An Ethical Framework for Evaluating Paternalism

In *The Spirit Catches You and You Fall Down*, Anne Fadiman documents the collision of Western medical science and the Hmong culture. She describes several instances in which Hmong immigrants were unwilling to accept treatments prescribed by American doctors. Lia Lee’s life-threatening case of epilepsy, the focus of Fadiman’s narrative, is one such instance. Believing that Lia’s illness was caused by soul loss, her parents refused to feed her therapeutic levels of medicine. In response, Lia’s doctors had her put in foster care for a year, claiming that it was in her “best interest.”

One of the central issues raised by this story is the question of paternalism – when is it permissible for the government, or any other agent, to make decisions for a person against his or her will? In this paper, I wish to create an ethical framework for evaluating paternalism in the context of the medical care issues that arise in Fadiman’s book. Through an examination of what I believe to be morally relevant factors, I will attempt to establish criteria that must be met for paternalism to be justified. The four criteria I present are necessary but not sufficient conditions for allowing paternalism. I find that no single consideration can always justify paternalism, but it is possible to set benchmarks that provide some basis for deciding about particular cases. After developing and defending my approach, I will demonstrate how it can be applied to Lia’s case.

The first factor we should consider is whether reasonable alternatives to paternalism are available. If we can resolve a conflict of values without forcing a decision on someone, we should prefer such a solution. Fadiman mentions several examples in which innovative
physicians found ways to work with the Hmong in providing medical care that satisfied both the
doctor and the patient. In one case, the doctor allowed his patient to consult a txiv neeb for
ceremonial treatment of a gall bladder problem. When the spiritual approach failed, the patient
consented to surgery, which cured the ailment.\textsuperscript{1} Compromises like this one are not always
possible, but they should be attempted before paternalistic methods are considered. A first
precondition for paternalism, then, is that reasonable alternatives have been explored without
success.

One might object that this criterion cannot be considered in situations of great medical
urgency. When the patient is near death on the operating table, there is no time to discuss
alternatives or compromises. If the patient or the patient’s family refuses to accept treatment, the
doctor must decide on the spot whether to take paternalistic action and proceed with the
treatment anyhow. This type of dilemma has often arisen with the Hmong.\textsuperscript{2} In reply, I agree
that time constraints need to be taken into account. For this reason, I have qualified the criterion
by referring to \textit{reasonable} alternatives. I won’t attempt to define exactly what “reasonable”
means, but I think it does include consideration of urgency and timing. Waiting until tomorrow
to address a problem that will run its course by the end of today is not a reasonable alternative. I
am not saying, however, that urgency justifies paternalism; I am merely suggesting that urgency
may restrict the range of alternatives that are available.

A second factor we should consider is the existence of cultural and religious differences.
Here, we can think in terms of Isaiah Berlin’s concept of pluralism, which holds that “there are
many different ends that men may seek and still be fully rational, fully men, capable of

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\textsuperscript{1} Anne Fadiman, \textit{The Spirit Catches You and You Fall Down} (New York: Farrar, Straus and Giroux, 1997), 269.
\textsuperscript{2} Ibid., 71.
understanding each other and sympathising and deriving light from each other."³ Although we may ultimately disagree on what values are important, the human imagination allows us to understand each other's beliefs.⁴ This understanding provides a basis for us to make judgments about other people's values, while still living together peacefully in society. On the pluralist view, paternalism cannot be justified unless we understand and respect these differences of culture and religion. Respect requires that doctors make genuine attempts to understand what their patients believe to be the cause of their illnesses and why they may wish to refuse treatment. This is exemplified by doctors like Dwight Conquergood, who practiced effective cross-cultural medicine by taking time to learn about Hmong culture first.⁵ The badge of professional authority does not lessen the need for mutual respect. We can use this as a second criterion for paternalism: there must be understanding and respect for cultures with different values from our own.

I think these first two criteria have been fairly straightforward ideas. The third consideration I want to discuss is a more difficult issue. It is the question of rationality—whether a person is capable of making decisions based on reasons and understanding the consequences of those decisions. I am hesitant to use this term because of Blia Yao Moua's statement that "Hmong culture is not Cartesian."⁶ But I don't believe that Blia is suggesting that the Hmong do not have reasons for what they do or cannot understand the connection between cause and effect; he seems to mean only that the Hmong do not see the world and its happenings

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⁴ Ibid., 10.
⁵ Fadiman, 36.
⁶ Ibid., 245.
primarily through the lens of science or formal logic. This fact does not interfere with my present line of thought. I want to examine two kinds of scenarios in relation to rationality.

First, let us take the case in which a rational adult patient does not wish to receive the treatment prescribed by a doctor. In this case, I think it is a strongly intuitive idea that paternalism has no justified role. The patient is aware of the consequences of her choice and has stated her conviction to accept them. She may have a different interpretation of the consequences or their desirability, and as pluralists we may judge this to be wrong and attempt to persuade her otherwise, but we are not justified in making the decision for her.

In a second scenario, let us assume a patient who lacks full rationality — a child or a mentally handicapped person, for example. Such a patient is still capable of making decisions, but may do so arbitrarily or without understanding the consequences. Since the patient’s well-being is at stake, we consider it appropriate that someone who does possess full rationality should make health care decisions for her. This point makes no suggestion as to who that decision maker should be, but it does provide us with a third criterion for paternalism. The person for whom decisions are being made must have limited rationality; otherwise, we would let the person make his or her own decisions.

To follow up on the previous point, my fourth consideration is the notion of a person’s “best interest.” This standard, which is often invoked in defense of paternalism, seems vague and ambiguous. It is also unclear why we would consider a person’s best interest to be more important than the person’s actual interest. Ordinarily, there is little justification for forcing people to change their decision to conform to their best interests. Presumably, we would only appeal to the best interest standard when one’s actual interest could not be determined, as in the case of a child who does not possess the full rationality needed to assess his actual interest.
I doubt that there is any perfect method of defining a person's best interest. But given that we are dealing with situations in which someone else will be making decisions for that person, I would argue that it is important for decision makers to bracket their own interests or biases. It may be difficult to determine a child's best interest and we may have to settle for the closest approximation of it that can be practically obtained, but a surrogate decision maker who has his or her own interests in mind is less likely to arrive at such an approximation. Thus, my fourth criterion for paternalism is that decision makers bracket their own concerns and focus on the best interest of the person for whom they are making decisions.

I have now completed my account of the criteria that must be satisfied by paternalism. Before applying it to Lia Lee's situation, I want to characterize the nature of my approach by responding to some possible criticisms of it. First, it could be argued that my position does not provide enough of a framework for the positive justification of paternalism. I will grant that my argument has more force in showing that instances of paternalism are not justified. A case that passes all of my criteria does not automatically receive moral clearance. But I believe there are good reasons for structuring my argument in this way. For one, we should be more concerned about making sure that we do not intervene in any impermissible cases than about trying to intervene in every permissible case. Another reason is that I do not believe there any principles that would always justify paternalism. Perhaps one might argue that the basic obligation to save lives would always justify paternalism. But even this idea, which seems quite minimal, is problematic. It is not at all clear, for example, that we are justified in prolonging the life of a terminally-ill, rational adult who does not wish to be resuscitated. And some cultures and religions have different notions of the meaning and importance of life. They might disagree on what it even means to save a life.
At the other end of the spectrum, one might object to my position by arguing that paternalism cannot ever be justified, and that my view still allows too much intervention. This challenge to my argument, however, has difficulty accounting for some of our basic intuitions. In particular, it goes against the widely accepted belief that children should not be free to make all the decisions concerning their welfare. One could argue, however, that additional constraints on paternalism need to be added to my list of criteria. This is very likely the case, and I don’t claim to have compiled an exhaustive list of necessary criteria. If I had, my position would be able to give a positive account of exactly when paternalism was permissible.

A third critique of my view could claim that I rely too heavily on intuitions in defending my criteria. It is true that much of my argument rests on what I take to be widely shared beliefs about right and wrong. I don’t think it is possible to avoid all appeals to intuition in making a moral argument. If, for example, I appealed to God as a source of moral justification instead of drawing upon the intuitions I have used, my argument would still rely on a belief in God. Anyone who did not believe in God would have no reason to accept my argument. While I believe that the intuitions I have relied on are fairly strong, I do wish to acknowledge that anyone who did not hold those intuitions might reject my view.

With these clarifications in mind, let us apply the criteria I have outlined to the case of Lia Lee. The particular question I will focus on is whether Neil Ernst, one of Lia’s doctors, was justified in removing Lia from the custody of her parents and placing her in foster care so that she would receive adequate doses of her medications.

My first criterion asks whether reasonable alternatives to paternalism have been explored. Neil and Peggy did try to improve parental compliance with the prescribed medicines. They sent nurses to visit the Lees regularly, and the nurses tested many different approaches to make
compliance easier for them.\textsuperscript{7} It is questionable, though, whether this can be considered a search for alternatives to paternalism. Neil and Peggy did not go out of their way to seek a compromise, and they were unwilling to adjust their therapeutic techniques. In their defense, I do want to point out that they faced both language and cultural barriers, and these were significant constraints on their ability to find reasonable alternatives.

Second, we should consider whether there was respect and understanding for differences in culture and religion. On this criterion, the Lia Lee case seems to be a failure. Neil and Peggy did not even ask the Lees what they thought Lia’s problem was, and the Lees jumped to their own conclusions about what the doctors were trying to do to Lia. No attempt at cross-cultural dialogue was made between the doctors and the Lees, and consequently, respect and understanding could not be achieved.

The Lia Lee case does satisfy our third criterion that the person for whom decisions are being made possess limited rationality. Lia is a young child, and she cannot make fully rational decisions concerning her own well-being. It is clear that someone else should make these decisions for her.

The fourth and final criterion is that the surrogate decision makers must avoid drawing upon their own interests and biases when trying to decide what is in a person’s best interest. Neil’s motivations are questionable here: “I felt there was a lesson that needed to be learned.”\textsuperscript{8} In wanting to send a warning to the Hmong community, Neil may have been acting on his own interest in promoting the idea that Western medicine is superior. Although he did have other reasons for his decision, he should not have allowed this personal factor to play a role – it had nothing to do with Lia’s best interest.

\textsuperscript{7} Ibid., 48.
\textsuperscript{8} Ibid., 79, emphasis added.
Based on these criteria, Neil’s decision to take Lia away from her family was an unjustified act of paternalism. It fails the second criterion of respect and understanding, and it produces questionable results on the first and fourth criteria. Since each criterion is a necessary condition for justified paternalism, I would consider this instance of paternalism clearly unjustified.

An important clarification, however, is that I do not want to suggest that Neil should be condemned as a terribly immoral person. My argument is only intended as a framework for determining whether paternalism is justified, and it does not tell us how blame should be assigned. We should keep in mind that as a doctor, Neil was legally required to report what he thought to be a case of child endangerment. Also, the kind of training he received at medical school may have been responsible for his insensitivity to non-Western medicine. The issue of responsibility is complex and should be examined separately.

I have tried to provide a foundation for evaluating paternalism by designing criteria that can be used as a test for given acts of paternalism. It draws our attention to several factors that need to be considered in cross-cultural medicine. While my framework is not exhaustive of all possible factors, it works reasonably well in assessing cases such as Lia Lee’s. It is most effectively used as an indicator of unjustified cases of paternalism.