Some Ethics Committee Perspective

and cause for concern and because the request is based on controversial conceptions of what might be in someone's best interests, I do not see why this is a decision that ought to be left to ethics committees. This is in no way intended to disparage the expertise of committee members or their commitment to arriving at robust and defensible decisions, but rather to protect them from having to take on the burden of such a decision. The patient's severe mental impairments pose limitations on the *kinds* of interests she may have, but this does not make the interests she *does* have any less complex and difficult to determine. Difficulties in communication, in understanding whether she is in pain and the degree of pain she might be experiencing, whether she is finding human contact comforting or distressing, whether she is upset by changes in her environment, and to what extent she is bonded with and dependent on her specific care givers make it very difficult to evaluate the relative merits of different options even after practical questions have been answered.

In conclusion, the conjunction of two factors, the lack of voluntariness and the disputed nature of the request, along with difficulties inherent in making decisions on behalf of this patient because of uncertainties about how we should interpret her interests, make this too difficult a case for an ethics committee to take on. To ask an ethics committee to make this decision is unfair, both in terms of placing the burden of the decision on them and in terms of holding them responsible for making it, whatever decision they happen to come to. Extreme cases, such as this one, are best left to the courts, which have both the means to explore all claims about the patient's best interests and the moral authority to decide on behalf of another person in such a disputed and difficult case.

Note

1. Battin MP. *Ending Life: Ethics and The Way We Die*. Oxford: Oxford University Press; 2005:58.

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Commentary: Weighing the Balance

Amnon Goldworth

I am inclined to agree with Arthur Caplan that a less invasive means than was employed in the case of Ashley X would have been preferable. But, such means do not, as yet, exist. Given these circumstances, what are the issues that the bioethics committee needs to consider prior to making a recommendation to the surgeon?

One issue is the fact that the requested surgery interferes with the natural development of the 9-year-old girl. Another issue is the fact that this surgery will be of convenience to the parents. A third issue is that performing the surgery will create a precedent for altering the physiology of a child solely at the behest of parents.

The first issue is of no great moral import given the fact that the surgical removal of breasts and limbs are commonly practiced procedures. Besides, given her extremely limited mental capacity, this child will not experience a sense of loss and therefore will not suffer. The fact that life will be made more convenient for the parents does not, by itself, count either for or against the surgery. What makes parental convenience morally acceptable is if the surgery is morally justified for the child.

The "slippery slope" that may be created by using the Ashley Treatment in this case is hardly an incline. The merit of the requested surgery depends on the purposes that it serves. Doing surgery in order, say, to eliminate a hare

lip does not constitute a threat to the physical integrity of a child. What is at issue in our present case is the benefits to the 9-year-old girl in relation to the costs in terms of the consequences of the surgery. And this relationship should act as a sufficient counter to possibly unwarranted invasive procedures.

Having dealt with these issues, the bioethics committee now needs to address the question, "What is in the best interest of the child?"

To answer this question the committee needs to focus on two normative principles that are of particular relevance in this case. The first is the principle of beneficence (promote what is beneficial). The second is the principle of nonmaleficence (do no gratuitous or unnecessary harm). If we combine these two principles, the bioethics committee can see that the harm done by the surgery, in causing pain or possible infection, is clearly outweighed by the benefits that will be produced. She will be cared for more easily; she will not experience the discomforts of menses; she will be less likely to suffer sexual abuse. Her life will be less of a burden and, as a consequence, she will have an improved chance of enjoyment within the limits of her mental state. In the light of these considerations, the bioethics committee should recommend that the surgery be performed.

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What Actually Happened

The ethics committee met and discussed the case with the surgeon. Just prior to this, the bioethics committee at a nearby medical center received a referral for a similar case. That committee had already undertaken a thorough review of the literature and the legal proceedings involved in the Seattle Ashley case. The medical center committee agreed to share their findings and deliberations with the children's hospital committee and sent two representatives (both attorneys) to present their information. In addition, members of the children's hospital committee had a conference call with the pediatric endocrinologist who had been involved with the case at the medical center.

After discussing the case, members of the children's hospital committee were divided in their opinion about what should be recommended. The proposed procedures would have involved a hysterectomy, breast bud tissue removal, and treatment with estrogen until growth had been stopped. This patient differed from Ashley in that she was older. In addition to the ethical issues raised, there was institutional concern regarding the potential public relations issues related to disability advocacy groups. The lack of agreement resulted in a recommendation to the surgeon that he should not provide the requested procedure. Committee members were aware that this was his preference as well; however, if he had chosen to proceed, it is not clear whether the hospital would have supported his performing the procedures at the facility. The director of pediatric critical care chief was asked to contact the mother to inform her about the discussion. He relayed the committee's recommendation to the surgeon. He also told her that her request was not unprecedented, as she remained vaguely aware of the earlier Ashley case in Seattle. He advised her that if she wished to pursue her daughter's case further, she would need to find both an endocrinologist and a surgeon who would agree to move forward with the medical procedures.