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Wahlberg, Ayo

Published in:
Clinical Ethics

DOI:
[10.1258/ce.2008.008033](https://doi.org/10.1258/ce.2008.008033)

Publication date:
2008

Document Version
Early version, also known as pre-print

Citation for published version (APA):
Wahlberg, A. (2008). Reproductive medicine and the concept of 'quality'. *Clinical Ethics*, 3(4), 189-193.
<https://doi.org/10.1258/ce.2008.008033>

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Ayo Wahlberg, BIOS Centre, London School of Economics and Political Science

Author biography

Ayo Wahlberg is a Research Fellow at the BIOS Centre, London School of Economics and Political Science, United Kingdom, working as part of BIONET, an EU-China collaboration on the ethical governance of biomedical research. He holds a PhD in Sociology from the LSE and an MSc in International Development Studies and Social Science from Roskilde University, Denmark. Academic publications include: ‘Bio-politics and the promotion of traditional herbal medicine in Vietnam’, *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 2006, 10(2): 123-47, ‘Measuring progress – calculating the life of nations’ in *Distinktion: Scandinavian Journal of Social Theory*, 2007, No. 14: 65-82, ‘A quackery with a difference – new medical pluralism and the problem of “dangerous practitioners” in the United Kingdom’, *Social Science & Medicine*, 2007, 65(11): 2307-16, and ‘Above and beyond superstition – western herbal medicine and the decriminalising of placebo’ in *History of the Human Sciences*, 2008, 21(1): 77-101.

Address

BIOS Centre, London School of Economics, Houghton Street, London WC2A 2AE, UK
Tel: +44 (0)20 7107 5201, fax: +44 (0)20 7955 7405, e-mail: a.j.wahlberg@lse.ac.uk

Reproductive medicine and the concept of ‘quality’

Abstract

Selection in reproductive medicine today relies on normative assessments of what ‘good life’ consists of. This paper explores the terms under which such assessments are made by focusing on three particular concepts of ‘quality’ – quality of life, biological quality and population quality. It is suggested that the apparently conflicting hopes, hopes and fears that surround reproductive medicine can co-circulate because of the different forms of normative assessment that these concepts allow. To ensure clarity in bioethical deliberations about selection, it is necessary to highlight how these differing forms of normative assessment are mobilised and invoked in practices of and debates about reproductive medicine.

Key words

Reproductive medicine, selection, biology, quality of life, bioethics, eugenics

Introduction

Technological interventions into human reproduction are among the most bioethically controversial today. Whether such interventions aim to prevent, terminate, promote, enable or direct reproduction, justifications are subject to intense bioethical scrutiny, especially as pertains any vulnerabilities on the part of the individuals who are their targets [1,2]. Yet, at the same time, reproductive medicine represents hope for large numbers of couples who are unable to reproduce without assistance as well as for couples who are burdened by a fear of genetically transmitting a life of suffering to future offspring [3,4]. And finally, as reproductive medicine continues to expand from the treatment of infertility towards the steering of reproduction through genetic screening, counselling and selection, many suggest that dangerous hype about future possibilities emerges [5,6].

In the following, I will show how the concept of ‘quality’ can help us to situate these apparently conflicting hopes, hopes and fears. In particular, I will focus on three different concepts of ‘quality’ – quality of life, biological quality and population quality – as a way to show how differing forms of normative assessment of what ‘good life’ consists of are central to the controversies that surround reproductive medicine today. It is exactly in attempts to set the terms of this normativity that bioethical controversies arise: What is a ‘life worth living’? Is there such a thing as ‘good stock’ that should be collectively promoted? What is an embryo ‘worthy of implantation’? Which ‘kinds of living’ are so poor that they should be prevented through termination of pregnancies? By exploring how the concept of ‘quality’ is mobilised in different ways in practices of and debates about reproductive medicine, I will show how developments in the reproductive field can at one and the same time generate eugenic fears, hopes to prevent or alleviate suffering, and, many would say, exaggerated expectations about a disease-free future.

‘Serious disease’ and quality of life

Over the last decades, reproductive medicine has enlarged its remit to include preconception, preimplantation and prenatal screening of partners, embryos and foetuses in situations of so-called (potentially) ‘at risk’ pregnancies [3,6,7]. These forms of assisted reproduction, where selective rather than ‘merely’ facilitated reproduction (i.e. infertility treatment) is at stake, have been highly controversial from their beginnings, especially in light of an all-too-recent eugenic past. I will return to the bioethical controversies surrounding selection later. For now, what I want to highlight are the contested justifications that are most often given for these screening technologies.

What links the genetic screening of couples, embryos and foetuses in reproductive medicine today is ‘serious disease’. This form of reproductive medicine aims to provide prospective parents with as much genetic information as possible about their partner (carrier screening), embryos (preimplantation genetic diagnosis) or foetus (prenatal screening) on the basis of which they then can make informed decisions about whether or not to begin or terminate a pregnancy. For some, any kind of genetic screening is unethical whatever the justifications, while for others, ethical dilemmas relate more to the question of what grounds are sufficient for terminating a pregnancy or selecting an embryo. And it is here that attempts to define what is meant by a ‘serious disease’ are contested. As pointed out in a recent report from the United Kingdom’s Human Genetics Commission, at the level of the family, what constitutes “serious” concerns on the one hand “conditions that are considered to lead to a very poor quality of life [for the future child]” and on the other “whether the family feels it could cope with the demands of a child with such problems” [12]. To find consensus on this – whether through public debate, legislative processes or institutionalised ethics commissions – is needless to say a great challenge:

“quality of life judgements are subjective, and... genetic disorders are variable in terms of severity and health outcomes. There is evidence to suggest that people with genetic disorders, their families and professionals all have different views about which conditions give rise to a poor quality of life... For example, there is no agreement on whether being born with Down’s Syndrome is to be born with such a poor quality of life that it would be better not to have been born” [12].

Quality, in the senses invoked in these debates, concerns ‘quality of life’. It is not a corporal or bio-physiological quality, rather it is a form of quality that is located in a subjective realm which is used to tell us something about the ways in which corporal life is experienced, negotiated, coped with and/or taken advantage of [13]. It concerns the ability of families to cope with bearing and rearing

children suffering from certain conditions as well as judgements about the quality of life a child would have living with certain debilitating diseases such as Tay-Sachs or Myotonic Dystrophy. The distinction between life and living is key, as in these deliberations, the normativity of what ‘good’ versus ‘poor’ quality of life is, relates to notions of a ‘life worth *living*’.

So, for example, in the UK, the Human Fertilisation and Embryology Authority (HFEA) requires that clinics applying for a licence to carry out preimplantation genetic diagnosis (PGD) for a certain disease evaluate not only the “known risk” and “mode of inheritance” of the disease, but also the “severity of the particular case”, the “likely degree of suffering associated with the condition” as well as the “way it affects the family”. While not explicitly stated, the HFEA’s list of licensed PGD conditions reads as a list of ‘(potentially) poor kinds of living’ (for the potential sufferers and families involved) that have been judged by the authority to be apposite for selective prevention [10,11]. It is also these forms of reasoning that have given rise to a series of ‘wrongful life’ and ‘wrongful birth’ lawsuits in the United States, where doctors have been charged by parents with either wrongfully allowing a life of pain and suffering to come into being, or wrongfully causing emotional pain and suffering for the parents as a result of negligent reproductive counselling. As Shelley Reuter has shown, in one such case, a mother suing her doctor testified that “[t]here is nothing on this earth that would have made me have a baby with Tay-Sachs Disease” [8]. And so the normative assessment of quality of life relies on judgments about the “likely degree of suffering” – whether on the part of prospective parents or the potential child – in particular cases.

Assessing the quality of gametes and embryos

Reproductive medicine, of course, relies on biological samples – blood, skin, hair, gametes, embryos, polar bodies, blastomeres, chorionic villi, amniotic fluid. It is these samples that will be manipulated and/or biopsied during the course of genetic testing and assisted reproduction. And when it comes to ensuring the best possible chances for success, it is the biological quality of these samples that is central to reproductive medicine. The development of ‘objective’ criteria with which to assess sperm, embryo and more recently oocyte quality has been a key part of advances in fertility treatment over the past decades. It is a predominantly visual form of assessment (aided by microscopes) where quality continuums work as vitality scales.

The better the quality of a gamete or embryo, the more aesthetically ‘good-looking’ or vibrant it is. Sperm quality is measured and graded according to criteria of motility, density, morphology, fructose level as well as pH level. Judgements are made not only about the number of sperm in a

sample but also about whether observed sperm have ‘good forward movement’, an ‘oval form’ and ‘smooth contours’. Embryos are also visually evaluated, in their case according to morphology, number of fragments as well as size of cells. Judgements are made about the ‘roundness’, ‘clarity’ and ‘symmetry’ of embryos after which they can be graded according to morphological scoring systems [14, 15]. In contrast, agreement on ‘reliable’ oocyte quality criteria has not come as far, although a number of embryologists are working on grading systems based on microscopy techniques [16].

Yet, better morphological quality is no guarantee for successful reproduction (although it does improve chances), nor does the morphologically-assessed quality of gametes and embryos tell you anything about the future offspring. This has become especially clear with the development of PGD techniques. As put by Sarah Franklin: “Some ‘top grade’ embryos, which are judged by their morphology to be the ‘best’ for selective reimplantation, may have invisible but lethal genetic or chromosomal defects that mean they are clinically useless—but no one can tell this ‘just by looking’” [17].

What this suggests is that the biological quality of gametes and embryos does not only concern the aesthetics of their morphology but also the conformity of their genetics. And since heredity is not something visible through a microscope, there are other ways in which the quality of gametes and embryos is assessed by patients, clinicians and geneticists. The first has a long history, namely appraising the person from which gametes originate. For example, the practice of sourcing ‘quality’ Ivy League eggs from university campuses in America for large sums when a donor is needed is well known and has raised a number of ethical questions about inducement and risks associated with egg donation. Moreover, sperm banks such as Cryos in Denmark are clear about their sources and screening practices: “The donors are ordinary, physically and mentally healthy men from a broad cross section of society. Most of them are students from institutions of higher education. Each donor candidate meets rigorous selection criteria and undergoes a thorough examination prior to acceptance” [18]. Couples searching for donors are provided with an extended, 8-page donor profile which includes detailed information about the donor’s physique, health, education level, hobbies, personality, family medical history as well as a sample of handwriting. So the ‘quality’ of a gamete or embryo also concerns what is considered its innate heredity.

In the social screening of gamete donors, it is assumed/hoped that the gamete’s innate qualities will be transmitted to the future offspring. However, as we saw earlier, when it comes to serious hereditary disease, neither morphological assessment nor social screening can tell you anything

about the genetic status of a particular gamete, embryo or foetus. For this, genetic diagnosis techniques based on DNA analysis are used to identify genetically 'tainted' carriers, embryos or foetuses as a way of selectively preventing transmission of a particular hereditary biological quality. That is to say, further to its morphology and social origin, the quality of a gamete or embryo is also assessed by its genetics.

And so, biological quality can be morphologically (scoring scales for sperm, oocyte or embryo quality), socially (social screening of potential gamete donors) and genetically (using PGD or prenatal diagnosis techniques) assessed, with the assumption being that the assessed 'quality' is *inherent to the biological sample itself*. Now, it is crucial to point out differences in how selective decisions are made about which embryos to implant and/or which pregnancies to terminate.

Morphological quality estimations are used by doctors to decide which gametes to use or which embryos to implant as a way of maximising a couples' chances for a successful pregnancy and birth. Social and genetic assessments of donors, embryos or foetuses are made by doctors and then communicated to prospective parents who must ultimately make an informed choice about which donor or embryo they wish to use/have implanted, or about whether or not to terminate a pregnancy.

There is, then, a clear distinction between selection to improve chances of successful reproduction and selection to promote or prevent the transmission of certain biological qualities to future offspring. It is this latter form of selection that is considered ethically problematic, for where does one 'draw the line'? One of the 'slippery slopes' reproductive medicine is seen to be balancing on concerns so-called 'designer babies' and what genetic traits it is ethically appropriate to prevent or allow being transmitted in individual cases [9]. Moreover, there is also debate about the 'widening scope' of PGD and prenatal diagnosis criteria to include so-called 'late onset' and 'lower penetrance' conditions [11]. The important point to make is that while assessment of the biological quality of gametes, embryos and foetuses will provide doctors and patients with information about the chances of transmitting certain hereditary traits, it does not tell them anything about which of these hereditary traits is 'good' or 'bad'. This normative assessment relies again on notions of what a 'good life' or a 'life worth living' is, as discussed above.

Selection and the eugenic legacy

The question of selection in reproductive medicine is without doubt the most ethically charged. Whether selection occurs prior to implantation following embryo biopsies or through the voluntary termination of a pregnancy following prenatal diagnosis, there has been comprehensive ethical

debate about, firstly, whether any kind of selection is ethically sound and, secondly, if some kinds of selection are acceptable, which kinds are not? To understand these debates it is necessary to look to the history of the concept of ‘selection’ itself in the context of human reproduction. Charles Darwin’s famous hypothesis of an evolution driven by chance mutations and natural selection played a pivotal role in 19th century theorising about the mechanisms of human progress. Having initially derived his law of natural selection from observations of animal species, in *Descent of Man* Darwin applied his schematic to humankind, only to suggest that natural selection ran into a problem in the so-called civilised countries:

“With savages, the weak in body or mind are soon eliminated; and those that survive commonly exhibit a vigorous state of health. We civilised men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws; and our medical men exert their utmost skill to save the life of every one to the last moment... Thus the weak members of civilised societies propagate their kind... It is surprising how soon a want of care, or care wrongly directed, leads to the degeneration of a domestic race.” [19]

This, of course, was the central problem for 19th and 20th century eugenicists: how to stop the degeneration of the ‘stock’ or ‘quality’ of the national race. If natural selection was being thwarted by human intervention, eugenicists argued, then it was up to those in authority to steer this selection through reproductive policies. In both Europe and America, encouraging marriage amongst people of ‘good stock’, controlled immigration, forced sterilisation of people of ‘bad stock’ and ultimately the catastrophic atrocities of the Nazi regime in the 20th century were all sold as attempts to direct selection in order to improve the ‘quality’ of national populations. Such policies and programmes have since been both condemned and abandoned, but their legacy continues to inform contemporary ethical debates concerning interventions into human reproduction.

For this reason, those who advocate selection of embryos or termination of pregnancies (the latter being far more common) following genetic diagnoses today, do so by stressing that such selection must only take place when a couple has given their explicit, informed consent. It must be a matter of choice and it must not be a decision made by anyone else, least so by those in positions of authority, whether they are a doctor, nurse or politician. Consequently practitioners working with reproductive medicine are bound by strict ethical codes of conduct which stipulate ‘non-directive’ assistance to couples [20].

Nevertheless, a crucial part of the bioethical debate on selection today concerns whether or not this is a form of ‘backdoor eugenics’ [1]. As put by Kerr and Shakespeare: “The focus may have shifted to abortion rather than sterilization or euthanasia, and to disease rather than social deviancy, but there are fine lines between these approaches” [5]. Also here, reproductive medicine is seen as balancing on a ‘slippery slope’ where the fear is that despite stipulations of non-directive assistance it is nonetheless the interests of the collective that pressure couples into reproductive decisions [21]. In these debates, public consultations, strict national regulations on how reproductive technologies should be used as well as improved ethical codes and informed consent procedures are called for in attempts to ensure that contemporary society steers clear of its eugenic past.

We can see, then, how bioethical deliberations over whether reproductive selection today amounts to eugenics invoke ‘quality’ or ‘stock’ as regards an aggregated collective – ‘population’, ‘society’ or ‘human gene pool’. It is feared that persons in positions of authority are making misguided judgements about reproductive selection not so much for the sake of a better quality of life for future parents or offspring, but rather for the sake of a ‘better society’ that would be ‘rid’ of certain debilitating diseases and thereby less ‘burdened’ (whether this burden is seen as genetic or socio-economic). ‘Population quality’, then, is a biological form of quality, but one that refers not to an individual or her/his gametes, but rather to the collective biology of a given (usually national) population. Bioethical critiques that see the new reproductive genetics as nothing more than eugenics suggest that selection resulting from genetic testing and counselling is in fact dangerously serving the interests of this collective, at the cost of some of the most vulnerable persons in today’s society.

Conclusions: life and living

In this article, I have shown how different notions of ‘quality’ inform and organise practices of selection in reproductive medicine as well as the ethical debates that surround them. Grading gamete and embryo quality, assessing the likely degree of impact on quality of life associated with a particular condition and invoking past atrocities which aimed to improve population quality all speak to a common, yet diverse, will to gauge, ensure, protect and/or improve individual or collective vitality, i.e. to optimise life. Yet these different forms of quality do not necessarily intersect very neatly: a bad quality sperm or embryo can result in a healthy child; a good quality embryo can be genetically ‘tainted’; sufferers of certain genetically transmitted diseases which have been licensed for PGD or PND may not consider their quality of life as low. Yet they are not

contradictions, rather they show how there are different concepts of quality used in assessments of what good life is.

This is where bioethical deliberation in reproductive medicine comes in: What criteria should be used to decide what a good quality of life is, or what a life worth living is? What biological qualities is it ethically justified to deliberately prevent or allow transmission of using assisted reproductive technologies? Does the collective (society, national population, human gene pool) have any interests that reproductive technologies should take into account?

In recent years, such bioethical deliberation has become increasingly institutionalised such that it is possible to distinguish between, on the one hand, national ethics commissions, public consultations, regulatory bodies and legislation which aim at capturing some kind of a ‘national public view’ on how new biotechnologies should be used in an ethically acceptable manner, and on the other, informed consent procedures, ethical review boards and codes of conduct which aim to protect vulnerable individuals. The former interpellate the collective – a public in need of stewardship – and they are put in place as safeguards against the ‘slippery slope’ that science is often times seen to be balancing on. The latter interpellate the citizen – an individual with rights that need to be protected – and they are put in place as safeguards against the potential coercion or exploitation of vulnerable individuals.

Yet, the introduction of such procedures and regulations have of course not resolved all bioethical concerns. In the field of reproductive medicine, as we saw, some argue that such safeguards have not prevented a dangerous form of ‘backdoor eugenics’ from flourishing and neither have they prevented couples from being coerced into terminating pregnancies following genetic diagnosis. Others dismiss the suggestion that reproductive medicine might eventually do away with disease and suffering as dystopian hype, far removed from the realities of an imprecise and ‘messy’ science.

At the same time, however, as we have also seen, it is not just hype and fear that surround reproductive medicine today. It is also a field saturated with hope. Hope for a *better* life for future offspring, families and ultimately society. What I have suggested in this paper is that the co-circulation of these hopes, hypes and fears are not necessarily contradictory – e.g. one can easily hope for the best possible life for one’s future child, while fearing the coercion implicated in forms of reproductive counselling that emphasise the collective. One way to see how they emerge in cohort is to look at the concepts that organise the debates, and I have shown how different concepts

of 'quality' and the forms of normative assessment that they enable, have done this. What must be kept clear in these debates are the conditions under which normativities of 'good life' are stabilised.

Acknowledgments

Research for this article has been carried out in my capacity as Research Fellow with the project 'BIONET Ethical Governance of Biological and Biomedical Research: Chinese - European Cooperation', funded by the European Commission's Sixth Framework Programme (FP6) (Contract no. 036788).

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