

## Scientific Contribution

### What is the scope for the interpretation of dignity in research involving human subjects?

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**Abstract.** Drawing on Lennart Nordenfelt's distinction between the four distinct senses of dignity, I elucidate the meaning of dignity in the context of research involving human subjects. I acknowledge that different interpretations of the personal senses of dignity may be acceptable in human subject research, but that inherent dignity (*Menschenwürde*) is not open to interpretation in the same way. In order to map out the grounds for interpreting dignity, I examine the unique application of the principle of respect for dignity in Canada's research ethics guidelines. These guidelines are unique because they consider dignity to be a foundational concept and the protection of the dignity of research subjects is regarded as a measure that prevents "the impoverishment of humanity as a whole". While the conception of humanity invoked here is incomplete, Canada's research ethics guidelines nevertheless represent a more European approach to biomedical policy. Finally, in order to correct a pervasive blind spot in contemporary policy on research involving human subjects, I sketch a functional model for attributing inherent dignity that avoids the untenable connotations of speciesism.

**Key words:** dignity, human subjects research, humanity, interpretation, moral community, Nordenfelt, policy

There is much debate about the relevance of the notion of dignity in biomedical policy. While it has been viewed as a moral absolute or first principle and an imprimatur of moral respectability by some (Kass, 1998; Pellegrino, 2005), others regard it as a useless and politically divisive concept (Caulfield and Brownsword 2006; Macklin, 2003). In this paper, I elucidate the meaning of dignity and show why it is an important foundational concept for regulating research on human subjects. In particular, I show that dignity is a complex concept that can be legitimately interpreted in different ways, up to a point. To illustrate the legitimate scope for the interpretation of dignity, I build upon Lennart Nordenfelt's distinction between *Menschenwürde* (which I translate as inherent dignity)<sup>1</sup> and the three kinds of personal dignity (dignity of merit, dignity of moral stature, and dignity of identity). I then show how this nuanced concept of dignity is supported in a unique fashion by Canada's research ethics guidelines, which are contained in the *Tri-Council policy Statement: Ethical Conduct for Research Involving Humans* (1998) (hereafter TCPS).

In addition to its unprecedented commitment to protecting the dignity of research subjects, there are three claims regarding dignity that we find in Canada's research ethics guidelines that make it exemplary: (1) the obligation to respect inherent dignity is a moral absolute that is not open to interpretation (i.e., one can never treat others merely as a means to an end); (2) personal dignity is open to interpretation by individuals and communities; and (3) all of humanity can be impoverished by research that shows disrespect for dignity. The wide scope of this last claim expresses what is most controversial about dignity as it is currently used in biomedical policy. Nonetheless, my commentary elucidates how all of these three claims hang together and delimit the meaning of dignity. Moreover, they show why we are obligated to promote and protect all senses of dignity.

Furthermore, given the relevance of Nordenfelt's interpretation of dignity to Canada's research ethics policy, we see the extent to which Canada shares a European sensibility on biomedical matters. Specifically, the notion of dignity employed in

Canada's research ethics guidelines avoids the temptation of reducing biomedical ethics to the legalistic, rights-based paradigm prevalent in the US and complements other foundational ethical principles such as autonomy, personal integrity and vulnerability. While Rendtorff reports that these principles constitute the prevailing biomedical guideposts in Europe that are ranked differently in different jurisdictions (2002, p. 236), this paper concludes by showing that dignity should be given more prominence across every jurisdiction to the extent that it reflects the gravity of past abuses of research subjects, motivates compliance, and complements the essential dimensions of these other principles.

In order to elucidate the meaning and value of dignity and identify the scope it affords for interpretation, I develop a general philosophical account of dignity that differentiates between the inherent and personal senses of dignity. I then present a schematic functional account of inherent dignity that avoids attributing dignity to human subjects solely on the basis of their genetic identity. On this point, my reconstruction of dignity is distinct from that of Nordenfelt and from most biomedical policies, but it is necessary to expand the grounds for dignity in this way in order to recognize that non-humans may legitimately be regarded as having dignity too. After drawing the basic conceptual distinctions, I interpret Canada's policy on research ethics involving human subjects in light of the philosophical account, paying special attention to how the procedural aspect of the policy and the provision of examples allow some room for interpretation while preserving the core commitment to respecting dignity.

### **An overview of policies governing research on human subjects**

Before discussing the meaning of dignity and the legitimate scope for interpreting the notion, I will present a brief comparison of some international research ethics policies. Doing so will help us to see why the duty to protect inherent dignity is a moral absolute and to appreciate the originality and value of Canada's policy. In this regard, the idea that there could be different senses of dignity does not contradict the fact that the protection of a core sense of dignity should be regarded as an absolute imperative.

Canada's research ethics guidelines are part of a tradition of research ethics policies that began post-World War II. The *Nuremberg Code*, consisting of

ten "Directives for Human Experimentation", was developed in 1949 by the International Military Tribunal as a result of their investigation of war crimes committed by Nazi physicians. The primary directive of the *Nuremberg Code* was to secure the consent of the research subject. Other directives concerned the prevention of harm to the subject, the pursuit of social goods, and the use of proper research methods (e.g., using animal models first and adhering to strict scientific standards of validity). There is no mention of dignity in the *Nuremberg Code*<sup>2</sup>; however, the development of these directives for research ethics was predicated on the outrage generated by the magnitude of the disregard for the dignity of the victims, i.e., their special moral status.

Dignity concerns were preeminent in the creation of the first official policy on research ethics because the *Nuremberg Code* was a principled response to the unprecedented use of modern medicine and science to brutalize other human subjects, most notably in Nazi concentration camps. In Joseph Mengele's experiments at the Auschwitz-Birkenau concentration camp, for example, research subjects (many of whom were twin children) were infected with tuberculosis and killed in the course of experiments designed to test the genetic basis of resistance (Müller-Hill, 2001). Other experiments designed to test the limits of human endurance and to justify Nazi hypotheses regarding genetics were also performed. Such abuse of human subjects was unprecedented; not because of the sheer number of victims, but because of who the victimizers were and the context in which the killings took place. That is to say, the perpetrators were not soldiers acting on battle-field priorities and targeting military combatants; instead, they were physician-researchers serving scientific and medical ends according to carefully constructed research protocols that showed utter disregard for the wishes of the research subjects and for the value of their lives. Reflecting on the justifications for these experiments, William Seidelman writes, "German medical science made it professionally acceptable to define and describe human beings as 'subhuman,' 'life without value,' 'useless eaters,' 'useless life,' 'ballast.' Not being considered human, the victims were stripped of any pretense of protection and dignity. As helpless victims, they were available to the academic enterprise for exploitation through inhuman research" (2000, p. 326). The belief that Jews and other victims of Nazi experiments were not human and had no inherent dignity allowed doctors to harm and murder them under the auspices of medical research. They were treated

merely as resources or unwilling instruments that could be exploited and disposed of when no longer useful in pursuit of ends that were of no direct benefit to them. Here we see in extreme form the dangers that follow from having no research ethics policy at all or a very weak and permissive policy.

In 1964, 15 years after the development of the *Nuremberg Code*, the *World Medical Association* adopted the *Declaration of Helsinki*. The *Declaration of Helsinki* was a more comprehensive set of research ethics guidelines. Respect for dignity was featured as one of the preeminent fundamental principles that the physician had an obligation to protect. Specifically, under Section B (Basic Principles for all Medical Research), Article 10 states that, "It is the duty of the physician in medical research to protect the life, health, privacy, and dignity of the human subject" (WMA, 1964). This principle explicitly invokes the concern for dignity that implicitly motivated the development of the *Nuremberg Code*.

The US guidelines for research on human subjects are silent on the question of dignity. In the *Belmont Report* (1979), which provides the ethical framework for the legislation known as the *Common Rule* (i.e., 45 CFR 46, Department of Health and Human Services, 1982), respect for dignity is not mentioned. Instead, the three basic principles specifically mentioned are respect for persons, beneficence, and justice (Part B). Moreover, the same three fundamental principles may be found in the Council for International Organizations of Medical Sciences' *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (CIOMS, 1982). Despite the absence of a specific principle on dignity, both the *Belmont Report* and the *CIOMS Guidelines* view the respect owed to non-autonomous human subjects (i.e., those who are immature or incapacitated) as a basic element of the respect owed to persons. Given this expansive notion of personhood, something beyond respect for autonomy is presupposed; arguably, the relevant consideration is respect for dignity. I say more about this below when discussing the relationship between dignity, autonomy, and personhood.

Despite the fact that dignity is not directly invoked in the fundamental principles of the *CIOMS Guidelines*, dignity is mentioned in the commentaries on two of the guidelines: one links dignity to consent<sup>3</sup> and the other refers to the mechanism for ethical review (Guideline 2). This latter reference is of particular interest because it leaves room for the interpretation of the meaning

of dignity. Specifically, the commentary on Guideline 2 states that, "A national or local ethical review committee responsible for reviewing and approving proposals for externally sponsored research should have among its members or consultants persons who are thoroughly familiar with the customs and traditions of the population or community concerned and sensitive to issues of human dignity" (CIOMS, 1982). This guideline draws our attention to the extent to which persons from different cultures may have different notions of dignity. As I show in more detail below, dignity also bears different personal senses even within a culture, without it being a relative notion on that account.

Finally, Canada's *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) was adopted in 1998 (with updates in 2000, 2002, and 2005). These research ethics guidelines apply to any researcher or institution that is funded by any of the three federal research councils (i.e., the Social Sciences and Humanities Research Council, the Natural Sciences and Engineering Research Council, and the Canadian Institutes of Health Research). Unlike the policies covering research on human subjects discussed in the previous section, Canada's policy places unprecedented importance on dignity as a cardinal principle that should guide research on human subjects.<sup>4</sup> Furthermore, it develops a substantive interpretation of dignity as a notion that has several senses, some of which are open to interpretation. The role that dignity should play in protecting research subjects is elucidated through detailed commentaries on the articles of the policy and by means of examples of actions that demonstrate disrespect for dignity. Before exploring Canada's policy in greater detail, I will undertake a broader conceptual analysis of the notion of dignity, paying special attention to its various senses and the scope they afford for interpretation.

### A basic typology of dignity

In the broader context of biomedical policy, dignity is a highly contested notion. Abortion and euthanasia are the primary battlefields, but in the research context, the dignity of embryonic human life and the mixing of human and non-human DNA have become key concerns. On these fronts, many advocates for biotechnology researchers and consumers argue that respect for their inherent dignity justifies a free hand (Caulfield and Brownsword, 2006), whereas others take an opposing view and

call for greater regulation on the grounds of protecting dignity (Pellgrino, 2005). Lost in the headlines are the personal senses of dignity that are vitally important to the well being, health and self-understanding of individuals and that allow different perspectives to flourish. In a pluralistic context of governance, such interpretability is a means for preserving diversity of opinion while maintaining an inclusive community.

The basic typology of dignity that I employ here was developed by Lennart Nordenfelt. His work synthesizes the vast literature on dignity while drawing attention to three important but overlooked senses of personal dignity. Given that this is an undertheorized aspect of dignity that makes a unique appearance in Canada's research ethics guidelines, I am especially interested in Nordenfelt's interpretation of personal dignity. A typology such as this is never absolute, however. There will be many overlapping points of interpretation between dignity and other moral notions such as integrity or autonomy, but this should not be a surprise given the fallibility of our moral reasoning and the non-ideal conditions of lived subjectivity. Unfortunately, I cannot explore these constraints in as much depth as they warrant. Instead, my modest aim is to establish that dignity has several legitimate senses that we can employ in our research policies in order to effectively protect human subjects. Canada's guidelines on research ethics are an example of this multi-faceted protection. Accordingly, it provides excellent grounds for increasing the obligation to protect dignity in research policies in other jurisdictions.

While all of the senses of dignity are interrelated and mutually supporting, each expresses a different kind of worth or value that may be ascribed to a subject.<sup>5</sup> Notwithstanding the range of meanings, all varieties of dignity share three features in common, according to Nordenfelt. That is to say, in addition to (1) being a "special dimension of value", dignity (2) commands respect (which may involve the recognition of rights or simply positive regard and esteem) and (3) presupposes a ground or property by which it is conferred on the subject (Nordenfelt, 2004, 70). I examine inherent dignity and the personal senses of dignity in the next section.

The first sense of dignity is that of *Menschenwürde*, which I translate as inherent dignity in order to de-emphasize its connection to human genetic identity. *Inherent dignity* refers to the status of subjects as free and equal members of a moral community. This kind of dignity reflects the absolute value of the subject, and one either has inherent dignity or one does not. In this regard, it

differs from the personal senses of dignity that can be diminished or enhanced (Nordenfelt, 2004, pp. 70–1). The various and variable *personal senses of dignity* include: dignity of *merit* (which reflects one's social status as valued by oneself or by others), dignity of *moral stature* (which reflects the excellence or goodness of one's character), and dignity of *identity* (which reflects one's uniqueness as an individual and one's self-esteem).

The primary virtues of this typology of dignity lie in its rich conceptual foundation and its empirical support. In particular, Nordenfelt has shown how the philosophical notion of dignity is intimately bound up with and helps to elucidate our individual lives and experience, e.g., with regard to improving care for the elderly or understanding the broader impact of illness (Nordenfelt, 2003). By and large, the first-hand, phenomenological perspective of individual subjects is invaluable but is often lost in the primary debates over dignity as an objective property.<sup>6</sup> Accordingly, in what follows I demonstrate how the philosophical elucidation of dignity supports the interpretation of dignity in the policy, is supported by empirical research, and complements other accounts of dignity that appreciate its relational and social dimensions, especially as understood in a Canadian context (Chochinov, 2002; Pullman, 2001), but also as practiced in Europe (Rentdorff, 2002).

### Inherent and personal dignity

As indicated above, there are two principal senses of worth and two corresponding senses of dignity: (A) inherent worth (inherent dignity) and (B) the worth of a particular person (personal dignity). I discuss inherent dignity first, followed by personal dignity.

#### A. Inherent dignity

##### *The concept of inherent dignity*

Inherent dignity is my translation of Nordenfelt's *Menschenwürde*. It is a formal and abstract sense of dignity that denotes the equal worth of all subjects who meet the relevant criteria. Nordenfelt notes that this value cannot increase or diminish: one either has it or one does not, and it cannot be taken away from one as long as one exists. In addition to being a "special dimension of value", the second feature that all forms of dignity share is that they entitle the bearer to respect from others (Nordenfelt, 2004, p. 70). In this case, respect for inherent dignity entails that certain rights must be respected, e.g., the

right not to be harmed, the right to life, and the right to self-determination. These rights are generally regarded as the foundations of moral community, and the link between dignity and personhood in the legal sense is very direct here. The third aspect of dignity, namely its ground, is extremely controversial. Nordenfelt notes that humans are generally considered to possess inherent dignity by virtue of either (a) their being created in God's image or (b) their faculties of reasoning and self-consciousness (2004, pp. 77–8). The latter functional ground is the least question-begging approach, but it is not widely endorsed. I discuss the problem of the ground for inherent dignity in more detail below.

Even though the grounds of dignity are debated, the idea that dignity should be the ground of basic human rights is enshrined in national and international laws and policies (Schachter, 1983). However, the nature and scope of those rights will vary depending on the relevant moral, legal, and political context (Shultziner, 2003). For example, inherent dignity is the foundation for moral community and is explicitly invoked as such in exemplary fashion in the preamble to the United Nation's *Universal Declaration of Human Rights* (1948), in Article 1 of UNESCO's *Universal Declaration on the Human Genome and Human Rights* (1997), in Article 1 of the *Basic Law for the Federal Republic of Germany* (Ullrich, 2003), and in Kantian moral and political philosophy (Gewirth, 1998; Kant, 1999; Habermas, 2003).

In order to expand our analysis of inherent dignity, it is necessary to say more about the unique value it denotes, its ground, and how it differs from autonomy. As introduced above, inherent dignity refers to the absolute value that distinguishes a particular class of subjects and denotes their special moral status. According to Rendtorff, dignity denotes the bearer's "outstanding position" (2002, p. 237). More specifically, inherent dignity places one inside the moral community as a person who deserves basic respect. There are two primary aspects to this unique position: inherent worth and equality.

A subject who has inherent worth is valued simply because he or she exists as a special kind of being, not because of any instrumental value he or she bears. In its classic Kantian form, this means that treating the bearer of inherent dignity instrumentally merely as a means to an end fails to respect the inherent (non-instrumental) worth of the person (Kant, 1999, p. 4:434).<sup>7</sup> In addition, by virtue of having inherent (non-instrumental) worth, whoever has inherent dignity has equal standing within the moral community (Habermas, 2003; Häyry, 2004;

Schachter, 1983, Shultziner 2003). Any discrimination between persons would therefore be unjustified and immoral on the grounds of dignity. Again, there is no shifting up or down the scale; inherent dignity is absolute.

Once we recognize the distinct character of this sense of dignity as inherent worth and equality, we are still left with another problem: who has this inherent dignity and why? There are two basic grounds for attributing inherent dignity: one is species-based while the other is functional. I summarize both briefly.

Species-based models consider being a human being in some biological sense or having been created as a human being by God to be the sole basis for dignity (Häyry, 2004). Such criteria are not linked to actual moral competence and are instead based on "speciesist" intuitions that have no rational justification (Singer, 2003) or are based on articles of religious faith. Typically, this very dominant perspective collapses into the view that all biological human life is sacred. To the extent that Nordenfelt's conception of *Menschenwürde* presupposes a species based-view in the strict ontological sense (i.e., by referring to die *Menschen*/humans), it is incompatible with the view I present here. However, if species-based conceptions are grounded in a pragmatic consideration of the link between human being and inherent dignity, then such views are perfectly compatible with my view. As I show in more detail below, we can assert that most humans have dignity and that being human is a sign of having dignity at a prima facie level; however, the foundations of dignity cannot be rooted in genetic identity at an ontological level if we wish to make dignity a non-arbitrary notion. Indeed, we cannot exclude other possible candidates from having dignity in a *definitive way*. Moreover, in Europe and North America we live in pluralistic societies in which some do not regard natural law or divine creation as the basis for assigning dignity. Therefore, the more agnostic term inherent dignity makes it less likely that we shall revert to naive speciesism while preserving what is essential about the moral dimensions of the term "humanity", e.g., as invoked in the idea of a crime against humanity. Moreover, in a research context where we can create hybrid beings with the potential to have genuinely human functioning, we are forced to abandon human genetic identity in the strict sense and focus on the phenotypic or functional basis of what we consider to exemplify human subjectivity.

According to a functional view of dignity, those beings that possess (or are likely to possess) the

relevant capacities or abilities have inherent dignity. Several functional accounts of dignity may be found in the philosophical literature, but most rely on a set of criteria consisting of high-level reasoning and decision-making abilities, self-consciousness, sentience (i.e., the capacity to suffer), and the capacity to communicate in varying degrees (Gewirth, 1998, Habermas, 1990, Kant, 1999, Nussbaum, 2006). These are non-arbitrary grounds for dignity to the extent that they are broad competencies required for being an agent in the moral community and for having moral status. The capacity to engage in moral deliberation and communication, the capacity to experience states of pleasure and pain (i.e., welfare) and the capacity to act freely are all constitutive dimensions of moral agency in this regard.<sup>8</sup>

Admittedly, marginal cases will challenge the functional account. For example, individuals with severe mental impairment such as anencephalics may not meet the criteria, and all infants may only have it in a prospective or promissory sense. Retrospective possession of that functioning in severely demented persons should also be considered equivalent to functioning. The key is that we need to be able to distinguish those who did or will function in the relevant sense from those who will not. Thus, depending on how realizable the functionality will be, we should be prepared to afford equivalent protection without claiming that our standards should be lowered. However, some higher primates such as bonobos may already meet the criteria but we remain unwilling to accord them the moral standing they deserve and are unwilling to think of how such moral pluralism could function (cf. Pluhar, 1995). By contrast, some robots or artificial life forms may mimic the relevant functioning without satisfying the criteria (cf. Bostrum, 2005).

As we see in the research ethics guidelines below, there is a meaningful continuum between subjects that are no longer functional in the relevant sense (e.g., persons with dementia), those who will become functional in an imminent fashion (e.g., children), fetuses and embryos that have the potential to become functional, gametes that have more remote potential to become a constituent part of a functional subject, and finally somatic tissue such as blood that is theoretically capable of becoming functional via somatic cell nuclear transfer (i.e., cloning). However, the fact that there is a continuum of potentiality here does not mean that we cannot make meaningful distinctions based on a functional conception of dignity and the degree of potential possessed.

Furthermore, since moral reasoning is fallible, the bar for meeting the relevant thresholds should be set rather low in order to be maximally inclusive. This is particularly important given that no one is born in full possession of the relevant capacities. Accordingly, a promissory dimension is necessarily built into our conception of inherent dignity given that we must nurture it (cf. Nussbaum, 2006). Moreover, the consequences of failing to recognize the dignity of some were illustrated in horrific fashion in the Nazi experiments documented above. Yet, the benefits of having inherent dignity are certainly great and should not be doled out too hastily (e.g., by allowing bonobos to vote).

Thus, despite disagreement over the exact set of capacities (and their thresholds) that are required to function in the relevant sense, it appears that a functional account is the only one that can avoid the charge of arbitrariness. That is to say, an argument from functioning is the only legitimate position to take within a pluralistic moral community predicated on justification through reasons, evidence and negotiation rather than faith or intuition alone (Hagendijk et al., 2006; Misak, 2000). While it is extremely difficult to avoid invoking human species membership as a criterion for dignity (and this is routinely done in health policy), we can and should regard human species membership as a pragmatic benchmark for dignity assignments that requires further justification and which cannot exclude other actual or possible beings.

Finally, in defending a functional view of the basis for assigning dignity, it has been pointed out that dignity seems to resemble autonomy to such a degree that it can be collapsed into the latter.<sup>9</sup> While there is a great deal of overlap in the capacities, dignity cannot be eliminated or explained away as a species of autonomy. This is due to differences in the scope and meaning of the terms. As the very schematic presentation of the inherent and personal sense of dignity presented above has shown, dignity is a distinct and irreducible moral concept that refers to the *worth* or *value* of a subject. By contrast, autonomy refers to a power or an ability of the subject, namely the ability to make informed and voluntary choices (or the act of making such a choice).<sup>10</sup> Similarly, dignity cannot be reduced to welfare: the welfare of the subject refers to a state of being, which is different yet again from the worth of that subject. These notions may overlap in significant ways, but they are distinct and irreducible. That is to say, the worth of a subject may be revealed by assuming a particular interpretive standpoint on a set abilities or an affective state without being reducible to either of those.

The autonomy that is typically attributed to persons (Beauchamp and Childress, 2001) is too narrowly defined as executive decision-making power. Inherent dignity depends on a broader range of capacities for self-consciousness, sentience, communication, and intellect, capacities that are constitutive of the kind of communicative competence that underlies moral agency along Habermasian lines (Habermas, 1990). Thus, unlike autonomy, which focuses exclusively on the individual, dignity is an assessment of worth relative to the moral community as a whole (cf. Horton, 2004). In other words, the grounds for attributing dignity to a being are directly related to the conditions for membership in a moral community. This is reflected in the tendency to view dignity through the prism of species-flourishing (Nussbaum, 2006) or in relation to Kant's "kingdom of ends" (Kant, 1998). Autonomy, by contrast, could be attributed to a subject simply on the basis of their capacity to act freely in accordance with their preferences. Strategic action may be autonomous and yet remain antagonistic to the very idea of a moral community (e.g., the community of thieves or of robots). Thus, even though dignity and autonomy are closely linked, dignity cannot be reduced to autonomy any more than it can be reduced to welfare or happiness.

*The scope for interpreting inherent dignity, with reference to the TCPS*

While personal dignity (see below) is a notion that may be interpreted differently by different individuals (i.e., it is subject-relative), inherent dignity is not open to interpretation in this way. There will be important disagreements over how inherent dignity should be specified in specific contexts, but it would be wrong to say that this implies that the meaning of inherent dignity as such is subject-relative. Rather, there is a "right answer" that the different parties are all trying to get at, even though they may disagree about what that answer is (e.g., whether bonobos or anencephalic infants have it). In the case of personal dignity, by contrast, there is no presumption of a right answer for all relevant parties, even though there may be broad agreement on one interpretation or another.

I should note, however, that there is an indirect relationship between inherent and personal dignity to the extent that violating the inherent dignity of others (e.g., by murdering someone or enslaving them) is very likely to diminish dignity of moral stature, personal identity, and social status in very significant ways. This connection helps us to see the unity behind the various senses of dignity. As we see in the next section, personal dignity adds the

subjective, phenomenological dimension to what would otherwise be a strictly formal and objective notion of inherent dignity that effectively de-personalizes or anonymizes the subject, as valuable as such a formal point of view may be.

Canada's research ethics guidelines emphasize a subject-neutral sense of dignity as inherent worth described here. In Part C of the section entitled, "Context of an Ethics Framework", the following fundamental commitment to respecting dignity is presented: "It is unacceptable to treat persons solely as means (mere objects or things), because doing so fails to respect their intrinsic human dignity *and thus impoverishes all of humanity*" (TCPS i.5; emphasis mine). In other words, the policy states that inherent dignity means that one cannot be treated solely as an instrument in service of another person's goals (or sacrificed for the goals of society). While there may be conflict over the interpretation of whether one research context does or does not violate such dignity, there is no room for disagreement about the basic meaning of inherent dignity provided here. In addition, the reference to the impoverishment of "all of humanity" extends the scope of dignity greatly and is a very ambitious claim. It lends gravity to the interpretation of inherent dignity, while at the same time risking incoherence if humanity is understood too narrowly as genetic human identity.

As I show in the next section, personal senses of dignity permit greater scope for interpretation relative to an individual or a community without applying universally. Inherent dignity, by contrast, must not be limited to particular communities because it encompasses moral community in the broadest possible sense. The UN's *Universal Declaration of Human Rights* (1948) captures this broad notion of moral community that transcends national and cultural differences. This has been viewed as the aspirational sense of dignity, which is often derided as hopelessly vague or as a mere conversation starter (Caulfield and Brownsword, 2006). However, on the most charitable reading, we should understand the goal of aspiration in terms of the struggle to actualize the ideal of fully equal and respectful treatment of all persons on a global scale (and even beyond the globe).<sup>11</sup> This is both a rhetorical claim that adds weight to the policy as well as a literal claim about the danger that crimes against humanity pose for all subjects, not just those who are directly affected. At a deeper level, this claim reflects the origins of research ethics policy in the response to Nazi medical war crimes. If the dignity of all humanity was not at stake, why were the *Nuremberg Code* and the *Universal Declaration of Human Rights* created?

Slavery is another compelling reminder, should we need one, that the victimization of a people reflects badly on those who stand by and watch as much as on those who perpetrate the crimes.<sup>12</sup>

### B. Personal dignity

#### *A conceptual analysis of the three senses of personal dignity*

There is another very important general sense of dignity, namely the worth of a particular person or personal dignity. Personal dignity is less formal and abstract than the notion of inherent dignity because it focuses on the evaluation of a particular individual's life as it is lived. That is to say, personal dignity can be diminished or enhanced by the events of one's life and actions one has taken whereas inherent dignity is something one either has or lacks (Pullman, 2001). As studies in palliative care have indicated, dignity in this sense has more to do with an individual's own values about what makes their own life meaningful along these three axes rather than simply the ability to choose how their life should end (Chochinov, 2002).

Lennart Nordenfelt has developed an excellent tripartite notion of personal dignity: dignity of *merit* (where worth derives from social status), dignity of *moral stature* (where worth derives from one's virtuous character) and dignity of *personal identity* (where worth derives from self-esteem or self-worth broadly construed) (Nordenfelt, 2003, pp. 100–1). In this section, I shall present each briefly before fleshing out the definitions with several examples of how they can be interpreted in different ways. Note that there is a great deal of overlap in these notions. I consider this to be evidence of the unity of the notion of dignity rather than an argument that these are too vague. Furthermore, the overlap with other notions such as integrity, self-respect, and autonomy cannot be regarded as a failing; rather, it provides evidence of the complementarity between these fundamental notions and their importance for our self-understanding.

The personal senses of dignity are much closer to the root of the term. In Latin *dignitas* denoted the excellence of the nobility. In this respect, dignity of merit is an essential sense of dignity that has a long history. The social value accorded on the basis of a high rank or a special position within society is constitutive of dignity of merit. Typically, respect for dignity of merit involves the recognition of rights, e.g., the right to make legislation (in the case of high-ranking politicians) or the right to enjoy other privileges (Nordenfelt, 2004, p. 72). This sense of dignity is highly variable

given the different criteria by which society ranks persons (e.g., wealth, genealogy, intelligence, or fame), and there need not be a particular moral dimension to that ranking (although one can see how excessive pride in one's position can lead to a diminished moral stature). Moreover, dignity of identity may be predicated on such dignity, with dire consequences for the individual's sense of self when that status is lost.

Dignity of moral stature denotes the value one has by virtue of one's good deeds and virtuous judgement. It is unlike inherent dignity and dignity of merit in that no rights follow from its possession. Rather, if one has a good character or behaves in a moral fashion, one is entitled to enjoy the high regard of others (Nordenfelt, 2004, p. 73). Often dignity of moral stature is the basis of self-respect, and it may play a large role in securing better social status or maintaining a strong dignity of identity. However, this sense of dignity is highly variable too, depending on how one conducts oneself throughout one's life. Assessments of one's own moral stature are not the sole ground for this sense of dignity. Others' perspectives will carry great weight, although unlike social merit, moral stature is not (or should not be) a matter of trends and public opinion. There is a truth of the matter, in other words, that makes moral stature more objective. This is true even if moral judgement presupposes intersubjective judgement rather than an objective table of values (Habermas, 1990; Edgar, 2004).

The last sense of dignity is dignity of identity. Nordenfelt defines dignity of identity as the "dignity that we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future with all our relationships to other human beings" (2004, p. 75). This is an innovative notion that is admittedly very broad. Nonetheless, it captures another essential sense of personal dignity, namely the unique value we accord to individual persons because of who they are (i.e., *this person*) rather than what they are (i.e., *a person*). The latter object sense is captured by the notion of inherent dignity, which is a more formal and objective sense of individuality. Dignity of identity is especially vulnerable to the impact of aging and illness, because here the individual is subject to profound changes that affect the core of their identity and their relationships to others. Humiliation and shaming by others also deeply affect this identity inasmuch as they cripple one's image of oneself in the eyes of others.

As it is closely linked to autonomy and integrity, we may be tempted to reduce dignity of

identity to both or either of these things. However, more than these latter notions, dignity of identity is overtly bound up with one's perception of oneself in the eyes of others. By contrast, integrity is more self-regarding, as it conjures up the coherence of one's life as a whole in a narrative sense (Rendtorff, 2002, p. 237). Autonomy too is focused on one's own agency, i.e., one's ability to direct the course of one's life. By contrast, dignity of identity is a more relational notion that places greater emphasis on the social dimension of self-hood. Finally, Nordenfelt claims that dignity of identity can be diminished even after death, unlike inherent dignity that attaches only to living beings.<sup>13</sup>

In many respects, these three senses of personal dignity are less morally weighty than inherent dignity. In particular, they do not translate into rights such as the right to life or to self-determination (although dignity of merit may do so in some contexts). However, diminishing any of these senses of dignity to a sufficient extent will certainly have a great negative impact on the well being of the subject. Indeed, whereas the moral status of embryos debate occupies so much attention, there is an immensely greater number of persons who are affected by diminished personal dignity. This is especially true in the case of the dignity of identity, where the individual's sense of self is most vulnerable. For example, in the context of research on human subjects, this sense of dignity can be harmed by research that stigmatizes the subject because of their genetic make-up or their race. In even more subtle ways, subjects who have lower dignity of merit can be manipulated into participating in research under false pretences (Burns et al., 2007). Nordenfelt's research has shown that dignity in these senses has been especially evident in the experience of the elderly (Nordenfelt, 2003), and the vast literature on dignity and nursing reveals the extent to which both care-givers and recipients of care feel the more subtle, interpersonal effects of dignity violations (Gallagher, 2004; Söderberg et al., 1997). The positive side of these problematic experiences is that we can enhance dignity as much as we can diminish it. Thus, we have even more reason to prioritize these neglected senses of dignity in order to improve the care of persons and the protection of research subjects.

*The scope for interpreting personal dignity,  
with reference to the TCPS*

The assessment of personal dignity concerns one's worth as a particular individual. As indicated above, there are three main kinds of personal dignity:

dignity of merit, dignity of moral stature, and dignity of identity. Judgements regarding all three of these basic forms of personal dignity may be directed at oneself or at others and will vary according to the events of one's life.<sup>14</sup> As such, personal dignity has a fundamental aesthetic or subjective dimension (Pullman, 2001). That is to say, any two individuals may differ in their views about their own or others' dignity without it being the case that either one is wrong. Often, these views will likely be shared within particular socio-cultural contexts, especially where social norms of merit or excellence of character are relevant or where the traditions of a given community are at issue. Moreover, at the limit of objectivity, some judgements bearing on personal dignity will involve fundamental ethical considerations that are true even if misinterpreted by the subject, e.g., when the researcher is obligated to protect the inherent dignity of the research subject. Failing to respect the dignity of the research subject will diminish the moral status of the researcher even if the researcher does not realize it because it is a violation of a basic moral duty.

To get a better sense of the various senses of personal dignity and how it may be legitimately interpreted in different ways, consider the following examples.

1. Someone addicted to drugs may become stigmatized and experience a loss in their social status (i.e., their dignity of merit) if that addiction is made public. In addition, that same addict may experience their addiction as a vice or weakness of will, which translates into a loss in their dignity of moral stature and may even exacerbate the addiction. However, in another culture (and perhaps with a different drug), the addict may not lose any social status or moral worth. Indeed, if the drug produces shamanic insight, that person may have increased dignity of merit and greater moral stature (e.g., their goodness is reflected in their being given the gift of being a visionary) (Nencini, 2002).
2. The elderly and those receiving palliative care are particularly susceptible to challenges that will either diminish or enhance their personal dignity (Chochinov, 2002; Nordenfelt, 2003). These challenges may be faced in idiosyncratic ways. For example, two persons may disagree about whether being on pain medication that makes one less alert and communicative affects one's dignity. For some Buddhist monks, identity, social status and moral stature are all at issue when presented with the option of using disorientating pain medication. These Buddhist monks see such

interventions as a barrier to their conscious grasp of the moment of death (Coward et al., 1998). The aesthetic or subjective aspect of this assessment, which is supported by cultural beliefs but affirmed by the individual presented with the choice, leaves the scope of personal dignity open to interpretation in a manner we can recognize as perfectly legitimate and consonant with our grasp of individual differences.

3. In the context of nursing, studies have shown that one's view of the dignity of others is enhanced by and enhances the dignity one attributes to oneself. For example, witnessing violations of patient's dignity are sources of great moral distress because they affect the dignity of the nurse (Gallagher, 2004; Söderberg et al., 1997). In this regard, the social context for understanding dignity has a great impact on how others' judgements about dignity affect one's own judgements. Something that may be regarded as a dignity-conserving choice by the patient (e.g., the decision to hasten their death out of concern for their personal dignity) may be regarded by the nurse as a compromise of her dignity of moral stature, should her assistance be required or should her inaction be viewed as complicity. The consequences of compromising one's dignity in such a scenario require that we be sensitive to how personal dignity will set limits to the kinds of behaviours that we can expect persons to participate in, notwithstanding their professional obligations as nurses, for example.

In the examples presented above, personal dignity is experienced along a continuum and is highly variable depending on differences in cultural norms and in the beliefs of individuals. As a result, it is expected that the meaning of personal dignity will often be a matter of interpretation. Canada's research ethics guidelines acknowledge this legitimate expectation without referring to personal dignity as such. Specifically, the policy states that, "The cardinal principle of modern research ethics, as discussed above, is respect for human dignity. This principle aspires to protect the multiple and interdependent interests of the person—from bodily to psychological to cultural integrity" (TCPS, i.5). The different senses of personal dignity are "multiple and interdependent" in the relevant sense. Whether they are expressions of dignity of merit, of moral stature, or of identity, the subject's interest in protecting their dignity is codified in very general terms that allow for subject-relative (and culturally relative) differences in interpretation.

The requirement that subjects consent to participate in research (TCPS, Section 2) and the measures taken to protect the privacy of the subject (TCPS, Section 3) (which is a notable part of the dignity of identity but which also encompasses dignity of merit and moral stature) are two features of the policy that allow subjects to opt out of research that they perceive to be a threat to their "bodily, psychological or cultural integrity" during the course of the research trial itself (the converse holds for opting in). The consent process in particular provides an example of how a procedural mechanism can protect dignity without setting out a fixed content or interpretation of dignity that would apply a priori to all subjects.

In this regard, the consent process itself may have to be implemented somewhat differently in different contexts. For example, the notion of "collective consent" has been developed in recognition of the influence that Aboriginal communities may legitimately exercise over the decision-making process of individuals (Kaufert et al., 2004). This authority can be regarded as legitimate given the commitment to the deliberative process that underlies membership in a Aboriginal community. This commitment is a unique feature of Aboriginal life that is predicated on a long history and passed on through oral tradition. Indeed, this rich identity is the source of much pride. Moreover, the framework for deliberation is entrenched in the policies governing native reserves, where Aboriginal communities have been given wide scope for self-direction. In this regard, the dignity conferred by being a member of a given culture has consequences for moral, social and identity-based conceptions of dignity that demand special consideration by researchers. Researchers who are unfamiliar with the political reality of reserves may be shocked that individuals would consent to that deferral of authority; however, the dignity of the individual is very much supported by their membership in that tradition and is not threatened in principle by the decisions of the elders. However, this assumes that the process is fair and provides recourse for appeals, which in the context of a given situation may not be the case. Where there is dissent on the part of an individual, there are certainly mechanisms that can be brought to bear in order to mediate the situation. For example, the Canadian *Charter of Rights and Freedoms* and the federal research ethics guidelines will still apply and there are dispute mechanisms built into these.

Finally, the prohibition against certain kinds of research ensures that prospective research subjects will not be presented with the option of participating in some kinds of research that will threaten their personal dignity. This prohibition is based on anticipating actions that would be disrespectful of the dignity of the subjects involved or affected by that research. The justification may be contentious because it has a paternalistic dimension; i.e., it assumes that subjects need to be protected from their own bad choices. However, disrespect for dignity is generally only one consideration among others that provides the basis for excluding certain kinds of research. In this category we find the prohibitions against selling gametes (TCPS, Art. 9.2) and against creating human embryos specifically for research (TCPS, Art. 9.3). I discuss the reasons why dignity considerations justify these and other prohibitions below. For the moment, I will only note that were one to participate in such research, it is expected that this would result in a diminished dignity of moral stature, given that the subject's participation in such activity would constitute a character flaw.

To sum up, personal dignity is in many respects open to interpretation by individuals; inherent dignity, by contrast, is agent-neutral in the sense that all must share a basic view regarding the content of inherent dignity (i.e., freedom and equality). Distinguishing these various kinds of dignity helps us to see how dignity can be best invoked in different contexts. In some cases, preventing subjects from interpreting dignity as they wish will constitute a harm. As the example of the Buddhist monk shows above, we can hold different views about our personal dignity without believing that all persons should endorse them. To think otherwise is to ignore the complexity of our moral experience and the importance of situated self-understanding. Research subjects will use their discretion to decide what does or does not violate their sense of self-identity and integrity. Moreover, in order to prevent wrongdoing and ensure that research subjects will not be complicit or victimized, it is necessary to prohibit certain kinds of research. We see examples of these various measures in the guidelines on human subject research described below.

### **Specific examples of disrespect for dignity in Canada's research ethics guidelines**

In addition to the overriding obligation to respect dignity summarized in Parts A (ii) and B (ii) above,

Canada's research ethics guidelines present a long list of specific applications of dignity. These examples provide guidance for judging the permissibility of proposed research activities that may be analogous in some essential respect. The use of examples reflects the kind of case-based, casuistic reasoning that is especially relevant to biomedical ethics (Toulmin and Jonsen, 1988). Not all of the justifications provided in the accompanying commentaries are as comprehensive as they should be, but that does not mean that we cannot improve upon them by reconstructing the argument or drawing on other references within the policy or in other policies. To this end, I will add my own brief commentaries.

My aim is to show how the various senses of dignity are implicated in the research and the scope for interpretation allowed for each. I acknowledge that several senses of dignity may be at play in any given interpretation and that they may overlap to a greater or lesser extent. Accordingly, at the expense of a finer grained analysis, I tend to distinguish inherent from personal senses of dignity generally in what follows, leaving the more refined analysis of the different senses of personal dignity to another paper. In other words, it is necessary to document the experiences and concerns of individual research subjects if we wish to take into account the full scope of personal dignity. I begin with Article 2.1 (a) of the TCPS, which links dignity and consent. Unless otherwise noted, the number in the parenthetical reference refers to the page number of the TCPS, not to the Article (which is cited in the commentary).

The first application of the principle of respect for dignity concerns *consent*: "Article 2.1(a) states the requirement in both ethics and law: to protect and promote human dignity. Ethical research involving humans requires free and informed consent" (TCPS, 2.1). This is a striking comment on the foundational value of dignity in all human research, given that Article 2.1 (a) focuses entirely on the need to secure and maintain the consent of research participants or to have a proxy consent for those who are incompetent.<sup>15</sup>

In part, the requirement to secure and maintain consent allows one to protect one's unique interests. This affords a procedural level of protection, as discussed in Part B above. Thus, one's personal dignity may be protected by the subject him or herself whenever faced with circumstances that would have an affect on dignity of merit, moral stature or identity. Consent requirements also implement respect for the recognition of the individual's inherent dignity as a moral agent

who has the right to decide what they wish to do. That is to say, the subject is likely to be their own best advocate for preventing themselves from being used merely to serve others' needs. As we know from historical precedent, the greatest assaults on human dignity and welfare in the context of research on human subjects were accompanied by the failure to get consent (see the discussion of Nazi research above). This failure was symptomatic of a general disregard for dignity because the subjects were treated merely as means to an end rather than as subjects who had inherent worth.

Article 2.3 (on *privacy*) and Section 5 (on *justice*) also invoke the personal and inherent senses of dignity, but I shall not discuss them in detail here.<sup>16</sup> Instead, I will turn to Sections 9 and 10 that apply the principle of respect for dignity to the use of human tissue. These sections focus on the use of human reproductive material such as ova, sperm, and embryos as well as non-reproductive tissue such as blood samples. Each article in these sections can be read in light of the big picture question as to whether there can be threats to humanity as a whole (the most powerful claim made in the TCPS). Moreover, we see how a concern for inherent dignity motivates the regulation of research involving early embryonic life, whereas a concern for personal dignity motivates the regulation of how parts of the body are used in research.

By and large, the application of the principle of respect for dignity varies depending on the kind of tissue used in the research, the manner in which the tissue is procured, and the research itself. The first problem concerning dignity broached in Section 9 is the *retrieval of tissue without consent*: "Respect for human dignity also means that it is unacceptable to obtain gametes from foetuses or individuals unable to consent for themselves" (TCPS, 9.2). This example plunges us directly into the deep waters of the moral status of "marginal cases", at least with regard to the moral status of the human fetus. That is to say, we cannot assign autonomy to the fetus (i.e., the right to consent) because it was never autonomous in the relevant sense. In the case of individuals who cannot consent, they may resemble the case of the fetus in that they were never autonomous or they may simply be no longer autonomous at the present time. Either way, in the absence of the functionality relevant to being a moral agent within a moral community, inherent dignity cannot be assigned directly to the fetus or to the non-autonomous individual. In other words, neither autonomy nor inherent dignity can be meaningfully attributed in this case, except in terms

of potentiality or prior possession. Instead, considerations pertaining to the inherent dignity of humanity as such provide the primary basis for excluding the collection of gametes, keeping in mind the TCPS's worry about research that can impoverish all of humanity (TCPS, i5). Here "humanity as such" should be read as a somewhat rhetorical and conventional way of referring to the moral community as a whole and of acknowledging the dangers posed to the conditions for moral agency in general.

We get a clearer sense of how an act performed on a fetus or a non-autonomous individual can be a threat to the moral community as a whole when we consider the case of the prohibition against selling reproductive tissue such as ova, sperm, or embryos (TCPS, Art. 9.2). The commentary states that, "Inspired by the fundamental ethical principle of respect for human dignity, Article 9.2 expresses the moral prohibition against the commercialization of human reproduction" (TCPS, 9.2). This is essentially a slippery slope argument: if you allow reproductive tissues to be commercialized, then we could create a culture in which it would be acceptable to commercialize persons as such. It has happened before. Indeed, slavery is the counterpart to the Holocaust in this respect: both are deep and egregious violations of the principle of respect for human dignity. Can we prove that commercializing reproductive tissue or harvesting fetal gametes without consent will definitively lead us down that slope that we have already gone down? No. But we can make assessments based on the available evidence knowing that this issue is important enough to merit great caution and requires that we exercise our moral imagination (Prusak, 2005). Moreover, we can argue from the standpoint of the moral community as such without assigning inherent dignity to the gametes, embryo, or fetus; rather, we act out of a concern that the inherent dignity of others and of the community as such will be endangered by commercialization. The prohibition against commercializing reproduction is one of the most direct applications of the principle of respect for dignity. We find corroboration for this application in Canada's *Assisted Human Reproduction Act* (2004), which regulates the use of assisted human reproductive technology and research involving human reproductive materials.<sup>17</sup>

By and large, the same justification based on a slippery slope argument underlies the *prohibition against creating chimeras* (TCPS, Art. 9.3) and the *prohibition against cloning embryos* (TCPS, Art. 9.5). With regard to chimeras, the commentary

reads, “Combining human genetic material with that of other species has the potential to create new life. The creation of hybrid individuals or species that may survive, or are intended to survive, violates our basic norm of respect for human life and dignity. Article 9.3 expresses this concern, while acknowledging that other related research may raise fewer ethical objections” (TCPS, 9.2). In this commentary, we see that the potential social and moral cost to the community as a whole is the basis for the prohibition. Admittedly, in light of the speculative nature of this slippery slope, it is hard to prove that such costs will accrue; accordingly, it is preferable to argue from clear-cut and imminent violations of autonomy and harm. Nonetheless, refusing to raise the question of dignity risks too much, especially when we keep in mind the origin of research ethics in the horrors of the Holocaust. The presumption is that we need to be extra cautious because the creation of hybrids poses very great risks of harm. Otherwise, the foundation for the claim is the speciesist assertion that we do not wish to dilute the “human stock”, assuming we could know what that really meant.

The final reference to dignity in Canada’s research ethics guidelines concerns the *dignity of human tissue*: “In Canadian society, it is generally held that human tissue itself deserves some degree of respect, for reasons of the dignity of the person from whom tissue is obtained” (TCPS, 10.1). This final reference is noteworthy as it implies that the dignity of the donor is the reason why the donated tissue has dignity (somehow the tissue reflects the dignity of the donor in the same way the moon reflects the light of the sun). Our acts with regard to the tissue reflect on our own dignity as moral agents and members of a broader moral community. Moreover, the caveat that this view is “generally held” (my emphasis) in Canada is striking. If that “generally held” view were to change, then this article would have to be substantially revised (and perhaps removed). Notice that this relativization of the article runs counter to the tendency in the Canada’s research ethics guidelines to view inherent dignity as having a fixed meaning that safeguards humanity as a whole. However, personal dignity rather than inherent dignity is invoked here as it concerns blood and DNA samples rather than reproductive tissues such as gametes or early stage human life (i.e., embryos and fetuses). That is to say, the tissues covered under Article 10.1 do not engage inherent dignity in the same way because they do not have the same proximity or resemblance to moral agency as reproductive tissues (i.e., in the causal sense of

having the power to become a live born individual). Instead, the relevant concern has to do with our cultural beliefs about how parts of our bodies should be treated.<sup>18</sup>

My elucidation of Canada’s research ethics guidelines has emphasized the importance of appealing to a broader cultural and moral community in order to understand the relevance of dignity. Moreover, I have argued that personal dignity does not engage the moral community as such in the same way that inherent dignity does, although the two primary senses of dignity are certainly interrelated and mutually supporting. However, as conscientious as Canada’s research ethics guidelines may be at explaining the relevance of dignity, this conflation is still prevalent and should be rectified by making a concerted effort to clarify the functional basis of inherent dignity.

Accordingly, before turning to some final reflections on the importance of dignity and the challenges we will continue to face while defending it, it is necessary to draw attention to the problematic references to “humanity” throughout the Canadian research ethics guidelines. Specifically, the need for a careful, functional elucidation of inherent and personal dignity is underscored by a conceptual sloppiness in Canadian and virtually all biomedical policies that invoke the value of human life. At best, the conflation of human identity and dignity helps us to see that dignity concerns are concealed under the banner of protecting what it means to be human, broadly conceived. At worst, it perpetuates conflict over marginal cases by framing dignity in terms of unfounded speciesist presuppositions. Nevertheless, the belief in the inherent value of human species identity is deep-seated and appears to stand guard at the gates of moral confusion (Baylis and Robert, 2003). A functional view of dignity that emphasizes communicative competence, sociality, rationality, self-consciousness, and that is maximally inclusive must be integrated into the biomedical policies I have been considering in order to avoid further confusion.

### **Making dignity a priority in research on human subjects: what do we have to gain? What do we have to lose?**

Recall that Canada’s research ethics guidelines expressed the worry that some research could threaten to “impoverish all of humanity” and should be restricted on that basis. Yet, as real the danger to the foundations of moral community

may be, the conflation of *all of humanity* with the moral community in the sense I have been presenting it here is unjustified to the extent that it relies on species-based criteria for inherent dignity. However, if humanity is expanded to mean all beings who meet the criteria for dignity, where *ex hypothesi* there may be species or forms of life we do not yet know about or whose capabilities we misjudge, then this claim preserves its powerful force as motivation for action and as a caution against misguided action. After all, a crime against humanity is never regarded as a literal affront to all human beings directly; rather, it is a value judgement about the magnitude of the crime and the need to set a harsh penalty so that others will never doubt the immorality of the act. The fact that disrespect for dignity is at the root of so many egregious injustices (e.g., genocide and slavery) makes it an especially resonant notion. It conveys the nobility and precious fragility of our moral interaction within a community of equals in a way that a more formal concept such as autonomy or even a more psychologically rich notion like self-integrity does not. Such connotations are even more valuable when we realize the magnitude of the challenge we confront in the realm of biotechnology.

One clear lesson that we should draw from Canada's research ethics policy is that distinctions in the domain of biomedical technologies are never clear-cut. Our moral and conceptual distinctions are strained in the face of novel technological possibilities, but we still need conceptual clarity if our moral reasoning is to be effective. After all, inherently valuable subjects (as well as things that subjects highly value) are placed in jeopardy every day in order to further the cause of research. Much of that research seeks to battle human suffering, but the battle for market share, profit, and prestige is also a powerful motivation. The dangers posed by failing to appreciate the magnitude of the activities currently underway cannot be underemphasized. Dignity, with all of its senses, is a notion comprehensive enough to symbolize the immensity and gravity of the task that lies at the feet of policy makers and ethicists. While it does not exhaust the field, it takes its rightful place near the centre of that field.

While Rendtorff (2002) has documented that four basic principles dominate biomedical policy in Europe, he remains agnostic as to which should be considered the most important. In part, the decision as to whether autonomy, integrity, vulnerability or dignity should be given more weight depends on the context. This is undoubtedly true. However, unless we wish to emulate the princip-

lism of Beauchamp and Childress (2001), and with it lose any principled way of adjudicating conflicts between principles, we need to give more direction for policy makers.

Based on the analysis provided in this paper and the evidence of Canada's research ethics policy, a dignity-based moral framework provides the strongest guidance for developing effective biomedical policies. This is especially true of research involving human subjects, where the abuses of Nazi medicine are fresh in our memories. To the darkness of such times, we can oppose the light of dignity, which has remarkable powers to motivate compliance. In part, this motivational power is due to the way in which dignity is routinely invoked as the basis for opposing the instrumentalization of persons. The idea that subjects have inherent value is essential to the notion of dignity. We see this again and again in the aspirational value of international declarations, where it has already become a keystone. However, the other senses of dignity provide even greater opportunities to increase the well being and even the health of all persons, not just research subjects. As I have shown, the personal senses of dignity can be enhanced or diminished. We do not always recognize the impact that such diminishment has on persons, but once we can name and identify these aspects of personal dignity, we can monitor them and ensure that we work to enhance them. Nursing and palliative care are excellent examples of this need. Thus, we have a moral obligation to promote the various senses of personal dignity for reasons of health but also out of respect for the essential part that dignity in all of its senses plays in our self-understanding as persons.

The fact that dignity has so many senses makes it even more valuable because it complements so many other important moral concepts. These include autonomy, vulnerability and integrity as well as many others. Admittedly, the senses of dignity described here seem to be synonymous at times with these other notions. However, the unity of the concept of dignity gives it an advantage over these other notions. That is to say, we are less likely to prioritize autonomy at all costs, for example, even where autonomy is regarded as an essential dimension of inherent dignity. We will not do so because other senses of dignity counterbalance the individuality denoted by autonomy. The same is true of integrity, which focuses on the psychological state of the individual more than that individual's relationship to others. When we apply the matrix of dignity to a problem, we are guaranteed to think of the problem from multiple points of view and to

include multiple stakeholders. The typology of dignity presented here should therefore be regarded as a tool that provides additional resources for the protection of research subjects. In other words, one should *not* conclude that the typology of dignity has to be precise and exhaustive and that the consequences of respecting dignity must be in every case distinguishable from related notions such as integrity and autonomy. The overlap with related notions should thus be seen as corroboration and as further confirmation of the importance of dignity as a mediating and foundational notion.

As I hope to have shown, Canada's research ethics policy is unique because in addition to the concern for voluntary participation and the prevention of harm, a more global sense of well being is introduced under the guise of a collection of dignity concerns. This practical example provides independent evidence of how important a nuanced interpretation of the many senses of dignity is when assessing the protection we can provide to research subjects. Given the pluralistic context in which we seek to develop governance solutions, the flexibility and openness of dignity to interpretation, within limits, makes it an eminently useful notion. Again, international declarations teach us that dignity can generate buy-in from different nations. Inasmuch as it keeps us at the table, it makes the chances of harmonization and consensus that much more likely. In this regard, dignity offers the best hope for an ethics that will protect "humanity" writ large, where this central notion is construed in the most universal of senses.

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### Notes

1. I do so for two reasons; first, to make the notion less exotic to English ears and, more importantly, to disengage dignity from the notion of human dignity implied by the word *Mensch*.
2. Although there is one reference to "humanitarian" considerations that should be kept in mind when considering acceptable risks involved in the research. Directive 6 states, "The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment" (International Military Tribunal, 1949).
3. Guideline 4: "By informing the prospective subjects, by repetition and explanation, by answering their questions as they arise, and by ensuring that each individual understands each procedure, investigators elicit their informed consent and in so doing manifest respect for their dignity and autonomy" (CIOMS, 1982).
4. It is therefore closer in orientation to the United Nations' *Universal Declaration on Human Rights* and UNESCO's *Universal Declaration on Human Rights and the Human Genome*. In Canada, we find a similar orientation around dignity in the Canadian Nurses Association's *Code of Ethics for Registered Nurses*.
5. Often dignity is ascribed to an action, but this reflects the character of the subject who carries out the action more than the action itself.
6. For example, the mysterious property "X" described by Fukuyama (2002).
7. We should draw an important lesson from an equivocation in Kant here; namely, dignity and autonomy are closely related but are in fact two different propositions inasmuch as dignity necessarily refers to the community (i.e., the "kingdom of ends") whereas autonomy is a personal affirmation of the subject's membership in that community. Another way to distinguish autonomy and dignity may be found in Gewirth's account of the difference between agency (which requires that you value the ends of your action) and dignity, which requires that you value the agent who is the "locus and source" of that action (1998, p. 169).
8. The possession of these abilities means that one can act as a moral agent in the relevant sense, although the degree to which this holds for any given capacity is subject to debate. Significantly, whether one is more utilitarian, virtue-oriented or deontological in approach may affect where one places the relevant thresholds.
9. Cf. Macklin (2003). I am grateful to the comments of an anonymous reviewer on this very important point.
10. See Beauchamp and Childress (2001) for a description of autonomy as a "decision-making" capacity" that produces judgements and actions that reflect one's own preferences (Chapter 3).
11. Carr (1991) refers to dignity in this sense (quoted in Gallagher, 2004).
12. In a related area of Canadian policy, respect for inherent dignity has been shown to underlie the "equality guarantee" of the Canada's *Charter of Rights and Freedoms*. Under Section 15 (1), the *Charter* states that, "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without

discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability". A recent decision has emphasized the relationship between respect for dignity and Section 15(1). In *Law v. Canada* (1999), the *Supreme Court of Canada* found that a perceived dignity violation may be evidence of a breach of equality. That is to say, the violation of dignity is indicative of inequality when it is accompanied by differential treatment in the law and when that differential treatment is based on a prohibited ground of discrimination (*Law v. Canada*, Paragraph 10). The virtue of this interpretation of dignity is that it acknowledges that dignity is an abstract concept that must be applied in light of circumstances that vary from individual to individual and case by case.

13. I do not have the space to discuss this very important notion here, but it is addressed in some detail in Burns, 2007.
14. Self and other-regarding judgements are also related such that one's view of others affects one's own dignity and vice versa (Gallagher, 2004).
15. Jumping ahead to the discussion of the use of fetal tissue, we see this link between dignity and the requirement to secure the consent of the woman who donates that tissue (TCPS, Art. 9.4). The woman's dignity is protected by means of the consent process.
16. Privacy engages personal dignity more than inherent dignity because it is concerned with how others may judge one's personal choice (privacy also permits the development of stable self-identity). A concern for justice is reflected in the principle of respect for vulnerable populations whose interests and dignity should be promoted (TCPS, Art. 2.9) and the application of this principle to Aboriginal groups in particular (TCPS, Art. 6.2). Those who possess inherent dignity deserve equal treatment and, in the cases just cited, extra effort must be made to level the playing field.
17. The history of the *Assisted Human Reproduction Act* is complex, going back to 1989 when the Royal Commission on New Reproductive Technologies was created. Its final report, entitled *Proceed with Care*, was published in 1993, and its findings helped to steer the deliberations that would follow. Bill C-47, the Human Reproductive and Genetic Technologies Act died on the order paper in 1997. This was followed by draft legislation that would become Bill C-56, the Assisted Human Reproduction Act. The draft legislation was revised on the basis of a 2001 report by the House of Commons Standing Committee on Health, entitled *Assisted Human Reproduction: Building Families* (hereafter cited as *Standing Committee*). Bill C-56 became Bill C-13 and then was finally given Royal Assent as Bill C-6, in 2004. Regulations to the AHRA are still being drafted, but the key provisions are in force (Health Canada, 2006). In this legislation, it is prohibited to solicit or provide payment for gametes, embryos or surrogacy services. While the act does invoke dignity in general terms, the justification for these particular provisions is described more fully in

*The Royal Commission Report on New Reproductive Technologies*. The principle of the "Non-Commercialization of Reproduction" is justified by the Royal Commission as follows: "commodifying human beings and their bodies for commercial gain is unacceptable because this instrumentalization is injurious to human dignity and ultimately dehumanizing" (*Royal Commission*, 55–6). Here we have a direct correspondence between the concern for dignity, the *Assisted Human Reproduction Act's* prohibition of payment for human reproductive tissue (i.e., embryos, sperm, or ova) (ss. 6–7) and Article 9.2 of the TCPS. Again, of all the inferences we may make regarding the application of the principle of respect for inherent dignity in the *Assisted Human Reproduction Act*, this seems to be the most direct. Indeed, it captures the core notion of dignity as intrinsic, non-instrumental worth.

18. The suggestion that interpretations of dignity may be relative to particular groups is taken up in Canada's stem cell policy guidelines. The *Updated Guidelines for Human Pluripotent Stem Cell Research* set out the ethical standards to which all federally funded research involving the derivation and use of human pluripotent stem cells must adhere. In the 2005 Update to the *CIHR Guidelines*, a significant reference to dignity was added to the principles section (and this change is preserved in the 2006 update). Article 4.0 states that, "The guidelines are based on the provisions of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS). Therefore, the guidelines are based on several guiding principles, such as [...] Respect individual and community notions of human dignity and physical, spiritual and cultural integrity (*CIHR Guidelines*, Art. 4.0). This reference to different views of dignity was not included in the original list of principles in the 2002 version of the stem cell guidelines. Nonetheless, it was implied inasmuch as the TCPS was always considered to be the primary basis for those guidelines.

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