Autonomy and Individual Responsibility

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Introduction

The Universal Declaration on Bioethics and Human Rights is an extraordinarily ambitious document. It seeks to "provide a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics" (Universal Declaration, Art. 2(a), 2005). Few, if any, intergovernmental instruments match its breadth in terms of subject matter covered ("ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions") (Universal Declaration, Art. 1, 2005). It is also notable for the unusually vast audience to whom it is addressed. Not only is it meant to offer advice to member states but also "to guide the actions of individuals, groups, communities, institutions and corporations, public and private" (Universal Declaration, Art. 2(b), 2005). The Declaration has received some attention from scholars and policy makers, both positive and negative. UNESCO itself has taken steps to circulate and promote it, including by publishing commentaries on its various provisions, authored by invited contributors, including the International Bioethics Committee itself. But one aspect of the Declaration has not yet received the attention it deserves, namely, its treatment of autonomy as an ethical principle. Whereas autonomy has been accorded pride of place as the dominant ethical principle in mainstream bioethics for decades, the Declaration offers a strikingly different approach. That is, it subordinates autonomy to other goods such as human dignity, solidarity, and protection of the vulnerable. In this way, the Declaration recovers and restores the original key animating good for public bioethics that gave rise to this new species of law and policy in the first instance. It marks an important return to the foundational principle of respect for persons.

This chapter will elaborate on this countercultural feature of the Declaration and offer an argument that it is a salutary development for public bioethics. To that end, it will proceed in the following manner. First, it will supply a necessarily

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compressed account of the shift from respect for persons to respect for autonomy as the dominant ethical norm in public bioethics. Next, it will argue that this singular emphasis on autonomy has impoverished public bioethics as a form of governance (and a field of inquiry). This chapter will then explain how the Declaration represents a turnaway from this approach, toward the embrace of a suite of goods squarely situated within the concept of respect for persons, richly understood.

Brief History: From "Respect for Persons" to "Respect for Autonomy"

The origins of bioethics in its scholarly and public forms are complicated and contested (Jonsen, 2003, offering a compelling account of this history; Snead, 2010, offering an extended discussion). As a field of interdisciplinary scholarly inquiry, bioethics seems to have emerged in the middle of the twentieth century (late 1960s) in large part as a reaction to the simultaneous increase in technical skills on the part of physicians (enabled by extraordinary advances in biomedical science) and *decline* in the humanistic dimension of medical practice. As doctors became more technically proficient, they also became (or were widely perceived as becoming) more humanly distant from their patients. The almost priestly role of the physician (who had historically ministered to the whole person and her family) gave way to a narrowed emphasis on the technical mastery of interventions aimed at correcting clinical pathologies. As a result, patients increasingly felt neglected as participants in their treatment. Worries about paternalism proliferated. In response, an interdisciplinary array of physicians, theologians, philosophers, legal scholars, and social scientists convened meetings and founded centers to explore these and related matters. These events, according to Albert Jonsen (and other commentators) marked the beginning of bioethics as a field of scholarly inquiry (Jonsen, 2003).

The birth of *public* bioethics (i.e., the *governance* of medicine, science, and biotechnology in the name of ethical goods), however, emerged in response to a very different series of events. Unlike the scholars and commentators described above, public officials charged with making, enforcing, and interpreting the law were not "driven by a desire to tame the imperialism and arrogance of medicine" (Schneider, 1994b, p. 1076, describing the theoretical foundations of bioethics and the role of autonomy as its dominant norm). Instead, they were moved to action in the face of a series of grave abuses of the weak and vulnerable by scientific researchers. Such abuses occurred at the hands of Nazi scientists in concentration camps (later prosecuted for crimes against humanity in a trial that culminated in the publication of the Nuremberg Code), by researchers who (from 1963 to 1966) deliberately injected children at the Willowbrook School for "mentally defective persons" with the hepatitis virus, by investigators who (in 1963) intentionally and without consent injected living cancer cells into patients at New York City's Jewish Chronic Disease Hospital, and by researchers in 22 separate clinical studies whose unethical practices were documented by Harvard's Dr. Henry K. Beecher in his groundbreaking 1966 article in the *New England Journal of Medicine* (Davis, 2008).

But two events in particular prompted members of the United States Congress to convene hearings in 1973. First, lawmakers in Congress were spurred to respond by reports of the Tuskegee Syphilis Study, in which scientists from the US Public Health Service enrolled 399 poor black men suffering from syphilis in a research project aimed at studying the progress of the disease in its untreated form. For 40 years, the researchers systematically deceived these men and their families about the nature and purpose of the project. Worse still, the researchers did not administer antibiotics to the subjects, even after the drug became established as an effective treatment for the disease in 1947 – 15 years after the study began. Second, lawmakers in Congress were animated by reports of experimentation on unborn children slated for abortion in protocols that involved temporary life support followed by direct killing in especially gruesome and painful fashion (Jonsen, 2003, pp. 94–95). Jonsen quotes one researcher as saying "I don't think it is unethical. It's not possible to make this fetus into a child, therefore, we can consider it as nothing more than a piece of tissue."

It is notable that in all of the aforementioned instances of abuse – from Nuremberg forward – the researchers involved attempted to defend their actions on the grounds that they had not created the underlying tragic circumstances facing the various subjects, nor would their interventions materially harm them further. The subjects were already destined to suffer from dread diseases or to be killed in any event. By their lights, the researchers were merely trying to salvage something useful from an unfortunate circumstance. Understandably, these arguments have been widely rejected and criticized. It is one thing to accept the unavoidable death or suffering of another. It is another thing entirely to appropriate and instrumentalize the circumstances and (as in the cases of some of the researchers described above) intentionally infect or even kill the otherwise doomed subject for the sake of research.

In response to these two particularly troubling examples of unethical and abusive conduct by researchers, Congress passed the National Research Act of 1974, which, among other things, established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Pub. Law No. 93–348). This development marked the first time an organ of government was created with explicit charge to "do bioethics" in the name of the state.

Given the constellation of research scandals to which the National Commission was a response, it is not surprising that an anchoring norm of its iconic 1979 *Belmont Report* was the principle of "respect for persons." This principle entailed a twofold protection for persons in the context of biomedical and behavioral research. First, the Commission asserted that respect for persons includes respect for their autonomy and self-determination (to be realized through legal mechanisms such as informed consent). Second, it claimed that respect for persons imposes an obligation "to protect those with diminished autonomy," including persons who are "immature and the incapacitated" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; Lysaught, 2004, pp. 665–680). Thus, while the National Commission proposed a principle for public policy that protected self-determination (in a way that aligned with the aforementioned concerns about medical paternalism), it likewise attended to worries about the vulnerable class of persons whose diminished cognitive abilities render them unable to defend their own interests. In this way, the Commission cast an admirably wide net of protection for people in a domain where the risks of extraordinary forms of abuse had already been tragically demonstrated.

In short order, however, prominent and influential voices moved to constrict the circle of protection constructed by the National Commission. As both M. Therese Lysaught and F. Daniel Davis have shown, in a series of high-profile commentaries and textbooks, the principle of respect for persons was replaced by a new, more limited principle – respect for autonomy (Davis, 2008; Lysaught, 2004). Lysaught details how this change of course emerged in particular in Beauchamp and Childress's first edition of *Principles of Biomedical Ethics* (1983).

Beauchamp and Childress's *Principles of Biomedical Ethics* has perhaps become the single most influential work on bioethics and departs significantly from the *Belmont Report*. Beauchamp and Childress restyled *Belmont*'s "respect for persons" simply as the principle of autonomy or *respect* for *autonomy*. Whereas the *Belmont Report* presupposed an inverse relationship between autonomy and protection, Beauchamp and Childress took the opposite view. In the framework set forth by the *Belmont Report*, the moral imperative to protect individuals from harm increases as their autonomy diminishes: "Respect for the immature and incapacitated may require protecting them as they mature or while they are incapacitated. *Some persons are in need of extensive protection, even to the point of excluding them from activities which may harm them*" (Lysaught, 2004, p. 669 quoting the *Belmont Report* 1979, p. B.1 3, emphasis added). Moreover, in the *Belmont Report*, the obligation to protect the vulnerable extends to all human beings, not merely those capable of individualized choice (Lysaught, 2004, p. 678). By contrast, Beauchamp and Childress distinguish autonomous and nonautonomous individuals, privileging only the former as full "persons" entitled to robust care and protection (Lysaught, p. 676). For Beauchamp and Childress, "respect" thus becomes something like "noninterference" and is defined almost solely by informed consent (Lysaught, p. 676). This form of respect is not due "to persons who are not in a position to act in a sufficiently autonomous manner" (Beauchamp & Childress, 1983, p. 64). The *Belmont Report*'s framework for protecting the vulnerable under the heading of "respect for persons" drops from consideration altogether.

Moreover, with the rise of autonomy to pride of place among bioethical principles, the concept of "personhood" itself became truncated to include only those human beings capable of rational choice. Ruth Macklin confirmed as much when she famously equated "human dignity" with autonomy. She argues that dignity (and the respect and protections that it entails) is owed only to those whose actions and thoughts are "chosen, organized and guided in a way that makes sense from a distinctly individual point of view" (Macklin, 2003, pp. 1490–30 quoting the Nuffield Council on Bioethics, Genetics and Human Behaviour). In a similar vein, Steven Pinker has argued that human dignity is "stupid," "a mess," dangerous, and should be abandoned in favor of a single-minded focus on respect for autonomy (Pinker, 2008).

This startling shift from respect for persons to the narrower respect for autonomy seems to emerge, in part, from a desire to push the boundaries of scientific research, especially with regard to abortion and embryo research. Lysaught argues persuasively that the shift to autonomy alone was meant to enable the endorsement of activities that "traditionally would have been strong candidates for violating 'respect' – for example, destroying embryos, creating embryos for research, creating embryos through cloning, and creating chimeras" as "morally licit" pursuits (Lysaught, 2004, p. 667 discussing National Bioethics Advisory Commission, 1999, internal citations omitted). The shift to autonomy likewise seems to be driven by the aspiration to identify an ethically "thin" principle that would command broad appeal in a pluralistic culture and thus provide a suitable basis for public policy.

The Consequences of the Hegemony of Autonomy in Public Bioethics

The consequences of this shift to autonomy as the singular lodestar of public bioethics have been profoundly deleterious. As Carl Schneider points out in his article, *Bioethics with a Human Face*, the notion of autonomy alone does not capture the whole truth of what it means to be human. He argues, "A powerfully stated and too-often simple autonomy paradigm has become the central feature of bioethical thought and law. Yet, despite the undoubted and true importance of that paradigm, its reiteration has become stale, flat, and unprofitable, and its simplicities have become too costly" (Schneider, 1994b, p. 1076).

The inadequacy of autonomy as the sole normative paradigm for bioethics becomes particularly apparent when one considers the profound vulnerability of patients in the clinical setting (Lysaught, 2004, p. 678). Patients seeking care surely desire information and the opportunity to give consent to treatment. But, first and foremost, they are asking for help. To entrench autonomy as the only normative polestar in this domain threatens to reorient the doctor-patient relationship itself. Carl Schneider warns that:

> If doctors and patients meet clad in the armor of their rights, both of them will lose as well as gain: 'The physician who is now instructed to obey the 'informed consent' of his patient, no matter how harmful he feels that action to be for the patient, is not only permitted but positively enjoined to separate himself from his patient, to respect his patient's "autonomy" by suppressing his own identifications, his self-confusions, with that patient.' (Schneider, 1994a, pp. 16–22 quoting Burt, 1977, p. 32)

As Charles Bosk writes, "The dark side of patient autonomy [is] patient abandonment" (Schneider, 1994a, pp. 16–22 quoting Bosk, 1992, p. 158). A simplistic emphasis on autonomy alone is "particularly injurious in bioethics, a field that treats people in their least rational moments, in their most emotional travails, in their most contextual complexity" (Schneider, 1994a, pp. 16–22 quoting Bosk, 1992, p. 158).

Further, the narrowed definition of "person" that results from a sole focus on autonomy radically constricts the circle of protection for the weakest and most vulnerable members of the human family. As Gilbert Meilaender has correctly observed (quoting Philip Abbott): "There are very few general laws of social science but we can offer one that has a deserved claim: the restriction of the concept of humanity in any sphere never enhances respect for human life" (Meilaender, 1998, pp. 108–109). The very victims whose plight motivated public officials to intervene in the practice of medicine and scientific research in the first instance – the unborn, the socially marginalized, the cognitively disabled, the elderly suffering from dementia – are deemed "sub-personal" under the autonomy-only paradigm of public bioethics. It is a paradigm that stands humankind's best moral traditions their heads – perversely privileging the claims of the strongest over those of the weakest.

Even aside from the grave concerns about the weak and vulnerable, the autonomy paradigm reflects an impoverished moral anthropology even for those capable of robust free choice. It conceives of persons as radically individualistic disembodied wills whose activities are reducible to bargained-for exchanges with other wills. Left ignored are bonds of kinship, community, and the *unchosen* obligations that characterize such relationships. The human good of solidarity is missing from this framework.

Restoration and Retrieval in the Universal Declaration on Bioethics and Human Rights

One of the signature achievements of the Universal Declaration on Bioethics and Human Rights is a turnaway from this inhumane paradigm, back toward a richer conception of human beings and their obligations to one another. The Declaration is grounded in a humanly robust moral anthropology – one of human dignity and solidarity – and situates autonomy within this framework. It rejects that conception of personhood that over time has become conflated with autonomy and decouples these notions. It recognizes that persons are not simply autonomous beings. In fact, the Declaration eschews the term "person" as an exclusionary category; rather, it uses the term "human beings" to orient the document and then uses "persons" in an expansive fashion. Furthermore, the Declaration mentions "persons" incapable of autonomous decision-making, so the cognitively impaired and cognitively immature are included in the Declaration's notion of personhood.

Most obviously, Article 5 ("Autonomy and Individual Responsibility") signals a return to the original conception of autonomy (as a subsidiary good), found in the *Belmont Report*. It urges respect for autonomy but reminds the reader that individuals bear responsibility for the choices they make and must pay due regard for the good of others. More importantly, Article 5 restores the injunction to protect "persons not capable of exercising autonomy," by ensuring that "special measures be taken to protect their rights and interests."

By acknowledging that there are "persons" who lack the capacity to exercise autonomy, Article 5 also strikes a blow against the use of "personhood" as a term of exclusion, about which Meilaender cautioned above. Likewise, Article 6 ("Persons without the Capacity to Consent") calls for special protections for "persons who do not have the capacity to consent." Thus, on their face, these provisions reject the notion that the capacity to exercise autonomy or to give consent is a necessary prerequisite to membership in the community of persons. By extension, all of the attendant protections of human dignity and human rights accorded to "human beings" in the Declaration are equally applicable to persons lacking the capacity for intentional, self-aware action.

A related virtue of the Declaration is its global use of the phrase "human beings" to describe the principal focus of its protections. By opting for this term, the Declaration offers its protections to the widest possible array of subjects and strengthens its human life-affirming provision even further. And these protections are significant. First, the preamble recognizes that human beings have a responsibility to protect one another. Additionally, the preamble provides that "all human beings, without distinction, should benefit from the same high ethical standards in medicine and life science research." Article 10 ("Equality, Justice and Equity") affirms explicitly the principle that "all human beings" are equal in dignity and rights and are to be treated justly and equitably. Article 8 ("Respect for Human Vulnerability and Personal Integrity") declares that in the development and application of science, technology, and medicine, "individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected." Finally, protection of future generations is declared to be an explicit aim of the instrument. This is made more concrete by Article 16 ("Protection of Future Generations"), which provides that "the impact of life sciences on future generations, including on their genetic constitution, should be given due regard."

Human dignity – not autonomy – is the most prominent ethical principle featured throughout the Declaration. The Declaration includes many provisions that serve to elevate the importance of human dignity and highlight the respect for human life. First, the preamble establishes human dignity as the very lens through which science and technology should be understood. It provides that "advances in science and their technological applications should be examined with due respect" for human dignity. The first "aim" of the Declaration relating to the development of ethical principles (Article 2[c]) declares that the purpose of the instrument is to "promote respect for human dignity." Similarly, the very first "principle" of the Declaration (Article 3), titled "Human Dignity and Human Rights," provides that "Human dignity, human rights and fundamental freedoms are to be fully respected." The Declaration forcefully asserts in several of its provisions that human dignity may not be ignored or transgressed. Indeed, the Declaration makes clear that full regard for human dignity is itself an explicit limitation on the application of other worthy principles. For example, the preamble recognizes the importance of "the freedom of science and research" and affirms the benefits that flow from "scientific and technological developments," but firmly reminds the reader that such activities should take place in a context that gives proper recognition to human dignity. Similarly, Article 12 ("Respect for Cultural Diversity and Pluralism") celebrates the virtues of diversity and pluralism but explicitly notes, "Such considerations are not to be invoked to infringe upon human dignity." Finally, the Declaration concludes (in Article 28) with the following injunction: "Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to . . . human dignity." Simply put, the concept of human dignity infuses the entire Declaration. The instrument literally begins and ends with statements underscoring its importance. There is no principle that animates the Declaration to the same extent.

The Declaration also strongly affirms the centrality and importance of respect for human life. Most obviously, it is tremendously significant that an explicit aim of the Declaration is "to promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law" (Universal Declaration, Art. 2(c), 2005).

Conclusion

The Universal Declaration on Bioethics and Human is anchored in the concepts of human dignity and solidarity and affirms the central importance of basic obligations of human beings to one another in virtue of their shared humanity. Although the Declaration is by no means perfect, its provisions reject the notion that respect for autonomy should remain the key animating principle in bioethics. In this way, the Declaration signals a vital recovery and return to the foundational anchoring norm of respect for persons.

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