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# Autonomy and the Role of the Family in Making Decisions at the End of Life

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## INTRODUCTION

How should healthcare professionals (HCPs) handle situations in which patients apparently let family or other intimates influence their decision making at the end of life? For many, the answer to such a question would be to eliminate, as much as possible, their influence on patients' decisions and to encourage them to make a decision for themselves. This is likely to be the approach taken by many HCPs when they are faced with such a situation. The reason that HCPs would likely take this approach is because the dominant decision-making paradigm in Western medicine has been the two-party physician-patient dyad, based on what I refer to as the traditional individualistic concept of autonomy. Under this traditional concept of autonomy, patients are viewed as, to quote George Agich, "robust and independent,"[1] and are expected to make decisions that are free from any outside influence. Although this interpretation of autonomy has received criticism from numerous authors and is no longer dominant among bioethicists, it seems to remain a dominant concept among many HCPs in the clinical setting. I believe this is due largely to two factors: (1) older-generation healthcare professionals who were trained prior to the criticisms of patients' autonomy within the last 20 years may not have been exposed to such criticisms and the alternative views of autonomy that have been presented in the literature; and (2) the concept of autonomy that tends to get passed down to younger-generation healthcare professionals, through bioethics education in their disciplines, is the relatively simple and straightforward traditional individualistic concept.[2]

My goal in this article is to encourage the adoption of a more meaningful understanding of autonomy in the clinical setting by arguing that the traditional individualistic concept of autonomy should be replaced with a relational interpretation of the concept. I begin by offering a case example to demonstrate how the individualistic concept of autonomy can create problems in the clinical setting. I proceed to argue that there are two main problems with the individualistic concept of autonomy. First, and most importantly, many patients simply do not fit the individualistic model of decision making that underlies the traditional concept of autonomy, which means a significant proportion of the patient population is not accounted for within the dominant decision-making framework. Second, relying on the traditional concept of autonomy may result in the unfortunate consequence of patients being alienated from their families in times of illness, and may even promote conflict between patients and families. I then introduce a relational interpretation of autonomy as an alternative, since such an interpretation would maintain what is important about the concept of autonomy (that is, control over one's life) while it incorporates the insight that influence from others does not necessar-

ily impede autonomy, and can actually enhance it. I maintain that shifting from the traditional individualistic interpretation of autonomy to a relational interpretation will provide a more rich and meaningful understanding of how autonomy works in the clinical setting, and will help HCPs better understand how to handle situations in which patients are not acting as robust, independent decision makers.

## THE CASE

Consider the following case as an example of the type of situation reflected in the question above. The patient was a woman in her sixties, suffering from end-stage lung cancer. She had been admitted to the ICU, as she had many times recently, due to exacerbation of her symptoms. Since her respiratory status was steadily declining, the healthcare team felt it was necessary to discuss with her what her wishes would be regarding intubation in case her status continued to deteriorate. When the resident broached the topic with the patient on several occasions, she was very evasive, refusing to even discuss the issue—until she finally gave a very revealing response: "Don't you see?" she said to the resident, "You're going to tear my family apart by forcing me to make this decision." As it turned out, the reason she was reluctant to engage in a discussion and make a decision was because she was afraid her adult children would react negatively if she decided against intubation. She thought that they would want her to keep fighting her illness and decide in favor of intubation, while she seemed tired of fighting, but was afraid that she would cause significant disharmony within her family by deciding against the intervention. Since the resident's interpretation of the situation was that the patient's family was influencing her decision, his instinct was to try to eliminate the influence on her decision by encouraging her to make her own decision independent of her family's wishes. The strategy did not work, however, and the patient still refused to make a decision regarding intubation, leaving the resident at a loss on how to proceed.

## THE INDIVIDUALISTIC CONCEPT OF AUTONOMY

The concept of autonomy has a long history, tracing back to ancient Greek political philosophy. Directly translated from the Greek, autonomy literally means "self-rule" (*autos-nomos*), and was used in reference to politically independent city-states. Since its political beginnings the concept of autonomy has been extended to the realm of moral philosophy, being used in reference to individuals who are able to control (rule) their own lives. Thus, as Beauchamp and Childress note, personal autonomy has traditionally been understood to mean, at a minimum, "self-rule that is free from both controlling interference by others and from limitations . . . that prevent meaningful choice."[3]

In recent decades, this notion of autonomy has come to play a significant role in Western healthcare, in part as a response to the traditional paternalistic nature of medicine. To ensure that patients' values and interests are protected in the healthcare setting, many argued that HCPs should respect the moral right of patients to make autonomous decisions, that is, decisions that are essentially free from controlling influence by others.[4] This individualistic concept of autonomy is nicely characterized in the following passage by Joseph Kupfer: "The autonomous person is one who chooses for himself what to think and what to do. . . . Moreover, his beliefs are arrived at independently, by means of critical reasoning."[5]

Notice how the language in Kupfer's description of the autonomous person is clearly individualistic: the autonomous person chooses *for himself or herself* what to think and do; his or her beliefs are arrived at *independently.* As noted by Agich, this individualistic understanding of autonomy has prevailed in healthcare because it gains support from the Western liberal values of independence of thought and action;[6] influence by others on one's decision making is considered an impediment to and a violation of one's autonomy. Thus, in the context of healthcare, families and other intimates who exert influence on the patient's decision (directly or indirectly) are considered to be interfering with the patient's right to make an autonomous decision. This is exactly why the instinct of the resident in the case above was to isolate the patient from her family and to encourage her to make her own decision.

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## PROBLEMS WITH THE INDIVIDUALISTIC CONCEPT OF AUTONOMY

A significant problem with the traditional interpretation of autonomy is that many patients simply will not fit into the individualistic decision-making paradigm. In a 1999 study that examined the question of whether patients would want their advance directives or their surrogates' decisions followed if the patients became incapable, Terry and colleagues found that concern for others played a significant role in patients' decisions. Of the 135 patients interviewed who responded that they would want their advance directives followed, 18 percent stated that their main reason for their decision was to protect the surrogate from the burdensome process of having to make the decision.[7] Of the 158 patients who stated that they would prefer their surrogates' decisions be followed, 21 percent said their main reason was concern for their surrogates' best interests.[8] Both statistics represent situations in which patients make important medical decisions with the interests of others at the forefront of their thoughts. As the authors note, the findings suggest that concern for others plays a significant role in the decision making of many patients and, therefore, that we need "a socially embedded notion of autonomy—one that sees humans as social beings and situates the patient in his or her family."[9]

It is not surprising that studies like that by Terry and colleagues report that concern for others plays a significant role in the healthcare decisions of many patients. After all, we are social animals; as it is in life generally, most patients will have intimate others of some sort who will be affected by their end-of-life decisions, and many of those patients will be genuinely concerned with how their decisions affect their intimate others. But even if patients do not make end-of-life decisions *for the benefit* of their intimate others, their inherent social nature will mean that their relationships will still influence their decision making in other ways. For instance, patients who are married or in some other committed relationship will likely prefer to make end-of-life decisions in consultation with their partners, as they probably would with other significant life decisions. A person who would not accept a job or purchase a house without consulting his wife would likely also not make a decision to refuse resuscitation without consulting his wife. And to expect that he should make such a decision for himself, based on his own values, and not be influenced by the interests of his family, represents an impoverished view of human decision making. As Reust and Mattingly note in their study of family involvement in medical decision making, patient participants described the decision-making process as "richly populated, in contrast to the two people of the standard physician-patient dialogue."[10]

Moreover, intimate others can influence patients' decisions in less direct ways. In addition to speaking of the affect of decisions on their intimate others, patients in the Reust and Mattingly study spoke of how treatment might affect their roles in the family. For instance, the decision to undergo chemotherapy for a mother of young children is not just a medical issue of how the treatment will affect her capacity for physical activity, but is also an issue of how the treatment may affect her role as a mother, that is, her ability to be active with and for her children.[11] Thus, the fact that she is a mother means her decision will be influenced by others in ways that would not affect the decision of a childless woman faced with the same decision. As Reust and Mattingly conclude, "The defect of standard medical ethics is its failure to acknowledge patients as social beings, as individuals whose lives are intertwined with the lives of intimates. It construes patients as dependent on physicians for health-related expertise but otherwise wholly independent to decide."[12]

Not only are many patients in general not individualistic in their decision making, but there are also groups of patients in which particular patients may be less likely to fit into the standard model. One such group is patients who come from cultural or religious backgrounds that value a different concept of autonomy and decision making. For instance, numerous authors have written about the stark differences between medical ethics in East Asia and in the Western world.[13] In contrast to the individualistic view of autonomy and decision making that has dominated Western medical ethics, both Fetters and Fan note that the dominant model of decision making in Japan could be referred to as a "family autonomy"[14] or "family sovereignty"[15] model. Based on cultural values of harmony, consensus, and deference to authority, Japanese culture prioritizes the family unit, rather than the individual, as the most fundamental unit of society.[16] In the

context of healthcare, this means it is the family unit that has ultimate decision-making authority, not the individual patient. A recent study comparing the views of Japanese living in Japan, Japanese-speaking Japanese-Americans, and English-speaking Japanese-Americans, reports that while the most acculturated group (the English-speaking Japanese-Americans) had a greater desire for personal autonomy in decision making, all three groups preferred a group decision-making model.[17]

Another example of this kind of cultural difference in views on autonomy and decision making is the Jewish community, which prioritizes family and community-oriented values. These values are particularly important among Jews partly because of the influence of Jewish religious beliefs and partly because of the history of anti-Semitism and forced communal isolation that has plagued the Jewish people.[18] In a 2001 study of the values that underlie end-of-life decisions by elderly Jewish Israelis and their family members, Leichtentritt and Rettig found that family considerations played a significant role in the thoughts of the participants. Participants referred to such interpersonal values as loyalty, interdependence, devotion, altruism, compassion, duty, and responsibility; loyalty was the value most commonly mentioned.[19] Of course this does not mean that all East Asians or all Jews subscribe to a family- or community-based notion of medical decision making—there can be at least as much variation between patients within the same cultural group as between patients in different cultural groups. But in multicultural societies such as Canada and the United States, it is important to recognize that patients who are admitted to the hospital in the Western world may not share values and views on decision making with the Western HCPs who treat them.

Another group of patients that may not fit the individualistic model of decision making is the elderly, a group that is becoming progressively more visible in hospitals and healthcare institutions as our population ages. As the older patient becomes increasingly impaired, he or she also becomes increasingly dependent physically, psychologically, and emotionally. This increased general dependence can translate into increased dependence in the realm of medical decision making. According to Kapp, "Many individuals of advanced years possess less desire for information about, and control over, healthcare decision making than do their younger counterparts. Many older persons welcome the opportunity to share what they perceive as the burden, not just the right, of decision making. Contrary to the pure autonomy model, some persons may not want to be empowered exclusively."[20]

When elderly patients are uncomfortable with making important healthcare decisions without their adult children, isolating them from their families and encouraging them to make an independent decision can be both counterproductive and harmful. When patients are afraid or intimidated, or feel isolated from their loved ones, encouraging them to make their own decision independent of their loved ones may only serve to intensify those feelings.

One final point worth mentioning about the reliance on the traditional concept of autonomy in healthcare is that encouraging patients to make decisions for themselves, free from family influence, can actually promote conflict between patients and their families. Consider the case at the beginning of this article as an example: the patient was reluctant to make a decision about intubation because she thought her children would be upset with her if she refused the intervention. Urging her to focus on her own interests and to make a decision for herself may cause her children to feel angry and resentful that she did not listen to their concerns, which may in turn make them more inclined to try to override her wishes, which in turn would make her angry and resentful of her children. Kapp suggests that one reason that older patients may want to share decision-making authority with their family members is to alleviate the tension and guilt that may arise among family members who feel they might have to try to override the patient's wishes on a particular issue.[21] Family harmony is an important value for many patients, and for some it is important enough to override other important values (such as the importance of retaining decision-making authority). In appropriate situations, therefore, family harmony should be considered an important value in the healthcare setting. It is important to remember that the isolation, pain, discomfort, and disorientation that often accompanies illness can make patients particularly anxious and vulnerable. What many patients need when it comes time to make important end-of-life decisions is emotional support and comfort from their intimate others, not further isolation from them.

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## THE RELATIONAL ALTERNATIVE

The traditional individualistic concept of autonomy makes sense in a context of independent patients who make individualistic decisions. What has become clear from the discussion thus far, however, is that, contrary to the individualistic model, many patients make end-of-life decisions in consultation with, for the benefit of, and out of concern for intimate others. Thus, it seems inappropriate to have an individualistic concept of patients' autonomy serve as a central underlying concept in medical ethics. What is needed is a concept of autonomy that takes patients as they *actually are* (that is, social beings) as its starting point.

This view of people as social beings is exactly the starting point of a relational interpretation of autonomy—the view that humans are beings-in-relationships and not asocial individuals. In philosophical circles this starting point is also known as the relational ontology. As Nedelsky states, it is an important feminist precept "that any good theorizing will start with people in their social contexts. And the notion of social context must take seriously its constitutive quality; social context cannot simply mean that individuals will, of course, encounter one another. It means, rather, that there are no human beings in the absence of relations with others."[22] The claim of a relational interpretation of autonomy is that humans are social beings, and they can still be autonomous even when they don't make independent and individualistic decisions. So the important question is: *Can persons still be autonomous when others influence their decisions?*

If we take a step back and look generally at what it is that we find valuable about autonomy, we will have to answer "yes" to this question. Autonomy has become an important value in Western society because we prefer having control over the courses of our lives, rather than having our lives controlled by others. This idea has become particularly important in the context of healthcare, because of the vulnerability that accompanies illness and the inherent power imbalance that exists between physicians and patients. Promoting a concept of patients' autonomy helps put some power into the hands of patients by helping to protect them from the controlling influence of physicians.

However, control over the course of one's life is not precluded by allowing others to influence one's decisions; not all influences are *controlling* influences. As Barclay states, "autonomous agency does not imply that one mysteriously escapes altogether from social influence but rather that one is able to fashion a certain response to it."[23] Because autonomy involves fashioning a certain response to social influence, it requires that we recognize the procedural component of autonomy—the capacity to reflect upon one's desires, values, relationships, and so on. Childress refers to this capacity as "second-order autonomy": being able to critically reflect upon the life plan that one has chosen for oneself.[24] Diana Meyers refers to the skills that enable people to reflect on their values and preferences as "autonomy competency."[25] However one describes this capacity, the crucial point is that one can be influenced by others without forgoing one's autonomy, as long as one is free to accept or reject those influences. Suppose, for instance, that the patient in the case example decided to accept intubation to maintain family harmony. The fact that she made her decision out of concern for her family does not *itself* render her decision nonautonomous. It would be considered nonautonomous if she were pressured or coerced by her family to accept intubation when she would otherwise have chosen to refuse the treatment. In that case, her family would be imposing their interests and values on her and acting as a controlling influence. But in the hypothetical scenario, the patient made the decision to accept the well-being of her family as a deciding factor because she identifies with their interests. Thus, although she was influenced by her family, this does not necessarily mean that such influence impeded her autonomy.

The case in favor of a relational interpretation of autonomy gains strength when we consider that influential relationships can actually enhance autonomy when they contribute to both the development of our reflective capacity and our decision-making aptitude. Being able to discuss important decisions with intimate others allows us to receive valuable input from others, which can help us to see new possibilities and can help us to learn to reflect more deeply and critically on our lives. In the study mentioned above, Reust and Mattingly noted that patients described being able to work through issues with their intimate others as an

important way "to explore pros and cons, consider fresh insights and perspectives, express and come to terms with their fears, and arrive at their own way of balancing competing values."[26] Because our intimate others know us well and are likely to have at least a basic idea of what our values and priorities are, they are in a good position to actively help us reflect upon those values and priorities. Moreover, as Jecker notes, intimate others can help patients exercise their autonomous decisions by offering emotional support, bridging communication gaps between patients and healthcare teams, and encouraging patients to express themselves.[27] Reust and Mattingly report that families advocated for patients primarily to enhance their autonomy, as in the case, for example, of an adult child who steps in to stop procedures for an aged mother who wouldn't speak up herself.[28] So not only is it the case that intimate others do not necessarily impede autonomy, as the traditional concept of autonomy assumes, but there are many ways in which intimate relations can actually help enhance the autonomy of patients.

The significance of a relational concept of patients' autonomy goes beyond just recognizing that influence from intimate others does not necessarily impede, but can also enhance, patients' autonomy. Because the starting point for relational autonomy is the relational ontology, adopting a relational view of patients' autonomy will encourage HCPs to acknowledge the general significance of relationships on the lives of their patients. For most patients, the significance of their relationships will be positive; for others it may be negative. Whatever the impact on the lives of patients, relational autonomy reminds HCPs that patients are social beings and, thus, patients must be taken in their social contexts in order to be properly understood.[29]

## CONCLUSION

Incorporating a relational view of autonomy into practice would not require doing anything above and beyond what HCPs already do when faced with difficult ethical situations. The difference, however, lies in the kinds of questions asked, the type of information gathered, and how that information is incorporated into the action plan. For example, as I have described in this article, culture can be an important element in end-of-life decision scenarios. Since it is unrealistic to expect that HCPs will be aware of the beliefs of the many cultural groups with which they will come into contact in the healthcare setting, it is important to explore whether a cultural element is at play in particular cases. This would also involve exploring, as Levine and Zuckerman suggest, what patients' expectations are, regarding the roles of their families in the decision-making process, and exploring the expectations of the families on the same subject.[30] Such exploration will help to ensure that no *assumptions* are made about the role of the family in decision making, so that both individualistic and relational decision makers will be accommodated. Other important questions that healthcare professionals should try to answer might include: Who are the patient's family members? Are there any other people, such as close friends or other relatives, whom the patient would consider among his or her intimate others? Are there any strange family dynamics at play? Have the patient's decisions in the past tended to be self- or other-motivated? Does the patient identify with his or her past other-motivated decisions, or have family members acted as controlling influences on those decisions? Does it seem as though anybody involved is exerting a controlling influence on the patient in this situation? How are decisions typically made in this patient's family?

Exploring these kinds of questions would have helped the resident in the above case to deal with his patient's reluctance to make a decision about intubation. Early in the patient's hospitalization, the resident should have explored the expectations of the patient and her family regarding the involvement of the family in making decisions. Since they seemed to be a relatively close family, the patient likely would have stated that she would want her family involved, and her family, if asked, likely would have said that they wanted to be involved as well. Rather than pushing the patient to make a decision based on an outmoded individualistic understanding of autonomy, the resident should have explored the patient's reluctance with him. Once the patient expressed concern about how the decision might impact the harmony of her family, the resident should have immediately explored that concern with the patient. Why is she concerned about family harmony? How confident is she that her children would react in the way she fears they might? Have they

discussed decisions like this previously? Have the children reacted unfavorably in similar situations in the past? Perhaps the resident should then approach the patient's children with their mother's concerns—it may be the case that she is simply mistaken about how they would react; or, if she is correct, it may be advantageous to discuss the issue with them privately to give them time to reflect on the situation. Getting the feelings of those involved out in the open and dealing with them would likely be a better approach than pressuring the patient to make a decision, independent of her family, and risking upsetting her children. Initially discussing the issue with the children privately, before bringing them into the room with their mother for a discussion, would also help the resident gauge whether the children are likely to be a controlling influence 1on their mother. This would help avoid the unfortunate scenario of the children pressuring their mother into accepting intubation when she would rather reject the intervention.

The contribution of a relational view of autonomy to situations like the case discussed in this article is the recognition of three basic claims: (1) the traditional concept of autonomy applies only to patients who are individualistic decision makers, and many patients do not fit the individualistic paradigm; (2) intimate others can play a significant role in the development, exercise, and expression of autonomous decision making for many patients; and (3) as long as intimate others do not exert a controlling influence, patients can make decisions relationally and still be autonomous. I believe that adopting a relational interpretation of autonomy, and taking steps like the ones described in this article to incorporate relational autonomy into practice, will go a long way toward helping healthcare professionals understand the role of the family in decisions at the end of life.

## NOTES

1. G.J. Agich, *Autonomy and Long-Term Care* (New York: Oxford University Press, 1993), 3.

2. Admittedly, my only evidence for this claim is anecdotal, based on my personal experience in clinical ethics. It would be interesting and informative to conduct a survey of healthcare professionals to see if this claim is supported by empirical evidence.

3. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics,* 5th ed. (New York: Oxford University Press, 2001), 58. It is the first part of this statement—freedom from controlling influence by others—that is significant for the purposes of this article.

4. It is important to point out that the concept of autonomy is commonly used in two different but interrelated general contexts: (1) to refer to a human capacity, i.e., the *ability* to govern one's life; (2) to refer to particular decisions or a person's decision-making process. It is generally argued that the autonomy in the first context is actually a prerequisite for the second, i.e., that in order for one to make an autonomous decision, one must have the capacity to do so. This capacity to be autonomous is referred to by some as the "procedural component" of autonomy.

5. J.H. Kupfer, *Autonomy and Social Interaction* (Albany, N.Y.: State University of New York Press, 1990), 9-10.

6. See note 1 above, p. 3.

7. P.B. Terry et al., "End-of-Life Decision Making: When Patients and Surrogates Disagree," *The Journal of Clinical Ethics* 10, no. 4 (Winter 1999): 288.

8. Ibid., 289.

9. Ibid., 291.

10. C.E. Reust and S. Mattingly, "Family Involvement in Medical Decision Making," *Family Medicine* 28, no. 1 (1996): 44.

11. Ibid., 41.

12. Ibid., 44.

13. M.D. Fetters, "The Family in Medical Decision Making: Japanese Perspectives," *The Journal of Clinical Ethics* 9, no. 2 (Summer 1998): 132-146; R. Fan, "Self-Determination vs. Family-Determination: Two Incommensurable Principles of Autonomy," *Bioethics* 11, nos. 3-4 (1997): 309-22; K. Hoshino, "Bio-

ethics in the Light of Japanese Sentiments," in *Japanese and Western Bioethics,* ed. K. Hoshino (Dordrecht, the Netherlands: Kluwer Academic Publishers, 1997); A. Akabayashi, M.D. Fetters, and T.S. Elwyn, "Family Consent, Communication, and Advance Directives for Cancer Disclosure: A Japanese Case and Discussion," *Journal of Medical Ethics* 25 (1999): 296-301.

14. Fetters, see note 13 above, p. 132.

15. Fan, see note 13 above, p. 319.

16. Fetters, see note 13 above, p. 135.

17. S. Matsamura et al., "Acculturation of Attitudes Toward End-of-Life Care: A Cross-cultural Survey of Japanese Americans and Japanese," *Journal of General Internal Medicine* 17 (2002): 537.

18. R.D. Leichtentritt and K.D. Rettig, "Values Underlying End-of-Life Decisions: A Qualitative Approach," *Health and Social Work* 26, no. 3 (2001): 151.

19. Ibid., 155.

20. M.B. Kapp, "Who's the Patient Here? The Family's Impact on the Autonomy of Older Persons," *Emory Law Journal* 41 (1992): 782-3.

21. Ibid., 783.

22. J. Nedelsky, "Reconceiving Autonomy: Sources, Thoughts and Possibilities," *Yale Journal of Law and Feminism* 1, no. 7 (1989): 9.

23. L. Barclay, "Autonomy and the Social Self," in *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self,* ed. C. Mackenzie and N. Stoljar (New York: Oxford University Press, 2000), 54.

24. J.F. Childress, *Who Should Decide? Paternalism in Health Care* (New York: Oxford University Press, 1982), 60.

25. D.T. Meyers, *Self, Society, and Personal Choice* (New York: Columbia University Press, 1989).

26. See note 10 above, p. 42.

27. N. Jecker, "The Role of Intimate Others in Medical Decision Making," *Gerontologist* 30, no. 1 (1990): 66.

28. See note 10 above, p. 42.

29. The reader might wonder at this point how the account of relational autonomy I offer here differs from the concept of "family autonomy" defended by John Hardwig, or the communitarian view defended by authors like Jeffrey Blustein or James Nelson. There is one major and important difference between these other views and the view of relational autonomy that I defend. What these views and relational autonomy have in common is the recognition of the importance and significance of relationships. The difference is that both Hardwig and communitarian authors are concerned with establishing the interests of intimate others as *limits* on the autonomy of individuals. In other words, on these views the autonomous decision making of individuals ought to be limited by concern for the interests of family and the larger community. The relational view I defend here, on the other hand, does not maintain that the autonomous decisions of individuals should be limited by concern for others, only that individuals can still be autonomous even when they exist within relationships and allow those relationships to influence their decisions.

30. C. Levine and C. Zuckerman, "The Trouble with Families: Toward an Ethic of Accommodation," *Annals of Internal Medicine,* 130 (1999): 151.