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# Vulnerability and the Bioethics Movement

by Rosemary Flanigan

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*"Vulnerable populations" did not become a keyword descriptor in the official Bioethics Thesaurus until 1997 although it was used as a proposed descriptor during the previous year. Today it is used as a buzz word to target new populations among the beneficiaries of ethical analysis. But is the concern new? I contend that the bioethics movement, although it has historically used different "search words," has always focused on those whom we call "the vulnerable." Bioethics is principally concerned with persons, and to be human is, by essence, to be vulnerable, which is especially true in sickness. The bioethics movement, by concentrating on enhancing the autonomy of the patient, attempts to overcome the vulnerability inherent in being a patient. What is new, then, is not vulnerability but the notion that there are some entire populations whose members are more vulnerable than others in their approach to the healthcare delivery area. This paper shows that we have an obligation in justice to secure increasing autonomy for these most vulnerable populations.*

**V**ulnerable" is variously defined as capable of being wounded, defenseless against injury, open to attack or damage, readily countered. "Vulnerable populations" entered the *Bioethics Thesaurus* as a keyword descriptor in 1997 although it was used as a proposed descriptor the previous year. What makes someone or some group vulnerable and the remedies to counter vulnerability have become a major bioethics project of the new millennium. The science of bioethics has come to be the disciplined analysis of the moral and conceptual assumptions of medicine, the biomedical sciences, and the allied health professions. It has become a rapidly developing special area of philosophy or ethics.

In this article I propose to trace the progenitor of the descriptor word, "vulnerable populations," which is, namely, the bioethics movement's emphasis on autonomy. I shall then show how the discussion of autonomy has led bioethicists to see the need to encourage whole populations to become autonomous in healthcare delivery situations. But if there are populations that cannot even conceive of this possibility, who but those engaged in bioethics can right this lack? To this

end, I propose other ethical anchors, beneficence and justice, that will motivate these populations to engage in this effort.

## **First Concerns — The Beginning of Bioethics**

The first concern of the fledgling science of bioethics was the conflict between the individual and common good primarily in the area of research on human subjects (Jonsen 1998). Historian of the movement, Al Jonsen, marks the beginning in 1966 when the first conference was held at Reed College, Portland, Oregon, on the topic, "The Sanctity of Life." Speakers included a philosopher, a British barrister, a sociologist, a theologian, and a professor of anesthesia — all of whom became pillars of the bioethics movement which would continue to model the interdisciplinary nature of the new science. The philosopher, Abraham Kaplan, ironically a logician more than an ethicist, described the role that philosophical bioethicists would serve in the future as one of exposing ethical oversimplifications. And it was his remarks in another context, which, according to Jonsen, presaged a dominant principle of future bioethics: "The moral judgment must accord with the principle of moral autonomy, as it

has been known in philosophy since Immanuel Kant. The moral will must be a lawgiver unto itself; . . . in that case, we are committed to respecting the moral autonomy of other moral agents as well." (quoted in Jonsen 1998).

Autonomy in a subject whose actions could be generalizable continued to be the focus of attention as bioethics grew and developed its vocabulary, its analytical tools, and its specialized content. For example, in its first foray into human research where the good of the whole is radically dependent on the activities of the few, Hans Jonas, a philosopher at the New School for Social Research, denied that contrasting the individual versus the common good was the proper way to frame the problem. He argued that experimentation does not aim to preserve human life but to improve it and participation in such experimentation is thus gratuitous, not obligatory. It must be an exercise of freedom for the participant, and since the researchers themselves are the most interested in the goal of the research, they should be the first volunteers (Jonsen 1998).

Voluntariness, freedom, autonomy, the denial that society can always claim pride of place over individual rights for the production of its future goods — these concepts claimed the attention of practitioners at the outset of the bioethics movement.

### **Doing Ethics**

Today's emphasis on "vulnerable populations" stretches the idea of autonomy to its logical limits. But first let us consider what one does when one "does" ethics. Ethics is a practical philosophical discipline; it does not tell us what is right or wrong, but it helps us articulate the assumptions used in our judgments of moral right and wrong. When we gather these assumptions into organized sets, we come up with theories, for example, that consequences alone are morally significant in our actions (utilitarianism) or that character is the guiding principle of right action (virtue ethic) or that the ethical quality of an action lies in discovering its end and conforming our actions to that end (natural law ethic).

While all these theories have served as guides within the bioethics movement, Beauchamp and Childress, in their often-revised *Principles of Biomedical Ethics* (1994, 4th edition), elucidated another ethical theory that has had a major impact on the development of bioethics. Many people call their theory "principlism" since it enunciates basic

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moral values that should guide ethical discourse. Beauchamp and Childress found these principles in the Belmont Report, in which early founders of the movement came to affirm respect for persons, beneficence, and justice as the ethical principles that "serve as rational justification for decisions and policies" (Jonsen 1998). Respect for persons leads to two ethical convictions: first, that individuals should be treated as autonomous agents; and second, that persons with diminished autonomy are entitled to protection" (cited by Jonsen 1998).

As "principlism" has its foundation in a dignity of person ethic, and as these principles became part of the early language of bioethics, they now serve to help us elucidate the moral dilemmas we find in addressing vulnerable populations.

### **Dignity of Person Ethic**

A dignity of person ethic has something of utilitarianism in it, because consequences are important; something of natural law, because the kinds of acts involved are important; and something of virtue ethics, because it considers the situational judgment (LaCroix 1999). The principles of autonomy, beneficence, nonmaleficence, and justice are values that belong to the

nature of being human. But these values are formal, so the dignity of persons theory encourages us to balance the consequences of our actions over against the dignity of the self-orderer with whom or for whom we act.

Clearly, consequences alone are not of sufficient moral significance to act as an ethical guide. How often, for example, have we reflected on proposed actions and opined, "I don't care if I succeed or not, I must do this." Likewise, the nature of actions themselves cannot capture how persons are affected by these actions. We find ourselves saying, for example, "I feel constrained to act in a certain way in this relationship even though I ordinarily would not countenance such actions."

### **Ethical Principles and Ethical Theory**

Ethical principles (e.g., respect for persons, beneficence, and justice) serve as foundations for moral rules. That is, they provide the rational structure that explains why certain rules are "good" rules. Ethical theories, on the other hand, are bodies of principles and rules more or less systematically related. Respect for persons points to a certain way of defining human nature. Dignity of person theory, as it is most often used, finds the anchor for value in persons, not in their ability to reason, but in the self-ordering capacity that expresses their freedom; hence, the importance of autonomy.

Self-ordering takes place within a distinction that we assume, namely, that there are certain existential values which are discovered to be important for persons, and there are moral values (principles) which one prescribes for oneself in order to bring certain values into reality. Thus, healthcare providers may know that confidentiality is an important value for those seeking care, but until providers order themselves to act to protect another's information, they are not acting ethically. Ethics does not happen within a person's head as the agent spins ever more complex theories to guide human interaction. Rather, ethics based on the dignity of person theory attempts to justify our actions in a world where the anchor for value in all human actions is respect for the dignity that is

inherent in being human and where consequences of one's actions must uphold that dignity. The person is seen to be an individual being who is an autonomous self-orderer, that is, one who rationally decides and brings into being those actions which existentialize the person's intentions. Echoing Immanuel Kant, the primary rule for one who justifies one's actions in this way is "act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only." (*Groundwork of the Metaphysic of Morals*, cited in Jonsen 1998)

### **Dignity**

Why isn't the theory simply called a person-centered ethic? What does "dignity" connote that makes it an essential term to explain this mode of ethical reasoning? What does "dignity" entail? When one refers to dignity, one is pointing out an inherent quality present simply by reason of the person's being. Dignity says, "I have no price. I am not fungible." The reason that all persons, by

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reason of being who they are, are to be treated with dignity, with respect, with the deference due to their personhood, lies in each person's self-ordering capacity. The dignity of person ethics says that this inherent quality is the unavoidable, unconditional horizon for ethical actions.

Unlike other ethical theories, the dignity of person ethic claims that human decisions constitute the moral order, not the consequences of those decisions, and not the nature of the actions decided on. When a person takes hold of temporal and

cultural elements in the world and “means some action” into those elements, then those material elements take on moral relevance. Our actions, not just our intentions, are concrete evidence that we are responding to the reality and the dignity of persons, and affecting the world as well as ourselves by so acting.

### **Autonomy**

The dignity of person ethic played a major role in the early ethical analyses of the bioethics movement because of the orientation of philosophers in the early days to Kantian thinking. But the use of the principle of autonomy also came ready to hand because of an interesting historical fact. The history of the practice of medicine had been highly paternalistic. Healthcare delivery particularly in hospitals was often characterized as having two positions: vertical and horizontal. White-coated verticals standing around the horizontally placed patient typically talked with one another and made all the decisions. Commentators have noted that the early history of the bioethics movement served

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to prop up the individual patient so he or she could get into the discussion of his or her own healthcare needs. Respect for the autonomy of all those engaged in the discourse led to radically altered practice guidelines.

As the history of the bioethics movement unfolded, autonomy retained pride of place although the values or moral principles of beneficence, nonmaleficence, and justice also came to be seen as bedrock to the moral interactions among people. The patients’ rights movement expressed entitlements claimed by

different participants in healthcare delivery, and the discussion of patients’ rights, most notably within health maintenance organizations, continues today. The very notion of rights flows from those items seen to be necessary for the self-orderer to act reasonably and thus humanly. But as the decades passed, it became apparent that something more than the recognition of autonomy was needed to bring whole groups of persons into the discussion.

### **Vulnerable Populations**

Although it can be argued that all human beings are essentially vulnerable by reason of their natural predilection to sickness, old age, and death, it has become evident that some “populations” are more vulnerable than others, especially where healthcare is concerned. Vulnerability pivots on the perception of a lack of control over the circumstances in which people find themselves and thus the lack of a voice to direct those circumstances. Poverty, malnutrition, inadequate education, many factors — social, environmental, genetic — contribute to the reality of a sense of vulnerability.

Philosophically, one can argue that while there is knowledge without words, there is no rational thinking or deliberation without words. Thus, the perception of lacking a voice to enter into the healthcare conversation can be traced to a lack of language. But there is a deeper vulnerability: a lack of capacity even to imagine being autonomous in certain conditions or in certain circumstances. This vulnerability is deeper than a lack of language. It is the inability to conceive of possibilities to which language can be applied. Even to conceive of oneself as autonomous, especially in healthcare matters, is often impossible for many people.

Traditionally, babies, children, and old people have been identified as vulnerable, but when their vulnerability is examined, that which impedes their imagination and autonomy is found in many more subject populations. Often, people living in poverty, disabled individuals, ethnic minorities, and undocumented aliens find themselves unable to conjecture about a world that includes healthcare decisions. Whole healthcare systems have been

challenged, in accord with their mission, to serve and act as advocates for those on the margin of society who have been identified as the poor, the uninsured and the underinsured, children and the unborn, single parents, the elderly, those with incurable diseases and chemical dependencies, racial minorities, immigrants and refugees, persons with mental or physical disabilities regardless of the cause or severity (National Conference of Catholic Bishops 1995).

Finally, during the debate on physician-assisted suicide, another population was classified as vulnerable: those who, by reason of their debility are inclined to seek the means to end their lives, not as an autonomous choice to die for one's own reasons, but rather as a population that is highly impressionable and prone to read meaning into what is said to them – or, sadly, not said. The frail elderly are at risk of thinking that their lives are a burden to the rest of us.

To help serve these populations, a vulnerability principle has found its way into the lexicon of assumptions, strengthening the nonmaleficence (“do no harm”) principle. “The duty to protect others from harm is stronger when the third party is dependent on others or is in some way especially vulnerable” (Burkhardt and Nathaniel 1999).

To recap: certain elements seem to characterize each of these vulnerable populations:

- They are victims of social injustice that results in diminished health. Because of money, class, race, social regulation, or social structures that reduce moral agency, whole populations suffer diminished health from factors over which they have no control. Being the victim of socioeconomic stress bears a direct relationship to poor health status.
- They experience an individual and group inability to overcome injustice. Diminished moral agency can paralyze whole groups, or, to put it another way, their lack of control can so alienate them that they are unable to make decisions and life plans for themselves.

- These “vulnerable” are whole groups or populations rather than isolated members. It seems easier to address the needs of a vulnerable individual than to address the injustices that keep whole groups, whole populations, in thrall.

### **Beyond Autonomy**

I contend that progress has been made in righting the existential features of healthcare delivery by emphasizing autonomy. But autonomy is simply one principle, though of essential importance, in bioethics, and was never assumed to be an absolute value. To deny autonomy demanded justification, but the denial could at times be justified so long as the dignity of the person was upheld.

But what about populations who fear and even hate healthcare providers and for whom the very notion of entering the world of healthcare is perceived to be a fate worse than death? There are some populations in which the physician and nurse are hated more than the police or the social worker. Such a population differs in vulnerability from the populations who need healthcare but are denied access for any number of reasons. The issues of nonaccess can be addressed with the usual language of distributive justice. But for the former populations, those without voice, or those unable to comprehend the availability of resources, as well as those whose perception of healthcare is skewed at the core, can such populations or members of such populations be helped by the bioethicist? My answer is “yes,” if centers of ethical responsibility within healthcare institutions — those dedicated to furtherance of the mission, to quality, to organizational ethics — work together to identify these vulnerable populations ascertained to be vulnerable and arrange strategic measures to alleviate their voicelessness.

The motivating force for this new thrust on the part of bioethicists will be justice. For too long the principal kind of justice addressed in bioethics has been distributive justice. Questions about allocating scarce resources or distributing burdens and benefits, call for a careful analysis of distributive justice. But a new meaning of justice is needed here,

perhaps the “welfarist” kind of justice alluded to by Brock (1999), where he distinguishes it from “resourcist,” or distributive justice. The formal principle of justice, to treat equals equally and unequals unequally, calls for the delineation of those obligations we owe one another as we coexist in society. Where a person draws the line between justice and charity will help define the kind of justice needed to address the ethical implications of vulnerable populations.

Whatever name is given to the meaning of justice in this respect, there is need to return again to the notion of the “common good.” When persons lack what we recognize as human rights, justice demands that we restore the balance. Specifically, if ethics committees in institutional settings were to identify those populations most vulnerable within the specific outreach of each institution and join forces with others within and outside the institution to address the vulnerability, change for the better could be effected within the entire community. Why? Because such action addresses the common good.

To address the ethical implications of “vulnerable populations,” bioethicists must seek to empower or repair diminished or damaged moral agency so that injustice may be corrected. I contend that the ethical structure needed to form persuasive arguments will continue to be a principle ethics, with dignity of persons as its anchor value. The goal of concentrating on such populations will be to restore or buttress the autonomy of their members, for once the vulnerability is pierced and conquered, then individuals must be taught to become their own deciders in healthcare matters. But bioethicists will only reach this objective, by justifying their arguments by the principles of justice and beneficence.

Ethics literature is replete with examples of ways to enhance decisional capacity in patients. But what of the self-ordering capacity itself in entire populations? Some have argued that one must go beyond justice to resurrect one’s altruistic, if not religious, roots (Orr 1999). Such writers assert that the motivating factors that must be exercised to

help people awaken their capacity to gain entry into the healthcare arena is a compassionate exercise that is charity-based, not rights-based.

It is not sufficient, however, to empower vulnerable populations by awakening them to the need for raised consciousness; one must go beyond knowledge to action. The outcome of the exercise must be raised consciences. Attention must also be paid to transforming the healthcare system itself, which has, if not encouraged, certainly not tried to change, the gulf between provider and patient. Justice arguments can eventuate in political action that will mandate systemic change just as civil rights legislation in the 1960s altered the landscape of American political life overall.

But let philosophers begin the discussion before jurists and legislators enter the arena.

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