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Review of *Informed Consent, Proxy Consent, and Catholic Bioethics: For the Good of the Subject* by Grzegorz Mazur

Daniel P. Maher
Assumption College, dmaher@assumption.edu

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Grzegorz Mazur, O.P.
Informed Consent, Proxy Consent, and Catholic Bioethics: For the Good of the Subject
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Reviewed by Daniel P. Maher

In this book, Rev. Grzegorz Mazur, OP, offers a Catholic appraisal of matters related to consent to medical research. He devotes just over one-third of the book to various understandings of informed consent in research, and in the balance of the book he examines what is usually called surrogate or proxy consent, first in relation to therapeutic research and then, at greater length, in relation to nontherapeutic research. Mazur's main interest is the enrollment of those not competent to give consent for nontherapeutic research; he turns to consent in the treatment context "for either comparative or supplementary purposes" (1). This relatively narrow focus enables him to steer clear of the numerous and complex issues he would have to address if this were a comprehensive examination of "informed consent" in Catholic bioethics. His analysis culminates in his endorsement, subject to certain qualifications, of proxy consent to nontherapeutic research and experimentation on non-competent persons, provided there is "no significant risk." Mazur thus adopts (and partially adapts) the position to which William E. May switched ten years ago and has since explained in various writings (see May's "Proxy Consent for Nontherapeutic Experimentation" *National Catholic Bioethics Quarterly* 7.2 [Summer 2007]: 239–47).

Mazur prepares his support for May's position by criticizing the dominant secular understanding of autonomy, regarded as pure self-determination. According to this view, the will makes things good by choosing or valuing them. Mazur sees this view of the will reflected in interpretations of the post-Nuremberg requirement of informed consent according to which a person has absolute freedom to consent or to refuse consent to research (or indeed to withdraw from it), you might say, willy-nilly. This purely subjective and non-rational view of the will, he argues, is self-defeating: "Severing autonomy from the objective good . . . ultimately undercuts the very possibility of freedom" (109). For a superior alternative, Mazur sketches Thomistic anthropology, according to which the will is responsive to the good apprehended by reason. In his favorite metaphor, Mazur calls for an "objective yardstick" to serve as the measure of choices. This "yardstick"—a knowable, objective moral order independent of human freedom—is integral to Mazur's analysis of appropriate standards for consent to medical research.

The argument unfolds in eleven chapters. In the first, Mazur challenges the view that the moral requirement of informed consent for medical research originated in Nuremberg; he finds that Catholic thought acknowledged the significance of this principle well before World War II. In the second chapter, he traces transformations of informed consent in several influential statements: the Nuremberg Code, the various incarnations of the Declaration of Helsinki and of the CIOMS/WHO International Ethical Guidelines, and the Belmont Report. Chapter 3 examines informed consent in Church teaching and in a select group of Catholic and non-Catholic bioethicists. Chapters 4 through 7 treat proxy consent "in the therapeutic situation," in which Mazur includes almost without distinction both "therapeutic research" and what he calls "the fully therapeutic milieu" (102). In this section he deploys his anthropology to point up the weaknesses he sees in the several prevailing standards for proxy consent—substituted judgment, best interests, and so on—each of which is implicated in the content-less view of autonomy mentioned above. Mazur concludes this portion of the book by endorsing the position combining the work of Germain Grisez and William E. May, according to which the Golden Rule guides surrogates to the impartial and virtuous pursuit of the objective good on behalf of the non-competent patient or research subject. The surrogate prudently pursues the objective good the non-competent person cannot pursue alone. This appeal to the Golden Rule is, Mazur claims, the only attempt in Catholic bioethics to provide a justifying rationale for proxy consent to therapeutic research.

In the final four chapters of the book, Mazur considers primarily nontherapeutic research. The substance of this section is an extended rehearsal of the 1970s-era conflict between Paul Ramsey, Richard McCormick, William E. May, the National Commission for the Protection of Human Subjects, Robert Veatch, Benedict Ashley, and various others on the legitimacy of proxy consent to nontherapeutic research, especially on children. The key to Mazur's resolution comes from May's change of heart precipitated by his participation in a colloquium sponsored by the Pontifical Academy of Life in 2002. For thirty years he had opposed such research in principle because children are beings of moral worth (and therefore cannot be utilized as mere means), but they are not competent as moral agents (and therefore cannot give the requisite consent to act for the benefit of others).

May revised this view once he determined that he should focus instead on the risk of harm. He came to see that Church teaching forbids all nontherapeutic experimentation on the unborn not because consent is lacking but because it necessarily involves some risk to life and limb. Accordingly, May now finds nothing unreasonable in a parent giving personal consent to nontherapeutic experimentation on children (excepting the unborn), provided that there is "no significant risk," only slight inconvenience, the promise of benefit from the research, and no possibility of performing the experiments on competent subjects. Mazur gives detailed consideration only to the first of these provisions, and he treats *minimal risk*, *no discernible risk*, and *no significant risk* as morally equivalent formulations (see 176, 181, *et passim*), although the last enjoys some superiority (194).

Mazur, while endorsing May's conclusion, also goes beyond it by adapting an idea from Rev. Benedict Ashley, O.P. According to Ashley, participation in nontherapeutic research ultimately benefits the child (179). As Mazur emphasizes, Ashley avoids saying the child has a moral obligation here (which McCormick did not shrink from saying). In Mazur's rendering,

our natural sociality means that the individual and the common good stand in a "close relationship" and are "mutually exclusive only to a degree" (195). Mazur concludes by combining May's view with a refined version of Ashley's view: parents can "in the name of pursuing the common good subject their infant to nontherapeutic research," assuming the qualifications stated above in connection with May's view (196–97). In Mazur's judgment, a proxy may pursue the common good without violating the non-competent person's individual good, and, thereby, the proxy might even be advancing that person's good.

To turn from the preceding summary to some evaluative comments, I would like to point out (1) the limited character of Mazur's conclusion in relation to his ambitions, (2) a substantive difficulty with that conclusion, (3) some defects that detract from the book, and (4) the genuine merits of the book.

First, Mazur's "yardstick" ends up furnishing little more than negative guidance. He concludes with May that consenting to nontherapeutic research on a child under restricted conditions "would not be unreasonable" and further with Ashley that it would be a good way to pursue the common good, but he does not say (or even consider) whether it would be unreasonable for the proxy to refuse consent. Pursuing the common good (in this and presumably in any other manner) is presented as non-obligatory (except, according to May, for some older children). Thus, proxies seem free to give or refuse consent, provided that they do not violate the good of their non-competent ward, but Mazur regularly characterizes this sort of choosing as arbitrary or capricious. His claim that "conscience furnishes proxies with reliable guidance" (185) thus rings somewhat hollow. Even if proxies understand conscience as ordered to an objective moral standard (as Mazur describes), his trust in their individual judgment conflicts with the harsh suspicion he has expressed earlier in the book (e.g., 30) toward proxies (as well as researchers, IRBs, and others involved in research).

Second, Mazur's primary focus in this discussion is that the research should pose "no significant risk." He adopts Grisez's interpretation of a significant risk as one that exceeds "the level of life's common risks," a level exemplified by the risk a child faces during a car ride (72). Unfortunately, Mazur never distinguishes between assessing risks in terms of the magnitude of harm and the statistical likelihood of harm. He interprets "minimal risk" as "negligible and trivial" (179), which might be true with respect to the percentages involved, but not with respect to the kinds of injuries at stake in an unnecessary car ride or medical experiment. Also, parents take newborns on rides only when the child needs to go somewhere or cannot safely be left at home. Before exposing a child even to Mazur's "minimal risk," do they not need some substantive, positive reason to do so? Recent editions of the *Ethical and Religious Directives* (ERD) state: "Moreover, the greater the person's incompetency and vulnerability, the greater the reasons must be to perform any medical experimentation, especially non-therapeutic." Mazur does cite the ERD, but he gives this sentence (and its implicit appeal to the principle of double effect) no attention at all. He does acknowledge the relevance of this kind of thinking with respect to therapeutic research (194), but he gives it no detailed analysis and dismisses it in connection with nontherapeutic research (161). His defense of proxy consent in nontherapeutic research does not integrate the assumption of risk with the pursuit of the common good.

Third, this book has the earmarks of a dissertation re-worked for publication. One sign is the unevenness with which the argument proceeds. Some matters receive too much attention

and others too little or none. For example, chapter 8's taxonomy of types of research (which proves far from clear on its own terms) has no role in his argument. And he omits any examination of parental consent to nontherapeutic and *non-experimental* medical intervention on children—e.g., consent to use a child as a blood, bone marrow, or kidney donor for the benefit of another. Furthermore, Mazur reads his intellectual opponents much more critically than his allies, and he depends too heavily on some secondary sources and often lacks direct contact with primary sources.

The most troublesome aspect of the text is systematic imprecision in the deployment of key terms and distinctions, such as *therapeutic* and *nontherapeutic*. In one passage, nontherapeutic research is distinguished by its goal—generalizable knowledge (84–85)—, but in most cases he writes as if research is therapeutic if it benefits the subject and nontherapeutic if it does not (87, 174); the distinction between aiming to benefit and actually benefiting is not respected. In yet another interpretation, Mazur's holds that in a randomized trial comparing a proposed therapy to placebo, the subject who lands in the treatment arm has consented to therapeutic research, but those in the control arm have consented to nontherapeutic research (130). He shifts puzzlingly between *subject* and *patient*; he speaks as if all control groups are placebo-control groups. Even when one knows how to correct for this imprecision, these difficulties place undue burdens on the reader.

Finally, Mazur's book does target a serious lacuna in Catholic thinking on the principles that justify proxy decisions in medicine. Mazur focuses on the content of the proxy's choice in the "impartialist" fashion (where *anyone* inclined to choose according to the Golden Rule is equally fit to serve as proxy). It would be helpful also to address the particular attachment that family and friends have to promoting the good of non-competent persons. His approach—acknowledging that good and bad exist for the dependent person, who is nevertheless unable to negotiate between them—provides a helpful perspective for displaying the inadequacy of autonomy understood as pure self-determination independent of any objective good. Mazur recognizes that informed consent in contemporary medical practice has been shrunken, often to nothing more than a legalistic shield insulating various parties from repercussions for their actions. His attempt to focus our attention on the moral quality of consent is a much-needed step in the right direction.