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SCIENTIFIC CONTRIBUTION

Inclusive and relevant language: the use of the concepts of autonomy, dignity and vulnerability in different contexts

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Abstract The article analyses the three terms autonomy, dignity and vulnerability. The relevance and practical application of the terms is tested in two spheres. First, as guiding principles in the area of ethics of medicines and science. Second, as human rights principles, serving to guide the conduct of public policies for an effective realization of human rights. The article argues that all human beings have the same dignity, but that the autonomy—and therefore vulnerability—differs considerably. Simply said, with reduced autonomy comes increased vulnerability, implying extra attention to the protective dimensions. The article finds that the three terms approach the protection of human beings in different ways and that all are relevant and applicable in both spheres, but that an isolated notion of autonomy and a 'group-based' notion of vulnerability are not adequate.

Keywords Autonomy · Bioethics · Dignity · Health care ethics · Human rights · Medical ethics · Vulnerability

In the debate over legitimate and illegitimate interference with the human body, two concepts tend to appear: autonomy and dignity. With some notable exceptions (Rendtorff and Kemp 2000, pp. 45–56; see also Braut 2000), less emphasis has been placed on the concept of vulnerability, but this concept is increasingly applied. Moreover, the concept of integrity, understood as 'being whole', emphasizing respect for the human person, has been emphasized in some studies (Rendtorff and Kemp 2000, pp. 38–45; Barbosa da Silva 2009). As the concept of integrity is related to dignity and is both referred to as a 'second-order value' and less frequently used (Dworkin 1988, p. 41; Rendtorff and Kemp 2000, p. 44), and as vulnerability is believed to be particularly useful in order to demonstrate the insufficiency of autonomy, the article will analyze the concept of vulnerability, in addition to the concepts of autonomy and dignity. There will, however, be references to the concept of integrity.

The clearest position regarding preferences of using the term autonomy rather than the term dignity has been expressed by Ruth Macklin, Professor of medical ethics at Albert Einstein College of Medicine. Her criticism appears in an article titled: 'dignity is a useless concept. It means no more than respect for persons or their autonomy' (Macklin 2003a). She holds that dignity is a vague notion, and that there are no criteria for determining when dignity has been violated. In searching for an explanation for why the term dignity is so frequently used, Macklin points to religious sources and human rights texts that refer to human dignity.

An alternative approach holds that dignity should have priority over autonomy (Barbosa da Silva 2009, p. 46).[1] The author finds that the main divide is between those viewing everyone's dignity as the basis within which

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[1] Barbosa da Silva (and Sinding Aasen) creates a divide between the 'humanistic' and the 'non-humanistic' viewpoints or perspectives, where only the former is characterized by universality, applying to all human beings, and emphasizing dignity as the basis of respect for a person's integrity and autonomy. The 'non-humanistic' perspective implies that a person's dignity is based on the individual's actual autonomy (Barbosa da Silva 2009, p. 46; see also Sinding Aasen 2009b, p. 107). His use of the terms 'humanistic' and 'non-humanistic' are problematic, as they entail clear normative ranking. To classify a person as being 'non-humanistic' will most likely meet with opposition.

autonomy is embedded and those viewing the actual exercise of autonomy of each individual as constituting the basis for this individual's dignity, and in a constructive interpretation "…dignity is something to be acquired by moral effort, rather than something absolute…" (Rendtorff and Kemp 2000, p. 34). Barbosa da Silva distances himself from this latter understanding, emphasizing that dignity is both *the* basic normative principle and fully applicable in medical ethics and bioethics (termed 'health care ethics'), and should be preferred over autonomy if the two collide (Barbosa da Silva 2009, p. 31; see also Sinding Aasen 2009a, p. 53–54). Hence, dignity is an intrinsic element of being human and is not preconditioned by the actual exercise of individual autonomy.

While the author concurs with Barbosa da Silva and Sinding Aasen, hence viewing dignity to be applicable and relevant in health care ethics, autonomy continues to be applied in both medical ethics and bioethics as a guiding principle. As it is relatively uncontroversial to state that autonomy differs between human beings based on their different abilities to conscientize and express themselves, while dignity applies equally to all human beings, it can be incurred that persons with less autonomy will have more vulnerability. This raises two questions. First, are there instances where the concept of autonomy is not appropriate, as there are human beings who do not have the ability to express themselves properly, making the concept autonomy ('self rule' or 'self determination') less relevant? Second, is the concept of dignity more acceptable universally? The former can be referred to as personal inclusiveness, while the latter can be referred to as cultural inclusiveness. This paper will analyze how these two forms of inclusiveness apply to autonomy, dignity and vulnerability.

Human rights provide the context for the paper. Rather than listing all relevant *substantive* human rights, such as the right to life [International Covenant on Civil and Political Rights (ICCPR) Article 6], freedom from cruel, inhuman or degrading treatment (ICCPR Article 7) and health [International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12], the article will rather emphasize how human rights *principles* seeks to involve the person concerned and provide guidance for decision-making on all levels.

The paper seeks to identify how these human rights principles apply differently to autonomy, dignity and vulnerability, the latter of which are analyzed in this article as *concepts*. In Rendtorff and Kemp (2000), autonomy, dignity, vulnerability—and integrity—are referred to as 'basic ethical principles' and in Beauchamp and Childress (2009) autonomy is recognized as a 'moral principle', together with nonmaleficence, beneficence and justice. The term 'concept' is chosen in this article, as it seeks to analyze autonomy, dignity and vulnerability from a theoretical perspective.

After a clarification of human rights principles, the paper will define autonomy, both in a Kantian sense and as applied by modern philosophers. Then, the paper will analyze the use of the concept of autonomy in the context of health care ethics, and how it concurs with human rights principles. Then, after a clarification of dignity, its use will be analyzed in the same contexts. Finally, vulnerability will be analyzed, also in these two contexts. These findings will then be applied to identify the strengths and weaknesses of the three concepts, and also how the three concepts provide for communication across cultural barriers.

The question that the paper seeks to answer is: *under which circumstances are the concepts of autonomy, vulnerability and dignity preferable, and under which circumstances are either of these concepts inappropriate?*

Human rights principles

The concluding chapter in a book on health care ethics says that the balancing of human rights is a way through which the respect for the human person can be ensured (Sinding Aasen et al. 2009, p. 207). While the present author does not disagree with this, it is believed that the highlighting of human rights *principles* provides a better approach than merely listing the relevant substantive human rights. The human rights principles are crucial for both understanding and ensuring realization of human rights. A distinction can be made between what can be termed the nature of human rights, on the one hand, and human rights principles, on the other hand, challenging other categorisations (Oshaug 2007, p. 433).

The nature of human rights have been outlined in the 1993 Vienna Declaration and Programme of Action (United Nations 1993, paragraph 5): "all human rights are universal, indivisible and interdependent and interrelated." Particularly the notion of universality is frequently misunderstood. Universality means that every human person independent of where this person resides is entitled to the enjoyment of human rights. Hence, the nature of human rights says something about how these rights are to be *understood*.

The human rights principles identify *general rules of conduct of public policy*. There is no universal agreement on what is a human rights principle. The following seven human rights principles, however, are widely accepted: dignity, non-discrimination, participation, empowerment, rule of law, accountability and transparency (FAO 2007). The content of each of these basic human rights principles will now be reviewed.

The first two principles must be said to be the basic foundation upon which human rights are built, namely that

all human beings are entitled to human rights protection independent of the characteristics with which they are born or their own capacities. Non-discrimination is about treating like cases like and unlike cases differently. Hence, different treatment is justified if this aims to enhance the possibilities for those who are in a less favourable situation, provided that this treatment is proven to have the intended effect and provided that the different treatment ends when the situation for those who used to be in a less favourable situation have had their situation improved up to a satisfactory level.

The next two principles emphasize the bottom-up approach. Participation is also recognized as a substantive human right in the convention on the elimination of all forms of discrimination against women (CEDAW) Articles 7(b), 7(c), 8, 13(c) and 14(a), and ICCPR Article 25. Empowerment is a consequence of appropriate participation.

The last three principles emphasize the top–down approach by highlighting the role of the state apparatus. Rule of law includes access to courts, independence of the judiciary and the availability of appropriate remedies to restore justice. Accountability is crucial in order to assess public conduct in accordance with internationally objective minimum standards. Transparency must be strived for within any public programme, legislation or agreement, and is also about making budgets available, and having access to reliable statistics.

There might be other principles which arguably could have been included in this listing, more specifically the principle of equality and the principle of information. Both of these are, however, embraced by the seven principles listed. The principle of affirmative action may be said to be within the principle of non-discrimination, as unequal treatment can be justified if this is done in order to ensure substantive equality. In the subsequent sections, these human rights principles will be included in the analysis of the three concepts.

Clarification of autonomy: Kant and subsequent philosophers

While acknowledging that a full review of the concept of autonomy will not be possible, it is natural to start with how Kant understood autonomy, namely as the capacity to act in accordance with the universal principle of morality. Kant (1993 [1785], p. 54 [452–453]) emphasizes that “the idea of freedom is inseparably connected with the concept of autonomy and this in turn with the universal principle of morality, which ideally is the ground of all actions of rational beings…” (see also Dworkin 1994, p. 166; Dworkin 1988, p. 34–47; Hill 1989). Hence, for Kant autonomy is embedded in the human ability to reason, and autonomy is the foundation for dignity.

While Kant justifies his notion of autonomy in metaphysical terms, the human ability to reason is evidently different among different individuals. Kant’s clear link between autonomy and dignity has therefore posed challenges for many writing in the tradition of Kant. Moreover, according to Barbosa da Silva (2009), p. 21, Kant’s concept of autonomy does not provide adequate guidance in concrete situations.

Dworkin (1988), p. 107, nevertheless, finds that autonomy is a richer notion than liberty as autonomy relates directly to the idea of being a subject. While Kant bases his teaching on the assumption that all human beings have the ability to reason, Dworkin acknowledges that not all have these abilities. In the context of inability to consent to a particular treatment for persons with reduced abilities he states: “the case of incompetency is one in which our autonomy has already been impaired, lost or not developed…” (ibid, p. 117). Therefore, when autonomy cannot be exercised, there is no denial of autonomy to let other decide for oneself. Dworkin also argues against a situation where persons are “…kept alive in conditions that are insults to our dignity and privacy…” (ibid). Dworkin, while building on Kant, pursues an empirical, rather than a transcendental, approach. It is argued that such an empirical approach is appropriate when we now assess autonomy in two different contexts.

Autonomy is in this article understood as the respect for the individuals’ own decisions, or self-determination, and applies also to giving consent to any decision which impacts on one’s situation, and the ability to withdraw such consent.

The use of the concept of autonomy in health care ethics

Autonomy applies differently to different persons, and some human beings have no abilities either to conscientize or express themselves.

Autonomy is frequently used in reports from public commissions addressing medical ethics. Three reports from Norwegian public commissions will be given as examples. Autonomy is linked to terms such as vulnerability (NOU 2004, Sect. 6.7: ‘personal autonomy and vulnerability’) and integrity (NOU 2001b, subsection 5.1.3: ‘autonomy, integrity and consent’). In a report from a public commission on xenotransplantation, there is a subsection titled ‘dignity’, where considerations relating to autonomy are brought in (NOU 2001a), where subsection 7.1.2: ‘dignity’ reads (author’s own translation from Norwegian):

> Autonomy or self determination is established as an important concept in medical ethics. To take away from a patient the right to self determination is to violate the integrity of this person; it is to set aside the person's dignity. Autonomy implies that one has a right to take decisions relating to one's welfare.

We see that the concepts of autonomy, integrity and dignity are applied together and conceived of as interrelated and understood as being mutually reinforcing.

In a European context, the concept of autonomy has been applied by the European Group on Ethics in Science and new Technologies, an expert body under the European Commission, in the context of self determination [The European Group on Ethics in Science and new Technologies (EGE) 2004, p. 17; EGE 1999, p. 9]; as a sub-category of the term dignity (EGE 2005, p. 16); or together with the term integrity (EGE 2006, p. 46). Also this indicates a wide application of the term. On the other hand, documents negotiated by states, such as the 1998 biotechnology directive (EC 1998) and the Council of Europe's Convention on Human Rights and Biomedicine (1997), with three additional protocols—the Cloning Additional Protocol (1998); the Transplantation Additional Protocol (2002); and the 2005 Biomedical Research Additional Protocol (2005)—have no explicit reference to autonomy, either in the recital, preambular or operative paragraphs.

One paragraph of the last Additional Protocol, however, has a meaning which is very close to the concept of autonomy: *"Recognising that every person has a right to accept or refuse to undergo biomedical research and that no one should be forced to undergo such research"* (Council of Europe 2005, preambular paragraph 11). Moreover, recital paragraph 26 of the Biotechnology Directive addressed similar concerns, by stating: *"the person from whose body the material is taken must have had an opportunity to express free and informed consent thereto"* (EC 1998).

In a global context, the concept of autonomy is not frequently addressed in international documents. Reviewing the different documents of UNESCO relating to bioethics, the Universal Declaration on Bioethics and Human Rights (UNESCO 1997); the 2003 International Declaration on Human Genetic Data (UNESCO 2003); and the 2005 Universal Declaration on Bioethics and Human Rights (UNESCO 2005a), there is only one reference to the term autonomy UNESCO 2005a, paragraph 5). For legal-ethical analyses of these documents, see Lenzerini (2006) and El-Zein (2008).

There are, however paragraphs which address concerns relating to autonomy. The 1997 Declaration says: *"In all cases, the prior, free and informed consent of the person concerned shall be obtained"* [UNESCO 1997, paragraph 5 (b); see also paragraph 5(e)]. Also the subsequent documents have clear provisions on consent [UNESCO 2003, paragraph 8(a); UNESCO 2005a, paragraphs 5 and 7]. The former Declaration applies the term 'informed expressed consent' while the latter paragraph of the latter Declaration says that the person 'should be involved to the greatest extent possible'.

Therefore, while the concept autonomy is hardly applied explicitly in the UNESCO declarations, the concept is implicitly recognized, as the expression of consent is a central element in these documents. Moreover, such consent must be understood as crucial to ensure that the integrity of the person concerned is fully respected. The paper will now proceed to analyze the relationship between autonomy and human rights, emphasizing human rights principles.

Is autonomy embraced by human rights principles?

In the listing of human rights principles, we saw that autonomy is not explicitly included as one of the human rights principles. The general understanding of autonomy, however, is self-determination, including respect for each person's ability to express and withdraw consent. It is relevant to remind ourselves of the fact that while human rights is primarily concerned with the protection of the individual, human rights also provide protection for families,[2] minorities,[3] peoples,[4] and future generations.[5] Therefore, human rights cannot be understood as promoting unrestrained individualism.

It will now be analyzed whether autonomy can be understood to fall within the scope of other human rights principles.

Does the principle of non-discrimination embrace the concept of autonomy? People who, for instance, are not able to conscientize or express themselves are not 'like' others, and must therefore be treated with extra concern for their interests and human rights. They are not 'like' other human beings as they cannot give consent. Extra concern for how these interests and human rights are to be ensured must therefore be exercised, by consulting family members or some public bodies mandated to act in the interests of for

[2] The International Covenant on Civil and Political Rights (ICCPR) Article 23.1; the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 10.1; and the Convention on the Rights of the Child Article 9.1 and 18.1.

[3] ICCPR Article 27.

[4] ICCPR and ICESCR, Article 1.

[5] Universal Declaration on Bioethics and Human Rights, Article 2(g).

instance patients. Therefore, autonomy can be understood to be embraced by the principle of non-discrimination.

The conduct of those with the capacity to act in a manner which affects the human being concerned, must be based on some standards, either national or international, legal or moral. Hence, the rule of law and accountability must be understood to apply with regard to autonomy. As regards the principle of transparency, according to the Norwegian Patients' Rights Act,[6] Sect. 5.1, the patient is entitled to have access to his or her medical records.

Moreover, autonomy must be understood to have a clear relationship both to participation and empowerment, as autonomy is expressed in various forms, from the minimum requirement of expressing consent to decisions affecting one's integrity, to more active involvement in influencing any relevant condition that affects one's well-being.

Hence, even if autonomy is not explicitly mentioned among the recognized human rights principles, autonomy can be understood to be embraced by non-discrimination, participation, empowerment, rule of law and accountability. Moreover, it seems reasonable to view autonomy as embedded in human dignity, simply as a human being shall not be subject to the dominion of others. This will be made clearer below.

Clarification of dignity

Macklin (2003a), p. 1419 claims that "appeals to dignity are either vague restatements of more precise, notions or mere slogans…" It will both be analyzed whether this understanding is correct, and whether it is correct—as also alleged by Macklin—that religious sources and human rights texts referring to human dignity are the explanations for why dignity tends to be more frequently applied than autonomy.

One author states that there are two distinct understandings of human dignity, one operating under a rights-driven ethics, in support of individual autonomy (human dignity as empowerment), and another operating under a duty-driven ethics, as a constraint on autonomy (human dignity as constraint; Brownsword 2008, p. 292). The former is close to the understanding of autonomy as expressed by Kant, quoted in the introduction of this article. The latter understanding is close to the approach of the conventions and declarations referred to in this article. Brownsword states that these two different understandings might conflict, and if "the particular meaning of human dignity had to be specified, there would have been no prospects of completing […] the Universal Declaration on Bioethics and Human Rights" (ibid, p. 293). This indicates that dignity is subject to various understandings.

Human dignity is to a lesser extent than autonomy associated with one philosopher (Kant), but notions of human dignity has been nurtured in the natural law tradition, and subsequently confirmed and developed through the social teaching of the Catholic Church. The Second Vatican Council said that "the roots of human rights are to be found in the dignity that belongs to each human being" (Catholic Church 2004, paragraph 153).

Some find that a Catholic understanding of human dignity stands out from other churches; therefore any approach towards human dignity that does not originate in a specifically Catholic teaching, is not appropriate. Kendall Soulen and Woodhead (2006), p. 2 claims that "Protestant Christians seem often to rely upon unexamined secularized notions of human dignity…" They also find that the concept of dignity "has suffered a kind of inflation through undisciplined use to the point where its value is endangered" (ibid).

When seeking to clarify the actual meaning of dignity, it is therefore natural to refer to Catholic social ethics, but not limit oneself to this tradition. The present author does not believe that a concept of dignity that is not rooted in a Christian—or even more specifically Catholic—tradition, will be devoid of its adequate content. If one wants to involve persons of different religious and non-religious backgrounds in reemphasizing dignity as a basis for assessing human activities in different fields, the notion of dignity cannot be 'owned' by one confession or one tradition. Hence, the author does not side with Kendall Soulen and Woodhead (ibid, p. 16), saying that "Christianity can 'host' the concept of dignity – and move it from its modernist captivity…"

Two dimensions of dignity have been identified. First, the recognition of a distinct characteristic or aspect of personality (Rendtorff and Kemp 2000, p. 31). Second, the recognition of the intrinsic value of each person's humanity (ibid, p. 32). The term 'human beings' as applied in Article 1 of the Convention on Human Rights and Biomedicine (Council of Europe 1997), has been understood to signify that "it is not only the concept of the rational legal subject that forms the foundation of legal protection" (ibid, p. 308). Hence, dignity is owned by every human, independent of its state of development or mental capacities. In other words, dignity constitutes the core of being human. This does not imply that animals should not be treated with dignity, but that there are differences between minimum standards of treatment of human beings and animals. Human beings cannot, unlike animals, be subjected to domination by others.

Hence, human dignity both defines what is common for all human beings, and what makes each and every individual unique, standing out from any others (Schachter

[6] Available in English at: http://www.ub.uio.no/ujur/ulovdata/lov-19990702-063-eng.pdf.

1983, p. 850–851; Clapham 2006, p. 535–548). Human dignity has been termed “the most fundamental principle” (Rendtorff and Kemp 2000, p. 20, n. 11), explaining this by referring to the position of the notion of dignity in the ‘Human Rights Declarations’.

Before testing whether these latter claims are correct, the actual use of the concept of dignity in relevant conventions and declarations in the realm of health care ethics will be analyzed.

The use of the concept of dignity in health care ethics

While we saw above several implicit references but only one explicit reference to autonomy in the eight legal documents studied, including one EU directive and two conventions, there are frequent references to dignity in the same documents (EC 1998, recital paragraphs 16 and 38; Council of Europe 1997, preambular paragraphs 10, 11 and 17; Council of Europe 1998, preambular paragraphs 6 and 8; Council of Europe 2002, preambular paragraphs 8 and 12; Council of Europe 2005, preambular paragraphs 8 and 12; UNESCO 1997, preambular paragraphs 1, 4 and 6; operative paragraphs 1, 2(a), 6, 10, 11, 12(a), 15, 21 and 24; UNESCO 2003, preambular paragraphs 12 and 14, operative paragraphs 7(a), 26 and 27; and UNESCO 2005a, preambular paragraphs 3 and 12, operative paragraphs 2(c), 2(d), 3, 10, 11, 12 and 28).

All these paragraphs are formulated so that they seek to provide constraints on the exercise of biomedical science. Hence, dignity must be understood to provide a general precaution of a protective nature. An appropriate understanding of dignity cannot, however, relate exclusively to the issues relating to care and protection. Human dignity must be exercised by every single individual as “a free responsible agent, capable of acting for reasons and directing the course of one’s life in accordance with one’s own values and understanding of the world” (Nuffield Council on Bioethics 2002, p. 130, paragraph 12.37).

In the eight legal texts studied, however, most of the references to human dignity are in the preambular parts of the documents. Only the three UNESCO declarations include dignity in their operative paragraphs. This is an indication that dignity is an overarching principle but is more difficult to actually apply. Nevertheless, the frequent application of human dignity in international legal texts indicates that it seen as an important principle.

Dignity as a human rights principle

While we analyzed above how autonomy related to the seven human rights principles, dignity is itself a human rights principle. In other words, any public policy decisions should be taken with the purpose of upholding human dignity.

The first preamular paragraph of the 1948 Universal Declaration of Human Rights acknowledged the ‘inherent dignity’ of all members of the human family. An understanding of human dignity which does not also emphasize the active individual, spiritually, mentally and physically, is not appropriate. Hence, the human rights principle of human dignity must also be seen in relation to the other human rights principles, being mutually reinforcing. As was seen above, dignity is held to be closely linked to empowerment in the Kantian tradition (Brownsword 2008, p. 292). Moreover, dignity is also applied explicitly in substantial human rights provisions, in the context of persons deprived of their liberty and in the context of the purposes of education.[7]

While dignity can be understood to be based on the social teaching of the Catholic Church, its use in human rights declarations and conventions makes dignity a universal concept, and dignity applied in the context of human rights cannot be linked to any religious justification. A related question, which was raised above, is whether dignity is the “the most fundamental principle” (Rendtorff and Kemp 2000, p. 20, n. 11) simply because it is a part of human right declarations. The present author finds this understanding somewhat problematic. If one tests the ‘fundamentality’ of a given principle simply in the context of whether or not it is a part of international declarations, this is not an adequately robust manner of establishing moral or legal principles. Rather, the present author would argue in favour of an understanding that human dignity is fundamental because it is part of most religious, moral and legal traditions. The fact that human dignity is embedded in the natural law tradition that developed in Europe and North America, cannot be used as an argument in support of the fact that dignity can be confined to only this part of the world.

Clarifying vulnerability

Vulnerability is a relatively recent concept in the realm of bioethics, and did not figure as separate sub-chapters in the *Principles of Biomedical Ethics* until its sixth edition (Beauchamp and Childress 2009, pp. vii; 89–93; 253–257). Article 9 of the World Medical Association’s Ethical Principles for Medical Research Involving Human

[7] ICCPR Article 10.1 reads: “All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.” ICESCR Article 13.1 reads (extract): “…education shall be directed to the full development of the human personality and the sense of its dignity…”.

Subjects, originally adopted in Helsinki in 1964 [Declaration of Helsinki] embeds vulnerability in the context of.

> …respect for all human subjects and protect their health and rights. Some research populations are particularly vulnerable and need special protection. These include those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence (WMA 2008; see Nicholson 2002, p. 20 for the 2000 version of the Declaration of Helsinki).

This definition is relevant as a starter. As stated initially, a proper approach is to see autonomy as changeable and dignity as unchangeable between different persons, and that persons with little autonomy have greater vulnerability than persons with full autonomy (Braut 2000). There is, however, a need for a more in depth understanding of the term vulnerability.

In the context of a project on bioethics commissioned by the Council of Europe, vulnerability was referred to as "the most original notion in the project" (Rendtorff and Kemp 2000, p. 46, n. 85), and it was only in 1997 that the term 'vulnerable populations' was included in the *Bioethics Thesaurus* (Flanagan 2000). A separate section on 'Vulnerable groups' is found in the 2002 version of Council for International Organizations of Medical Sciences' (CIOMS) International Ethical Guidelines for Biomedical Research Involving Human Subjects, while the concept vulnerability did not appear in the 1993 Guidelines (CIOMS 2002a).[8] Moreover, the concept of vulnerability was not found in the Declaration of Helsinki until 2000.[9] A change from the 2000 to the 2008 version was the adding of the category 'educationally disadvantaged', in addition to the 'economically or medically disadvantaged'. Hence, there is a relatively wide understanding of who the vulnerable are.

Defining vulnerability is also challenging because the Anglo-American and the Continental European tradition use different terms, with the former emphasizing respect for autonomy, beneficence, nonmaleficience and justice (Beauchamp and Childress 2009), while the latter applies dignity, autonomy, justice beneficence & non-maleficience and solidarity (EGE 1999, p. 9) or dignity, autonomy, integrity and vulnerability (Rendtorff and Kemp 2000). Hence, on the face of it, vulnerability is recognized in the Continental European tradition, but less so in the Anglo-American tradition. If one goes beyond the terms of the Anglo-American tradition, however, vulnerability is specified under both respect for autonomy and justice (CIOMS 2002b, p. 17–18).[10] In the background study to the CIOMS 2002 Ethical Guidelines, it is the principles developed in the Anglo-American tradition which are presented (ibid).

Moreover, the divide between the Anglo-American and the Continental European tradition can also be seen in the basic approaches of the two, where the former emphasizes the need for categorizing and classifying persons and populations in need of additional protection, while the latter emphasizes vulnerability as a basic human condition of everyone, hence being understood as a universal principle (Solbakk 2010). This must, however, imply that human beings act under various degrees of vulnerability in various contexts. Hence, it is reasonable to state that vulnerability is explicitly a normative concept, but also a concept which can be applied in various senses, ontological, phenomenological, natural, medical, cultural and social, all referring to various notions of fragility ((Rendtorff and Kemp 2000, p. 46).

We see that there are different understandings of vulnerability in the different traditions, but vulnerability is nevertheless found to be a bridging factor between moral strangers (Solbakk 1996). This article confirms the basic notions presented by the French philosopher Emmanuel Levinas that the recognition that one's receptivity for others can be increased by acknowledging one's own vulnerability (Rendtorff and Kemp 2000, pp. 50–51). This will apply within cultures and between cultures.

In summary, it seems relevant to state that Article 9 of the revised Declaration of Helsinki can be understood as being too narrow. A problem with the definition is that it uses the term 'populations' and not 'persons' or 'human beings'. The term 'populations' allows for categorisation, and might limit the ability to see the unique individual. A wider understanding of vulnerability is found in the Declaration on Bioethics and Human Rights, the term vulner-

[8] The CIOMS 1993 Guidelines listed in Guidelines 5 through 8 research involving children, persons with mental or behavioural disorders, prisoners and 'subjects in underdeveloped communities', respectively.

[9] Paragraph 8 of the 2004 version read (extracts): "Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.".

[10] CIOMS 2002b says about vulnerability under 'respect': "protection of persons with impaired or diminished autonomy, which requires that those who are dependent or vulnerable be afforded security against harm or abuse" (CIOMS 2002b, p. 17); and under 'justice': "'Vulnerability' refers to a substantial incapacity to protect one's own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group. Accordingly, special provision must be made for the protection of the rights and welfare of vulnerable persons" (CIOMS 2002b, p. 17).

ability is not explicitly defined, but Article 24 refers to those “rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources” (UNESCO 2005a). Therefore, contextual conditions can make an otherwise well-functioning person more vulnerable. An even wider understanding says that as all human beings are vulnerable, all are in need of some form of protection (Solbakk 2010). Acknowledging the strengths of a wide definition, we will now proceed to analyse how vulnerability is specifically applied in the context of health care ethics.

The use of the concept of vulnerability in health care ethics

The concept of vulnerability is hardly ever introduced in international conventions and declarations. The most notable acknowledgement of human vulnerability is seen in the 2005 Declaration on Bioethics and Human Rights:

> 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 (UNESCO 2005a; Article 8).

We see that the link between human autonomy and respect for personal integrity is made very explicit. Solbakk (2010) argues that the first sentence is close to the European Continental tradition, while the second sentence is close to the Anglo-American tradition, and that the whole paragraph therefore must be considered as a compromise. Based on Braut’s (2000) understanding that autonomy can differ considerably between individuals and that those with the weakest capacity for autonomy have the highest vulnerability, it seems fully justified to view vulnerability as a concept that should be emphasized in health care ethics.

Therefore, as the relationship between autonomy and vulnerability is fundamentally non-reciprocical, the latter increases when the former decreases. Those who cannot decide for themselves are simply more vulnerable (NOU 2004, Sect. 6.7).

However, while the concept of vulnerability and the criteria for designating vulnerability has been criticized for being vague (Ruof 2004, p. 411), the present author does not believe that we will come to a definition by categorising specified population groups. Rather, the strength of the concept of vulnerability in health care ethics is an acknowledgement that every human being is vulnerable, and an understanding of vulnerability as being person-specific, condition-specific and situation-specific.

Is vulnerability embraced by human rights principles?

Vulnerability is not explicitly mentioned among the seven human rights principles, but protection is nevertheless at the core of human rights (Morawa 2003). All actors of society must ensure the adequate respect for every human being’s ability to enjoy all human rights, and in some situations this is done through various protective measures. In some situations it might be organs of the state which constitute a threat to the integrity of the individual, while in other situations, it might be non-state actors. An indication that protection is most relevant in the context of vulnerability, is the title of one of the first comprehensive analysis of vulnerability (Goodin 1985; see also Macklin 2003b).

On the other hand, protection must not impede the adequate facilitation of the human rights principles of participation and empowerment. Backlar (2000) says that protection cannot mean exclusion. In short, the maximum participation must be ensured in order to allow for the empowerment of human beings. If the result of seeing a person as vulnerable is only to view this person with pity for their condition, this is not appropriate. All actors involved in the encounter with persons who are particularly vulnerable, must act accountably, and by ensuring the immediate and long-term interests of the persons.

Particular attention must be paid to the most vulnerable persons. Therefore, special treatment of some persons does not constitute discrimination, if this special treatment is undertaken in order to ensure more substantive equality in the enjoyment of the human rights—provided, of course, that the special treatment is brought to an end when the inequality ceases to exist.

Comparing autonomy, dignity and vulnerability

There is no doubt that dignity is more frequently applied in health care ethics, at least if one compares relevant conventions and declarations, but there are different understandings of what dignity entails. Autonomy is applied in both the Anglo-American and the European continental tradition. An interesting question is whether this term communicates adequately in societies with a more collectivistic mentality. Vulnerability has gained increasing acknowledgement, but has a different understanding in different traditions, and the term ‘vulnerable population’ being applied in the Anglo-American tradition is considered by the present author to be inappropriate, as it serves as a too rigid categorization rather than seeing each individual as unique with particular needs. As vulnerability is a fact of life in most non-Western cultures, one should expect that vulnerability is a concept that can be acceptable

in different cultures. Moreover, this article argues that a person's vulnerability must be seen in light of the various abilities which constitute a person's autonomy.[11]

Therefore, there are obvious links between the three concepts. We saw above that concerns relating to autonomy are introduced under a subsection titled dignity (NOU 2001a, subsection 7.1.2). Moreover, the link between dignity and autonomy is outlined by Brownsword, emphasizing the "(dignity-based) human right to individual autonomy…" (2001, p. 183). Brownsworth hence sees autonomy to be embedded in human dignity. Acknowledgement of vulnerability can be understood to be implicit in an acknowledgement of dignity. On dignity, autonomy and vulnerability, see also Henriksen and Vetlesen (2006) and Vetlesen final chapter in Ruyter and Vetlesen (2004).

Religions are predominantly preoccupied with notions of dignity (Starck 2002; see also Macklin 2003a). The *Evangelium Vitae* is a strong defense against any attempts of making human dignity conditional. The Pope warns strongly against "the mentality which tends to equate personal dignity with the capacity for verbal and explicit, or at least perceptible, communication" (Pope John Paul II 1995, paragraph 19).

There might be a perception that dignity entails passivity while autonomy entails stronger notions of the active individual, as evidenced in the terms 'choice' and 'consent'. The dimensions of dignity involve, however, more 'activitiy' than frequently believed, emphasizing that the individual behaves in a "…rational way, capable of deciding about himself, and with a tendency to self-realization" (Catholic Church 2004, paragraph 270).

Autonomy can be said to provide a specific precaution in a given circumstance, saying that the individual shall never be treated as an object, but always as the subject. The linkage that was found between autonomy and several of the human rights principles confirms that autonomy is appropriately placed within the highest legal norms that the international community has agreed about for protecting the life, integrity and welfare of all human beings, namely international human rights. Autonomy understood as individuals making decisions and being responsible for these decisions, is a central element in most religions. This understanding is in line with Immanuel Kant (1993 [1785]), emphasizing that autonomy relates to acting as a moral agent. At the same time, autonomy can in some cultures have a too individualistic notion. Autonomy, while being increasingly recognized, is still understood by some as a 'chart de blanche' for excessively individualistic behaviour, which contrasts with the norms of a given society. On the other hand, cultural factors cannot legitimately be applied in order to restrict the individual's enjoyment of all human rights, subject to the specified restrictions included in the various human rights treaties.

Dignity is crucial both within the world's main religions and within a human rights framework. The notion of human dignity cannot, however, be said to be fully embraced globally. Especially in cultural contexts where the equal worth and dignity of certain persons are questioned, due to traditional understandings of honour, shame and uncleanness, one can ask whether the equal worth of all human beings is a basic attitude shared by everyone. Any attitudes which seek to question the equal worth of all human beings should be challenged appropriately. One such challenge is found in the Universal Declaration on Cultural Diversity (UNESCO 2001) which states that "The defense of cultural diversity is an ethical imperative, inseparable from respect for human dignity",[12] but the Declaration on Bioethics and Human Rights emphasizes that cultural diversity and pluralism "are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms…" (UNESCO 2005a, Article 12). Hence, dignity and diversity are interlinked. These two (non-binding) provisions cannot, however, ignore the fact that the respect for every human beings dignity differs between cultures.

Both dignity and autonomy can therefore be seen as being met with some suspicion, while both of them are recognized explicitly or implicitly as human rights principles.

While an acknowledgement of vulnerability has a central place in the overall framework of human rights protection, it is not recognized as a separate human rights principle. As vulnerability is increasingly being recognized in health care ethics, it must be expected that increased attention will be devoted, both from ethical and religious traditions. It is surprising that vulnerability has not been given more attention from the religious traditions, as vulnerability has clear ethical and theological perspectives. For one attempt of developing an understanding of the term vulnerability and its specific application in political life, see Church of Norway (2002).

[11] Professor of philosophy Glenn Hughes emphasized at a seminar at the Norwegian Academy of Science and Letters 9 December 2008, titled 'Human Dignity - a Universal Concept?' that dignity is comprised of four element: liberty, responsibility, uniqueness and vulnerability, and liberty and responsibility must be understood as central elements in autonomy.

[12] UNESCO 2001, Article 4 (extracts). Note that the 2005 **Convention** on the Protection and Promotion of the **Diversity** of **Cultural** Expressions (UNESCO 2005b) does not establish similar links between cultural diversity and human dignity, but introduces the phrase 'dignity of cultures' by stating in Article 2.3 (extracts): "The protection and promotion of the diversity of cultural expressions presuppose the recognition of equal dignity of and respect for all cultures…".

Conclusion

This paper has sought to demonstrate that human rights principles, which seeks the active involvement of the person concerned and guides the decision-making, are applicable in the context of health care ethics.

The paper has consulted conventions, additional protocols and non-binding declarations in the area of biomedical research and human biotechnology, to identify the use of the concepts of autonomy, dignity and vulnerability. It was not found that the concept of autonomy is frequently used in European documents, even if it is a recognized principle in health care ethics. Both the European documents and UNESCO documents apply dignity much more frequently than autonomy. The concept of vulnerability is only found in the UNESCO Declaration on Bioethics and Human Rights (UNESCO 2005a), but has gained increased acknowledgement by its inclusion in two standards developed by two international medical associations (WMA 2008; CIOMS 2002a).

When vulnerability is increasingly acknowledged within health care ethics, it will also give a better understanding of autonomy. As dignity applies to everyone, also autonomy and vulnerability apply to everyone, but the two latter differ between persons depending on their internal abilities, external conditions and specific situations. All three terms therefore have an adequate personal inclusiveness.

Regarding cultural inclusiveness, the analysis undertaken does not provide for a strong and broad-based conclusion. As stated above, while differences between cultures must be acknowledged, no cultural factors can justifiably restrict the free enjoyment of all human rights. Autonomy is commonly held to be the most 'Western' principle, but the individual's active choice is not alien neither to traditional cultures nor traditional religions.

Finally, also with regard to cultural inclusiveness, the paper warns against a monopolization of the concept of dignity, as a 'property' of the social teaching of the Catholic Church. This does not imply that one should not apply a precise and distinct definition of dignity. Hence, one should reject understandings which are incompatible with a definition of dignity, more precisely the distinct quality applying to all human beings irrespective of their mental and physical capacities, giving all human beings the same worth. Therefore, it is reasonable to state that dignity, which is equal among all human beings must be at the core of health care ethics.

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References

Backlar, P. 2000. Human subjects research, ethics, research on vulnerable populations. In *Encyclopedia of ethical, legal and policy issues in biotechnology*, 2nd edition, ed. T.H. Murray and M.J. Mehlman, 641–651. New York: Wiley.

Barbosa da Silva, A. 2009. Autonomy, dignity and integrity in health care ethics—a moral philosophical perspective. In *Human rights, dignity and autonomy in health care services: Nordic perspectives*, ed. H. Sinding Aasen, R. Halvorsen, and A. Barbosa da Silva, 13–52. Antwerp: Intersentia.

Beauchamp, T.L., and J.F. Childress. 2009. *Principles of biomedical ethics,*, 6th revised edition. Oxford and New York: Oxford University Press.

Braut, G.S. 2000. Verdigrunnlaget for medisinen i kommende tider. *Tidsskrift for den Norske Laegeforening* 120(30): 3743–3745.

Brownsword, R. 2001. Freedom of contract, human rights and human dignity. In *Human rights in private law*, ed. D. Friedmann and D. Barak-Erez, 181–199. Oxford and Portland: Hart Publishing.

Brownsword, R. 2008. Genetic engineering, free trade and human rights: global standards and local ethics. In *Genetic engineering and the world trade system*, ed. D. Wüger and T. Cottier, 287–314. Cambridge: Cambridge University Press.

Church of Norway. 2002. Vulnerability and Security: Current challenges in security policy from an ethical and theological perspective [written by Commission on International Affairs in the Council on Ecumenical and International Relations]. http://kirken.no/english/engelsk.cfm?artid=5850.

CIOMS. 2002a. International ethical guidelines for biomedical research involving human subjects.

CIOMS. 2002b. International ethical guidelines for biomedical research involving human subjects [book]. http://www.cioms.ch/publications/layout_guide2002.pdf.

Clapham, A. 2006. *Human rights obligations of non-state actors*. Oxford and New York: Oxford University Press.

Council of Europe. 1997. Convention on human rights and biomedicine, adopted 4 April 1997, entered into force 1 Dec 1999, CETS 164.

Council of Europe. 1998. Additional protocol to the convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine, on the prohibition of cloning human beings; adopted 12 January 1998, entered into force 1 Mar 2001, CETS 168.

Council of Europe. 2002. Additional protocol to the convention on human rights and biomedicine concerning transplantation of organs and tissues of human origin; adopted 24 Jan 2002, entered into force 1 May 2006, CETS 186.

Council of Europe. 2005. Additional protocol to the convention on human rights and biomedicine, concerning biomedical research; adopted 25 January 2005, entered into force 1 Sep 2007, CETS 195.

Dworkin, G. 1988. *The theory and practice of autonomy*. Cambridge: Cambridge University Press.

Dworkin, R. 1994. *Life's dominion*. New York: Vintage Books.

EC. 1998. Directive 98/44/EC of the European Parliament and of the Council of 6. July 1998 on the legal protection of biotechnological inventions.

El-Zein, S. 2008. The regulation of human genetics by international soft law and international trade. In *Genetic engineering and the world trade system*, ed. D. Wüger, and T. Cottier, 315–342. Cambridge: Cambridge University Press.

European Group on Ethics in Science and new Technologies (EGE). 1999. Ethical issues of healthcare in the information society, opinion 13.

European Group on Ethics in Science and new Technologies (EGE). 2004. Ethical aspects of umbilical cord blood banking, opinion 19.

European Group on Ethics in Science and new Technologies (EGE). 2005. Ethical aspects of ICT implants in the human body, opinion no. 20.

European Group on Ethics in Science and new Technologies (EGE). 2006. Ethical aspects of nanomedicine, opinion No 21.

FAO. 2007. Focus on the rights to food: Right to food and indigenous peoples. http://www.fao.org/righttofood/wfd/pdf2007/focus_indigenous_eng.pdf .

Flanagan, R. 2000. Vulnerability and the bioethics movement. *Bioethics Forum* 16: 13–18.

Goodin, R.E. 1985. *Protecting the vulnerable: A reanalysis of our social responsibilities*. Chicago: University of Chicago Press.

Henriksen, J.-O., and A.J. Vetlesen. 2006. *Nærhet og distanse*. Oslo: Gyldendal.

Hill, T. 1989. The kantian conception of autonomy. In *The inner citadel: Essays on individual autonomy*, ed. J.P. Christman, 91–105. Oxford and New York: Oxford University Press.

Kant, I. 1993 [1785]. *Grounding for the metaphysics of morals* (translated by James W. Ellington) 3rd ed., Indianapolis, IA: Hackett Publishing.

Kendall Soulen, R., and L. Woodhead. 2006. Introduction. In *God and human dignity*, ed. Woodhead Soulen, 1–24. Grand Rapids MI and Cambridge, UK: William B. Eerdmans Publishing.

Lenzerini, F. 2006. Biotechnology, Human Dignity and the Human Genome. In *Biotechnology and international law*, ed. F. Francioni and T. Scovazzi, 285–340. Oxford and Portland: Hart Publishing.

Macklin, R. 2003a. Dignity is a useless concept. It means no more than respect for persons or their autonomy. *British Medical Journal* 327: 1419–1420.

Macklin, R. 2003b. Bioethics, vulnerability and protection. *Bioethics* 17(5–6): 472–486.

Morawa, A.H.E. 2003. Vulnerability as a concept in international human rights law. *Journal of International Relations and Development* 6(2): 139–155.

Nicholson, R. 2002. Who is vulnerable in clinical research? *Bulletin of Medical Ethics* 181: 19–22.

Nuffield Council on Bioethics. 2002. Genetics and human behaviour: the ethical context. http://www.nuffieldbioethics.org/fileLibrary/pdf/nuffieldgeneticsrep.pdf.

Oshaug, A. 2007. Monitoring the human right to adequate food at country level: challenges and needed actions. In *Food and human rights in develeopment*, vol. II, ed. W.B. Eide and U. Kracht, 425–456. Antwerp: Intersentia.

NOU. 2001a. *18: Xenotransplantation*. Oslo: Departementenes Servicesenter.

NOU. 2001b. *19: Biobanks*. Oslo: Departementenes Servicesenter.

NOU. 2004. *18: Coordination and plan in the social and health sectors*. Oslo: Departementenes Servicesenter.

Pope John Paul II. 1995. Evangelium vitae. http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.html.

Rendtorff, J.D., and P. Kemp. 2000. *Autonomy, dignity, integrity and vulnerability, Vol. 1 of basic ethical principles in european bioethics and biolaw: Report to the European Commission of the BIOMED-II Project*. Copenhagen: Danish Center for Ethics and Law.

Ruof, M.C. 2004. Vulnerability, vulnerable populations, and policy. *Kennedy Institute of Ethics Journal* 14(4): 411–425.

Ruyter, K.W., and A.J. Vetlesen. 2004. *Omsorgens tvetydighet: Egenart, historie og praksis*. Oslo: Gyldendal.

Schachter, O. 1983. Human dignity as a normative concept. *American Journal of International Law* 77(4): 848–854.

Sinding Aasen, H. 2009a. Dignity and human rights in the modern welfare state. In *Human rights, dignity and autonomy in health care services: Nordic perspectives*, ed. H. Sinding Aasen, R. Halvorsen, and A. Barbosa da Silva, 53–68. Antwerp: Intersentia.

Sinding Aasen, H. 2009b. Autonomy, human dignity and treatment of individuals with cognitive impairment. In *Human rights, dignity and autonomy in health care services: Nordic perspectives*, ed. H. Sinding Aasen, R. Halvorsen, and A. Barbosa da Silva, 105–127. Antwerp: Intersentia.

Sinding Aasen, H., R. Halvorsen, and A. Barbosa da Silva. 2009. Conclusions and challenges. In *Human rights, dignity and autonomy in health care services: Nordic perspectives*, ed. H. Sinding Aasen, R. Halvorsen and A. Barbosa da Silva, 207–210. Antwerp: Intersentia.

Solbakk, J.H. 1996. *Vulnerability as a bridging factor between moral strangers. In Working Papers, Research Projects Vol. 1*. Copenhagen: Centre for Ethics and Law.

Solbakk, J.H. 2010. The principle of respect for human vulnerability and global bioethics. Forthcoming in R. Chadwick, H. Ten Have and E. Meslin (ed.) *Handbook of health care ethics*. London: SAGE.

Starck, C. 2002. The religious and philosophical background of human dignity and its place in modern constitutions. In *The concept of human dignity in human rights discourse*, ed. D. Kretzmer, and E. Klein, 179–193. The Hague: Kluwer Law International.

The Catholic Church. 2004. Compendium of the Social Doctrine of the church, Vatican: The Catholic Church. http://www.vatican.va/roman_curia/pontifical_councils/justpeace/documents/rc_pc_justpeace_doc_20060526_compendio-dott-soc_en.html.

UNESCO. 1997. Universal declaration on the human genome and human rights, adopted at the 29th session of the UNESCO General Conference 11 Nov 1997.

UNESCO. 2001. Universal declaration on cultural diversity, adopted at the 31st session of the UNESCO General Conference 2 Nov 2001.

UNESCO. 2003. International declaration on human genetic data, adopted at the 32nd session of the UNESCO General Conference 16 Oct 2003.

UNESCO. 2005a. Universal declaration on bioethics and human rights, adopted at the 33rd session of the UNESCO General Conference 19 Oct 2005.

UNESCO. 2005b. Convention on the protection and promotion of the diversity of cultural expression*s*, adopted at the 33rd session of the UNESCO General Conference 20 Oct 2005.

United Nations. 1993. Vienna declaration and programme of action, A/CONF.157/23.

WMA. 2008. Ethical principles for medical research involving human subjects.