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Consultation response to the Nuffield Council in Bioethics

The ethics of prolonging life in fetuses and the newborn

The **Scottish Council on Human Bioethics** (SCHB) is very grateful to the **Nuffield Council on Bioethics** for this opportunity to respond to its consultation on assisted suicide entitled ***The Ethics of Prolonging Life in Fetuses and the Newborn***. It welcomes the Nuffield Council on Bioethics' intent to promote public understanding and discussion on this topic.

In addressing the consultation, the SCHB has formulated the following responses (not all questions will be addressed):

Question 1. In cases where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, what measures may it be appropriate to take to sustain the life of the fetus or, where possible, to correct those abnormalities before birth?
Do you consider that there are ever circumstances when it would be appropriate to override the wishes of the pregnant woman?

Question 2. In which of these circumstances, if any, would it not be appropriate to use medicine and surgery to prolong the life of the newborn?

- **When the baby is extremely premature**
- **When the baby has congenital abnormalities**
- **When the baby has poor prospects for survival because of a genetic or other disorder, or because of growth restriction during the pregnancy**
- **When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life**

The SCHB agrees with the statement in the Nuffield Council on Bioethics Consultation Paper that a decision about whether or not to prolong the life of fetuses or the newborn should be made on a case by case basis with physicians and families relying on regulations and professional codes of practice to guide their decisions at each stage. [1]

Question3. In your view, are these the principal ethical questions that the Working Party should consider?

1. **The moral status of the fetus**
2. **Acting and omitting to act**
3. **Questions about the quality of life**

Which of these or other ethical questions would you identify as the most important?

The above questions should be considered. However, issues relating to the quality of life should only become relevant when an infant is dying and any aggressive therapy prolonging the life of the baby for a relatively short period of time would be seen as inappropriate. It is important to recognise the point where medical treatment becomes futile and abusive, where the burdens of treatment exceed the benefits.

In addition, the SCHB would consider the inviolability of human life and human dignity as the most important issues.

Question 4. The Working Party has identified the following questions for discussion:

- **What might we mean by 'quality of life' for a child?**
- **How do religious and spiritual influences affect decisions?**
- **How do the mass media influence decisions?**

In your view, are these questions that the Working Party should consider? Should any of these questions be omitted, or are there additional questions that should be included? Which social questions would you identify as the most important?

The SCHB is of the view that the above questions should be considered by the Working Party.

However, an additional question which should be considered is the one of human dignity which may be examined in the context of religious and spiritual aspects. In other words, the SCHB notes that, to some extent, any person who accepts the concept of human dignity is basing his or her reasoning on a belief which may be comparable to a religious and/or spiritual concept.

Discussion relating to human dignity

Like many other terms in ethics and philosophy, 'dignity' has often been used as an empty slogan, or a cover for intellectual undress. [2] Indeed, it cannot be fully accounted for by other concepts such as respect and autonomy, beneficence, non-maleficence or justice. But this does not invalidate the basic idea.

In the Oxford English Reference Dictionary, 'dignity' is defined as the *'state of being worthy of honour and respect*'. [3] In other words, it incorporates aspects of 'honour' and 'respect' which can be bestowed or recognised by:

1. oneself but only if one can 'see' oneself from another person's perspective and/or
2. other persons.

This means that if a solitary human being found himself or herself on a desert island and if this individual did not believe in any celestial being nor on the existence of anyone else on earth, then the human dignity which would come from another person would not exist. If, in addition, the individual did not consider himself or herself worthy of any honour and respect then he or she could not be considered as having any human dignity whatsoever.

It should also be noted that the concept of human dignity is not a scientific one. No individual will ever be able to prove whether or not a person is endowed with human dignity. From a scientific perspective, a human being is made up of a 'large pile of cells' containing about 70% water and a few other chemical compounds who is eventually destined to become, with time, a handful of dust. Thus one of the problems about bestowing human dignity to others or to oneself is the circular nature of this process. Scientifically, the assignment of human dignity from a 'pile of cells' to another or the same 'pile of cells' does not have any meaning!

Because of this, it should be remembered that secular human dignity is only a belief, a belief which is somewhere 'out there'. And in our modern societies, this important belief in human dignity has also become a belief that everyone agrees should always be believed is found in everyone to an equal extent. This universal nature of human dignity has arisen in order to address the unacceptable abuses which took place in the past history of humanity. For example, before the slave trade was abolished or during the Second World War, many persons believed that specific categories of peoples did not have the same human dignity as themselves and were, therefore, considered as second class citizens.

Therefore, in order to support the concept that human dignity can never be taken away, national and international declarations have been prepared which seek to confer human dignity to all persons of society. In so doing, they define, in a way, what all human persons should believe (but cannot prove scientifically). This was done for example with the:

United Nations' *Universal Declaration of Human Rights* [4] which states in:

Article 1:

> *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*

Article 3:

> *Everyone has the right to life, liberty and security of person.*

Council of Europe's *Convention on Human Rights* (1950) which states in:

Article 2.1:

> *Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.*

Council of Europe's *Convention on Human Rights and Biomedicine* [5] which states in

Article 1 (Purpose and object):

> *Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.*

In this respect, the official Explanatory Report of the ***European Convention on Human Rights and Biomedicine*** [6] indicates that *Article 1* should be interpreted in the following manner:

> *17. The aim of the Convention is to guarantee everyone's rights and fundamental freedoms and, in particular, their integrity and to secure the dignity and identity of human beings in this sphere.*
>
> *18. The Convention does not define the term "everyone" (in French "toute personne"). These two terms are equivalent and found in the English and French versions of the European Convention on Human Rights, which however does not define them. In the absence of a unanimous agreement on the definition of these terms among member States of the Council of Europe, it was decided to allow domestic law to define them for the purposes of the application of the present Convention.*
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> *19. The Convention also uses the expression "human being" to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began.*

At the national level, the German Constitution is the most impressive example of the need to base the whole social and political order on the principle of human dignity which was prepared only a few years after the Second World War. This was done in order to avoid a return to the inhuman ideologies and practices which had recently taken place in Germany. Thus the German Constitution's first article states that [7]:

> *Human dignity is inviolable. To respect and protect it is the duty of all state authority*.

Many other national constitutions also affirm this principle as the basis of legal systems. [8]

These texts emphasise the universal and absolute nature of the concept of human dignity. In other words, they support the notion that no person (including oneself) can lose his or her human dignity at any time in his or her life. Indeed, to reject such a notion would not only seriously challenge the whole concept of human dignity but would be an extremely serious precedent in a world that has fought so hard to endow all persons with the same dignity. In addition, the concept of a person being able to lose human dignity would dangerously undermine the most fundamental ideas embodied in these texts which often form the foundations of our modern societies.

Discussion relating to Quality of Life

As the Nuffield Council on Bioethics Consultation Paper indicates [9], in the context of a medical condition, the term 'quality of life' usually refers to the overall effects of a combination of factors, including health and the presence of symptoms, and reflects a person's ability to function physically, psychologically and socially. The term can include subjective feelings of well-being, fulfilment or satisfaction resulting from factors beyond the specific impairment. Somebody with a disability but who is otherwise healthy might be expected to report a good quality of life, whereas someone with a troublesome and painful chronic disease that restricts what they are able to do in which they have a perceived a paucity of hope, meaning and self worth would likely report that their quality of life is poor.

But one of the modern trends in biomedical ethics is to replace the notion of human dignity with that of quality of life. However, one of the problems with considering quality of life is the question of how this is defined and by whom. A consideration of someone's quality of life may be very different to that of the person who is living the life. Moreover, if a person's quality of life becomes the measure in which a life is 'worth' living then human life could be graded in relation to the amount of satisfaction it could be considered to produce with different qualities having different and very unequal values.

The consultation also seems to imply that if a quality of life of a baby is extremely poor or non-existent then this life is not worth living and should be terminated. But issues relating to the quality of life do not remove the challenges relating to the belief in the inviolability of life. Indeed, the SCHB notes that the quality of life of an individual cannot be linked with whether he or she should live. To do so would undermine the basic structure of civilised society. In other words, no person in society can say that a life is not worth living based on any 'quality of life' arguments. If this happened, a dangerous precedent would take place which would undermine the inviolability of life which is itself based on the belief in human dignity supporting the founding principles of:
- The United Nations' Universal Declaration of Human Rights,
- The Council of Europe's Convention for the Protection of Human Rights and Fundamental Freedoms (which is based in the Universal Declaration of Human Rights), and

- The Council of Europe's Convention on Human Rights and Biomedicine.

Quality of life may be partial or very much reduced but does that mean that a life has no worth of should not be lived?

Question 5.

- **Who is best placed to judge the quality of life for a child?**
- **When families as well as professionals are involved, whose decision should carry the most weight on whether or not to intervene to prolong the life of a fetus or a newborn baby? Examples of people likely to be involved: the mother, the father, other family members, doctors or other healthcare professionals, healthcare managers, the courts, the social services.**
- **When parents are involved, whose views should take precedence? For example: mother, father, parents together.**
- **Who else should be involved?**
- **How should such decisions be made, and how should any differences in view between the parties involved be resolved?**
- **When, if at all, do you think that people should use the law to challenge medical advice?**

The SCHB notes that 'quality of life' issues should be secondary to those of human dignity. Thus, if necessary, society should intervene into the decisions of a family or healthcare professionals when the protection of the baby is at risk.

Question 6. How much weight (if any) should be given to economic considerations in determining whether to prolong the life of fetuses or the newborn?

The SCHB is concerned that this question may lead to consider certain lives as more expensive than others in monetary terms. Of course economic issues do play a role in the general considerations of the National Health Service and prioritisation in certain circumstances is necessary but the cost of bringing up a child with a severe disability is not disproportionate to other NHS treatments.

It would also be appropriate to not only consider such individuals as a burden or as being costly. Just by being who they are can also enrich society even if this enrichment is not economic.

Question 7. Should a quality-adjusted life (QALY) (or another measure of health gain) for a newborn child be give the same weight as a QALY for a middle aged or elderly person?

The SCHB is concerned that any measure of quality-adjusted life may be considered as very subjective.

Question 8. Would drawing up more directive professional guidance be helpful to parents and professionals?

If so, should the UK follow practice in other countries and set a minimum age below which resuscitation normally would not be permitted?

The SCHB is of the view that additional non legally binding directive professional guidance may be helpful to parents and professionals.

The SCHB agrees with the statement in the Nuffield Council on Bioethics Consultation Paper that a decision about whether or not to prolong the life of fetuses or the newborn should be made on a case by case basis with physicians and families relying on regulations and professional codes of practice to guide their decisions at each stage. [10]

Question 9. Would drawing up new legislation in this area be helpful to parents and professionals?

The SCHB concurs that the present legislation is fexible enough for decisions to made on a case by case basis with physicians and families relying on regulations and professional codes of practice to guide their decisions at each stage

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1. Nuffield Council on Bioethics Consultation Paper on the Ethics of Prolonging Life in Fetuses and the Newborn, p. 11.

2. Commenting on the appearance of this vague usage in connection with end of life treatment, a US presidential commission observed: "Phrases like... `death with dignity'... have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred.": President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forgo life-sustaining treatment. Washington, DC: US Government Printing Office, 1983: 24.

3. The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

4. Adopted and proclaimed by United Nations General Assembly resolution 217 A (lll) of 10 December 1948, http://www.un.org/Overview/rights.html

5. Council of Europe Convention on Huma Rights and Biomedicine (ETS No.: 164), http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc

6. Explanatory Report of the European Convention on Human Rights and Biomedicine, http://conventions.coe.int/Treaty/en/Reports/Html/164.htm

7. See a detailed commentary on this article by Ernst Benda: «Die Würde des Menschen ist unantastbar», in Beiträge zur Rechtsanthropologie, ed. Ernst-Joachim Lampe, Stuttgart, Steiner Verlag, 1985, p. 23. In Roberto Andorno, The paradoxical notion of human dignity, http://www.revistapersona.com.ar/9Andorno.htm

8. See Constitution of Belgium, art. 23; Constitution of Switzerland, art. 119 (concerning biotechnological interventions on human beings and nature); Constitution of Ireland, Preamble; Czech Republic Constitution, Preamble; Constitution of Spain, art. 10; Constitution of Sweden, art. 2; Constitution of Finland, art. 1; Constitution of Greece, art. 7.2; Constitution of Poland, Preamble, art. 30; Constitution of Lithuania, art. 21; Constitution of Slovenia, art. 34; Constitution of Russia, art. 21; Constitution of South Africa, Section 7.1 and Section 10; Constitution of Mexico, art. 3.1, 25; Constitution of Israel, art. 1; Constitution of Brazil, art. 1; etc. See a selection of legal texts which mention dignity explicitly, in Dignity, Ethics and Law, ed. J. Knox and M. Broberg, Copenhagen, Centre for Ethics and Law, 1999. In Roberto Andorno, The paradoxical notion of human dignity, http://www.revistapersona.com.ar/9Andorno.htm

9. Nuffield Council on Bioethics Consultation Paper on the Ethics of Prolonging Life in Fetuses and the Newborn, p. 19.

10. Nuffield Council on Bioethics Consultation Paper on the Ethics of Prolonging Life in Fetuses and the Newborn, p. 11.