COMMENTARY

"Eugenics" By Another Name?

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Members of the Canadian neurological community may be aware that the Society of Obstetricians and Gynaecologists of Canada (SOGC) recently put forth an amended guideline regarding non-invasive prenatal screening for fetal aneuploidy (e.g. Trisomy 21[Down syndrome]).[1] Unlike most suggestions regarding clinical practice formulated by professional groupings, these guidelines have generated coverage by the national lay press and public controversy.[2-4] Careful examination of the content of this guideline and the relevant issues touched upon may reveal why such controversy has occurred.

The present guideline represents a modification of one addressing this particular issue from 2001.[5] The older guideline adopts a passive contingent approach and suggest that prenatal screening should be offered if a counseling program was locally available. The most recent guideline adopts a more activist posture stating that all women (irregardless of their possible risk of occurrence) be offered prenatal screening for fetal aneuploidy and access to counseling. Better screening methods and guaranteed counseling is sought which would clearly be predicated on an expansion of relevant provincial programs (e.g. Fetal Alert Network-Ontario).[6] As these programs are publicly funded, careful consideration must be given to the practice and ethical implications that may result from implementation of these suggested guidelines.

Though one is loathed to use the term due to its acquired negative connotation as a result of recent historical abuses, this guideline represents what can only be characterized as an effort at promotional voluntary eugenics. Eugenics ("eu"-good, "gen"-birth) simply stated in value neutral terms, concerns itself with the improvement of human genetic qualities.[7] It is not solely a modern construct predicated on a scientific knowledge of inheritance. In his model society (*The Republic*) ruled by Reason, personified by the Philosopher-Kings, Plato envisioned eugenics in stark explicit terms; "we must, if we are to be consistent, and if we are to have a real pedigree herd, mate the best of our men with the best of our women as often as possible, and the inferior men with the inferior women as seldom as possible, and bring up only the offspring of the best".[8] Plato was well aware of the social implications of this policy as he adds the necessity for secrecy; "and no one but the Philosopher-Kings must know what is happening".[8]

Screening within a medical framework is conceptualized as implementing mechanisms to identify pre-symptomatic disease so that earlier interventions can be offered, hopefully lessening the subsequent burden of suffering and morbidity.[9] This implies the necessary pre-condition that there exists a treatment for the disease being screened for.[9] For fetal aneuploidy no such antenatal treatment exists except for the termination of the affected pregnancy.[1] It is not the lessening of morbidity that is sought, but rather its complete elimination. Elimination of a defective gene/chromosome improves the genetic quality of the population as a whole and thus merits the label of "eugenics", especially given the clarion call for universally available screening.[7] This is the reality involved in the SOGC guideline and rather than being explicitly stated this reality is framed within the guideline by the language of individual "choice".

True "choice" depends on options and a full objective disclosure of information pertaining to the options available. Individual autonomy is the bedrock of our Western society and healthcare ethics.[10] This is the triumph of our embrace of the Enlightenment creed. There is no need in this issue to revisit a woman's right to choose about matters related to such a private and personal domain as reproduction. What we do have to avoid is falling into the trap that because the technology exists it should be utilized (i.e. we can, therefore we should). As Martin Heidegger noted "technology is a human activity" representing the distillation of our collective wisdom and intelligence with the freely chosen applications of this wisdom a reflection of our intrinsic values.[11]

Thus the key element in prenatal screening is the counseling and information given at the time of diagnosis. Indeed counseling should ideally be undertaken prior to actual screening so that parents are aware of what choices they may have to make in the event of abnormal screening results. To truly permit choice the counseling made available must be non-directive and value neutral. It has been noted that; "a critical component of the screening process is the context, language and manner in which the conversation about the possibility,,,,,occur".[12] Future research is needed to clarify the critical elements of the counseling process and factors contributing to deciding regarding choices. The content, language and communication of counseling needs to be critically evaluated. Yet little attention has been paid to this counseling process and the actual information content there-in.[12] Reasonable concerns may arise that a publicly funded program of detection and counseling occurring at a time of funding limitations will be driven by a cost-containment emphasis that may weigh the scales of choice in one direction. Significant genetic diseases are indeed chronic, have high associated hospitalization costs and are responsible for more than 10% of all pediatric hospital admissions.[13] Various surveys have identified a recent decline in documented morbidity and mortality associated with genetic disease that has been attributed by the investigators to antenatal intervention (i.e. selective termination) under the rubric of secondary prevention.[14]

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Furthermore, it is clear that in assessing health related quality of life, that is the impact of disease or illness on an individual and their caregivers, perspectives differ between affected individuals, proxy caregivers and health professionals, with the last group typically being most pessimistic.[15] In addition, there is a tendency to emphasize objective measures, deficits and impairments rather than more subjective humanistic values.[16] It is clear that those providing counseling must be well trained, aware of their own inherent biases and willing and able to impart a variety of viewpoints and provide ready access to a wide spectrum of information sources. Ideally this should include those personally affected by the condition under question. There are thus considerable personal and societal challenges that must be met in order to preserve true "choice" in the domain of prenatal screening.

A final issue relates to being aware that there is a risk that considering a condition suitable for antenatal termination may impart to those being born with such a now "preventable" condition, lesser qualities of personhood or to their families a lesser obligation of providing available societal supports.[17] Our common morality is predicated on the recognition of others as persons, to whom it is owed universal standards of duties and obligations that bind us together, irregardless of the possession or lack there-of of certain features.

There is no doubt that those behind the recent SOGC prenatal screening guideline are motivated by the best of intentions; healthy pregnancies and births. Positive interventions that include providing a barrier-free access to all women, reducing invasive testing and the reassurance of negative testing (i.e. no aneuploidy documented) should be mentioned and not underestimated. The practice of "eugenics" is not their explicit intent. However, as noted above there are a number of issues raised by the potential implementation of this guideline. These implications have practical and philosophical relevance. Given that screening represents a public policy, there is no need to restrict such debate solely to modern day Philosopher-Kings. Thus a full, frank, and transparent public discussion of this issue is necessary given its societal implementations. As physicians who care for individuals who may have neurologic compromise as a result of an underlying genetic disorder, Canadian neurologists, and in particular Canadian pediatric neurologists, need to be a key party to such a debate. While not qualified or indeed in a position to decide what should be done once an aneuploidy is found, we as neurologists are in a position to counsel what can be expected from a neurologic perspective if an affected child is carried to term. Such counseling must take into account a balanced perspective of both potentials and impairments.

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