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SHOULD FAMILIES MAKE HEALTH CARE DECISIONS?

JACQUELINE J. GLOVER, PH.D.*

INTRODUCTION

The short answer is yes, families should make health care decisions. I write in support of so-called "family decision" acts that presume families are appropriate surrogates for incompetent patients until shown otherwise. What follows is an articulation and critique of the current conceptual framework for understanding the role of families, a discussion of proposals to change the conceptual framework, and some ideas for what a reconceptualization means in clinical practice.

I. WHY THE DISPUTE?

Discussion of the role of family in health care decisionmaking tends to focus on the extremes. We either identify with a more idealized notion of the family and downplay real difficulties like incapacity, enmeshment, disinterest and neglect. Or we identify only with the problems, downplaying the reality of essential and positive family involvement. We are informed by our own family experiences and by the families we encounter in clinical practice. My own experience teaches me that families vary widely in their reaction to the question of whether they should make health care decisions. Most are surprised by the question, because they either assume, "of course" or "that's the doctor's role."

Research seems to indicate that a majority of persons would prefer that family members make decisions when they cannot.¹ Actual clinical practice tends to assume a role for families and health care professionals routinely turn to families for consent, even when the legal basis is unclear.²

Yet the authority of families is highly circumscribed. We move quickly from the question of whether they should be involved to the

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1. See, e.g., Dallas M. High & Howard B. Turner, *Surrogate Decision-Making: The Elderly's Familial Expectations*, 8 THEORETICAL MED. 303 (1987); see also TIMES MIRROR, CENTER FOR THE PEOPLE AND THE PRESS, REFLECTIONS OF THE TIMES: THE RIGHT TO DIE 12 (1990).

2. See, e.g., Judith Areen, *The Legal Status of Consent Obtained From Families of Adult Patients To Withhold or Withdraw Treatment*, 258 JAMA 229, 229-35 (1987).

question of how much. Perhaps the short answer in the first paragraph is more accurately "Yes, but." We do not really trust families to make the "right" decision. Our laws and policies reflect Baby Doe³ worries that families will provide too little care, Baby K/Wanglie⁴ worries that families will insist on too much, or generic worries that families will not accurately reflect a patient's wishes, or worse, will act to override them.⁵

The concept of family itself is almost conceptually irrelevant under the current framework.⁶ Family integrity and interests, if legitimate at all, are always secondary to the values and interests of the individual patient.⁷ For the most part, the authority for family decisionmaking flows not from concerns inherent to the family, but from patient autonomy and patient beneficence.⁸ The analysis of whether a decision reflects what the patient would have wanted or what is objectively determined to be in his or her best interest does not include the family relationship.⁹ To borrow Nelson's language, such accounts of moral authority fail to take the family seriously.¹⁰

II. CURRENT CONCEPTUAL FRAMEWORK

A. Defining Family

Before discussing the current framework and its difficulties in more detail, it is important to provide at least a working definition of what is meant by family. For many skeptics of family decisionmaking, one of the major problems is the difficulty in understanding who

3. The original Baby Doe case involved the withholding of highly successful surgery to correct duodenal atresia in a baby with Downs Syndrome who subsequently died. The limitation of life-sustaining treatment in newborns is now incorporated into child abuse legislation. See Health and Human Services Child Abuse and Neglect Regulations, 45 C.F.R. § 1340.15 (1992).

4. Baby K is a current case involving the court-ordered treatment of a baby who is missing all of the brain except a rudimentary brain stem (anencephaly). The hospital had petitioned to withhold life-sustaining ventilation over the objections of the mother. See *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994), *cert. denied*, 63 U.S.L.W. 3009 (U.S. Oct. 3, 1994). The case of Helga Wanglie involved a hospital's petition to stop life-sustaining intervention that professionals regarded as nonbeneficial over the objections of the husband. *In re Helga Wanglie*, No. PX-91-283, Fourth Judicial District (Mn. D. Ct., Hennepin County 1991).

5. See Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882 (1991).

6. See James L. Nelson, *Taking Families Seriously*, HASTINGS CENTER REP., July-Aug. 1992, at 6.

7. *Id.*

8. *Id.* at 6-7.

9. See *id.* at 9-11.

10. *Id.* at 6.

counts as family. Individuals have an entire range of kin with wide variability in how closely they are connected. Often individuals are closer to others outside a more traditional understanding of the family unit. There are certain associations we simply find ourselves in through birth or adoption. Yet there are also those important relationships we choose, such as our life partners and close friends.

As Jecker suggests, perhaps we should understand family more in terms of intimacy rather than filial status.¹¹ In this view, family more appropriately refers to those relationships that are long-term and characterized by such things as interdependence, dedication, caring, and self-sacrifice.¹² Such terms often describe our "found" associations.¹³ The concept of family unavoidably will have some gray boundaries and any account of decisionmaking will have to struggle with who counts at the bedside.¹⁴

B. Traditional Family Roles and Models of Moral Authority on Which They are Based

1. *Family as Clinical Helper.*—One of the oldest roles that we attribute to families in the medical setting is that of helper to the professional care team. It is the doctor who knows what is best for the patient, and families are instrumental in helping accomplish good medical outcomes. They provide emotional and financial support and perform a wide range of caregiving tasks. Obligations to the patient are an outgrowth of filial obligations in general. The willingness to provide what is needed for the patient to get better flows from love and concern. Decisionmaking is not really a part of this model of the role of family.

2. *Family as Tape Recorder.*—A more current model of the role of the family incorporates the above helping role, but adds the responsibility for speaking for the patient when he or she no longer can.¹⁵ Rather than assuming that doctor knows best, this model is based on the moral authority of patient autonomy.¹⁶ Families have a role to play in medical decisionmaking because they can provide the missing

11. See Nancy S. Jecker, *The Role of Intimate Others in Medical Decision Making*, 30 GERONTOLOGIST 65 (1990).

12. *Id.* at 68.

13. *Id.*

14. See *id.*

15. Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2068 (1992).

16. See Dan W. Brock, *What is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients?*, 3 J. CLINICAL ETHICS 121 (1992).

ingredient to a good decision—the values, views, and preferences of the patient.¹⁷ The assumption is that families are in the best position to know what the patient would have wanted.¹⁸ When making medical decisions, families under this account are instructed to provide a substituted judgement.¹⁹ They substitute or stand in for the patient, but only to speak as the patient would have.²⁰

There are several difficulties with this model. As many authors have indicated, recent research challenges the assumption that families do, in fact, know what the patient would want.²¹ Additionally, it reduces the family to mere tape recorders of patient preferences, especially if the requirement exists for a family to provide clear and convincing evidence. The knowledge families have is usually of a more indirect sort, based on the fact that they are familiar with values in general and not necessarily tied to specific health care interventions.²² As Brock points out, however, this “conventional view” of the basis for the moral authority of families to make decisions, with its shortcomings, is not necessarily definitive. It is just that no better alternative has yet been identified. Other sources of the moral authority of families to make decisions can be offered.²³ For example, the fact that patients themselves usually prefer family members as surrogate decisionmakers provides a basis for moral authority because it respects patients’ rights to self-determination.²⁴ Similarly, a policy or law, which is the result of a democratic political process that supports family decisionmaking, also provides moral authority for family decisionmaking.²⁵ Emanuel and Emanuel suggest, however, that patients would need information about research describing the inadequacies of family proxies before exercising the proxies.²⁶

17. Emanuel & Emanuel, *supra* note 15, at 2068.

18. *Id.*

19. *Id.*

20. *Id.*

21. See, e.g., Jan Hare et al., *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 154 ARCHIVES INTERNAL MED. 1049, 1049-54 (1992); Allison B. Seckler et al., *Substituted Judgment: How Accurate are Proxy Predictions?* 115 ANNALS INTERNAL MED. 92 (1991); Tom Tomlinson et al., *An Empirical Study of Proxy Consent for Elderly Persons*, 30 GERONTOLOGIST 54, 54-61 (1990); Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Treatment Preferences*, 43 J. GERONTOLOGY M115, M119 (1988); Nancy R. Zweibel & Christine K. Cassel, *Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies*, 29 GERONTOLOGIST 615, 615-21 (1989).

22. Brock, *supra* note 16, at 121.

23. *Id.* at 121-22.

24. *Id.* at 122.

25. *Id.* at 121-22.

26. Emanuel & Emanuel, *supra* note 15, at 2070.

3. *Family as Assessor of Patient Best Interest.*—Families are often identified as appropriate surrogates because a regard for the patient's best interest flows from the families' strong bonds of affection. Even if they cannot or do not know what the patient would have wanted, they will act out of their obligation to promote the individual's well-being. There is a rich tradition that is supported in current law and policy that families are primary care providers and have wide-reaching obligations to do so. The state only steps in when families cannot fulfill this caretaking role, and the threshold for intervention is fairly high. The duty of beneficence is the basis of this role, just as it was of the helper role. A major difference, however, is in who gets to determine best interests. Rather than assuming simply that doctor knows best, this model suggests that families know best, too. A decisionmaking role is an extension of their caretaking responsibility.

An obvious difficulty with this model is that families do not always have strong bonds of affection or do not always act upon them. Additionally, it can be argued that families have a more subjective assessment of best interest, which cannot equal some kind of objective assessment. The bonds of affection that provide the rationale for family decisionmaking, may, in fact, get in the way. They may not be able to see what is 'truly' in the patient's best interest because they are too close and cannot separate their own values and emotional and physical needs. Although some would regard the fact that families share the consequences of medical decisions as a basis for their moral authority,²⁷ the above argument would suggest that it is, in fact, a moral liability.

C. *Traditional Role of Health Care Professionals*

Families are not the only moral agents involved in medical decisionmaking for incompetent patients, and as the current conceptual framework suggests, maybe they are not the primary ones. What counts more than the moral obligations of the family, are the values/preferences of the patient and the duties of the health care team. Health care professionals are regarded as independent advocates for the well-being of their patients, a duty that flows from professional obligations of beneficence and respect for autonomy. Their moral framework is patient-centered and their duties are regarded in very individualistic terms. Families are largely instrumental to pursuing independently determined goals of patient well-being. According to the

27. See John Hardwig, *What About the Family*, HASTINGS CENTER REP. Mar.-Apr. 1990, at 5, 5-10.

model, a good decision is a combination of what medicine can provide and what a patient would prefer.²⁸ There is only indirect concern for the family. In fact, professionals are obligated to protect their patients from the patients' families. Except for family practice, it is almost as if the family and patient are viewed in adversarial terms, as the common phrase "the family is not my patient" would suggest.²⁹

The current conceptual framework and the roles articulated for families and health care professionals seem largely a result of the fact that they grew out of profession-based reflections rather than more general moral beliefs.³⁰ Doctors and lawyers are concerned about their professional obligations and the institutionalized mechanisms through which they are fulfilled. The moral questions and concerns of individuals and families are rarely a starting point, even though we primarily inhabit other roles besides patient and litigant. Perhaps it is time to try and bring the two worlds closer together.

D. *Expanding the Moral Authority of Families*

The bases for the moral authority of families as decisionmakers articulated above are individualistic in that they focus on the patient. Families are viewed in primarily instrumental terms. They know the patient's values; they are who the patient would choose; they are who love the patient best and who will look out for his or her interests; or they are chosen through a democratic process that aggregates the preferences of potential patients. Other bases for family decisionmaking point to shared consequences among family members, and the "moral importance" of the family as an essential social unit.³¹ However, such bases are viewed as more controversial.³² None focus on the moral authority of the intimate attachment itself.

A few authors have begun to challenge this omission. Hardwig points to the importance of considering the interests of patients' fami-

28. See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 89 (1983); see also HASTINGS CENTER, *GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING* (1987).

29. I do not mean to suggest that all health care professionals disregard the family, only that our current conceptual framework does not require it. Also, family practice is itself struggling with who really is the patient, and how to view both the patient in the family and the "family in the patient." See, e.g., Barry Hoffmaster & Wayne Weston, *The Patient in the Family and the Family in the Patient*, 8 *THEORETICAL MED.* 321, 321-32 (1987).

30. Baruch A. Brody, *Hardwig on Proxy Decision Making*, 4 *J. CLINICAL ETHICS* 66, 66 (1993).

31. See Brock, *supra* note 16, at 122.

32. *Id.*

lies.³³ Nelson speaks of families as valuable in themselves.³⁴ They are joined by others, such as High,³⁵ who discusses the concept of family autonomy, and Schoeman,³⁶ who discusses the concept of parental authority. The family is an organic and enduring entity. It is not merely the source of information about an individual's values, it is integral in the initial and continuous development of these values. As Brody writes,

It is not simply that the patient does not really know whether he will be a burden to his family, and how much, until "the facts" are better spelled out for him. At a deeper level, this patient cannot really know what values he holds, relative to this situation, until he goes through a process of "trying on" various value stances and "bouncing them off of" others whose opinions and reactions he cares about. The question, "Is this value authentically mine?" requires for its answer complex questions such as, "If I act this way, how would my loved ones react? If they reacted that way, how would I feel then? And is causing them to react that way, and feeling about it the way that I would, consistent with the sort of person I want to be?"³⁷

Movement toward the moral authority of families based on the intrinsic characteristics and value of the family itself requires movement away from the traditional conceptual framework for understanding the role of families in medical decisionmaking.

III. RECONCEPTUALIZING THE ROLE OF FAMILIES

A. *Family as Necessary Connection—Taking Intimacy Seriously*

Most of current moral deliberation seems to assume that we are primarily strangers to one another. We are not united in any shared conception of the good life, so a liberal framework seems essential to help ensure that each of us can protect our interests and freely pursue the life course that we regard as best. A liberal framework is highly individualistic and focused primarily on preserving a sphere of nonintervention around the individual. Moral bonds are primarily of an

33. See Hardwig, *supra* note 27; see also John Hardwig, *The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions*, 2 J. CLINICAL ETHICS 20 (1993).

34. Nelson, *supra* note 6, at 7.

35. High, *supra* note 1, at 315.

36. Ferdinand Schoeman, *Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making*, 10 J. MED. & PHIL. 45, 45-61 (1985).

37. Howard Brody, *The Role of the Family in Medical Decisions: Introductory Guest Editorial*, 8 THEORETICAL MED. 256 (1987).

individual's own making. Our social fabric is woven from actual contracts among independent agents or from some theory of ideal social contractors.

But a theory that assumes we are basically strangers does not serve us well when we are trying to understand obligations among intimates. Certainly we choose some of our moral obligations, and contracts are a major way we do so among strangers. Yet we do not choose all our moral obligations. We simply find ourselves already embedded in certain relationships that carry with them important obligations. We are indebted to our families for the nurturance they provide. But beyond that, we are indebted to them simply for who they are—the people who love us and whom we love. Our very conception of who we are depends on the relationships in which we are involved. I am wife, mother, daughter, sister—not only professional and citizen. My self identity is necessarily interwoven with these other selves. As a family, we are an emotional, social, and moral unit that is greater than simply the collection of individual emotions, needs, or values.

The usefulness of a liberal framework is also challenged to provide a more complete understanding of interests. My interests cannot even be fully understood independent of the interests of those with whom I share my life. That is not to say that we share all interests in common or that my family could not act to harm important interests of mine. But in determining best interests, our current framework tends to emphasize the merely biological interests that pertain to an isolated person,³⁸ rather than those interests that are psycho-social and pertain to the individual within the family relationship.³⁹

Any account of the role of families in medical decisionmaking must take account of the fact that lives are shared. Not only do families have obligations to patients, but patients have obligations to their families. Respect for patient autonomy should not mean whatever the patient wants. Rather, a truer understanding of autonomy also incorporates the notion of responsible choosing.⁴⁰ Health care professionals should not ignore the family and their concerns and interests, because patients themselves must not ignore them. Respect for patient autonomy is not a license for unqualified self-concern. Another way to conceptualize such obligations is through a principle of justice.

38. Hardwig, *supra* note 27, at 6.

39. Jecker, *supra* note 11, at 68-70.

40. Hardwig, *supra* note 27, at 8-9.

B. Family as Commons—Taking Justice Seriously

Regarding only the interests of the patient to the exclusion of the interests of others is simply unfair. Hardwig argues that it is wrong to assume that the patient's interests immediately trump the interests of others.⁴¹ At minimum, the priority of the patient requires argumentation. The presumption should be that all interests are equal and the task of the family is to balance competing claims. Such balancing occurs in every other sphere of family decisionmaking. What is so special about the medical context? Even acknowledging that there are unique vulnerabilities that attach to illness, it would be a mistake to always regard them as overriding. As the benefits attainable for a family member who is sick diminish, the obligations of family members to provide them diminish as well—given that they have obligations to provide a whole range of benefits to other family members. Family members certainly are stewards of the well-being of their sick members. But they are also stewards of the well-being of those who are not sick. The patient himself or herself is also to be regarded as such a steward for the well-being of other members. As Jecker writes,

A tragedy of the commons occurs if members seek to take more common goods than they are entitled to or refuse to make appropriate sacrifices and contributions. A commons flourishes only if each party is willing to acknowledge that resources are shared commodities and respect others' stake in preserving them. Thus, even if competent patients formulate clear preferences, these preferences are not the final word on what constitutes an ethically sound decision.⁴²

Taking justice seriously in a reconceptualization of the role of families in medical decisionmaking has implications beyond surrogacy for incompetent members. I purposely omitted a reference to incompetent patients in the title of this article. If we truly take the role of families seriously, we will be lead beyond the narrow confines of the incompetent patient. The family is a necessary part of health care decisionmaking because the patient himself or herself should make decisions as a family member.

C. Justice Among Intimates

Yet all this talk about justice among family members seems somehow inappropriate for such an intimate sphere. We do not usually make rights claims against each other. I wrote earlier about love and

41. *Id.*

42. Jecker, *supra* note 11, at 69.

devotion, which seem to appeal to concepts of mercy and self-sacrifice, rather than balance sheets of interests.

More importantly, how do we determine an appropriate balance of competing interests? Hardwig's own proposal of a family meeting to balance everybody's interests for each medical decision⁴³ seems far-fetched. For all his discussion that suggests a unique kind of connectedness, his solution seems to be based more on individual autonomy in a democratic process. And how does he account for special obligations to the voiceless and vulnerable? We must remember that it is also a matter of justice when the patient does not receive due consideration. It is difficult to speak of equality in the face of circumstances that necessarily involve enormous inequalities in ability and opportunity. The great risk of more serious attention to the interests of families is the endangerment of less powerful members. The risk of not taking families seriously is the inability to move outside a hyper-individualistic framework to a necessary account of community obligation.

We falter because we cannot conceptualize what a proper balance of interests would look like, especially for the hard cases. And are they all inherently hard since we are weighing very different sorts of claims? But before we give up because we cannot conceive of a precise algorithm for a proper balancing of familial interests, perhaps there is ground to be gained by attention to the process rather than the outcome. Maybe we need to learn a lot more about how to talk about balancing interests before we decide it cannot or should not be done.

Carse describes some tools she thinks are necessary to understand fully what it means to be acting as a good or virtuous family member. She writes,

what must be sought through ethical deliberation and justification is not so much individually validated solutions to moral conflicts, as shared interpretations of problems and collective success in promoting understanding, reconciliation, and compromise among the parties involved in a case. We need to shift the focus in our accounts of moral adjudication away from the moment of individual choice to the *process of* collective reflection on the goods at stake in the choice.

This further suggests that we must pay attention in our ethical models of this process to those virtues needed to attune ourselves properly to the conditions of others—to others' values, fears, capacities, commitments, predicaments,

43. Hardwig, *supra* note 27, at 9.

or felt needs. Central to our conception of the moral self will be an account of those skills that help us to express ourselves and listen to others, to interpret what others say or do with sensitivity and insight, and to remain open in principle to transformations in our conceptions of the good at stake.⁴⁴

The role of families can be identified primarily as one of engaging in very personal dialogue about what it will mean for all when each becomes sick. Rather than some abstract concept of advance directives that puts primary emphasis on getting a person's wishes down on paper, attention is paid to the values that are formed and articulated in a mutual process. An advance directive may then become a sign that this process has reached a certain level—although the process of dialogue certainly continues.

D. The Role of Health Care Professionals

If we shift our moral analysis away from a more professional orientation to a more family-centered one, there are important consequences that follow for our understanding of how professionals should interact with families. There is no longer the conceptual luxury of viewing patients in isolation while viewing families only as instrumental to meeting patient needs. Professionals will have to learn more about patients and their families and become aware, if not involved, in the deliberation about family interests. If family interests are on the table, professionals will have to deal with them in positive ways, and not simply as indicators that the family is not functioning as a proper surrogate.

Some might suggest that taking families' concerns and needs seriously would diminish the role of health care professionals, rather than increase it, as I am suggesting. Rhoden, for example, views the physician as an advisor to the family, which maintains primary control.⁴⁵ When you shift away from the dominance of the medical model with its values, then the values of the family take priority. However, it is inappropriate to frame discussion as either doctors win or families do, as though decisionmaking is only an issue of power. The relationship among patients, families, and professional caregivers certainly involves issues of power, but that is not exclusive of the relationship. All maintain their moral agency. I think it is still appropriate to regard a good decision as one that combines both the subjective and objective views in a way that does not presume trumps. We must acknowledge that

44. Alisa L. Carse, *Justice Within Intimate Spheres*, 4 J. CLINICAL ETHICS 68, 70 (1993).

45. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 440 (1988).

the so-called subjective and objective views are not as easily distinguished as we tend to assume. Professionals, including doctors and lawyers, also bring their expectations and values to the discussion with family. What is needed is greater openness and communication.

Health care professionals also must maintain their role as unique advocates for the patient. They serve an important social function in helping trigger both informal and formal mechanisms when families seem to be acting in a negligent manner. Health care professionals will be the first to raise such concerns. What is changed under a reconceptualization is the acknowledgment that determinations of a threshold for neglect cannot only reflect a professional perspective. The interests of families must be part of our deliberation, not simply an automatic trigger for suspicious surrogacy.

IV. IMPLICATIONS FOR A RECONCEPTUALIZATION OF THE FAMILY ROLE

A. *More Accurate Theory*

One of the first implications of a reconceptualization is the development of a more accurate moral theory to help us understand our obligations to those who are sick and vulnerable. It is important to be sure we are operating with a theory that provides the best account of the moral universe. One advantage is that an improved theory may help us bridge the gap between conversations about what is owed this particular individual and what is owed each of us together.

It is ironic to me that as modern Bioethics begins to grapple with the limits of patient autonomy, we immediately jump over the family to discuss concerns about the allocation of scarce resources among strangers. Then we find that efforts at health care reform break down because many of us simply do not care about strangers. We like to talk about belonging to a community, but we are not sure if we want to join. And we see it as a matter of joining. Individual autonomy must be maintained. Perhaps discussions of justice among intimates can help bridge the gap between an idealized notion of individual autonomy, and an idealized notion of community. Families serve as the most basic level of community. If we can openly acknowledge the ways in which we are already in relationships, and the obligations thus entailed, maybe we can expand our sense of belonging.

If we continue the fantasy that we can only be concerned about isolated patients at the bedside, we will never be able to square this with our broader obligations of justice. And if we pretend that family interests do not count, how will we ever accept that anyone else's interests count?

One might answer that justice requires us to consider only universal limits and to worry about the idiosyncratic choices of families. Ironically, we acknowledge differences in access to health care across counties and states, perhaps, for many of us, as a starting point to a more universal plan. Wouldn't regarding the family as a commons be a more helpful starting point? We may solve many of our problems by acknowledging, first of all, that patients are not entitled to unlimited access to family resources. They are also not entitled to unlimited access to society's resources. When families are tempted to demand too much, our theory reminds us that there are limits to what a family can demand on behalf of a patient, because there are limits on what a patient can demand for himself or herself. Patients have obligations of justice, and families and health care professionals are not entitled to behave as though they do not.

B. *Improved Policy*

I have tried to show how our current conceptual framework, and the policy it supports, are deficient because they are based on a very narrow conception of autonomy and best interests. Advance directives and professional judgment are not sufficient. Family decision statutes are superior because they provide room for the family and a process of mutual deliberation at the bedside.

They also diminish the role of the courts⁴⁶ and help bring medical decisionmaking more in line with the role of family in other parts of our social life. The family enjoys a great deal of privacy when it comes to other types of decisions. Perhaps we have exaggerated the role of the state when it comes to medical decisionmaking. Acknowledging a state interest in the preservation of life has led us to behave as though people never die. As Rhoden points out, this exaggerated emphasis on preserving life for as long as possible is based on a medical model.⁴⁷

A family decision statute strikes a proper balance between supporting the family and safeguarding individual interests. In other social arenas, families are presumed to be meeting their obligations unless they are shown to be abusive or neglectful. The threshold is fairly high. The burden of proof lies with those who claim that fami-

46. There is disagreement about whether family statutes will increase or decrease court involvement. Emanuel and Emanuel suggest that they will increase court involvement. See Emanuel & Emanuel, *supra* note 26. Capron, however, suggests that they will not. See Alexander M. Capron, *Where is the Sure Interpreter?*, HASTINGS CENTER REP., July-Aug. 1992, at 26, 27.

47. Rhoden, *supra* note 45, at 379.

lies are neglecting their members. And even when they are, our social agencies work very hard for reunification.

A family decision statute also provides a mechanism for individuals to choose the person they think is best suited to make their choices. But it would be problematic to assume that no one exists to make decisions in the absence of such a directive. Such a presumption falsely rests the authority for family decisionmaking solely on the principle of respect for autonomy.

C. *Setting Limits on Family Authority*

A final thorny issue must be addressed. Regardless of conceptual framework, everyone acknowledges that there are limits to family authority. The disagreement comes in determining where we ought to set the threshold. A more traditional framework sets limits when the family does not "know" the patient's wishes, or has interests that make a particular decision suspect. The family has authority so long as they comply with an externally determined choice.

An alternative would be to assume the family has authority to make decisions according to their own moral deliberation in dialogue with professional caregivers, unless they can be shown to be incompetent or negligent. The standard for negligence should be the family decision can only be overruled if no responsible mode of thinking supports the decision.⁴⁸ Families would not be disqualified simply because they disagree with professional caregivers.

On the other hand, that may be too high a threshold. But what actually constitutes neglect? For many of us, experience with the Baby Doe regulations has led us to question a formulation that sets the threshold too low. Now, except in very circumscribed conditions, like imminent death or permanent unconsciousness, nontreatment may be considered neglect.⁴⁹ Quality of life judgments, which are an integral part of medical decisionmaking, are denied. But what are the boundaries?

We may reject the threshold of current Baby Doe regulations and still maintain that it would be wrong to allow nontreatment of babies like the original Baby Doe with Downs Syndrome. Most would agree that some mechanism for review should be triggered if a family wishes not to treat their elderly mother's pneumonia when she is otherwise in good health and they have recently moved her out of her home so

48. See Schoeman, *supra* note 36, at 58 (referring to standards for parents' decisions for their children).

49. Baby Doe Regulations, *supra* note 3.

they could move in. But a decision not to treat a family member who is severely demented and unaware of her surroundings should not be considered neglect. We can only struggle in the middle and use our paradigm cases to help draw boundaries that are necessarily gray.

CONCLUSION

I have argued that families should make health care decisions for incompetent patients, and beyond, that even competent patients should consider their familial obligations. A reconceptualization of the framework for understanding the role of families will look to the intrinsic value of family and not merely its instrumental value. Theories of justice among intimates will allow us to confront the worry that families will demand too much on behalf of their loved ones. And a concept of neglect will help us confront the worry that they will demand too little. Family decision statutes are an appropriate mechanism for balancing the interests of families and their individual members.