
Reconsidering Wisdom, Keywords, Concepts, and Models

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I. INTRODUCTION

The contributions to this issue of the *Journal*, despite their range, exhibit a core concern: to reassess themes and perspectives in bioethics that, when expressed in familiar terms and phrases, may fail to be viewed in their full complexity or analyzed with sufficient rigor to do justice to novel clinical situations. Bioethics, as any theoretical or practical discipline, is hardly immune to this general failing—to be lulled into unwarranted confidence in a discourse that has become second nature. There is, however, an obvious irony in bioethics succumbing to that tendency. In an age of biotechnological innovation, the meanings of nature itself, as a primary referent, have come under severe scrutiny. *A fortiori*, our seeming certainties about concepts or habits of thought that appear “second nature” deserve at least as much scrutiny as the primary concept which lends that ascription its metaphorical force.

II. KEYWORDS AND PHRASES IN BIOETHICS

The first three articles are introduced with brief remarks by Tod Chambers, because they were developed from presentations at recent meetings of the American Society for Bioethics and Humanities. In his introduction, Chambers draws the following moral: the history of bioethics, writ broadly, can be seen as a “series of skirmishes over the precise meanings of words” (Chambers,

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2004). The emphasis here is that developed by cultural historian Raymond Williams. Keywords are not simply terms with an etymological pedigree, but are both sources and reflections of ongoing clashes in meaning and application. Keywords in this dynamic sense are well exemplified in bioethics discussions, and the articles in this issue provide object lessons of Chambers's point.

David Nantais and Mark Kuczewski review the history of "quality of life" as a central appeal in debates about resource allocation and end-of-life decision making. In both contexts, at least in principle, "quality of life" judgments may be validly employed if they are meant to provide a replicable measure of the efficacy of a particular treatment. On the one hand, Nantais and Kuczewski rightly criticize certain standardized approaches in allocation debates. The Quality-Adjusted-Life-Years (QALYs) scale, for example, in its early formulations, relied too narrowly on an acute care paradigm, with changes measured strictly as overt improvements in an underlying condition. That approach, they argue, fails to capture the subtler realities of chronic illness, especially possibilities for improvement that may not be readily measurable in terms of strictly medical betterment.

On the other hand, the authors acknowledge that Quality-of-Life Measures may have an appropriate function in responsible rationing decisions, because they measure the relative efficacy of treatments within diagnostic classes. Even HRQLs, however, if they continue to rely on a narrow medical model, may fail to measure many health-related matters that produce no quantifiable improvement in physical health but positively affect quality of life. (The authors' useful example here is the provision of a wheelchair to a paralyzed person.)

Nantais and Kuczewski are more favorably disposed toward non-standard or so-called "subjective" approaches, especially when such assessments serve to identify the relative merits of different treatments and services within a given disease cohort. Still, the authors remain less sanguine about subjective assessments, even as cohort-based generalizations, when they are deployed *across* different diagnostic classes.

Nantais and Kuczewski also consider quality of life discussions in the context of end-of-life decision making. They fault much of that discussion for its tendency to move from assessing the burdens and benefits of particular interventions to broader judgments about the quality of the patient's life. In light of that tendency, the authors call for a resuscitation of traditional categories from Catholic moral theology—the language of ordinary and extraordinary treatment, or proportionate and disproportionate interventions. To be sure,

reclaiming that vocabulary poses problems in its own right, because considerations of ordinary and extraordinary, which historically developed as patient-centered criteria, often devolved into judgments about what is medically indicated in response to a given pathology. Moreover, whether judgments about burdensome treatment can be easily isolated from judgments about the burdensomeness of ongoing life after treatment remains a subject of debate in recent discussions in moral theology.

Therese Lysaught reviews the shifting meanings and implications of respect for persons as a core principle in modern bioethics. In response to the National Bioethics Advisory Commission's (NBAC) recommendation of "respect" for human embryos in its 1999 report on stem cell research, Lysaught questions the cogency of NBAC's articulation of that value and proceeds to review the earlier history of bioethics for major examples of the ways respect has been interpreted. She traces significant shifts in the ways that the notion of respect has been articulated and justified, as well as marked differences in the stringency of the moral constraints generated by those various interpretations. Her survey includes Paul Ramsey's, *The Patient as Person*, the 1975 National Commission Report on Fetal Research, the 1979 *Belmont Report* on Research with Human Subjects, the 1979 Department of Health, Education, and Welfare (HEW) Ethics Advisory Board's Report on In Vitro Fertilization, Beauchamp and Childress's *Principles of Biomedical Ethics*, the 1994 NIH Report on Human Embryo Research, and the NBAC Report with which her discussion begins.

In Lysaught's judgment, 1979 marks a pivotal turning point in the way that respect is construed, with the publication that year of both the HEW Report on In-Vitro Fertilization and Beauchamp and Childress's *Principles of Biomedical Ethics*. The 1975 National Commission Report on Fetal Research, coming three years after *Roe v. Wade*, had deliberately tabled questions about fetal personhood, but had called for "moral concern" to be extended to "all who share human genetic heritage." By 1979, the HEW Report on IVF, while stating that human embryos are entitled to "profound respect," ceases to view them as protectable subjects based on a common genetic heritage. That shift, echoed in subsequent reports, is significant, according to Lysaught, because embryos are no longer deemed non-autonomous subjects, protectable under to the principle of respect.

Lysaught also finds a shift in the meaning of respect for persons as articulated by Beauchamp and Childress in their influential *Principles*. On her reading, Beauchamp and Childress redefine that principle as a subcategory of the

principle of autonomy. The result, she argues, is that the protections accorded non-autonomous individuals under the *Belmont Report's* interpretation of respect are now determined by the principles of nonmaleficence and beneficence. In her judgment, not uncontroversial, the latter principles “lack the moral security of respect” and are too easily reduced to utilitarian calculations.

Nancy Berlinger analyzes the increasing prevalence in recent discussion of the putative connections between “spirituality” and medicine. While she expresses reservations about the protean character of the spirituality being invoked, her primary intent is to identify the *ethical* issues raised by calls for the inclusion of “spirituality” in medical practice (as distinct from the concerns of pastoral caregivers). Berlinger assesses several core recommendations of the 1999 Medical School Objectives Project (MSOP) Report on “Communication in Medicine,” which included spiritual aspects of patient care as the focus of several learning objectives, including the ability to take a spiritual history and to master “data” on the impact of spirituality on health and medical outcomes. Berlinger reviews the MSOP objectives with a measured though critical tone. While not unsympathetic to the tacit dimensions of patient care, she details the confusion surrounding current claims for necessary links between spirituality and medicine and the possibilities for moral mischief (or something more serious) in efforts to institutionalize such putative links in the clinical environment. After all, the possibility that paternalism may assume a newly mandated spiritual form makes it no less problematic.

III. IMPLICATIONS FOR CLINICAL AND RESEARCH SETTINGS

Tom Koch, drawing on an exchange between noted utilitarian Peter Singer and Harriet McBryde Johnson, an advocate for the disabled who is herself disabled, employs their respective positions to discuss two rival paradigms in bioethics. One school, which Koch call “critics of difference,” defines personhood according to capacities for autonomy, self-determination, and independent action. The second approach, which Koch dubs “critics from difference,” defines personhood primarily in relational or communal rather than individualistic terms.

Singer’s account of personhood is, of course, well known, McBryde Johnson’s less so. The theoretical differences between the two accounts are stark, as are their practical implications for specific cases, especially those involving severe disability. Koch makes clear his preference for McBryde Johnson’s relational account, and concludes that a failure to care for the severely disabled

reveals a fundamental misunderstanding of personhood as socially embedded. Koch's account engages important definitional questions. At the same time, in light of Nantais and Kuczewski's discussion of quality of life, his defense of relational personhood does not, of itself, address, much less resolve, the matter of how to develop fair and efficient allocation criteria in the context of limited health care resources.

Ruth Grant and Jeremy Sugarman analyze the use of incentives in clinical research. In their review of earlier discussions, the authors question the cogency of interpretations that view incentives as a form of "undue influence" or "coercive offer." The authors detail the sometimes subtle differences among several terms—incentives, compensation, reimbursement, wages, and market forces—that are quite often conflated.

As Grant and Sugarman observe, their inquiry "resides at the intersection" of two different sets of considerations. One set of considerations is relevant whenever incentives are employed, while a second set is "distinctive to research with human subjects." While the authors find the use of incentives to be generally innocuous, they discuss several factors that, solely or in combination, do make incentives a form of undue influence, though not as a form of coercion but as a corruption of a subject's judgment. In their judgment, undue influence "occurs when an incentive is attractive enough to tempt people to participate in a research 'against their better judgment'" (Grant & Sugarman, 2004).

In the final article, Eugene Boisubin and Laurence McCullough analyze how the widespread use of sildenafil citrate (Viagra)—and of similar future drugs—requires that we expand the traditional focus on the dyad of physician and patient to include explicit ethical concern with the patient's sexual partner(s). The authors emphasize the duty of physicians to provide respectful and comprehensive counseling of patients who request the drug. In light of the broader compass of clinical concern, Boisubin and McCullough assess the relevance and adequacy of three standard models of informed consent as applied to the Viagra case—that of public health, justified limits on patient confidentiality (which often overlaps with the first), and a biopsychosocial approach. In their judgment, because the biopsychosocial model necessarily includes concerns about the psychic and social components of health disease, it best comports with the expanded requirements for informed consent in the Viagra case. The authors also consider several other issues that may arise in the prescription of Viagra, including possible tensions between role-related obligations and considerations of personal conscience.

By way of a concluding word, the six substantive articles in this issue of the *Journal*, in diverse fashion, exemplify and confirm the point that Chambers emphasizes in his introduction. Key words and phrases, clinical concepts and models for decision making, remain contested territory. We do well to reassess regularly what passes for conventional wisdom, in bioethics and elsewhere.

REFERENCES

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