individuals of which they are composed: the "we" that is made up of Sally and her family, Gilbert might say, has its own beliefs and reasons and is capable of intentional action.⁸ On such a reading, when Sally says, "I cannot refuse them that," she's not exercising her final and ultimate authority to choose. She is rather finding out what her commitment to sharing her life with her family requires of her.

The focus on autonomy makes mischief elsewhere in the study as well. As the authors see it, the problem with Sean isn't so much that family members might be constricting his autonomy as that he himself won't exercise it. "[I've] never even thought about anything like [making a decision about DNR]," Sean says. "But I think, yeah, I think my answer would have to be, well, . . . I'd be happy that the family, whoever were around at the time, would do just what they wanted to do." To the authors of the study, this is evidence that Sean is neglecting his own autonomy, abdicating responsibility for decisions that are properly his to make. And they write as though they disapprove: despite their general view that patients should not be forced to make decisions they don't want to make, they regard his "failing to make an autonomous, adult decision about his own healthcare" as leaving him "subject to moral censure."

Here again, we think, the autonomy-driven analysis has produced a distorted understanding of what the subject of the interview is doing. To clear an obvious point out of the way first, we note that refusing to exercise one's right to self-determination is, contrary to what the authors imply, no sin. That patients have a *right* to reflect critically on the recommendations of their caregivers does not mean that they have a *duty* to do so; as the authors elsewhere acknowledge, rights, typically, can be waived. We suspect, though, that Sean is doing something more interesting than waiving a right. Instead he may well be asking his family to engage in an instance of *substituted agency* (as contrasted to substituted judgment). He wants them to act, not only in his interests, but *in his stead*. If that's correct, then Sean doesn't care as much about the outcome of the decision as he does about who makes it.

Let's suppose the contrary — that what matters most to Sean is the outcome. In that case, he might make the decision himself. He could exercise his autonomy by trying to determine how far his cancer is likely to have progressed by the time he suffers a cardiac arrest, figure out what quality of life, if any, CPR under those circumstances might buy him, and decide accordingly. Or he might think that he doesn't know enough to make the decision himself. He could then exercise his autonomy by asking his doctor to draw on her expert knowledge to make the decision for him. In fact, in the not too distant future, we could even imagine him programming all the relevant information about his physical condition and his personal values into a computer that could predict with 99 percent accuracy what he would choose when he got to that point.

But Sean does none of these things. Instead he says he wants whoever in his family is around when the time comes to do what they want. This suggests that while the outcome doesn't seem to matter to him (or that he doesn't think he's in a position to predict what considerations will be relevant when the time comes), he does care that the outcome be effected by the agency of those he loves. He doesn't turn to his doctor, and we suspect he wouldn't turn to the hypothetical computer, either. He turns to his family, not because they can be counted on to make the decision as he would have made it (substituted judgment) but because whatever the decision is, he wants it to be *their* decision (substituted agency). Sean's preference isn't for everybody, but given the alternatives of guessing when one has only a hazy grasp of what the situation will be when a decision about CPR must be made, or having a stranger (whether physician or machine) make the decision for you, we imagine that others beside Sean would want to leave these matters to be decided by those with whom, as we sometimes say, they identify.

In their discussion of what Sean says, the authors, perhaps against their own better judgment, treat autonomy as if it were a substantive moral or medical goal: a good to be pursued for its own sake. At least as understood in bioethics and sound clinical practice, however, autonomy is not the highest human good, but a procedural value: it's a side-constraint on how goods are pursued. That it's disrespectful for medical professionals to treat competent adults as though they were children goes without saying (or should, although

it's still sometimes necessary to say it), but it's not the business of healthcare professionals to promote certain character types — planners and organizers, informed consumers, take-charge guys — among their patients. Claims about the roles and responsibilities of patients are best established on philosophical rather than empirical grounds. At most, empirical studies could only show that some people want to take up executive roles regarding their medical care, not that they have the responsibility to do so. Nothing about the concept of autonomy as a consensus value in healthcare entails that taking such roles is a general moral requirement.

WHAT FAMILIES ARE FOR

The authors note that

the terms *family* and *next-of-kin* may be problematic. Their use obscures the fact that the entity to which they refer is composed of individual members in different relationships to the patient (who is also part of that family), who have different sets of values, experiences, and needs. In nominating family members as surrogate decision makers, participants reproduce the construction of the family as a homogenous "superpersonality" that thinks and acts as one, despite evidence to the contrary. . . .

Two things in particular strike us about this observation. The first, as we've already suggested, is that families are often more than the sum of the individuals they comprise, so worrying that the designation "obscures" the fact of differences among those individuals is a bit like worrying that the term 'orchestra' takes away from the violinists, bassoonists, and clarinetists who are playing the music. The other thing that's striking, though, is how often the term 'family' is lamented as problematically homogenous, when we so seldom hear similar worries about 'doctor,' 'nurse,' or 'treatment team' — as if the concord or discord among individuals in these groups were of little importance to their involvement with patients.

We concur with the authors' view that it's a mistake to idealize families as decision makers, as individual family members can be selfish, overcome by emotion, over involved in the care of the patient, sexist, withdrawn, or just plain mean. But the same holds true for *all* potential decision makers, whether doctors, ethics committees, or the patient herself. And while it's a mistake to idealize any of these players, it's just as much of a mistake to idealize the decision. The best end-of-life decision making doesn't necessarily replicate as precisely as possible what the patient would have chosen; if it did, to hearken back to our reflections on substituted agency, the patient would be obligated to find the best possible decision maker (or computer program) to make the decision for her.⁹ Instead, the goal is to attend to the needs and values of the dying person, which may be better served by taking pains over who decides, rather than what is decided.

The responsibilities of a terminally ill patient's family members are hardly exhausted by making treatment decisions when the patient can't. They have a wide array of other tasks to perform. Families (a) provide hands-on care, in increasing amounts and of increasing complexity; (b) provide financial support; (c) monitor the quality of the patient's professional care; (d) fill out insurance forms and do battle with insurers; (e) drive the patient to doctors' offices and therapy sessions; (f) monitor the patient's medications; (g) sleep at the patient's house so someone will be there in the middle of the night; (h) sit with the patient; and (i) much, much more.

In the course of all this activity, we argue, they are also doing something of enormous moral importance: they are holding the patient in her identity. By this we mean that they are mitigating the force of the illness's assault on the patient's sense of who she is. The physical, mental, and spiritual changes that terminal illness inflicts on its victims cannot, of course, be staved off altogether, but by interacting with the patient in familiar ways, being with her as she enters unfamiliar territory, and keeping her nested within the web of intimate relationships that sustain her, family members remind the patient of who she has been and help her to continue to be it.

Terminal illness can and frequently does play havoc with one's identity. To be even seriously ill for more than a few days is to lose control over one's physical and mental processes. It puts a stop to one's usual activities and interferes with one's memories, hopes, plans for the future, and ongoing projects. It usually involves hospitalization, which means that one is uprooted from one's customary surroundings and thrust into a milieu governed by insider understandings to which one isn't privy. All of this contributes to a disintegration of one's sense of self. The physician Eric Cassell conceptualizes this disintegration as *suffering*: to suffer is to feel oneself coming undone. Suffering persists, writes Cassell, until the threat to the identity has passed or until the integrity of the identity can be reestablished in some manner.¹⁰

It's when a patient suffers in Cassell's sense of the word that she most needs the help of others to hold her in her identity. Torn out of the contexts and conditions in which she can maintain her own sense of herself, the patient runs the risk of losing sight of who she is — at least temporarily — unless someone else can lend a hand. Because family members are typically the people with whom the patient's life has been longest and most closely intertwined, they are the ones who, not only by their actions but also just by their presence can make the patient feel more like herself.

The changes in the patient are terrible and real: she is no longer, nor ever can be again, exactly the same person she was before she became ill. But there can be greater or lesser degrees of continuity between the self she was then and the self she is now — selves are not, to use Charles Taylor's language, temporally punctual.¹¹ Because some important things about us stay the same even as other important things change, the disconnect between past and present selves is never complete. That we are someone's wife, sister, or mother endures, which is what makes it possible for the people with whom we are in those relationships to hold on to us as we navigate the changes that assault our self-conception.

Family members also often need to hold each other when one of their own faces death. The loss of a parent, a spouse, or (especially) a child can inflict profound changes in who we are, and it's particularly then that we need others to anchor us lest we lose ourselves altogether. In the study, Pete says, "I know with my neighbor, she stood by her husband's bed day and night saying all the time 'Don't you dare leave me, don't you dare leave me.'" Pete's point is that his neighbor couldn't make good treatment decisions for her husband; our point is that she herself needs care, of the kind that those closest to her are often in the best position to provide. If she were to receive it, she might be an excellent proxy for her husband, although clearly that is not her primary claim to care.

The various manifestations of holding we describe here can be done well or badly. Pete's neighbor holds on to her husband frantically and desperately; other families can't let the patient go when it's time. Family caregivers become overwhelmed and take out their frustration on the patient. Others in the family refuse to do their share, or don't see why the primary caregiver needs a respite. These considerations don't, however, detract from the moral value of holding people in their identities when it's done well, any more than foolish treatment decisions lessen the importance of respecting patients' autonomy.

We would like to see discussions of shared and proxy decision making situated within the full range of responsibilities family members assume when one of their own is terminally ill. If this were done more often, bioethicists might better understand the practical and moral context in which families operate, the values that guide their thinking, and the roles and relationships that are likely to characterize them. As we've argued elsewhere, the failure to appreciate the distinctive features of families causes confusion and frustration in healthcare settings, distorts the way families interact with members who are ill, and puts pressure on families' precarious understanding of themselves.¹² What has happened, we think, is that healthcare treatment decision making has come to be seen as a 'carve-out', a detachable function that can be unplugged from the rest of family life and plugged into the healthcare context, where it is assessed according to the moral standards that govern the behavior of healthcare professionals. But because the delivery of healthcare is only one of many familial functions, and because families don't exist merely to serve others' ends, they are too different from healthcare institutions to share the same code of values. Treating them as if they did is disrespectful at best, and sometimes causes genuine harm.

We close with a caution against evaluative imperialism. It's true that the ethics of families has received little scholarly attention, possibly because families have been relegated to the private sphere by moral philosophers who are far more interested in the moral relations that hold in the marketplace than those that hold at home. For that reason and probably others, it's not hard to see why bioethicists and healthcare professionals alike might fail to notice that the differences between families and healthcare institutions give rise to different sets of norms and values. That said, however, when professional caregivers regard family members as extensions of the healthcare system, valuable only instrumentally — for the information they can provide about an incapacitated patient's former values or as a source of cheap semi-skilled labor — they are open to the charge of arrogance, whether they intended it or not. A closer look at what families are actually up to, unbiased by the assumption that medical ethics should govern everything to do with the care of patients, reveals all kinds of interesting things that would otherwise escape our notice. Here, as in so many other arenas of life, a little humility takes us a long way.

NOTES

1. G.E. Taffet, T.A. Teasdale, and R.J. Luchi, "In-Hospital Cardiopulmonary Resuscitation," *Journal of the American Medical Association* 260 (1988): 2069-72; F.J. Landry, J.M. Parker, and Y.Y. Phillips, "Outcome of Cardiopulmonary Resuscitation in the Intensive Care Setting," *Archives of Internal Medicine* 152 (1992): 2305-8; M. Karetzky, M. Zubair, and J. Parikh, "Cardiopulmonary Resuscitation in Intensive Care Unit and Non-Intensive Care Unit Patients: Immediate and Long-Term Survival," *Archives of Internal Medicine* 155 (1995): 1277-80; L. Bialecki and R.S. Woodward, "Predicting Death after CPR: Experience at a Nonteaching Community Hospital with a Full-Time Critical Care Staff," *Chest* 108 (1995): 1009-17.

2. Landry, Parker, and Phillips, see note 1 above.

3. R.S. Hoke and D. Chamberlain, "Skeletal Chest Injuries Secondary to Cardiopulmonary Resuscitation," *Resuscitation* 63, no. 3 (2004): 327-38.

4. D.H. Adams and D.P. Snedden, "How Misconceptions Among Elderly Patients Regarding Survival Outcomes of Inpatient Cardiopulmonary Resuscitation Affect Do-Not-Resuscitate Orders," *Journal of the American Osteopathic Association* 106 (July 2006): 402-4.

5. The standard discussion of this is A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1989), pp. 122-33.

6. C. Rovane, *The Bounds of Agency: An Essay in Revisionary Metaphysics* (Princeton: Princeton University Press, 1998), p. 127.

7. M. Bratman, *Faces of Intention: Selected Articles on Intention and Agency* (New York: Cambridge University Press, 1999).

8. M. Gilbert, *On Social Facts* (Princeton, N.J.: Princeton University Press, 1992).

9. This leads to the interesting question whether the patient is the best person to decide who the decision maker should be. And, of course, who the best person is to make that decision.

10. E. Cassell, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306, no. 11 (1982): 639-45.

11. C. Taylor, *Sources of the Self: The Making of the Modern Identity* (Cambridge: Harvard University Press, 1989).

12. H.L. Nelson and J.L. Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (New York: Routledge, 1995).