# Respect for Human Vulnerability and Personal Integrity

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## Introduction

Article 8 of the UNESCO Declaration on Bioethics and Human Rights (2005) reads as follows:

> In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

This article, therefore, is concerned with two concepts – special vulnerability (seemingly, an effort to distinguish "mere" vulnerability from a higher level of vulnerability), and respect for personal integrity (which is often used almost interchangeably with the concept of human dignity). In 2011, UNESCO's International Bioethics Committee (IBC) issued a report on this article.

As the IBC puts it:

> The specific task of this Article is to address special vulnerabilities that occur, whether as a consequence of personal disability, environmental burdens or social injustice, in the contexts of health care, research and the application of emerging technologies in the biomedical sciences. Article 8 enjoins everyone to exercise vigilance in protecting the well-being of individuals and groups in these contexts. As the Declaration (taken as a whole) confirms, every human being has a claim to our care that must be respected. (para 5)

Importantly, Article 8 of the Declaration, "….entails both a 'negative' duty to refrain from doing something and a 'positive' duty to promote solidarity and to share the benefits of scientific progress. There is an integral relationship between respect for the integrity and dignity of persons on the one hand and the vulnerability of persons on the other." (para 3) This is, therefore, a dynamic article of the Declaration, encouraging action to fulfill its aims, specifically in the context of healthcare delivery, even when that action might be construed as failing to do something. However, arguably, the concepts at the heart of Article 8 are not

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unproblematic, and it is necessary, therefore, before going further to spend a little time considering precisely what is meant by both "vulnerability" and "personal integrity."

## Vulnerability

While its meaning may seem self-evident, in fact, various efforts have been made to define what is meant by the concept of vulnerability, and no consensus on its precise content has emerged from the wealth of literature and commentary associated with these efforts. However, despite this, it is sometimes easy to identify situations in which people are vulnerable. Schroeder and Gefenas (2009), for example, offer one relatively straightforward example where vulnerability seems evident: the old lady walking with difficulty, followed by a group of drunken youths bent on trouble. Unless the old lady is a black belt, or armed with a lethal weapon (and perhaps even then!), it is easy to identify her as vulnerable in this setting. She is weaker and less able to defend herself from imminent attack and lacks the ability to escape from this potentially dangerous situation. She is, therefore, vulnerable both as a result of personal attributes (her difficulty in walking) and her situation (that is, the context in which she finds herself).

However, not all attempts to describe vulnerability are quite so straightforward. While vulnerability as a concept appears in a number of international reports and guidelines, its precise ambit remains unclear. The International Ethical Guidelines for Biomedical Research Involving Human Subjects Prepared by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), for example, refer to vulnerable people in the context of human subject research in guideline 13. In the commentary on this guideline, vulnerability is described in the following way:

> Vulnerable persons are those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests. (Council for International Organizations of Medical Sciences [CIOMS], 2002, available at: http://www.cioms.ch/publications/guidelines/guidelines_nov_2002_blurb.htm)

The most recent (2008) version of the World Medical Association's Declaration of Helsinki also refers to vulnerable individuals and populations, indicating that certain groups or populations who are potential research subjects may be "particularly vulnerable": for example "those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence." (Article 9) For Merry, "the conception of vulnerability hinges on the idea of agency. The vulnerable person is one who has little choice or capacity to escape pain and injury" (Merry, 2007, p. 195)

Although the concept may be difficult to describe in detail or to place boundaries around – and clearly other examples either within or outside of the research context could be found – there is an apparent consensus that vulnerable individuals, groups, and populations (however defined) are worthy of special protections. Whatever the source or cause of vulnerability, its presence demands the highest standards of care and protection of human rights. This requirement is strengthened when individuals or groups are regarded as being especially vulnerable, and it is with these people that Article 8 of the UNESCO Declaration is specifically concerned. Of course, if defining vulnerability itself is problematic, ex hypothesi defining "special vulnerability" is every bit as challenging.

Interestingly, unlike some of the commentaries and guidelines already discussed, the IBC specifically declined to attempt a definition of vulnerability, or special vulnerability, preferring instead to provide examples of situations within the healthcare enterprise in which "special" vulnerability can be clearly identified. As the report says, "attempts to define vulnerability in general risk drawing the concept too widely or too narrowly, thereby triggering disputes rather than resolving them...." (para 7). This approach has the benefit of not focusing on the minutiae of definitional specifics, but rather concentrating on the concrete (but by no means exhaustive) examples the report describes. States and other agents/organizations can use these examples as templates for triggering appropriate responses and assisting in devising the protections that, it seems universally to be agreed, need to be put in place in certain circumstances and for specific individuals/groups/populations.

## Personal Integrity

As has been seen, Article 8 specifically rolls together two concepts, the second of which is respect for the personal integrity of those who fall into the category of "special vulnerability." Unfortunately, perhaps, while widely used in human rights instruments and bioethical literature, this concept also can present definitional problems. Indeed, it is common to see the concept of "personal integrity" subsumed within, or accepted as a necessary facet of, human dignity. Both concepts recur in human rights instruments, and the literature that focuses on them. Indeed, Article 1 of the (UN) Universal Declaration of Human Rights says "All human beings are born free and equal in dignity and rights...," and Sulmasy (2008) reports that dignity is mentioned five times in the Universal Declaration. However, the Declaration does not explain what dignity actually is. Like vulnerability, however, it is a concept that seems to attain form and content by experience and implicit understanding. Just as there are obvious situations in which people would be widely recognized as vulnerable, so too the conclusion to Article 1, that exhorts people to "act towards one another in a spirit of brotherhood," serves to put some flesh on the bones of the concept, by emphasizing the importance of respect, equality, and solidarity.

Merely by belonging to the human species, people are entitled to respect, and it is this that triggers the attribution of human rights; perhaps the most significant political tool of the twentieth and twenty-first centuries. Definitional difficulties aside, as Sulmasy argues, "People do not have dignity because they have rights; they have rights because they have dignity..... All human rights depend upon the concept of dignity" (Sulmasy, 2008, p. 25) As one important aspect of human dignity, respect for personal integrity is integral to the attribution of human rights, thereby offering the protection of “negative” rights, such as freedom from discrimination and exploitation, as well as “positive” rights, such as the right to self-determine.

## Vulnerability Revisited

As has been noted, attempts to define vulnerability have proved problematic, yet as a concept it is in widespread use. Indeed, as Coleman says, “Even if there is no consensus on what vulnerability actually means, calls for ‘protecting the vulnerable’ seem to have an intuitive ethical appeal, and are therefore likely to continue” (Coleman, 2009, p. 14) Although, in Fox’s words, the concept can be described as “plastic,” nonetheless, it can serve as a trigger for important and sometimes essential protections (Fox, 2002). The International Bioethics Committee’s decision not to focus on definition, but rather to provide relevant (albeit not exhaustive) examples, arguably successfully navigates the choppy definitional waters and provides a practical template for the implementation of Article 8. Focusing on outcome rather than definition allows for attention to be paid to the fundamental underpinnings of respect for persons in general and for the vulnerable in particular. Running the two concepts together, according to the IBC report, “. . ..reinforces this commitment by linking it to respect for personal integrity and the need to protect vulnerable individuals and groups” (International Bioethics Committee [IBC], 2011, para 1).

It is widely accepted that vulnerability is universal. At some time in life, everyone is vulnerable, irrespective of social status, intelligence, authority, or economic power. However, for many, the state of vulnerability is transient or contextual rather than inherent. While not unimportant, such states can often be overcome, or at least they pass in time. However, it is to those individuals, groups, or communities for whom vulnerability is not a transient state that attention is particularly important. It was to address the isolation, discrimination, and powerlessness of these individuals and groups that the IBC document was drafted, and it is to these individuals and groups in particular that the responsibility of seeking to rectify wrongs and obviate harms is owed.

Importantly also, people must be vulnerable *to* something. Vulnerability, then, is not merely a passive, but also an active, notion; political systems, socioeconomic or health-related circumstances to name but a few can individually or collectively conspire to attack or constrain capacities, life choices, and experiences. People are then, for example, vulnerable *to* disrespect, discrimination, stigmatization, and lack of agency.

While each and every person may be vulnerable at some time(s), some commentators have preferred to identify vulnerability by group characteristics. Thus, it is often claimed, for example, that children, pregnant women, the elderly, and people with disabilities are all ex hypothesi to be thought of as vulnerable. To be sure, this categorization may reflect both historical and contemporary realities. There is little doubt that women are disproportionately disenfranchised, even in modern times, in some cultures and countries. Children all too often are at risk of exploitation – sadly, even by their own parents. The treatment of the elderly in some societies leaves much to be desired in terms of respecting them, and people with disabilities often identify disrespectful treatment in healthcare settings.

However, when commentaries, international statements, and guidelines direct special attention to groups or populations, the potential downside is the temptation to characterize all members of a discrete group as necessarily vulnerable. This is by no means uncontroversial, of course. Grady, for example, notes that:

> . . ..current concepts of vulnerability are usually applied to whole groups of people, without distinguishing between individuals in a group who might truly have a compromised capacity to protect their own interests from those who do not. Considering all poor people, pregnant women, members of ethnic or racial minorities, and people with terminal illness as inherently vulnerable in research has been particularly controversial. (Grady, 2009, p. 19)

While Grady's comment was made in specific reference to the healthcare research context, it resonates throughout life and transcends the clinical or research setting.

Thus, while there may be cases where all members of a group are vulnerable (perhaps, for example, in human population, genetic research on poor and isolated communities), it is important that the concept is sufficiently nuanced to ensure that the protections triggered by it are targeted appropriately and not indiscriminately merely because a person is a member of a group. This goes back to the question of definition, since it might be thought that it is the ability to describe those encapsulated by the concept that allows for strategic interventions to be made. However, problems emerge from this effort. Hurst expresses the impact of this definitional deficit concisely and clearly:

> Broadly, we agree that the vulnerable should be afforded some kind of special attention, or protection. Defining vulnerable persons or populations, however, has proved more difficult than we would like. This is both a theoretical and a practical problem. On a theoretical level, uncertainty as to what we mean by vulnerability is unsatisfactory because although we agree that this notion has a strong pull, we cannot account for this pull, justify it, or define its limits. On a practical level, we cannot know who should be afforded the protection due to vulnerable persons, or what form this protection should take. Contradictory definitions can lead to confusion for those who are supposed to protect the vulnerable, and wrong definitions may be acted upon. (Hurst, 2008, p. 191)

It is evident from this that translating aspiration into practice can be as challenging as finding a definition of vulnerability itself, and ultimately it is the imperative actually to *provide* the appropriate protections that is, or should be, at the heart of national and international endeavors. While, however, it may be difficult concisely and definitively to describe just *who* is vulnerable, it may be more straightforward to describe *when and where* people are vulnerable and what they are vulnerable to. One situation in which people may be thought of as especially vulnerable, and where their right to respect for personal integrity may be challenged, is in the provision of healthcare and its associated technologies.

## Vulnerability in Healthcare, Research, and Technological Advances

The IBC report specifically divided the provision of healthcare into three discrete, albeit sometimes overlapping, areas: the routine clinical relationship, the research setting, and biotechnological advances. For ease, this essay will follow that pattern in what follows. However, it should be noted that special vulnerability and threats to personal integrity or human dignity can arise outside of the healthcare setting as well as within it.

## The Clinical Context

People who are, or perceive themselves to be, unwell are dependent on healthcare professionals for diagnosis, prognosis, and – where appropriate – treatment. Irrespective of context, the sick person is vulnerable. That vulnerability has far-reaching consequences for his/her ability to self-determine. For this reason, laws have been developed over centuries that seek to secure protection of the individual's right to respect by focusing on the responsibility of healthcare providers to ensure that individual patients are well-informed, and ideally active, participants in any decisions made about their treatment and care. These laws, underpinned by the concepts of autonomy and respect for personal integrity, are intended to redress, to the extent possible, the imbalance between the healthcare professional and the patient, an imbalance based on characteristics such as context, knowledge, and authority. In combination with the law, professional guidelines increasingly stress the need to respect patients and their decisions, and to take care in ensuring that the dignity and rights of patients are respected.

If "average" patients can be described as vulnerable in their interaction with healthcare, there are others who can be described as being especially vulnerable and for whom the basic rules of law and professional guidelines offer insufficient protection. Although it has been argued to be inappropriate to make generalized assumptions about people simply because of their membership of a group, advocates, for example, for the elderly and people with disabilities, often argue that there is systemic disrespect within healthcare systems for these particular groups of people who are often regarded as inherently vulnerable. Inadequate funding may be routed into their care in general, they may be treated as "second-class citizens" even when care is available, and their specific needs may be neither adequately identified nor met. The principles articulated in Article 8 reinforce the need for action in such cases and, because they are directed at individuals as well as states, reinforce the obligations of solidarity and compassion that are owed to those who are especially vulnerable.

The dependent role of the patient in respect of healthcare providers seems self-evident. Irrespective of economic status, intellect, or any other characteristic, in a very real sense, individuals surrender something of themselves to the authority of healthcare professionals when they are, or believe themselves to be, ill. They are, therefore, vulnerable to being ill informed, misled, or becoming passive recipients of, rather than active participants in, healthcare decisions that affect them. However, although it is clear that people can be described as vulnerable even in the standard therapeutic interaction, it is on the area of research that much commentary and activity has been focused, not least because in this setting the traditional, beneficent relationship between healthcare professional and patient is fractured by the very nature of human subject research. The primary aim in research is to identify potentially beneficial treatments for future patients, even if the individual research subject may also benefit. The research protocol, in order to be scientifically valid, must to some extent distance the researcher from the subject in a manner that does not exist in a good therapeutic relationship.

## The Research Context

The need to undertake human subject research is generally accepted. Without it, medicine would not progress; novel treatments and technologies would not emerge, to the detriment of human health. While the law of consent also applies to the research context, and may even require that more information needs to be provided in this setting, concern remains that people invited to participate in human subject research are particularly vulnerable. Striking an appropriate balance between individual interests and rights and those of the wider society – current or future – is a challenge whose significance cannot be underestimated. Yet it is also a balance that is difficult to achieve. The importance of potential benefits may obfuscate the fact that research subjects may be exploited in the name of the greater good, even if that exploitation poses minimal risks to the subject.

There are a number of factors that may generate special vulnerability in the research context. These may be individual to the research subject or patient themselves; they may relate to the quality of the information provided by researchers; they may be socioeconomic or specific to the kind of research being proposed. These factors, according to Grady, may be more important than the subjects' identification with a specific group, reinforcing the claim that simple categorization as belonging to a particular community may be insufficiently nuanced to act as a rule of thumb for triggering special protections. Indeed, one consequence of such thoughtless homogenization has historically been not the inclusion, but rather the exclusion, of certain groups from engagement in the research enterprise. For example, particularly in the aftermath of the thalidomide case, pregnant women were routinely deemed unsuitable for involvement as research subjects, even though they too are entitled to the benefits of medical research. The International Ethical Guidelines for Biomedical Research Involving Human Subjects devised by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO) declare in Guideline 13 that "Special justification is required for inviting vulnerable individuals to serve as research subjects and, if they are selected, the means of protecting their rights and welfare must be strictly applied." However, it must also be borne in mind that people can also be rendered vulnerable by their *exclusion* from research.

It has already been indicated that the law in many jurisdictions has developed so as to attempt to provide protection for patients, primarily through the law of consent. Naturally, consent is also an important feature in medical research. However, it can be questioned to what extent the law of consent is able to offer the most appropriate level of protection to those who are especially vulnerable in the research setting. It is the nature of research that an hypothesis is being tested; by definition, the outcome is not known. This makes it more difficult for an open, full, and honest discussion of possible harms and benefits of the research to be undertaken, and requires a level of trust between research subject and researcher that is arguably even greater than in the standard clinical setting.

Yet, for some individuals and groups, the apparent protections of the law of consent may be more apparent than real and the necessary trust may not exist. Sadly, examples of research misconduct do exist and have been reported on; more than basic legal rules is, therefore, required. Broadly speaking, the additional protections recommended for vulnerable groups lie in, and are dependent on, procedural requirements. For example, the Declaration of Helsinki says that:

> Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research. (Article 17)

These additional criteria are designed to add another level to the protection ostensibly afforded by laws on consent. Of course, however, they are not always applied, nor are they always easy to apply. For example, in the case of human population genetic research which has been referred to already, the research is neither generally designed to benefit the specific population nor is it the case that the community will benefit without a genuine commitment to benefit sharing. The subjects of this research may agree to participate based on misconceptions, pressure, or lack of awareness of the implications of participation. Given the nature of the targeted populations, they may be poor, ill educated, and isolated; in other words, they are especially vulnerable. Lack of education, lack of healthcare resources, and poor understanding of the research enterprise as a whole, coupled with ancient cultural traditions, may mean that even the most scrupulously designed research project fails to protect the personal integrity of these vulnerable groups. Their vulnerability may stem from a wide range of sources, not least that their lack of authority in the face of the global research enterprise may cause them to engage in a particular project without fully understanding what may be lost by their involvement, or because they simply feel powerless to refuse. As Grady argues, “Individuals may have difficulty rejecting unfair offers and protecting their own interests if they do not recognize the offer as unfair, if they accept an unfair offer as better than nothing, or they feel as if they cannot refuse” (Grady, 2009, p. 21). In addition, and in apparent contrast to the requirements of the Declaration of Helsinki referred to above, there may be no benefit for the group or its individual members; indeed, there may be no intention or expectation that any such benefit will flow from their involvement.

Outside of what might be seen as a somewhat extreme example, the research context requires careful attention to the actual or potential vulnerability of research subjects and to respect for their personal integrity. The fact that research will generally be conducted in an effort to benefit future (albeit sometimes current) patients should not be permitted to obfuscate the possibility that subjects are exploited. Nor is this risk necessarily affected by the *nature* of the research. For example, while invasive research with potentially limited benefits might trigger careful consideration and mandate special protections by way, for example, of strict adherence to a high level of information sharing and additional requirements imposed by ethical review bodies, less intrusive research might be treated more casually, especially where the potential benefits are significant.

Research design must be sensitive to the fact that any intrusion – physical or emotional – can be harmful. Every protocol, therefore, must pay special attention not just to the possible vulnerability of the subject but also to the impact of the research itself on the respect to which each person is entitled. Sacrificing this for the greater good, while it may sometimes be tempting, disregards the commitments contained in Article 8.

Equally, it may be that potential benefits may override respect for personal integrity and ignore or minimize human vulnerability where the situation seems urgent. Again, the greater good may be used as a justification for circumventing some of the requirements of best medical research. For example, in situations where certain diseases are prevalent, it may be tempting for researchers and/or companies to test developing vaccines in protocols that, for one reason or another, have not been, or would not be, approved by the relevant ethical review committee in the country leading the research. Very often, as is the case with population genetic research, the researchers will come from a developed country and the subjects will be from one that is developing, creating additional levels of vulnerability in the target group to those which exist in any case because of disease prevalence.

Of course, medicine is expected, and needs, to progress and research is an integral part of that. Nor is it intended to imply that the vast majority of research is not conducted both for good reasons and also in clear, respectful, and scientifically valid protocols. However, there is an obligation on researchers, and those who authorize the project, to bear in mind not just the scientific validity of the project, but also any special vulnerability of the target individuals and/or groups, and ensure that special attention is paid to the need to ensure that their rights are respected.

## Technological Advances

Over the course of the last century and a half, medicine and its potential have developed almost beyond recognition. The development of anesthesia and antibiotics, for example, has saved uncounted millions of lives. More recently, advances in assisted reproduction and human genetics have changed the face of medicine yet again. While for the moment, these developments have more relevance for the developed world than elsewhere, the issues raised by them are emblematic of the problems that can be generated by scientific advances and their applications. Medicine is now capable of doing more than palliating or curing; it can circumvent established problems, as well as use the human body – particularly its genetic components – as a source of information of potentially wide-ranging importance and effect.

For many individuals and couples, the ability to reproduce – to establish a family – is a fundamentally important desire. As the causes of infertility became better established, and as the number of people reporting themselves as having fertility problems continued to rise, the devastating individual effects of the inability to conceive or carry a pregnancy to term became clearly identifiable both in individual terms and – sometimes – in community terms. While in some parts of the world, overpopulation is a serious threat to well-being, in (mostly) western countries, the inability to found a family is seen by some as a personal and social evil, or at least as the thwarting of a powerful desire. While arguments historically abounded about whether or not satisfying the desire to have a child was the proper business of medicine, that debate seems largely to have been resolved. The advances in assisted reproduction and associated technologies (ARTs) have placed this aspect of fertility control firmly within the medical domain.

For largely psychological, and sometimes social, reasons, people who find themselves in need of assistance to found a family feel themselves disadvantaged. In some communities, they may even be stigmatized. Two primary sources of vulnerability emerge from this. From the perspective of some feminist writers, women become vulnerable to pressure to conform by having children and are victims of social norms that prevent them either from coming to terms with childlessness or seeing themselves as "full" members of the community if they fail to breed (Sherwin, 1992; Corea, 1988; Rowland, 1992). Proponents of this school of thought would maintain that medicine's focus on facilitating women's reproductive role is a male-driven conspiracy to keep women within the constraints of their traditional role as carers and home makers, making their full integration into social, economic and political life more difficult. Not only are they vulnerable to this pressure, but they are also disrespected by the coercion to take advantage of ARTs that arises from societal expectations.

On the other hand, those who require assistance to reproduce may see themselves as vulnerable in a very different way. The availability of the technology to facilitate reproduction may be limited by state regulation regarding "fitness to parent" or by financial constraints. For these people, the inability to participate on an equal footing with those who do not need assistance is what renders them vulnerable and disrespects their dignity.

In this situation, women are rendered vulnerable by virtue of their overwhelming desire – some would say need – to have access to the technology that allows them to become a parent. With the best will in the world, this leaves open the opportunity for exploitation – that is, it may encourage women to engage in practices that they would otherwise not agree to. For example, schemes have been developed that allow women to circumvent the restrictions on availability of ARTs, which may be seen as ethically problematic. In some situations, women who are unable to afford the services they seek may be given free treatment if they volunteer to share their eggs with other infertile women. This may result in the stranger becoming pregnant, but the egg donor remaining childless, with all of the psychological sequelae that may flow from this. For those for whom having a child is an overriding goal, it is *prima facie* unlikely that they would willingly give away some of the opportunities they may have to do so. Yet they may see themselves as having no option but to do this, given that the alternative is no treatment – no chance at all of becoming a parent. While affecting a relatively small number of women, a variation on this scenario was regarded as sufficiently important to be used as one of the examples proffered in the IBC's report on Article 8.

Not mentioned in the report, but arguably of additional concern, is the question whether or not the assisted reproduction revolution is also implicated in the creation of a new group of vulnerable people – namely, the children born as a result of its application. While there is no evidence to support their claims, opponents of assisted reproduction often use these children as a reason to limit its availability. The argument is that children born into unconventional families, which assisted reproduction now permits, will necessarily suffer psychologically, and may also be stigmatized, for example, by being born into a same sex family or as the result of a surrogacy arrangement.

The other so-called medical revolution that raises issues about vulnerability and respect for personal integrity – perhaps even more acutely – arises from the rapidly developing area of human genetics. While advances in this area have the potential to explain the causes of ill health or disability, to develop treatment and perhaps ultimately cures for these conditions and to prevent the birth of children destined to suffer, as yet, it must be said, the much vaunted benefits have yet to emerge in significant numbers. Nonetheless, healthcare professionals, scientists, researchers, and multinational companies continue to press ahead with research and development. There are, obviously, both medical and financial benefits to be obtained.

While awaiting the therapies and cures that were so confidently predicted at the beginning of this revolution, vast amounts of genetic information are stored either for anonymized research purposes (such as in so-called biobanks) or in medical records. At a general level, the mere possession of this information is argued to render people vulnerable. Since it is now known just how many conditions have a genetic basis, and predictions can be made about future health status, inappropriate disclosure of the information may lead to stigmatization and discrimination. On the other hand, there is a lobby suggesting that disclosure of this kind of information in certain contexts is not inappropriate, but is rather entirely relevant.

For example, it can be, and has been, argued that employers and insurers have a right to information about the actual or potential health status of those whom they employ or are invited to insure. In terms of employment, it is argued, employers would be able to make more informed decisions about who to employ or retain based on predictable health-related information. Of course, this makes the assumption – often not accurate – that genetic information is predictive rather than probabilistic. Certainly, in some cases, genetic information can predict with some certainty that disease will eventuate – for example, in the case of Huntington's disease – but more often than not all it conveys is a possibility or probability that a condition will emerge. Even in cases such as Huntington's disease, the mere presence of the disease gene does not predict the time of onset of the condition, yet this information may be used negatively in employment decisions.

For insurers, it might also seem to make sense that they are informed about genetic predispositions. After all, health-related information is routinely required for health and life insurance, and, it may be argued, genetic information is merely another type of medical information. In addition, family histories are also generally taken in these situations and this too allows insurers to identify patterns of illness which may be inherited. This kind of argument raised early fears of the creation of a "genetic underclass" of people who would be uninsurable (and possibly also unemployable). Should this eventuate, these would become the "new vulnerable": unable to participate fully in the life of a modern society and their privacy rights ignored.

Admittedly, such fears have not become a widespread reality, but it is arguable that the potential remains. Even if no underclass emerges, individuals may feel themselves challenged psychologically by the mere fact that genetic information exists in their respect. With whom will that information be shared? To whom might they have an obligation to disclose it? Do people have an obligation to their families and/or future generations to seek this information in the first place? These are realistic situations which may compel people to discover information about themselves that they would otherwise not wish to have, in breach of what has been termed a "right not to know," or to have information shared with relevant third parties that they would prefer to maintain in privacy.

## Conclusion

Despite the relative vagueness of the concepts of vulnerability, special vulnerability, and personal integrity, Article 8 of the UNESCO Declaration nonetheless moves some way toward serious reflection of the national and international obligation to protect those who are in a weak position in the healthcare setting, either as a result of personal characteristics, socioeconomic factors, or any other indicator of disadvantage. This is important, not because there is an assumption that healthcare professionals, scientists, researchers, or even global corporations necessarily act in bad faith or for impure motives; rather, its significance lies in the explicit recognition that the very nature of the enterprise predicts a power imbalance between "consumer" and "provider" that is institutional. The responsibility, therefore, lies on providers, agencies, companies, and states to ensure that – to the extent possible – protections are built into the system. Where the vulnerability is special, the obligation is greater, and specific consideration needs to be made as to how to minimize or obviate vulnerability and ensure that people's rights are respected. The Article emphasizes that everyone is vulnerable at some times and in some situations, but focuses specifically on those whose position is particularly in need of protection. In tandem with the IBC's report on this article, this is a clarion call to action to protect rather than exploit those whose agency is diminished by their life experiences and the lethargy or lack of respect from third parties and/or organizations such as the state that create or increase their inability to self-determine.

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