

QUAESTIO DISPUTATA: WHEN DOES QUALITY OF LIFE COUNT?

A RESPONSE TO GILBERT MEILAENDER

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[Editor's note: The author argued earlier that the distinction between ordinary and extraordinary means is essential to quality-of-life considerations. Gilbert Meilaender responded that quality-of-life considerations are not appropriate for incapacitated patients or those relying on others. Wildes insists that these considerations are inescapable for any patient and are a constitutive element in assessing the efficacy of treatment for any patient. He suggests that Meilaender has failed to distinguish between useless treatment and burdensome treatment.]

GILBERT MEILAENDER in a very thoughtful essay,¹ has raised an important question about my discussion of "quality of life" as a crucial element in the ordinary-extraordinary-means distinction.² Meilaender's central point is that I fail "to take account of the substantially different moral situation that arises when others make treatment decisions for incapacitated patients."³ I agree with Meilaender that I did not draw a distinction between patients who can participate immediately in their treatment decisions and those who can not. My central concern was not about incompetent patients but about the meaning of the distinction. The differing situations of patients is a point that deserves attention since the ordinary-extraordinary-means distinction is so patient centered. I think I can develop my earlier work to address Meilaender's concerns. One can distinguish between competent and incompetent patients. One can further distinguish incompetent pa-

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¹ Gilbert Meilaender, "Ordinary and Extraordinary Treatments: When Does Quality of Life Count?" *Theological Studies* 58 (1997) 527-30.

² Kevin W. Wildes, S.J., "Ordinary and Extraordinary Means and the Quality of Life," *TS* 57 (1996) 500-12.

³ Meilaender, "Ordinary and Extraordinary Treatments" 527.

tients into two classes: those who once were competent but now are not, and those who have never been competent (e.g. the severely mentally retarded).

In taking Meilaender's critical remarks to heart I would like to build on his concern for incapacitated patients and argue that not all incapacitated patients are the same. There is a significant difference between those who have never been competent and those who are no longer competent. The latter can, in some way, still participate in the decision. I argue also that, in developing his concerns, Meilaender neglects the distinction between useless and burdensome treatment that I set out in my original essay, mishandles the issue of personal identity (for a Christian), and argues for a position that may even worship at the high altar of vegetative life.

Meilaender confuses the issues at hand by implicitly equating treatments that are "useless" and treatments that are burdensome. This is not something that I did. He writes, for example, that "for a patient who is not a dying patient—who may, in fact, live for years if fed—it is difficult to claim that such feeding is useless."⁴ I argued that, before all else, in the ordinary-extraordinary-means distinction, a treatment must offer some hope of health (*spes salutis*) if it is to be considered morally obligatory (ordinary). Traditionally treatments are useful when they offer some hope of health. In the current practice of high-technology medicine it is helpful to note that treatments can be useful for persons or for a goal.⁵ A medical treatment can be useful in achieving a goal (e.g. nutrition) while not being useful in serving a patient's goals (e.g. recovery). The ordinary-extraordinary distinction was informed by the different senses of usefulness. One of the problems of contemporary medicine that poses a moral danger for patients and practitioners is the tendency to view medical interventions in isolation from one another. Treatments are judged to be useful simply from the view of achieving some medical goal. This way of judging treatments often leads to a failure to look at the whole patient; it also leads to the temptation to deploy a medical intervention without evaluating its use in the context of the patient's health. The ordinary-extraordinary-means distinction, in my judgment, profoundly challenges modern medical practice that tends to look at treatments in isolation from a patient's goals and life. In order for a treatment to be morally obligatory, it must be useful for both medical and personal goals. The mere fact that a treatment is useful, however, does not suffice to make that treatment obligatory.

The distinction also held that, in order to be morally obligatory, a treatment had to be both useful and not burdensome. What I argued for earlier, and may not have made clear, is that the decision that

⁴ Ibid. 529–30.

⁵ I am indebted to John Langan, S.J., for his insight on this distinction about "usefulness."

something is burdensome will be tied, in large measure, to the way a patient views her life and the treatment at hand. "Burdensome" and "useless" are not the same. These elements overlap if a distinction is drawn between treatments as useful to a medical goal and useful to a patient. A treatment may not be useful to a patient, because it is burdensome, while still being useful to a medical goal.

This same logical problem is found in the futility debate that has gone on for nearly a decade in bioethics. Health providers have argued that futile treatments need not be offered nor continued (because they are useless). However, such treatments may be of value to the patient or the family, as in the celebrated case of Baby K. To insist that a treatment can be judged useful to a patient without knowing the patient's view of his own life is to separate the person from the body and its condition.

If one stays with the language of "burden," so central to the ordinary-extraordinary-means distinction, then patients have much greater latitude in refusing treatment. Patients may look at a treatment, or the life that will result from a treatment, and say, "I do not want to live like that" (*vehemens horror*). Meilaender seems to be concerned also that the language of burden will be used by others who do not want the burden of a particular patient. He is right to have such concerns. The application of the distinction to cases where we have no sense of the patient's wishes is inappropriate. However, this type of application is different from one in which a person looks at his future and at possible medical treatments, and then concludes, "I do not want to be a burden to my family." Such conclusions have been drawn from the distinction since its origins. One has always been asked to consider not only the benefits of a treatment but the burdens of treatment to one's self *and others*. This point was clearly made by Pope Pius XII in 1958.⁶ Indeed, *not* to ask such questions seems peculiarly unchristian.

In his concern for those patients who have others making decisions for them (those incompetent patients who once were competent), Meilaender seems to dismiss both families and friends as well as the previously articulated wishes of the patient. Allow me to start with the latter. Meilaender expresses a concern about advance directives that has been found in the secular literature of bioethics. Because of epistemological skepticism about metaphysical claims, neither modern philosophy nor secular bioethics has been able to develop an account of personal identity. Modern philosophy lacks unity. There are numerous metaphysical systems, but there is no privileged place from which to judge which of the many systems may be true. This multiplicity, combined with skepticism about our capacity to know, limits our ability to speak of personal identity.

Meilaender's concerns about personal identity and wishes are problematic for secular moral philosophy and bioethics. It seems peculiar,

⁶ See Pius XII, "The Prolongation of Life," *The Pope Speaks* 4 (1959) 393-98.

however, that this should be a problem for a Christian. Christians believe that our lives are narratives and that decisions of the past can have binding force on decisions in the present. So Christians think that the person who commits herself to another at twenty-five ought to honor that commitment at fifty-five (as in the case of marriage or religious vows). It would seem obvious that Christians, in living their lives before God, will have views about what constitutes a good death and a bad death in light of the views they have about good life. There is a real risk that the simple prolongation of life could turn into idolatry of life and not be an act that reverences life. One would think that Christians ought to be concerned to honor an individual's view of his or her own life and death however that has been expressed (living wills, advance directives, family members recounting of desires, and the life that has been lived).

There is also a class of incompetent patients who have never been competent (e.g. the profoundly mentally retarded). Such patients will not earlier have expressed desires about treatment, since they have never been able to express them. Here the distinction is not applicable, since it is a patient-centered distinction. In such cases we simply have to make decisions based on our views of the best interest of the patient and the hope of health.

Finally, I perceive a deeper ambiguity at work in Meilaender's response to my essay. Following the ideas developed in his important book on bioethics,⁷ Meilaender is concerned with preserving the importance of the body as part of our moral decision making. He wants to resist the language often used in bioethics that separates person from body. With this view I would wholeheartedly agree. However, *human* life is *bodily* life. And when the body is so broken that it loses its potential for anything other than existing, our obligations to continue treatment that seeks to cure and prevent death have ceased. One can argue that in such cases our obligation is to provide good palliative care.

This analysis seeks to consider the human being as a whole; it emphasizes the profound integration of body and soul, or matter and spirit. One can draw a conceptual distinction, for purposes of analysis, between the bodily life and the "person," and yet not commit one's self to an ontological distinction. When biological mechanisms have been damaged beyond repair, integration is lost. Without the biological substratum, human beings are vegetative and unable to achieve "personal" life as human beings. There are reliable tests for diagnosing damage to the brain and other organs, and for predicting a patient's chances for recovery. When it is known that there is *no* hope of recovery, there is no need to appeal to the distinction between ordinary and extraordinary means.⁸

⁷ Gilbert Meilaender, *Body, Soul, and Bioethics* (Notre Dame: University of Notre Dame, 1995) esp. chap. 2.

⁸ My thanks to John Langan, S.J., Denis Bradley, and Kevin Quinn, S.J., who read earlier versions of this piece.