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The Instruction *Dignitas Personae*

This article summarises and comments on the new Vatican Instruction on bioethics.

On 12 December 2008, the Congregation for the Doctrine of the Faith (CDF) released a new Instruction on bioethics. It is titled *Dignitas Personae* ('The Dignity of a Person'). It is dated 8 September 2008, the feast of the birth of Mary. Bioethical questions were previously addressed particularly in the CDF's 1987 Instruction *Donum Vitae* ('The Gift of Life'), and in Pope John Paul II's 1995 encyclical *Evangelium Vitae* ('The Gospel of Life'). The new Instruction applies the principles articulated in these documents to new biomedical technologies. It is just over ten thousand words in length, with about another thousand words in footnotes. The CDF also released a summary of the document.¹

The purpose of the document is both to contribute to "the formation of conscience" (#10), and to promote biomedical research which is ethically sound and which truly serves human beings (cf #3). It was released as the United Kingdom's *Human Fertilisation and Embryology Act 2008* became law, as US President Barack Obama prepared to lift restrictions on embryonic stem cell research,² and as France prepares for a major review this year of its own bioethics laws.

Dignitas Personae was approved by Pope Benedict XVI, and is part of the universal ordinary magisterium. Catholics are called to inform their consciences with its teaching, receiving its contents "with the religious assent of their spirit." (#37)

The document has three Parts between a brief Introduction and a brief Conclusion. We will consider each in turn:

The Introduction

The essential teaching of *Dignitas Personae* is stated in the first two sentences of its Introduction: "The dignity of a person must be recognized in every human being from conception to natural death. This fundamental principle... must be at the center of ethical reflection on biomedical research." (#1)

Does this mean that the embryo³ is a person whose spiritual soul has been infused by God at the moment of conception, or simply that the embryo should be *treated* as a person? This question has been discussed in #12-13 of the CDF's 1974 *Declaration on Procured Abortion* (*Questio de Abortu*), in Question 1 of Part I of *Donum Vitae*, and in #60 of *Evangelium Vitae*. None of these documents answered the question definitively. For

example, footnote 19 in the *Declaration on Procured Abortion* noted that the tradition is not "unanimous" on "the moment when the spiritual soul is infused," and therefore that the *Declaration* left this question aside. *Donum Vitae* noted that "no experimental datum can be in itself sufficient to bring us to the recognition of a spiritual soul." However, it also reflected on embryological development, and asked, "How could a human individual not be a human person?" After pondering the matter, John Paul was content to repeat the conclusion of *Donum Vitae* that "the human being is to be respected and treated as a person from the moment of conception."

Vatican officials have noted that this document represents something of an advance. For example, at the press conference to present *Dignitas Personae*, Bishop Rino Fisichella, secretary of the CDF, said that the new Instruction "virtually enshrines the embryo... as a person." He added, however, that "the recognition is implicit." Boston College theologian Lisa Sowle Cahill commented, "It doesn't take a final position on it. Although it states it more strongly, it's still shy of an unequivocal endorsement."⁴

In any case, the primary concern here is not metaphysical, but practical.

Part I: Ethical Principles

Part I of *Dignitas Personae* sets out the ethical principles which inform its analysis. These are repeated from *Donum Vitae*, and there are two of them. The first is that "the fruit of human generation, from the first moment of its existence, that is to say, from the moment the zygote has formed, demands the unconditional respect that is morally due to the human being in his bodily and spiritual totality." From conception, "his rights as a person must be

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recognised, among which in the first place is the inviolable right of every innocent human being to life.” (#4) The second principle is that “the origin of human life has its authentic context in marriage and in the family, where it is generated through an act which expresses the reciprocal love between a man and a woman. Procreation which is truly responsible vis-à-vis the child to be born ‘must be the fruit of marriage.’” (#6)

The document demonstrates that these principles are part of the natural law which can be discerned by reason and philosophical reflection alone, and also that our understanding of these principles is deepened and perfected by revelation and faith.

Part II: Procreation

Part II of *Dignitas Personae* addresses seven issues:

(i) In Vitro Fertilisation (IVF): The Instruction endorses techniques which “assist” procreation, including “hormonal treatments for infertility, surgery for endometriosis, unblocking of fallopian tubes or their surgical repair.” It also encourages both adoption, and research “directed at the prevention of sterility.” However, it rejects techniques which “substitute for the conjugal act,” including homologous IVF (which uses the couple’s gametes) and heterologous IVF (which uses gametes from at least one donor). (#12-13) In IVF, “the number of embryos sacrificed is extremely high.” This encourages “a purely utilitarian treatment of embryos,” and “leads to a weakening of the respect owed to every human being.” (#14-16)

(ii) Intracytoplasmic Sperm Injection (ICSI) involves “the injection into the oocyte of a single sperm.” It is “intrinsically illicit” because “it causes a complete separation between procreation and the conjugal act.” (#17)

(iii) Freezing Embryos: “Cryopreservation is incompatible with the respect owed to human embryos: it presupposes their production *in vitro*; it exposes them to serious risk of death or physical harm, since a high percentage does not survive the process of freezing and thawing; it deprives them at least temporarily of maternal reception and gestation; it places them in a situation in which they are susceptible to further offense and manipulation.” (#18)

The Instruction also considers what should be done with “the large number of frozen embryos already in existence.” It rejects the destructive use of these embryos either in research or in the treatment of disease. It also rejects giving these embryos to childless couples, and at least frowns upon embryo adoption by Christian couples as a service to life. It concludes that this is “a situation of injustice which in fact cannot be resolved,” and pleads that “the production of human embryos be halted.” (#19)

Critics of embryo adoption are concerned that it involves complicity in an immoral procedure, and that

it may even encourage embryo freezing. Supporters such as Maria Lancaster (whose daughter Elisha was adopted as an embryo) protest:

If we don’t, as Christian people, embrace the lives of frozen embryos... then societal culture will step in and define that for us... They’ll say, ‘They’re just medical waste.’

Dominican Fr Nicanor Austriaco of Providence College observes that “the debate is not really closed,” but that the Instruction “places the burden of proof on supporters.”⁵

(iv) Freezing Oocytes: While the cryopreservation of oocytes is not in itself immoral, “cryopreservation of oocytes for the purpose of being used in artificial procreation is to be considered morally unacceptable.” (#20)

(v) Embryo Reduction is “a procedure in which embryos or fetuses are directly exterminated.” “It always constitutes a grave moral disorder.” (#21)

(vi) Pre-Implantation Genetic Diagnosis (PGD) occurs when “embryos formed *in vitro* undergo genetic analysis before being transferred into a woman’s womb.” It is done “in order to ensure that only embryos free from defects or having the desired sex or other particular qualities are transferred.” “Such discrimination is immoral and must therefore be considered legally unacceptable, just as there is a duty to eliminate cultural, economic and social barriers which undermine the full recognition and protection of disabled or ill people.” (#22)

(vii) Interception and Contraception: Methods of birth control are interceptive “if they interfere with the embryo before implantation.” The Instruction states that the IUD (intrauterine device) and the morning-after pill are interceptive, and adds that in both cases “scientific studies indicate that the effect of inhibiting implantation is certainly present.” Methods are contraceptive “if they cause the elimination of the embryo once implanted.” Examples are methotrexate and RU-486 (mifepristone). “The use of means of interception and contraception fall within the *sin of abortion* and are gravely immoral.” (#23)

Will the Instruction resolve whether or not emergency contraception may be administered after rape? There are differing views. John-Henry Westen on LifeSiteNews argues that those who administer the morning-after pill after rape “will find themselves out of step with the Vatican.” However, Marie Hilliard argues that the Instruction supports the use of emergency contraception after a negative ovulation test. And Richard Doerflinger, the associate director of the United States Conference of Catholic Bishops’ Secretariat of Pro-life Activities, says that the Instruction “doesn’t say that what Catholic hospitals are doing to prevent pregnancy in rape victims has been established as an abortifacient and therefore can’t be used.”⁶

Part III: Embryo Manipulation

Part III of *Dignitas Personae* addresses five issues:

(i) Gene Therapy: Somatic cell gene therapy is the insertion of genes into a person's cells and tissues to treat disease in that person. Germline gene therapy is the insertion of genes into the oocyte, sperm or early embryo to treat both this person and their progeny. Gene therapy is therapeutic when it seeks to treat disease, or for enhancement when it seeks to improve on what is natural. The Instruction rejects gene therapy for enhancement. It states that "procedures used on somatic cells for strictly therapeutic purposes are in principle morally licit." Germline gene therapy is "not morally permissible... in the present state of research... because the risks... are considerable and as yet not fully controllable." (#26)

(ii) Human Cloning: Cloning for reproduction is "a grave offense to the dignity of that person." Cloning for research or medical therapy (so-called therapeutic cloning) is "gravely immoral": "to create embryos with the intention of destroying them... is completely incompatible with human dignity." (#29-30)

The Instruction is also cautious about Altered Nuclear Transfer (ANT) and Oocyte Assisted Reprogramming (ANT-OAR). These involve making some change to the materials for cloning (either the enucleated oocyte or the somatic cell nucleus which is transferred into it) so that what is produced cannot develop into a human embryo. The Instruction is concerned that the product of these procedures might still be a human embryo. It cautions that "the mere probability that a human person is involved would suffice to justify an absolutely clear prohibition." (#30)⁷

(iii) Therapeutic Use of Stem Cells: It is ethical to collect adult stem cells, stem cells from umbilical cord blood, and stem cells from fetuses who have died of natural causes, because this collection does "not cause serious harm to the subject from whom the stem cells are taken." For this reason, "research initiatives involving the use of adult stem cells... should be encouraged and supported." On the other hand, "the obtaining of stem cells from a living human embryo... invariably causes the death of the embryo and is consequently gravely illicit." (#32)

(iv) Attempts at Hybridization involving a human cell nucleus and an animal oocyte are "an offense against the dignity of human beings." Further, "the possible use of the stem cells, taken from these embryos, may also involve additional health risks, as yet unknown, due to the presence of animal genetic material in their cytoplasm." (#33)

(v) Human 'Biological Material' of Illicit Origin includes human embryonic stem cells (HESCs) and vaccines made using material from aborted fetuses.⁸ The Instruction calls on researchers "to

refuse to use such 'biological material,'" though it also accepts that more junior staff might not have this choice. And while it calls on everyone to demand ethically produced vaccines, it accepts that "danger to the health of children could permit parents to use a vaccine which was developed using cell lines of illicit origin." (#35)

The Conclusion

In the twentieth century, the Church through its social teaching and social action fought for the rights of workers. Nowadays, "when another category of persons is being oppressed in the fundamental right to life, the Church feels in duty bound to speak out with the same courage on behalf of those who have no voice." And lest the Instruction seem a collection of too many 'noes,' the Conclusion reminds us that "behind every 'no'... there shines a great 'yes' to the recognition of the dignity and inalienable value of each single and unique human being." (#37)

There is therefore a great deal in the Instruction, and *Dignitas Personae* merits our careful study. We should note that it still offers no ethical assessment of GIFT (gamete intrafallopian transfer), and that it does not mention induced pluripotent stem cells (iPSCs). Perhaps another Instruction in the future will address these matters.

ENDNOTES

¹ Congregation for the Doctrine of the Faith, *Dignitas Personae & Summary of the Instruction Dignitas Personae*, Holy See, http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20081208_dignitas-personae_en.html & http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20081212_sintesi-dignitas-personae_en.html

² President Obama signed an Executive Order to do this on 9 March 2009. For comment about this by Cardinal Justin Rigali, chairman of the U.S. Conference of Catholic Bishops' Committee on Pro-Life Activities, see USCCB, <http://www.usccb.org/comm/archives/2009/09-052.shtml>

³ The usual convention is to refer to the early human being as a single-cell zygote, then a morula and a blastocyst, then an embryo which has implanted in the womb, then (after about the eighth week) a foetus which is recognisably human. *Dignitas Personae* generally uses the term 'embryo' to refer to all the early stages of human life.

⁴ "Vatican affirms 'dignity of human embryo,'" www.google.com/hostednews/afp/article/ALeqM5hkivig14vZUYrnaSGRQsfBdazehg; Manya A. Brachear, "Vatican bioethics guidance condemns stem cell research," Chicago Tribune, http://archives.chicagotribune.com/2008/dec/13/science/chicago-vatican-abortion_13dec13

⁵ John L. Allen, "Vatican issues new document on biotechnology," National Catholic Reporter, <http://ncrcafe.org/node/2327/print>; Kevin Birnbaum, "New Vatican document hits close to home," Archdiocese of Seattle, <http://www.seattlearch.org/FormationAndEducation/Progress/012009/VaticanBioethicsDocument01-22-09.htm>

⁶ John-Henry Westen, "Vatican: Use of Morning After Pills 'Fall Within the Sin of Abortion' – Will Catholic Hospitals

Now Stop Using them for Rape Victims?" LifeSiteNews, <http://www.lifesitenews.com/ldn/printerfriendly.html?articleid=08121804>; Marie T. Hilliard, "Dignitas Personae and Emergency Contraception," *Ethics & Medics* 34, no. 2 (February 2009): 3-4; Allen.

⁷For more on ANT and ANT-OAR, see Allen and <http://alterednucleartransfer.com>

⁸Theresa Deisher says that the use of illicit materials is "so per-

vasive" that it is now difficult to find ethically produced vaccines. She has founded AVM Biotechnology to source, develop and provide such vaccines. See Birnbaum.

All on-line documents accessed 10 March 2009.

Kevin McGovern



Public Health and Human Rights

In this era, health has been redefined. The emphasis has shifted from the individual-focussed bio-medical model to a preventative model of collective health. This model of public health often challenges the concept of individual autonomy, the basis of human rights, in the name of the greater good. This article explores the relationship between public health and human rights, and the need for a public health ethic based on the principles of human rights.

Public Health

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."¹ This definition indicates that the determinants of health extend beyond the quality and availability of health care services. Therefore, the traditional bio-medical model of health care, based on diagnosis and treatment of individual patients, is deemed to have a critical, yet limited, impact on the health of the population. The U.S. Institute of Medicine defined public health as "what we as a society do collectively to ensure conditions in which people can be healthy."² The evolving field of public health, with its wider population focus and emphasis on collective measures to promote and protect health, presents the opportunity for greater improvement in people's well-being. Unlike patient care provided by individual doctors or institutions, public health is considered to be a state responsibility.

Human Rights

Human rights aim to promote and protect the well-being of individuals by ensuring respect for individual rights and dignity.³ Human rights have evolved over time and modern human rights have several characteristics, namely; "they are rights of individuals; these rights inhere in individuals because they are human; they apply to all people around the world; they treat all people as equal; they encompass the principles of humanity; they principally involve the relationship between the state and the individual; and the promotion and protection of human rights is not restricted by geographical boundaries of sovereign states."⁴

After its inception in 1945, the United Nations (UN) adopted the *Universal Declaration of Human Rights* (UDHR) in 1948. Article 25 of the UDHR stipulates that basic human rights of all people include: "the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."⁵

The UDHR was subsequently complemented by two international treaties: the *International Covenant on Civil and Political Rights* and the *International Covenant on Economic, Social and Cultural Rights*. Together, these three documents constitute the *International Bill of Human Rights*, which forms the basis of modern human rights practice.⁶ These accords serve as legally binding documents for nations that have endorsed them and many have incorporated them into national legislation. However, the extent and nature of this inclusion varies between countries.

The Public Health - Human Rights relationship

The contrasting ideologies of public health - based on preference for the collective good over individual rights - and human rights - based on individual autonomy - often result in tension between proponents of the two fields. Jonathan Mann, the visionary who first promoted the integral link between health and human rights, theorised that these entities are inextricably connected and despite varied philosophies have a common objective: to improve human well-being. As mentioned above, both public health and human rights encompass the relationship between individuals and the state, and this further consolidates their inter-dependence. Mann proposed a three-tiered approach to unravel the health and human rights nexus:

The first link between health and human rights is represented as $H \rightarrow HR$. This refers to the impact of health interventions, policies and practices on the human rights of a population. To further illustrate this link, the three main functions of public health and how they may result in violation of human rights, must be considered. Firstly, public health aims to assess health problems and needs of a population through data collection. In this regard, the methods used for data collection, as well as state access to that data, may impinge on the right to privacy. Further, given that it is not feasible to collect data on all possible health issues, if the identification of priority issues is partial, and marginalises a population group, it in fact results in the violation of the right to non-discrimination. Secondly, public health endeavours to develop policies designed to address priority health issues.

In this instance, human rights violations may occur either in the selection of priority areas, if health issues of a population are systematically under-prioritized; or during the development of health policies, if the state withholds the scientific basis of the policy and prohibits debate on its merit. Thirdly, public health is concerned with the implementation of health programs to achieve policy goals. If these programs fail to consider the logistic, financial and socio-cultural accessibility of services to the population, human rights violations are likely to occur.

The second link between health and human rights is represented as $H \leftarrow HR$. This conveys the idea that violations of any and all human rights have detrimental effects on physical and mental health, as well as social well-being. Human rights violations such as torture and imprisonment in inhumane conditions have obvious health impacts. However, the health impact of violations of rights such as the right to dignity, social equality, security, safe employment and education are under-documented and not completely understood. The poor health status of marginalised groups in a population, is not always the sole result of unhealthy living conditions and poverty, but may have more subtle causes such as lack of cultural compatibility, language barriers or discrimination. The spread of HIV/AIDS among monogamous, married women in East Africa, illustrates the impact of the violation of women's rights on their health. Despite knowledge about HIV, for these women, the risk factor is their inability to control the sexual practices of their partners – or even, if their husbands have been promiscuous, to negotiate protected sex. This inability stems from fear of physical harm and/or divorce with drastic social implications. Providing rights protection to these women would play a major role in reduction of HIV transmission in this population and their offspring. With increasing research on social and psychological determinants of health, the impact of various rights violations on health may be better understood.

The third link between health and human rights is diagrammed as $H \leftrightarrow HR$. This link represents the synergy and inter-dependence of health and human rights. Drawing on the previous two concepts, this link signifies that promoting and protecting health requires explicit efforts to protect and promote human rights, and fulfilment of human rights demands measures to address health issues and their determinants.⁷ The *Ottawa Charter for Health Promotion*,⁸ which forms the basis of health promotion in this era, identifies the conditions essential for health. These include peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity. Since many of these conditions have been identified as basic human rights by Article 25 of the UDHR, this provides support for the paradigm of co-dependence between health and human rights.

Evolution of the relationship

Mann refers to the current state of affairs in the historically strained relationship between public health and human rights in this way: “In the modern world,

public health officials have, for the first time, two fundamental responsibilities to the public: to protect and promote public health, and to protect and promote human rights.”⁹ This observation draws attention to the evolving state of public health which has brought it a long way from its strong roots in utilitarianism.¹⁰ The notion of usurping individual rights for the good of the community has been challenged by the advent of human rights which are considered to be the “dominant moral vocabulary of our time,”¹¹ and the ‘de-medicalization’ of determinants of health has revealed the impact of human rights on health. For these reasons, no public health measure can be complete without consideration for human rights.

Human rights frameworks for public health

Having made the case for the significance of human rights in health, it is essential to comment on the paternalistic approach (defined as actions to protect or benefit people against their wishes) that is often seen in public health interventions and which may undermine basic human rights. It is crucial to ensure that these interventions are re-formulated in accordance with human rights principles.

Among the social determinants of health, the significance of individual autonomy - in other words, the human right to free choice - is increasingly being recognized. The aspect of autonomy that affords health benefits is being in the position to decide, not be decided for, and to be able to choose to accept reasonable constraints on one's behaviour.¹² As paternalistic endeavors encroach upon this right, the need arises for frameworks in public health that can balance individual rights and community benefits.

One such framework was presented by Childress et al,¹³ which comprised 5 major justificatory conditions that must either be satisfied individually – or if conflict arises among the conditions, resolved justifiably – before the public health intervention is implemented. These conditions are *effectiveness*, that infringing individual rights will protect public health; *proportionality*, that public health benefits outweigh the infringed considerations; *necessity*, that all policies are necessary to realize the public health goal; *least infringement*, that the encroachment of rights be minimized as much as possible; and *public justification*, that when a policy intrudes on individual rights, it is essential that public health professionals explain and justify it to all stakeholders, especially those most affected by the infringement.

This framework was recently revisited by Childress and Bernheim, who suggested another condition that must also be satisfied for the implementation of freedom-limiting public health interventions, that of *impartiality*.¹⁴ This condition entails that fair and similar standards be applied in all public health measures specifically coercive ones, and there should be no discrimination on the basis of race, socio-economic status or geographical location.

In short, the most effective way to protect and promote public health is to respect human rights rather than violate them; undertake voluntary measures rather than coercive ones; protect confidentiality; and engender egalitarian concepts of social justice.¹⁵ To this day, we have been unable to realize this utopian state, and, as Jonathan Mann puts it, “all public health policies and programs should be considered discriminatory until proven otherwise.”¹⁶ Mann, therefore, calls for the development of a public health ethic guided by human rights to ensure that public health does not go too far in the name of the ‘greater good.’

Conclusion

All fields of practice need ethical contextualization, and it would be erroneous to assume that public health with its focus on the ‘greater good’ is any exception. When, however, we look for that ethical contextualization, we find that all present sources of moral guidance are inadequate. Unlike the clearly defined code of ethics within the bio-medical model, the field of public health lacks ethical guidelines tailored to its practice. Although biomedical ethics and human rights in their present perspective provide significant starting points for a ‘public health ethic,’ they cannot be adopted within public health in their current state. This highlights the need for an ethical framework based on both these established codes of conduct but formulated specifically for public health practice.

Numerous frameworks for defining the public health ethic have been suggested, and as the field evolves more complex frameworks may arise. However, the first real challenge lies not in attempting to formulate the right strategy, but firstly recognizing the need for such a framework and then comprehending the core values on which it must be based. These core values are - and must be - respect for human rights.

ENDNOTES

¹ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the repre-

sentatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

² International Federation of Red Cross and Red Crescent Societies and François-Xavier Bagnoud Centre for Health and Human Rights, “Public Health: An Introduction,” in *Health and Human Rights – A Reader*, ed. Jonathan M. Mann, Sofia Gruskin, Michael A. Grodin, and George J. Annas. (New York: Routledge, 1999), 29-36.

³ International Federation of Red Cross and Red Crescent Societies and François-Xavier Bagnoud Centre for Health and Human Rights, “The Public Health – Human Rights Dialogue,” in *Health and Human Rights – A Reader*, 46-53.

⁴ Jonathan M. Mann et al., “Health and Human Rights,” in *Health and Human Rights – A Reader*, 7-20.

⁵ United Nations, *Universal Declaration of Human Rights* (Geneva: United Nations, 1948).

⁶ Office of the High Commissioner for Human Rights, *International Bill of Human Rights* (Geneva: United Nations, 1996).

⁷ Jonathan M. Mann et al., 1999.

⁸ World Health Organization, *Ottawa Charter for Health Promotion* (Ottawa: World Health Organization, 1986).

⁹ Jonathan M. Mann, “Medicine and Public Health, Ethics and Human Rights,” *Hastings Center Report* 27, no. 3 (1997): 1-11 at 5.

¹⁰ Stephanie Nixon and Lisa Forman, “Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts,” *BMC International Health and Human Rights* 8, no. 2 (2008): 1-9.

¹¹ Paul Gready, “The politics of human rights,” *Third World Quarterly* 24, no. 4 (2003): 745-757 at 749.

¹² David R. Buchanan, “Autonomy, paternalism and justice: Ethical priorities in public health,” *American Journal of Public Health* 98, no. 1 (2008): 15-21.

¹³ James F. Childress et al., “Public health ethics: Mapping the terrain,” *The Journal of Law, Medicine & Ethics* 30, no. 2 (2002): 170-78.

¹⁴ James F. Childress and R. Gaare Bernheim, “Public health ethics,” *Bundesgesundheitsblatt – Gesundheitsforschung - Gesundheitsschutz* 51 (2008): 158-163.

¹⁵ Childress et al., 2002.

¹⁶ Jonathan M. Mann, 1997.

Rida Usman Khalafzai ✕

Organ Donation after Cardiac Death

After a brief account of the process, this article considers three significant ethical issues about Donation after Cardiac Death.

Over the last forty years, most organ transplants from dead donors have been from Donation after Brain Death (DBD). In recent years, there has been a return to Donation after Cardiac Death (DCD, previously called non-heart-beating organ donation or NHBOD). There were 8 DCDs in Australia in 2006, and 19 in 2007. This increases the number of organs available for transplant. It can also honour a person’s wish to be an organ donor.

DCD donors are usually on a ventilator in an Intensive Care Unit (ICU). They are unlikely to become brain dead. However, because they will not recover, a decision has been made to remove mechanical ventilation and to allow

them to die. Also, they are likely to die within an hour after ventilation is removed. (This is important so the organs are not damaged as they die.)

The possibility of organ donation is discussed with the family. They agree that this is what their loved one would want. If they wish, they can be with their loved one when ventilation is removed until their death. They are asked to decide whether this will be in the ICU, or whether they will permit their loved one to be moved beforehand either to the operating room or another room near it. There are some antemortem interventions which might be done before death to improve the quality of the organs for

transplant. If these are possibilities, the family is asked whether or not they will permit them. For organ donation to proceed, the family must leave soon after their loved one dies. The family must be told about this beforehand, and they must be willing to do so. They must also be told that if their loved one does not die within an hour after ventilation is withdrawn, organ donation will not be possible.

On the day, the treating team care for the dying patient. Other treatments and ventilation are gradually withdrawn, usually over 5 to 10 minutes. The patient might not breathe at all. Or they might breathe for some time, though their breathing will probably not be enough to maintain life. The treating team keeps them comfortable and pain-free with analgesia and sedation as required. Eventually, because of lack of oxygen, their heart stops beating (asystole). A doctor who has been monitoring their heart determines this, waits a set number of minutes to ensure the heart will not re-start, and then declares the patient dead. The family leaves, and the organ procurement team removes the organs. Afterwards, when the body is sutured and restored to a semblance of normality, if they wish the family are able to view the body.¹

Donation after Cardiac Death raises at least three significant ethical issues:

Managing conflicts of interest

This is an important issue. The fear that doctors might not make every effort to save the lives of potential donors is one reason that many people do not join organ donor registers.² Further, patient care would be greatly complicated if a family feared that the doctor was secretly manoeuvring so their loved one would die and become a donor.

Such fears are understandable. However, they are also ill-informed and unrealistic. The health care professionals who work in Intensive Care Units are dedicated to saving lives. Planning to end someone's life – even for a good purpose – would be deeply inconsistent with their character, their training, and their professional standards. Thus, the best protection against what is feared here is simply the professionalism and integrity of our health care professionals.

At the same time, two procedural principles minimise both conflicts of interest themselves and the perception that such conflicts might exist. The first of these is clear separation between the medical team that cares for the potential donor, and the organ procurement team. In consultation with the family, the treating team is responsible for end-of-life decision-making, end-of-life care, and determination of the patient's death. The organ procurement team should not be involved in any of these matters, and no one should be involved in both teams.

The second procedural principle is that there should be clear separation between end-of-life decision-making, and decisions about the possibility of organ donation. It is good if someone apart from the treating team – for example, a donor coordinator – works with the family as they consider organ donation. As a general rule,

discussion with the family about the possibility of organ donation should not occur until after a decision has been made to remove life support.³

Antemortem interventions

There are several things which might be done before the donor's death to improve the quality of the organs for transplant. The donor could be moved to the operating room or a room near it, for this will reduce warm ischaemia time probably by about ten minutes. The anticoagulant heparin and perhaps the vasodilator phentolamine might be given to minimise the risk of organ damage. There might be cannulation of the femoral vessels so organ-preserving solutions can be infused rapidly after death. Are these antemortem interventions ethically acceptable?

A first consideration is whether or not these interventions might cause or hasten death, for if they do, they cannot be ethically acceptable. Obviously, this does not apply to moving a ventilated patient from one room to another. The US Institute of Medicine notes that the use of anticoagulants and vasodilators might be harmful "under certain circumstances and in certain patients." It therefore recommends "case-by-case decisions about their use." However, while some dispute this, the consensus is that in general it is highly improbable that the administration of heparin would cause or contribute to death. Cannulation too is unlikely to cause or hasten death.⁴

Are these interventions in the best interests of the donor? The Guidelines *Organ Donation after Cardiac Death* from NSW Health assume that they are not. These Guidelines forbid "consent to [these] pre-mortem interventions by substitute decision-makers" because under NSW law substitute decision-makers may only authorise treatments that "promote or maintain the health and well-being" of the patient. However, Bernadette Richards and Wendy Rogers criticise this position for relying on a "limited interpretation of best interests." They continue:

When a person is dying, his or her physical interests diminish. The only interests left to be furthered are intangible interests, such as a wish to donate organs.... If we agree that it is in a person's interests to have his or her wishes fulfilled, then taking all necessary measures to do so seems a logical step.⁵

Bernadette Tobin supports these ante-mortem interventions by applying to them a statement from the *Code of Ethical Standards*, which states:

Persons with the maturity to make decisions freely and with understanding may allow themselves to be subjected to procedures which are not therapeutic for them and which involve some risk to their own life and health...⁶

This highlights that explicit consent must be given for these antemortem interventions, either by the donor before their incapacitation or by their family. If the donor and their family consent, these interventions may be used. But if they do not consent, they must not be attempted.

This is the position of both the National Health and Medical Research Council, and the Australian and New Zealand Intensive Care Society.⁷

Determination of death

Our reflection here is guided by two considerations. The first is the ‘dead donor rule,’ which states, “Donor patients must not be killed or their deaths hastened by the taking of organs.”⁸ The second is the standard definition of death, which defines death as “(a) irreversible cessation of all function of the brain of the person, or (b) irreversible cessation of circulation of blood in the body of the person.”⁹

After asystole, we can distinguish two separate points in time. There is a phenomenon called autoresuscitation, whereby a non-beating heart re-starts without external intervention. The first point in time, then, is when autoresuscitation is no longer possible. (We will discuss the timing of this point later.) After this, it may still be possible to re-start the heart through external intervention (eg cardiopulmonary resuscitation and defibrillation). The second point in time, then, is when the heart cannot be re-started even with external intervention. Our first question, therefore, is which point must be reached for the cessation of circulation to be “irreversible”?

A minority view holds that irreversible literally means “incapable of being reversed,” and therefore that we must wait for the second point.¹⁰ The majority opinion, however, is that it suffices to wait for the first point. In these cases, a decision has already been made that external resuscitation will not be attempted. In such circumstances, then, it does seem reasonable to declare death once autoresuscitation is no longer possible. Thus, for example, the American College of Critical Care Medicine distinguished between “a ‘stronger’ meaning of irreversibility” that “the heart cannot be restarted *no matter what intervention is done,*” and a “weaker’ meaning” of irreversibility that “circulation cannot be restored without... those means refused by the patient.” They added that in these cases, only the weaker meaning is required. Similarly, a national conference on DCD in the United States in 2005 concluded that in these cases “death occurs when... cardiopulmonary function *will not resume spontaneously.*” They added that “this meaning of ‘irreversibility’” can also be described as “the ‘permanent’ cessation of respiration and circulation.”¹¹ This is the standard which has been followed in most protocols both in the United States and in Australia.

Let us turn to another issue. When the nature of death was critically considered in the 1960s and 1970s, it was recognised that death is essentially the death of the brain. On the other hand, the cessation of circulation counts as death simply because it soon leads to death of the brain. Thus, for example, an editorial in the *New England Journal of Medicine* noted:

[I]t is clear that a person is not dead *unless* his brain is dead. The time-honoured criteria of stoppage of the heartbeat and circulation are indicative of death only when they persist long enough for the brain to die.¹²

Thus, there is a difference between the two criteria in the standard definition of death. The first criterion – irreversible cessation of all function of the brain – is death. On the other hand, the second criterion – irreversible cessation of circulation – simply *leads to* death. Indeed, it may take ten or fifteen minutes after circulation has ceased before the entire brain dies.¹³ As we shall see, however, many protocols require only two to five minutes’ delay between asystole and organ retrieval. Thus, our next question must be: Is the DCD donor dead at the moment of organ retrieval?

There are at least two views. Michael deVita and his colleagues believe that DCD donors are dead at the moment of organ retrieval. Certainly, if circulation is restored within fifteen or so minutes of its being lost, some brain function might also be restored. However, this does not mean that brain function has continued in the interim. To the contrary, deVita and colleagues point to “data which demonstrate rapid cessation of neurologic function within seconds of circulatory collapse.”¹⁴ In patients where external resuscitation will not be attempted and autoresuscitation does not occur, this cessation of neurologic function is permanent. And once again, permanence which is the weaker meaning of irreversibility suffices to constitute death.

On the other hand, Jerry Menikoff draws on the stronger meaning of irreversibility and argues that we cannot declare death of the brain until its neurons have actually died. Thus, Menikoff believes that at the time of organ retrieval, DCD donors are dying and close to death but not yet dead. However, he argues that organ retrieval at this point does not violate the dead donor rule which, as we have noted, requires that organ retrieval neither kills the donor nor hastens their death. Let us assume that organ retrieval begins two to five minutes after asystole. The donor is sedated, so he experiences no pain. Menikoff writes:

Would this kill him? Clearly not, because his brain is still functioning at this point, and it will remain functioning until lack of oxygen permanently destroys it... Does removing these organs in any way hasten John’s death?... [I]t most likely does not! Because John’s blood circulation has stopped, the removal of these organs has *no effect* on the timing of his death, which is being determined by the rate at which his brain cells decay.¹⁵

Menikoff therefore concludes that, when organs are retrieved two to five minutes after asystole, “the ‘dead donor’ rule, correctly understood... is not violated.”

Whether or not a donor is dead at the time of organ retrieval will continue to be debated. But let us now consider what stand-down time is required to exclude the possibility of autoresuscitation. Michael deVita and his colleagues cite data from six studies involving 109 cases to argue that there is no evidence of autoresuscitation after one minute. Similarly, James Bernat notes that “autoresuscitation has never been reported after 65 seconds of asystole.” From this sort of evidence, the 1993 Pittsburgh Protocol required a stand-down time of 2

minutes. In 1997, the US Institute of Medicine recommended 5 minutes. They noted that this was “on the conservative side of the current range,” but argued that it is important to ensure that death has occurred, to reassure the public of this, and to prevent the appearance of haste. In 2001, the US Society of Critical Care Medicine (SCCM) concluded that “no less than 2 minutes is acceptable, and no more than 5 minutes is necessary.” The 2005 US national consensus conference endorsed the SCCM position. More recently, ANZICS recommended “absence of circulation... for a minimum of two minutes.”¹⁶

In mid-2008, the Denver Children’s Hospital reported a protocol for infant donors which required a stand-down time of only 1.25 minutes (75 seconds). This provoked much, generally unfavourable comment. Bioethicist John Paris commented that “it is not clear that the Denver Children’s Hospital committee had the medical expertise or legal acumen to make such a judgement.” Transplant ethicist Arthur Caplan recommended a US consensus committee and conference to develop national guidelines. James Bernat predicted that these guidelines will “exclude... death determination at 75 seconds of asystole.”¹⁷

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¹ For fuller accounts of DCD, see National Health and Medical Research Council, *Organ and Tissue Donation After Death, for Transplantation* (Canberra: Australian Government, 2007): 27-31; Australian and New Zealand Intensive Care Society (ANZICS), *The ANZICS Statement on Death and Organ Donation*, 3rd ed., 45-50; ANZICS, <http://www.anzics.com.au/uploads/ANZICSstatementfinal26sept08.pdf>; Shelly Ozark and Michael A. DeVita, “Non-Heartbeating Organ Donation: Ethical Controversies and Medical Considerations,” *International Anesthesiology Clinics* 39, no. 3 (Summer 2001): 103-116; and Christine A. Zawistowski and Michael DeVita, “Non-Heartbeating Organ Donation: A Review,” *Journal of Intensive Care Medicine* 18 (2003): 189-197.

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³ Ozark and DeVita, 107; NHMRC, 23, 27, 30; ANZICS, 31, 33, 46, 48.

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⁷ NHMRC, 29; ANZICS, 49-50. ⁸ IOM, 8.

⁹ This is the definition in the US *Uniform Determination of Death Act*. In 1977, the Australian Law Reform Commission recommended that this be adopted as the statutory definition of death in all Australian jurisdictions. While current Australian state and territory laws vary, they are all based on this recommendation. For this, see ANZICS, 12.

¹⁰ For example, James Tibballs, “The Non-Compliance of Clinical Guidelines for Organ Donation with Australian Stature Law,” *Journal of Law and Medicine* 16 (2008): 335-355 at 348.

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¹² William H. Sweet, “Brain Death,” *New England Journal of Medicine* 299, no. 8 (24 August 1978): 410-412 at 410. Similarly, the Pontifical Academy of Sciences stated that “cerebral death is the true criterion of death, since the definitive arrest of the cardio-pulmonary functions lead very quickly to cerebral death.” Pontifical Academy of Sciences, “Report on Prolonging Life and Determining Death,” *L’Osservatore Romano* 18, no. 45 (11 November 1985): 10.

¹³ “If deprived of blood flow for at least 10-15 minutes, the brain, including the brain stem, will completely cease functioning.” See President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Defining Death: A Report on the Medical, Legal and Ethical Issues in the Determination of Death* (Washington, D.C.: US Government Printing Office, 1981): 16-17.

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Kevin McGovern



Racial Discrimination and Health

This article explores race as a social construct, discrimination based on race, and its impact on health.

Modern society has come a long way from the era when race formed the basis of the social hierarchy. Though

racial discrimination is socially unacceptable today, it is still extant in many societal domains. Racial

discrimination or racism is based on an ideology of superiority – that one race is inherently better than another. This ideology manifests as “discriminatory practices which work to constantly exclude, marginalize and disadvantage the subordinate racial groups and reproduce the power, privilege and domination of the superordinate racial group.”¹

Defining racial discrimination

To comprehend racial discrimination it is imperative to understand the foundations of race. Early definitions of race were based on biological and genetic criteria. However, this has changed over time due to lack of scientific evidence to support a biological view of race, and the fact that the concept of race predates all modern genetic knowledge.² Therefore, it may be concluded that the concept of race is a socio-political construct that has no empirical basis and is devoid of scientific merit.³ It has been propagated and shaped by political and cultural considerations, and has been used to further various ideological agendas in society.

The concept of race fosters the idea of differentiation between people on the basis of physical and social characteristics, and thus demarcation among individuals and creation of ‘the other’. The United Nations defines racial discrimination as “any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.”⁴

Racial discrimination varies in form and is characterised by how it occurs, who the perpetrator is, and who is affected. It is mainly divided into two broad, but not mutually exclusive, categories: interpersonal and institutional discrimination.⁵ *Interpersonal racial discrimination* occurs when there are discriminatory interactions between individuals. This is the most direct and potent form of racial discrimination, is usually intentional and, therefore, has great personal impact. This form of racial discrimination is frequently associated with adverse mental and physical health outcomes for affected individuals. On the other hand, *institutional discrimination* refers to discriminatory policies or procedures inherent within organizational structures. This is an indirect form of racial discrimination, and may or may not be intentional. The impact of *institutional discrimination*, however, is wider and may greatly influence the socio-economic status, and employment and education opportunities of the ethnic minority group.

Racial discrimination causes social exclusion

Social exclusion is defined as “... a comprehensive formulation, which refers to the dynamic process of being shut out, fully or partially, from any of the social, economic, political or cultural systems which determine the social integration of a person in a society. Social

exclusion may therefore be seen as the denial (non-realization) of the civil, political and social rights of citizenship.”⁶ Racial discrimination undermines the social status, civil liberties and political rights of marginalised groups. Hence they are oppressed and alienated by society, their ties with mainstream life are severed, and as a result they are socially abandoned and excluded. The roots of social exclusion, as of racial prejudice, are deep, historical and are continually reproduced and propagated in contemporary society, in old ways as well as new.⁷

Impact of racial discrimination on health

Scientific research on the impact of racial discrimination on health is a novel and recent phenomenon. There is a dearth of quality research studies in the area, perhaps due to the pervasive nature of racial discrimination, non-reporting of discriminatory experiences and methodological complexities in measuring and documenting these experiences. Assessing the impact of racial discrimination on health is further complicated by the fact that little is known about psychosomatic interactions, and the nature and extent of their effect on health and well-being.

Despite these issues, researchers have primarily measured self-reported experiences of racial discrimination in an attempt to gauge their impact on health. A recent review⁸ of studies in this area reported that, despite considerable methodological variation among studies, the experiences of racial discrimination were significantly associated with a number of adverse health outcomes. Adverse mental health outcomes such as stress, depression and anxiety, were most consistently associated with racial discrimination. However, in terms of physical health, racial discrimination was found to be associated with high blood pressure, obesity, smoking, low birth weight and high mortality.

These seemingly simple associations have been shown to be greatly influenced by various psychosocial factors.⁹ Factors such as possessing a strong sense of ethnic identity, spirituality, religious/social support seeking and hardiness, were found to attenuate the adverse effects of racial discrimination. On the other hand, lack of education, low socioeconomic status, stressful events, substance abuse and internalizing responses to racial discrimination, were shown to intensify its detrimental effects on health. Studies have also shown that “people from ethnic minority groups have lower incomes and are concentrated in environmentally and economically poorer geographic areas, in poorer quality and more overcrowded accommodations, in less desirable occupations, and in longer periods of unemployment than their ethnic majority counterparts.”¹⁰

The impact of interpersonal racial discrimination is often individually limited, while institutional or systemic racial discrimination has wider implications. The former is commonly thought to be biologically-mediated. However, the impact of the latter may be more complex, and mediated through differential exposure to the socio-economic, environmental and behavioural

determinants of health.¹¹ A key aspect in this regard is the differential access to, and quality of, health care services. This may affect both clinical as well as preventative health care services, thereby resulting in poor health outcomes for these population groups.

This discourse brings forth the issue of racial discrimination in health care. Johnstone and Kanitsaki note that, “when suggestions are made that racism is at least implicated in, if not casually related to, racial and ethnic disparities in health and health care, health service providers and researchers alike have tended to reject the idea that ‘racism is a problem here’...”¹² Yet increasingly research is linking racial discrimination in health care services to racial and ethnic disparities in health. This includes discrimination at both the interpersonal and institutional levels.¹³ It has been repeatedly documented that “ethnic minorities are generally underserved by local health care and other social services, experience unequal burdens of disease, confront cultural and language barriers to accessing appropriate health care, and receive a lower level and quality of care when they do access health care compared to the average (majority) population.”¹⁴

In summary, racial discrimination has a significant detrimental impact on both mental and physical health. This impact outlasts the actual experience and the outcomes are significantly worse for chronic experiences of racial discrimination. This clearly highlights the scope of damage that can be inflicted by perpetuation of the unsubstantiated social construct of race.

Racial discrimination in Australia

The impact of human rights impingement on health is well established. And under the *Universal Declaration of Human Rights* (UDHR) freedom from racial discrimination is also a fundamental human right. In Australian federal legislation, Section 9 of the *Racial Discrimination Act 1975*, based on the United Nations *Convention on the Elimination of All Forms of Racial Discrimination*, has made it unlawful to commit an act of racial discrimination that may impinge upon a human right.¹⁵

It is well documented that Indigenous Australians have a state of health and wellbeing not just far below non-Indigenous Australians but also similar groups in other nations.¹⁶ The major social issues impacting Aboriginal health include low income, low literacy rates, high rate of unemployment and incarceration, substandard housing, and high prevalence of substance abuse. All these factors contribute to a high burden of morbidity and mortality, which has resulted in a seventeen year life expectancy gap between Indigenous and non-Indigenous Australians. Though it may be difficult to quantify the extent to which racial discrimination may have contributed to this state of affairs, research has shown that it does have a significant impact on Indigenous health.

Studies of the prevalence of racial discrimination experienced by Indigenous Australians have found that

58–79% report such discrimination.^{17,18} Another survey found that 40% of Indigenous respondents reported being physically or emotionally affected by their experience of racial discrimination.¹⁹ As discussed above, such experiences have been directly associated with ill-health among affected populations. Institutional or systemic forms of racial discrimination, especially those within health services, have also been documented to significantly impact Indigenous health. Studies have shown that, Indigenous Australians were about one-third less likely to receive appropriate medical care across all conditions compared to non-Indigenous Australians with similar medical needs.²⁰ Hall et al,²¹ and Coory and Walsh,²² also observed a similar pattern for lung cancer treatment and coronary procedures. They were also three times less likely to receive kidney transplants than other Australians with the same level of need.²³ In this instance, Paradies et al.,²⁴ make an important observation that these findings are not matched by self-reported experiences of racial discrimination in health care settings. When asked whether they were treated worse than their non-Indigenous counterparts, only 4% of Indigenous respondents indicated that they felt they were treated worse, while 90% reported being treated the same.²⁵ This paradox highlights “the covert nature of systemic racism and the difficulty individuals have in identifying such racism in institutional settings.”²⁶

The association of racial discrimination with psychological distress, depression, diabetes, smoking, substance abuse and poor self-assessed health status, signify that a large burden of disease among Indigenous peoples is attributable to racial discrimination.²⁷ It has been estimated that racial discrimination explained at least one-third of the prevalence of depression and poor self-assessed health status among Indigenous Australians.²⁸ In light of this evidence, it can be concluded that efforts to reduce all forms of racial discrimination against Indigenous Australians may considerably reduce their burden of ill-health, and thereby contribute towards closing the 17 year life expectancy gap.

Towards social inclusion, equality and better health

There is a growing body of literature on racial discrimination as a determinant of health. Increasingly government and health authorities are recognising the link between racial experiences and health. With rapid globalization, more and more societies are becoming multi-cultural, with various racial/ethnic groups co-habiting. In this era, racial experiences have become more commonplace and thus concern all those living in such societies. The eradication of racial discrimination is a social responsibility, and fulfilling this responsibility will go a long way in improving the health of minority groups, thereby reducing the inequalities in health.

As mentioned above, racial discrimination results in social exclusion. Therefore, it seems prudent that, measures which ‘include’ all members of society may

reduce racial discrimination. This gives rise to the concept of social inclusion. Lavery observes that “social inclusion is achieved when all people within a community feel valued, their differences are respected, and their basic needs are met such that they live in dignity.”²⁹ Social inclusion frameworks are being developed by Australian, State and Territory governments, which is a testament to their commitment to addressing the adverse effects of exclusion and discrimination. However, effort at the highest bureaucratic level alone is not sufficient. We must involve schools, workplaces, as well as community and welfare groups in efforts to socially include all people. These efforts will promote multi-culturalism and make society more tolerant and accepting of racial differences, recognising that despite these differences we are all human and thus similar, and that our community is enriched because we are also different.

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