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## The Armchair Ethicist: It's All about Location

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Where one sits in relation to an ethical issue matters. It changes the way things look, it changes the nature of the problem one faces, and it may require different tools of analysis than the same ethical issue faced by someone sitting in a different place with regard to that issue. Why is this important? Quite simply because the ethics consultant involved in a clinical case or the academic ethicist writing a paper or assisting in developing policy will almost always confront an issue differently and ask different questions than a person who is more personally immersed in the problem. It should thus come as no surprise that family decision making in the medical context sometimes fails to correspond to our notions of surrogate decision making, autonomy, or informed consent. The ethics consultant in a clinical case must remain mindful that the ethical question faced by a patient or family may be quite different than the one they are being asked to address as ethics consultant, and that the tools of analysis must fit the question if the result of the consult is to be meaningful.

We can confront ethical issues at a number of levels, and figure 1 illustrates at least four of those. I have labeled these levels as primary through quaternary because, as one moves through those levels, one's proximity to the primary level and what is personally at stake both decrease. The level at which one engages an ethical issue will determine the nature of the question being asked and the appropriate tools of analysis. While different people may interact over the same ethical concern, they often engage the ethical issue at different levels because their relationship to the issue differs. A lack of awareness of that fact can lead to a lack of clarity about the nature of the problem and the appropriate means to solve it.

**Figure 1. Levels of Engagement in Ethical Analysis**

Level	Question	Role	Tools/Considerations
1st	What should I do?	Agent/actor	Personal ethics
2nd	What should she or he do? Will I assist or cooperate?	Counselor/educator	Ethics consultation
3rd	Will I tolerate her or his decision?	Judge	Criminal law
4th	Should we make a rule?	Citizen/legislator	Public policy

## LEVELS OF ENGAGEMENT

An ethical concern is engaged at a primary level when it directly confronts the primary moral agent. It is *your* problem, and *you* must decide what to do. The primary ethical question here is, "Given who I am and what I see, what should I do?" The question is not simply "What is the right thing to do?" but "What is the right thing *for me to do given my responsibilities in this situation?*" Someone confronting an issue at this level is the central moral agent in a drama. This is the woman who is perhaps reluctantly or unwillingly pregnant who must decide whether or not to have an abortion, the physician who must decide whether or not to meet with a pharmaceutical representative in her office, and the parent who must decide whether to immunize a child. It is the terminally ill patient who must decide whether to ask a physician for active assistance-in-dying.

To engage an issue at the secondary level is to be one step removed from the person directly confronted by the primary choice. While the moral concern confronts the other person more directly, you are being asked to participate in some way, perhaps by giving advice, perhaps to pass judgment, and perhaps to enable, support, or cooperate with the primary moral agent as he or she embarks on a chosen path. This is the level at which a family member, a clinician, or an ethics consultant may confront an ethical issue related to a specific patient. The secondary ethical question is likely to take the form, "Will I help this person in what they have chosen? Will I cooperate with him or her and provide what he or she has asked?" This is the friend or relative of the reluctantly pregnant woman who is asked for advice or asked for help and support when the woman has made a decision to proceed with abortion, or the gynecologist asked to perform the abortion who may or may not choose to cooperate with the woman's request. It is the colleague or ethics consultant or teacher who provides guidance about the moral issues related to a physician's meeting with pharmaceutical representatives, the physician who is confronted with a family who has chosen not to immunize their child, and the physician who must decide whether she can in good conscience write a prescription at the request of a patient seeking assistance-in-dying. These individuals all confront an ethical issue, and in some cases what is being asked of them may be as difficult and integrity challenging as it is for the primary moral agent. But the question being asked of them is not the same as that being asked of the primary moral agent.

Engagement of an ethical issue at the third level represents a different relationship to the ethical concern than either of the two previous levels and poses a different sort of question. Rather than asking "What should I do?" or "What do I think is the right thing for him or her to do?" or "Am I going to assist or cooperate with this person?" the question here is "Am I going to *tolerate* the decision that someone else has made in relation to the ethical issue at stake?" A person confronting an ethical issue at this level acts as judge of the other's actions, and the central concern goes one step beyond deciding whether someone's proposed course of action is right or wrong, to whether it constitutes the sort of decision that ought to be disallowed. This is the person who decides to actively interfere with a woman who has chosen to have an abortion, the colleague who questions whether to do something about a physician who appears to be behaving unethically with regard to his relationships with pharmaceutical representatives, and the physician who must decide whether a family who refuses to immunize their child should be reported to child protective services for medical neglect. The third level is the level at which many ethics consultants and ethics committees engage ethical issues arising from conflict between a patient or family and the medical team. While a consultant or members of a committee engaging an issue at this third level might address what they believe to be the right course of action, they are generally being asked a different question: "Are there grounds to interfere with the decision that the family is trying to make?"

On occasion, ethical issues are engaged at a fourth level. This is the level of public policy. The question here goes beyond whether to interfere with someone's choice *this time*, and moves to whether the sort of action or decision should be outlawed *for everyone* under certain circumstances. This is the activist who seeks to change the laws regarding abortion, the institution or legislator or licensing agency that seeks to establish rules about physicians' interactions with industry, or public health authorities who make decisions about whether vaccination should be required for all children and whether there should be any exceptions to

that rule. At this level, public concerns become much more prominent, and, rather than focusing solely on the personal aspects of the ethical concern, those engaging an issue at the fourth level focus on whether it is justifiable to systematically interfere with individual freedom and autonomy for the sake of some compelling public good or competing interest. Considerations of justice and politics are more likely to be introduced at this level of engagement.

### **LEVELS OF ENGAGEMENT AND THE ETHICAL QUESTION**

As illustrated above, the ethical question faced by a person will change depending on which level the moral concern is engaged. "What kind of a decision is right for me with regard to end-of-life care and who do I want to make those decisions if I cannot?" (1st level) differs from "Am I willing to make decisions for my husband should he become incapacitated and unable to do so?" (second level) and "How will I determine whether the decisions made by the patient's surrogate decision maker are consistent with the patient's desires, in his best interest, or sufficiently harmful to him that I will seek to have the surrogate's decisions overturned?" (third level) and "Should we have a law that establishes who will serve as a medical surrogate for an incapacitated patient and dictates the parameters within which that person must act?" (fourth level). Different people involved with the same situation or "case" might face very different questions.

This has implications for how we view the kinds of discussions that occur between family members around end-of-life issues. While these families struggle to weigh the value of possible medical interventions against the burdens those interventions might impose, decide how to make those decisions, and determine whether they can assume the responsibility and burden of surrogate decision maker should the patient become incapacitated, a consultant may focus on whether surrogacy is legitimate, what standards we should use to judge the adequacy of surrogate decision making, on what basis those decisions can be justifiably overturned or ignored, and what process should be in place to assure that the decision is made defensibly and not arbitrarily (all issues that the patient and the family do not address).

### **LEVELS OF ENGAGEMENT AND THE TOOLS OF ANALYSIS**

Moral agency exists at each level of engagement, but the manifestation of that agency will differ. Academic bioethicists are skilled at applying a set of analytic tools to an ethical issue. They may try to bring those tools to the bedside, and find that the tools that served them well in an academic analysis of an ethical issue don't always fit well when consulting on a case, or that the appropriate tools may differ depending on the reason they were asked to consult. Likewise, those tools may bear little resemblance to the way in which the patient or family or clinicians approach the issue. For example, in this issue of *The Journal of Clinical Ethics*, Elliott and Olver present their findings from interviews with dying cancer patients and their families. These interviews are viewed through a frame of autonomy, and the authors conclude that "different aspects of autonomy were invoked to render family members as both appropriate and inappropriate surrogate decision makers." These interviews provide important insights into the world of dying cancer patients, their families, and the different ways in which they make decisions. The frame of autonomy may not be the best way to understand these discussions, however. It represents an attempt to make sense of ethical deliberation at the primary level, using tools of analysis that are better suited in this case for someone at the tertiary or quaternary level. How so?

The patients described in these interviews face death in the near future. They must struggle with how to make sense of that death, how to make the process of dying fit their vision of a "good" death, or at least one that is "better" or "tolerable" or "reasonable" for themselves and those they care about. These decisions clearly have moral dimensions, because the choices they make will affect others around them. A patient may choose to include family members in these decisions, trying to craft the kind of death they envision as best, but also one that is tolerable for their family. For someone in this position, autonomy is not a particularly useful construct. These patients can certainly be described as exercising autonomy, but the principle of

*respect for autonomy* is one of respecting autonomy, not exercising it. For the person in the position of facing his or her own death, the principle of respect for autonomy provides little guidance in making decisions, since a dying patient struggling with end-of-life issues rarely focuses on the question of how to respect the autonomy of others. The ways in which a patient struggles with end-of-life decisions are better understood in terms of virtue ethics or narrative ethics, since these patients are trying to answer questions like "How do I want my story to end?" and "What do I want my death to say about the kind of person I was?"

My wife's cousin recently died of cancer, and spent his last weeks and months planning for his death and what would follow. He planned his own funeral, wrote his own obituary, and continued to make decisions until the end. His final days, his death, and his funeral were orchestrated in a way that "fit" his life. They were just so "like Dale." The principle of respect for autonomy just doesn't help much in capturing the ethical nature of his decisions, at least not without the help of a crowbar. The principle of beneficence works better, since one of the questions he asked is "How can I make my dying less burdensome to others?" Like the patients in the interviews cited by Elliott and Olver, he had conversations with his wife and respected her autonomy by including her desires in those decisions, but, in doing so, he was most concerned about her welfare (beneficence) than a desire to respect her autonomy.

The family members whose voices are heard in these interviews speak from a somewhat different place than the cancer patients. They face these end-of-life issues at a secondary level. They are not being asked to decide how they themselves wish to die and what obligations they have to others in making those decisions, but they are being asked whether they can cooperate in some way with the dying person, perhaps by providing advice, assisting in decision making, or serving as a surrogate decision maker or guardian of the patient's decisions should the patient become incapacitated. The principle of respect for autonomy makes more sense in this context, since the family members are trying to balance their own interests (and perhaps perceived limits) with the principle of beneficence ("I want what is best for my dying family member") and respect for autonomy ("I should make sure my decisions reflect the wishes of the dying person"). Perhaps the most important question these family members face is whether they are willing to assume the role of surrogate, and, if they do so, whether they will respect the wishes of the dying patient in exercising that role.

Were an ethics consultant to be involved in these cases, perhaps because there was some disagreement about what the now-incapacitated patient would have wanted, the tools for analyzing the situation may differ from those used by either the patient or the family. While the ethics consultant would no doubt describe the principle of respect for autonomy as guiding his or her thinking about the case and explore whether any objective evidence of the patient's wishes exists, in many cases that objective evidence will be lacking, and the true questions that must be settled include "Whose choice is this?" "Who gets to decide what the patient would have wanted?" and "Are there any constraints on what kind of decision a surrogate can make?" The principle of respect for autonomy is only helpful here insofar as our ability to determine what the patient's wishes might be. Without any objective guidance from the patient, the standard fall-back has been the best-interest standard, a standard that provides little guidance in these cases, precisely because the disagreements that lead to the request for an ethics consult are frequently disagreements about what constitutes the best interest of the patient. The background question being asked of the consultant is not whether the surrogate is making a decision that is in the best interest of the patient, but, rather, whether the institution should seek legal action to prevent the surrogate decision maker from making certain kinds of decisions. This engages the issue at the tertiary level of ethical engagement, and the question here is really about whether to tolerate someone else's decision, and the tool of analysis — as I have argued previously — should be the *Harm Principle*: the consultant must ultimately decide whether the surrogate is making a decision that places the patient at significant risk of serious harm, as compared to any alternative decision.<sup>1</sup>

## THE ETHICIST IN THIS FRAMEWORK

The ethics consultant nearly always sits in a different place in relation to an ethical issue than the patient or family member sitting at the center of a request for consult. Likewise, the bioethicist writing an academic

paper will frequently address a different set of questions and use a different set of analytic tools than a patient or physician facing the issue discussed in that paper. Discussions of physician aid-in-dying, for example, frequently rely on arguments about the social context within which that practice occurs, the potential for abuse, concerns about the slippery slope, and perhaps claims about the identity of the physician. These arguments address whether the practice of physician aid-in-dying should be allowed, and the arguments relate more to societal concerns than to whether the practice would be right or wrong in an individual case. Slippery slopes, claims about physicians' identity, and potential for abuse have little relevance to a thoughtful, fully competent individual who is trying to decide whether it would be ethical to make this request for him- or herself (at the first level of engagement). Because the nature of the arguments differ, it may also be the case that one's conclusion at one level of engagement (that is, whether a patient is morally wrong to seek aid-in-dying) does not necessarily correspond to one's conclusion at another level (that is, whether physician aid-in-dying ought to be outlawed). Presumably, if the patient were to ask for guidance from an ethics consultant in order to help arrive at a decision for herself, the conversation and the issues discussed would be different than those faced by the same ethicist writing a paper about the permissibility of physician aid-in-dying or providing guidance to legislators concerning whether a law is needed to prohibit or limit the practice.

In his essay "Meditation in a Toolshed," C.S. Lewis relates his experience in a dark toolshed one bright sunny day. He observes a sunbeam as it comes through a small crack in the shed's ceiling. Looking at the beam provides one perspective: a striking ray of light illuminating the specks of dust that float through it. Then he moves, so that the beam falls upon his eyes. The previous image vanishes as he now looks along the beam. From this perspective he sees instead, framed in the small crack, the green leaves moving on the branches of a tree above, a butterfly flitting by, and beyond that the brilliant source of the light, the sun itself.<sup>2</sup>

Lewis uses this metaphor to urge those of us who consider ourselves experts to recognize the limitations of that expertise in describing the experience of those who sit in a different place. For example, he contrasts the lover's experience of being in love (looking along the beam) with the psychologist's or biologist's description of that experience (looking at the beam). The same can be said for ethical issues. They look different depending on where one is situated with regard to the issue, and the questions change as one moves into different relationships with regard to the ethical concern.

These observations will seem obvious to some readers, and I would expect others to quibble with the four levels of engagement I have suggested. Nonetheless, it has been my observation that many individuals remain conceptually unclear about the fact that ethical issues will be experienced differently by people who sit in different places with regard to those issues. As bioethicists consult, teach, and write, we need to be clear about the level at which we are engaging an ethical question and recognize that the tools of analysis that work well at one level of engagement may not be helpful at another level. At the same time, the conclusion we might draw at one level (that is, it would be wrong for her to do x) does not necessarily determine our conclusion at another level of engagement (that is, her decision to do x should not be tolerated), since the relevant question and considerations change from one level to the next.

## NOTES

1. D.S. Diekema, "Parental refusals of medical treatment: the harm principle as threshold for state intervention," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 243-64.

2. C.S. Lewis, "Meditation in a Toolshed," in *God in the Dock: Essays on Theology and Ethics*, ed. W. Hooper (Grand Rapids, Mich.: Eerdmans, 1978), 212-5.