No to infant euthanasia

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Although I am not a physician, and although there is surely much about the medical complexities of this case that I do not fully understand, it is clear even to me that this baby is likely to have a short, perhaps very short, life even under the best of circumstances and with the best medical care. What follows from that? What follows, I want to suggest, is that it is our obligation to seek for this little boy a death we can live with; a death that does not undermine our equal dignity but that cares for his life and honors his time among us from first to last.

Faced with the sadness and suffering of such a case, and forced to confront the limits of our own expertise and ability to help, we are tempted to turn in either of 2 directions, which seem at first sight to be complete opposites but which in fact are closely related kin.¹ We are tempted either to struggle with all our power and technical skill against death, never giving up that fight until have we nothing left to do and must admit defeat, or we are tempted to decide to intentionally cause death, solving the problem of suffering by eliminating the sufferer.

However different these 2 approaches may seem on the surface, each is a form of abandonment. Neither constitutes care for this child, and our obligation is precisely to maximize care. I will outline briefly 3 kinds of wisdom (moral, political, and medical) that should invite us always to care and never to kill in cases of this sort.

First, deeply embedded in our moral tradition is the distinction between, on the one hand, allowing someone to die, and, on the other hand, intentionally causing death. For this child with heterotaxy syndrome and for many others, both young and old, who face life-threatening illness, maximizing care will sometimes mean ceasing to struggle against death. Medical treatments may rightly be withdrawn if they are either useless or excessively burdensome. Perhaps in the case of this little boy they are both; I do not know for sure. Perhaps even well-trained

physicians, if they are honest with themselves, will not always know for sure. Anyone who simply plunges forward, certain that he knows which possible treatment approach is best, needs to learn to live with a little more fear and trembling.

Still, we can be clear that no one should be subjected to useless treatment and that no one need suffer any and all possibly life-saving or life-prolonging treatments, however burdensome they may be. That much can be clear, even if we do not always know how best to evaluate the facts of a particular case. The questions we should ask ourselves are questions about what is medically indicated, what is medically best for the child: Will a treatment benefit the life this child has? Is a treatment excessively burdensome to the life of this child? These questions are a little different from others we may be tempted to ask ourselves: Is it a benefit to have this life? Is this life a burden?

The latter questions distance us from the one who needs our care. They invite us not just to allow this child to die but to embrace his death as a good at which we aim; that is, to take into our character a willingness intentionally to kill the innocent. That would be to think of ourselves not as fellow human beings and fellow sufferers with this child but, instead, as people who are fit to exercise a kind of ultimate authority over the life of another. We often speak of the need for compassion when we think about such troubling cases, but we do not always pay close attention to what the word actually means and what it asks of us: that we suffer with the one who needs our care, entering as best we can into his suffering, not distancing ourselves from him as if we were not equals in dignity. Indeed, a readiness not to distance themselves from their patients has been deeply embedded in physicians' professional practice.

Second there is also a tradition of political wisdom that instructs us always to care and never to kill in cases such as the one we are considering. In recent decades, as the issue of euthanasia has become more widely debated in North American societies, supporters have regularly appealed to 2 sorts of warrants. One is compassion for the suffering, about which I have already said something. The other is autonomy or self-determination. The "whose life is it anyway?" question has great appeal for us. If for decades I have been making important decisions about the course my life should take, why, some may ask, should I not also decide at some point that the game is no longer worth the candle?

Opponents of euthanasia have argued that these 2 warrants turn out to reinforce each other in ways that would in time expand the class of candidates for euthanasia.² After all, if compassionate relief of suffering is so important, we

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may be hard pressed to understand why it should be available only to those who are autonomous and self-determining. When now we find our political communities beginning to consider whether we should euthanize a child such as the one in this case, we do well to remember the critics who argued that such expansion was inevitable. Once a society begins to blur the line that distinguishes allowing to die from killing, it can become very difficult in law and in practice to limit the permission to take life. And that, in turn, can undermine our commitment to human equality.

The danger to equality arises from 2 angles, both that of the person who seeks euthanasia or, as in the case of this child, for whom it is desired, and that of the person who offers it. If I seek to give ultimate authority over my life to others, I become something less than their equal. I join what John Locke called the “inferior ranks of Creatures,” and I make my person an object to be possessed and controlled by others.³ And the same is true when I give such authority over this child’s life to others. Likewise, the person who carries out the euthanizing deed pulls rank and, in effect, exercises a more-than-human authority over the life of one who is, in fact, his moral and political equal. For us to try to exercise such authority is to pretend to be what we in truth are not: something other than beings of equal dignity. And that would be to lose one of the greatest achievements of our political tradition: an affirmation of equal dignity laboriously gained at great cost over centuries.

Third, in a setting such as this meeting, we should certainly remind ourselves of the medical wisdom that teaches physicians always to care and never to kill. After all, although the background to our deliberations is the general question of whether it is morally or politically wise for a society to endorse euthanasia, the actual question we face is narrower and more pointed. How did the case end? What did it ask us? The question is: “Should the physician help them in this way?”

I have been arguing that we should not agree to euthanize this baby. I have not tried to decide which of the alternatives to euthanasia is most choice worthy. Perhaps we should provide comfort care only; perhaps we should not embark on a series of surgeries that will probably give at best a couple decades of life. Or, on the other hand, perhaps we should not assume that a couple of decades even of medically burdened life is an unacceptable choice. After all, each moment of life is equidistant from eternity. Your thinking, your doing, your caring, and your loving are all important in this moment even if you will not wake up

tomorrow. Hence, although we should choose life for this child, I am not sure which of the available life choices would really maximize care for him.

But I do know that if we never attempt any of those life choices, if we simply sweep such children off our doorstep every morning with euthanasia, medicine will never learn better ways to help them and others like them. That may not be the best way to understand the vocation that is yours.

In any case, if we do not sweep such children off our doorstep, and whatever course we decide maximizes our care for them, it is certain that genuinely compassionate and caring physicians themselves bear heavy burdens here. I do not underrate those burdens. Nevertheless, your burdens are inextricably connected with your good fortune.

For it is your good fortune to have found in medicine work that can be genuinely worthwhile, as you seek to impart at least a small measure of wholeness (healing and health) to your patients. But, of course, in giving yourselves to this work you risk, as William F. May once put it, drowning in the sea of human need in which you swim daily. That may tempt you, as it could tempt any of us, to try to eliminate suffering by eliminating the sufferer. We are tempted to “avoid ties to the perishing,” lest they drag us down with them.⁴

Faced with that temptation, physicians may understandably take refuge in a kind of managerial competence, using their technical skills to manage death. Still, good medical care does not forget that all patients must sooner or later die. The task of the physician is to accompany them on the way to that death, neither abandoning them by imposing treatments that are useless or excessively burdensome, nor abandoning them by deliberately aiming at their death. Neither of those seemingly opposite but, in reality, related forms of abandonment can constitute a medical success story. Our goal as physicians, as citizens, as parents of suffering children, and as patients or potential patients ourselves should be to affirm life even in the midst of death, and to commit ourselves to helping to shape a death we can live with.

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