

Respect for vulnerability is a human right: Article 8 of the UNESCO Declaration on Bioethics and Human Rights, and senior citizens in South Africa

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It is untrue that the elderly in South Africa (SA) are probably discriminated against in healthcare as the result of inadequate legislation that does not conform to international standards. The National Health Act recognises vulnerability and gives expression to it. Respect for vulnerability has not yet been introduced to fundamental political and bioethical frames of reference in SA and that is probably the reason why the concept and right have not become part of the ethical awareness in healthcare. The appeal of this article is that respect for vulnerability must be brought to conform to the Universal Declaration on Bioethics and Human Rights by declaring the ethical principle as an independent human right.

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An increasing awareness of the problems and suffering posed by the human condition of vulnerability calls for reflection on an ethos of vulnerability. The topicality of the theme of vulnerability is confirmed by Ten Have, who indicates that the number of scientific articles using 'vulnerability' as a key word have increased exponentially from 10 in 1967 to 3 277 in 2014 (search conducted on *Pub Med*), the majority of the articles having been published since the year 2000.^[1] According to Ten Have, the ethical concept has gained momentum because of factors like globalisation (which brings about asymmetric power through medical research), failed states (which bring about poverty and hunger), natural disasters, the AIDS epidemic and market driven economies that do not consider the wellbeing of citizens.^[1]

In a recent scientific study, it has been pointed out that vulnerable elderly citizens are discriminated against in the health environment in South Africa (SA).^[2] Wareham, who is on the academic staff of the Steve Biko Centre for Bioethics, has shown (based on a study project by the Community Law Centre of the University of the Western Cape)^[3] that at the micro level, individual physicians refer elderly patients less frequently than other patients for more specialised (hospitalisation) and tertiary (speciality diagnosis and treatment) treatment. At the meso level of hospital care and practitioner policy, it also frequently occurs that training for geriatric care is not prioritised. At the meso level, it has been found that national or provincial policy and decisions focus mainly on the treatment of HIV/AIDS patients, sometimes to the disadvantage of geriatric treatment programmes, as the former group consists mainly of young people.^[2]

In this study, article 8 of the *Universal Declaration on Bioethics and Human Rights (UDBHR)* of the United Nations Educational, Scientific and Cultural Organization (UNESCO) will be investigated to identify principles that relate to the human condition of vulnerability. Article 8 has the specific heading 'Respect for human vulnerability and personal integrity', and it 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.'^[3]

The UDBHR is to my mind one of the most important instruments in the development of human rights and bioethics, as the international community (191 member states) accepted it unanimously in 2005. This means the declaration was the first global political and bioethical text to which all the governments in the world, also SA, committed themselves. It is still the only document with such a widespread acceptance.^[5-7]

The primary aim of this article is to promote awareness of the UDBHR in SA (and Africa). Article 23 of the UDBHR makes an appeal to states that have signed the Declaration to promote the principles of the article through education in all areas. Mathooko and Kipkemboi, two UDBHR researchers from Africa, are convinced that bioethical teaching is necessary in Africa.^[4] The problem statement arises from UNESCO research results showing the UDBHR has had little or no impact in SA.^[5] This conclusion is, among others, confirmed by the fact that the two excellent academic books published in the field of bioethics and human rights, namely *Bioethics, Human Rights and Health Law: Principles and Practice* (2011)^[10] and *Medical Ethics, Law and Human Rights: A South-African Perspective* (2011)^[11] have no discussion of or reference to the UDBHR. To bring into effect the primary aim of creating an awareness of the UDBHR in SA, UNESCO's understanding of the principle of respect for vulnerability will be explained briefly. It is also important to consider that the establishment of an ethos of human rights in (South) Africa will depend on all citizens' understanding of and concurrence in the fundamental content of the UDBHR. With regard to the latter, it can be mentioned that in contrast to all other bioethical instruments, the UDBHR is definitely aimed at developing countries.

From the primary aim, two related aims flow forth. In the *Handbook of Global Bio-Ethics*,^[8] which uses the UDBHR as a frame of reference, it is stated that legislation in Africa, and by implication in SA, does

not conform to international bioethical standards. This statement implies that inadequate legislation is probably the reason for the above-mentioned discrimination against the elderly. The second aim, the first of the two related aims, is therefore to ascertain whether the National Health Act^[12] of SA conforms to international political, bioethical and legal guidelines as found in article 8 of the UDBHR. Awareness of article 8 will be created by testing SA legislation according to the international guidelines that will be identified in UNESCO's understanding of the principle of respect for vulnerability (the first aim). The third aim, the second of the two related aims, is to suggest a possible reason for the discrimination against the vulnerable elderly in healthcare.

To bring the first aim into effect (directed at the second aim), a brief discussion of UNESCO's understanding of article 8 follows below.

Respect for vulnerability in global perspective

Respect for vulnerability embodies the following seven matters according to UNESCO literature that explains article 8:

'Respect for vulnerability' as an ethical concept, in the first place, is a relatively new concept in contemporary bioethics. It was used in the Belmont Report in 1979 for the first time. Since 1982, it has also been used in the guidelines of the *Council for International Organizations of Medical Sciences (CIOMS)*, and since 2000, in the Declaration of Helsinki. The concept has never evolved into a completely independent principle. Although the CIOMS has referred to the protection of vulnerable people as a 'principle' since 1991, its guidelines are ambiguous. On the one hand, it describes vulnerability as a 'principle', but on the other hand, it incorporates the protection of vulnerable people as a secondary concept within the principles of respect for persons and justice.^[1,6] Furthermore, vulnerability is restricted to research in the above-mentioned documents. There is no denying that the UDBHR in 2005 was the first international document that gave the concept of respect for vulnerability the status of a fundamental independent ethical principle and human right, not only in research, but also in the field of medical intervention and technology. Its status as a fundamental and independent principle implies that the principle now has a position equal to other principles, e.g. autonomy, and that it has to be considered and balanced in the same way as those principles.^[13]

Human dignity, in the second place, serves as motivation for special protection of vulnerable people. It is the basic point of departure of the UDBHR as found in article 3. The above argument is confirmed by article 2 of the UDBHR, which states that the aim of the declaration is, among others, 'to provide a universal framework of principles', with the specific aim 'to promote respect for human dignity'. Article 8 is a powerful universal acceptance of the dignity of the human being and of his or her right to be treated with dignity.^[6,14]

It must be noted, in the third place, that the UDBHR does not provide a definition of vulnerability; therefore, conclusions can only be made from the limited information in the UDBHR itself and from commentaries. As an introduction, UNESCO accepts that vulnerability is a permanent condition of all humanity. This expresses the fragility and finiteness of human existence and therefore vulnerability is a characteristic that is shared by all people. According to Neves and Ten Have,^[1,6,13,15,20] this fact is acknowledged in article 8 by the appeal that 'human vulnerability' should be taken into account and respected.

Neves and the International Bioethics Committee (IBC) point out that the words 'special vulnerability' in article 8 indicates that some people in certain circumstances are more vulnerable than others. They are more vulnerable because of an inability, which could be caused by internal and external factors, to make autonomous decisions. Children and disabled persons are examples of vulnerability because of internal factors; poor women are examples because of external factors; and elderly persons move between internal and external factors.^[13,15]

The term vulnerability is derived from the Latin word *vulnus*, which means 'wound'. A wounded human being is a weakened human being on whom further harm can easily be inflicted. The concept of vulnerability relates to human fragility or debility, which implies that a human being that exists in certain circumstances (e.g. a new-born baby) does not have the ability or means to protect him- or herself against harm or to promote his or her personal advantage.^[6,13,16,18]

When the question is asked, in the fourth place, who could be more vulnerable, the UDBHR offers three answers:

- Both articles 8 and 24 refer to individual vulnerability
- In article 8, there is an unspecified reference to 'groups of special vulnerability'
- Article 24 singles out two groups, namely ill and disabled people, but it also mentions other conditions or circumstances that can render people more vulnerable. Examples are personal, societal and environmental conditions, as well as limited resources.

According to McLean,^[17] individuals and groups with special vulnerability may include the following: embryos and fetuses, children, women, pregnant women, the disabled, the poor, terminally ill persons, illiterate persons, the elderly, minority groups and isolated populations. The IBC points out that vulnerability is not a 'one-off concept', but that it must be identified or ascertained. Further, the identification of vulnerability is a delicate process that has to be conducted very carefully and judiciously. The IBC is also of the opinion that vulnerability is mostly determined at an individual level (as part of the group or community), as the UDBHR associates vulnerability with the personal integrity of the individual.^[6,15,18,19]

In which areas or domains of bioethics, in the fifth place, can special vulnerability be expected? Although the meaning of the term 'bioethics' is not spelled out in the UDBHR, it is understood in a broader sense than its meaning in (medical) research. According to article 8, vulnerability is discussed in the areas of research, medical practice and technology. The principle of vulnerability acknowledges the fact that exercising autonomy (and giving informed permission) does not necessarily eliminate vulnerability, which implies that autonomy can be reduced in a subtle and unperceivable way. Today, it is generally accepted that even patients whose physical and cognitive abilities are intact, are uniquely vulnerable in the bioethical environment because of the bigger expertise and social authority of the treating doctor. Here, mention is made of an unequal power relationship that can increase vulnerability. The patients vulnerability can further be aggravated by disease, pain, discomfort and the desire for healing, which can influence good reasoning and common sense. The latter is *a fortiori* true of those patients whose physical and mental abilities are seriously afflicted so that their capacity of self-determination is limited or absent. In the context of healthcare, the patient is to a greater or lesser extent dependent on the skills, expertise, judgement and goodwill of the caring professional. Individually and collectively, it means patients can be uniquely vulnerable.^[6,13]

From the discussion above, in the sixth place, it has become clear that respect for vulnerability as a principle must have definite ethical implications. 'Vulnerability without the perspective of resisting it results in misery and fatalism,' Ten Have states.^[1] The first implication of acknowledging vulnerability as a global principle is the fact that vulnerable human life demands or puts one under the obligation to protect the vulnerable. What is meant by protection? First, article 8 puts an obligation on states to support and create the necessary international and national laws, bargains and/or arrangements, ethical frameworks (like the UDBHR), infrastructure and protocols in which patient rights are outlined and which can be used as instruments to protect vulnerable people. Second, a strong functioning infrastructure that includes independent multidisciplinary and pluralistic ethical committees must be created with the purpose of evaluating all research that involves people and testing the research according to the principle of vulnerability (UDBHR art. 19).^[4,6,15]

The second ethical implication emerges when the UDBHR describes vulnerability in a positive sense as help to vulnerable people. Vulnerable people must not only be protected, but their wellbeing must be promoted ('human vulnerability should be taken into account').^[4] Vulnerability can also be understood as a form of affirmative action. The idea is to 'empower' vulnerable people. Ten Have verbalises the positive approach as follows:

'It expresses the normative requirement that these vulnerable fellow human beings need special care. More is needed than non-interference; they should receive assistance that will enable them to realize their potential as human beings.'^[1,15, 20,21]

Respect for human vulnerability in the UDBHR is formulated as a normative prescription with the purpose not only to protect vulnerable people against abuse, but also to seek them out positively and then help them to reach their full potential, which is known as 'ethics of care.'^[16] Priority must be given to vulnerable people. In the light of the above discussion of the first domain, positive help to vulnerable people could mean the following according to the IBC: 'States to intervene directly by providing adequate health education and access to available therapies. International solidarity to be encouraged to facilitate such provision.'^[14-18]

Who is responsible, in the seventh place, for the protection against harm and for the promotion of the wellbeing of the vulnerable human being? Because vulnerable people cannot protect their personal interests effectively themselves, other people are responsible for protecting their interests and promoting their wellbeing. The other can be '... States ... individuals, groups, communities, institutions and corporations, public and private' (UDBHR art. 1). 'Being ill, receiving treatment and care, participating in research are first of all individual affairs; involving others requires consent and individual decision-making. Precisely such discourse was questioned in the philosophical perspective on vulnerability,' Ten Have states.^[1, 4, 14, 15, 20, 21]

In order to reach the second aim, a brief evaluation of the National Health Act will now be given in light of the guidelines for respect for vulnerability that have emerged from the study of article 8 of the UDBHR.

Respect for vulnerability in SA

It is clear that the international community recognises respect for vulnerability as an ethical principle and human right. In the National Health Act, the concept of vulnerability is referred to in four instances.

The purpose of the law is stated as follows:

'The objects of this Act are to regulate national health and to provide uniformity in respect of health services across the nation by... (c) protecting, respecting, promoting and fulfilling the rights of ... (iv) vulnerable groups such as women, children, older persons and persons with disabilities.'^[12]

To give expression to this aim the Act determines that the following actions could be considered for vulnerable groups:

- Free healthcare issuing certificates of need with the purpose to realise and promote the following in society: equitable distribution and rationalisation of health and promotion of access to health services and the optimal utilisation of healthcare resources
- Identifying health research priorities regarding health needs.^[21]

From this reference, it can be concluded that the National Health Act conforms to the international guidelines of UNESCO regarding the following matters:

- Vulnerability is recognised as a reality of being a human being.
- Recognition is given to vulnerable groups. (Different from the UDBHR, the act specifies vulnerable groups such as women, children, elderly persons and the disabled).
- Disabled persons are specifically mentioned as being vulnerable.
- Vulnerable people must be protected.
- Vulnerable people must be positively helped where possible.
- Legislation gives attention to the concept of vulnerability.

From the above discussion, it is clear that the SA health legislation does indeed give expression to the concept of vulnerability; therefore, the reason for the above-mentioned discrimination cannot be solely ascribed to a lack of conformity to universal principles and guidelines. At the most, one could to my mind reason that the Act does not elaborate on the principle of respect for vulnerability within the context of medical practice (as well as in scientific knowledge and associated technologies); this incompleteness could lead to the above-mentioned discrimination.

What could be put forward as the reason for the above-mentioned discrimination against the elderly despite the fact that the National Health Act does indeed want to promote respect for vulnerability? One of the most important reasons according to Wareham is the following:^[3]

'The strongest basis for discriminating against the elderly is the principle that we should do the most good and provide the most benefit with the resources at our disposal. This common sense idea is related to the bioethical principle of beneficence and has a theoretical foundation in utilitarian ethical theory. On the face of it, it seems likely that more benefit will accrue by treating the young rather than the elderly. A person who receives a heart transplant at the age of 40 is likely to gain many more healthy life years than a person who receives a transplant at the age of 85. The older person is likely to have poorer health and die from other causes before he or she can enjoy the full benefit of the intervention.'

The larger problem is that although the phenomenon of vulnerability is recognised in SA, respect for vulnerability as an independent value in its own right, as found in the UDBHR, has not yet been accepted as a human right in SA; therefore, it has not yet become part of the ethical

awareness of the health and political community of SA. Despite the fact that the UDBHR was accepted by SA, respect for vulnerability as an independent human right and ethical principle is nowhere to be found in political documents. Therefore, there is no reference to respect for vulnerability in the South African Constitution and The Patients' Rights Charter, for example in the case of the right to privacy.^[22] Because vulnerability has, as yet, not been established as an independent right and principle, no principle and right exist against which the utilitarian bioethical principle of beneficence can be weighed. Consequently, beneficence in the medical practice is considered as the only principle, whether consciously or unconsciously.

Conclusion

From the above discussion, it is clear that the statement that the elderly are probably discriminated against in healthcare as a result of inadequate legislation that does not conform to international standards is untrue. The National Health Act recognises vulnerability and gives expression to it. Respect for vulnerability has not yet been introduced to fundamental political and bioethical frames of reference in SA and that is probably the reason why the concept and right have not become part of ethical awareness in healthcare. A first step on the way to attain respect for vulnerability in SA is by declaring the universal ethical principle of vulnerability as an independent human right.

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