SUPPORT and the Invisible Family

John Hardwig

"I just have to believe that my mother simply isn’t aware of what she’s doing to me and my life."

The tone of weariness and near desperation in my friend Jane’s voice made it clear that if she did not believe this, she would be filled with anger and resentment at her dying mother. Despite terminal heart disease, her mother, Helen, an eighty-three-year-old former nurse, keeps opting for life-prolonging treatment. For the past eighteen months, the hospital has pulled Helen through crisis after crisis, each time discharging her back home, lucid and grateful, and only slightly more dependent than she was before.

For millennia, medical ethics has focused on the doctor-patient relationship. Thus, the SUPPORT trial to improve clinical decision making for seriously ill patients can be viewed as a report about the failure of this dyadic relationship. That is the way I expect most people to read it. And there clearly is a failure of this dyad: physicians who are so unconcerned about patient preferences that they don’t even bother to look at them when they’re placed in the chart, and patients who do not take advantage of opportunities to discuss their treatment preferences with their physicians.

Helen’s case, though, is different. Intelligent, articulate, and assertive, Helen has made her preferences for treatment very clear to her physicians and her wishes are being followed. The dyad seems to be working fine here.

If we look only at Helen, the story seems to be an unqualified success. A very difficult case (this woman might not have pulled through this episode) managed well. Discharged back home, still in a lucid state. End of the case, a job well done. Congratulations all around for one of those spectacular successes of modern medicine.

But we need to understand Jane’s weariness, frustration, anger, and resentment. These are not feelings generated by a simple success story with a happy ending. We must learn to tell the story from Jane’s point of view and not to end the story when Helen is discharged. Jane’s story is usually not heard. Helen has many advocates—doctors, nurses, ethics committees, most bioethicists, and our entire legal system. Jane will usually have none.

If Helen’s case is viewed simply as Helen’s case, Jane becomes invisible. The impact of the treatment on her life is not considered, her interests do not even enter the equation. At best, she is marginalized: her interests are considered, but Helen’s interests always trump Jane’s. Often, she is treated as a means (“family support system”) for helping her mother achieve her goal of continuing to live in her invalid state. Helen does have a strong family support system and that system is Jane. The home to which Helen is discharged is, in fact, Jane’s home.

I cannot do justice to Jane’s story here. But I will at least mention some of the things her mother’s fight against death have meant for her. She has been driven to the edge of physical, emotional, and economic collapse. Her savings have been exhausted. The prospects for her own old age have been devastated—a fifty-five-year-old with a modest income has too little time left in her employable life to rebuild a nest egg for retirement. Jane clings to a full-time job and another part-time job, desperately needing the money. She also knows that if she quits or is fired, she will have to relocate or change careers, neither a simple task for a single woman of her age. Fortunately, she can do much of her work at home, sandwiched between periods of caring for her mother. Jane has no social life now and no time to herself except during the periods when her mother is rehospitalized. That’s also when she can get some rest. Jane’s employers have begun to worry that Jane is not doing a very good job these days.

Viewed in terms of its impact on Jane’s life, her mother’s treatment is not a miracle of modern medicine, a triumph, or even a clear success. It is more like a disaster. Jane’s story is not unusual—there are literally millions of people in similar circumstances. To their credit, the authors of the SUPPORT studies have not confined themselves to a dyadic or triadic ethics. In fact, they have documented at least the most measurable impacts of treatment decisions on families in a recent article in JAMA.1 That part of the SUPPORT study deserves to be read in conjunction with this one.

Read by itself, this part of the SUPPORT study invites the wrong conclusions. The SUPPORT intervention asked physicians to take into consideration patient preferences and prognoses. The physicians failed to do so. Thus, this study strongly suggests that inappropriate treatment decisions are being made at the end of life and that they are being made by the wrong decisionmakers. I believe both are true. But if we think only in terms of the usual dyad or triad of bioethics, we may conclude that patient preferences and prognoses are the salient variables in defining appropriate treatment at the end of life. If this conclusion is drawn, families become invisible or are

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treated as means to the well-being of terminally ill patients.

How can we give patients' families their due? We can begin by at least acknowledging our responsibility for their plights. Those with a serious illness in their families are not simply people stuck in a bad situation. They are not just victims of unfortunate circumstances, bad luck, or cruel fate. Although an illness in the family may well be simply unfortunate, the treatment of that illness is something we decide. So, families are also the victims of our treatment decisions, our health care system, our bioethics. We have seriously compromised the lives of patients' families, often in ways they can never recover from. We must acknowledge as much.

We must also recognize that families are not simply or even primarily "patient support systems." They must not be thought of or treated that way by doctors, hospitals, health care planners, or bioethicists. To do so is immoral, as Kant made plain. It involves treating the rest of the patient's family as a mere means to the preferences of the patient. Others are implicitly treated as mere means whenever only one person's interests and goals are allowed to shape decisions that alter the lives of many people.

Everyone is an end in herself. The implications for the life plans of all family members must be weighed in responsible treatment decisions.

When this is done, the very definition of "appropriate treatment at the end of life" will be altered. If families are not marginalized, patients who survive to discharge back home in a lucid state cannot be viewed as unambiguous success stories. A treatment may be inappropriate even if the patient was treated according to her preferences and the cost was modest.

How modest is the cost, really? Cost to whom? Consider just the monetary costs. We are currently engaged in a badly needed effort to control health care costs. But if we think simply in terms of the triad, measures designed to save money will often simply shift much of the cost to the families of patients. Where they are, once again, largely invisible to us. We don't have to pay these costs, so we congratulate ourselves for developing a more efficient health care system. But the family may well have lost its entire savings, its home, and much of its income. That is not a modest cost.

So, who has the right to determine that treatment is inappropriate? Who has the right to make such decisions? The standard answer is clear: "Only the patient herself, at least within the options available to her in our health care system." Patient autonomy is still the supreme value we acknowledge in medical treatment decisions. That is one reason the SUPPORT study is so troubling: it suggests that patient autonomy is not upheld in the care of the terminally ill.

The SUPPORT study indicates that physicians are undermining patient autonomy by arrogating to themselves decisions that rightfully belong to the patient. But why should treatment decisions be restricted to the dyad? A genuine attempt to promote everyone's autonomy dictates that many treatment decisions should be family decisions. After all, that's the way people with families should make decisions that will dramatically alter the lives of members of their families. Medical decisions are no different. Sometimes, no doubt, family decisions are not possible, practical, or desirable. Even then, treatment decisions must attempt to maximize the autonomy of everyone whose life will be affected by the decision. If they do not, some people are inevitably marginalized or treated as a means merely.

Despite this argument, some may want to insist on preserving patient autonomy—the right of patients to make "their own" treatment decisions. After all, frightened and seriously ill people may not be able to hold their own in difficult and emotional family conversations. So, for practical reasons, it may be best to continue to let the patient decide.

But with autonomy comes responsibility. Indeed, the effects of our choices on the lives of others is the very cradle of moral responsibility. Thus, if we insist on patient autonomy, we must also insist that patients shoulder weighty moral responsibilities. We must learn to ask patients to consider not only what they want, but also the impact of their decisions on the lives of others. Often, what I want may not be a morally legitimate choice for me because it would impose burdens that are too great on others, particularly those who cannot easily refuse me.

Thus, many competent patients like those in the SUPPORT study have not only a right to discuss treatment decisions with their physicians, they have an obligation to do so. They have not only a right, but a duty to fill out appropriate advance directives. And for many terminally ill patients, it is wrong to choose life-prolonging treatment, no matter how much they may want it. Often, it is even wrong not to choose, for that saddles the family with the burden and guilt of having to do so. An obligation to choose one's own death when one wants to live is a heavy obligation, indeed. But such may sometimes be the moral price of patient autonomy.

The physicians in the SUPPORT study have taken on the role of decisionmakers. It would be interesting to know why they have done so. One possibility is that they believe both patients and their families are incapable of making stable and responsible treatment decisions because both are in the throes of serious emotional crises. If family conferences are often not workable and patients should not be asked to bear the moral responsibility that comes with autonomy, perhaps decisions should be made by physicians after all. Perhaps so. But not by physicians like those in the SUPPORT study. Not by any physicians who think of themselves as patient advocates, as most presumably still do. The role of patient advocacy may seem a noble one, but it is one-sided and unfair. It has seemed so self-evidently justified only because we have restricted our view to the traditional dyad. The advocacy stance is, in fact, one of the major reasons for the invisibility of families and their treatment as means to the patient's well-being. An ethic sufficiently sensitive to the patient's family would require physicians and other health care professionals to abandon the role of patient advocate. Or it would insist that they not make treatment decisions.
for patients with families. An advocate for one person is morally debarred from making decisions when more than one have legitimate interests at stake.

We must, then, move beyond the ethics of the dyad or even the contemporary triad. Instead, we must learn to think in terms of family justice. Fairness to all concerned will be a major factor in determining both who should decide and also what is the appropriate treatment at the end of life. That's the way decisions by and for people with families ought to be made—with everyone thinking about what will be best and fairest for all.

This idea might seem hopeless because families are so different and have such different conceptions of justice. We certainly have no theory of familial justice that is even remotely adequate. But questions of family justice cannot be legitimately avoided. Attempts to do so marginalize people. If families emerge from their invisibility, we will all be able to see many cases in which benefits to patients are not sufficient to justify the burdens they impose on their families. Ask yourself, Would you rather lose your career and all your savings at age fifty-five, or lose a 50 percent chance of living an extra year with a terminal disease at age eighty-three? Would anyone prefer the chance of an extra year?

But a health care system sensitive to the burdens treatment decisions impose on families is nowhere in sight. In fact, those who focus on the doctor-patient dyad will not even agree that such a system would be morally legitimate. In the foreseeable future, then, families will continue to be invisible, marginalized, or reduced to means. Costs will, no doubt, continue to be shifted to families. We will continue to be largely oblivious to the impact of our health care system and our treatment decisions on their lives.

In this context, the better the family—the more loyal, sensitive, and loving the caregivers within the family—the more we will take advantage of their resources and virtues. Unable or unwilling to divorce herself from her terrified and dying mother, Jane just keeps trying to hang in there. She and I have developed a little ritual. “How ya doing?” I ask when our paths cross. “I’m still vertical,” Jane responds. “That’s terrific, Jane, just terrific!” We smile sadly at the gallows humor. But the last time I saw her, she said, “If this goes on much longer, Mom is going to outlive me.”

References
2. Many patients agree. There is beginning to be evidence that patients would prefer that life-prolonging treatment be discontinued when it has a serious financial impact on their family members. (See, for example, Ashwini Sehgal et al., “How Strictly Do Dialysis Patients Want Their Advance Directives Followed?” JAMA 267 (1992): 59-65.) But the interests of other family members do not have standing because the patient wants them considered; they have standing whether or not the patient wants to consider them.

From Consumer Choice to Consumer Welfare
by Carl E. Schneider

In trying to understand the SUPPORT study, it may be useful to think of contemporary bioethics reform in terms of the principles of consumer protection. The central tendency of that reform (particularly in my own field—the law) has been to employ the model of consumer choice. That model sets as its purpose to allow consumers to choose the kinds of products they prefer. It seeks to accomplish that purpose primarily by supplying consumers the information they need to make choices and by insisting that they are given what they chose. Thus, for example, merchants may be required to reveal the actual terms under which they sell goods on credit, so that customers may decide whether they wish to pay the price. And once the customer has chosen a purchase, the merchant is held to the terms originally agreed upon. In short, the consumer choice model seeks to allow customers to make successful choices by providing them with a market that works in the economist’s sense, efficiently.

Bioethical reform may be understood along these lines. The doctrine of informed consent is, plainly, intended to provide patients the information they need to make wise choices that express their preferences. The patient is thus to become a consumer well-enough informed to make sensible choices in the market for medical care. The patient’s choices are then given more binding effect by, for example, various provisions for advance directives.

The consumer choice model is hardly startling and surely makes a good deal of sense. The free-market prescription was, for instance, quite