Socially repugnant or the standard of care

Is there a distinction between sex-selective and ability-selective abortion?

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hy do most medical authorities accept, endorse, and even encourage prenatal genetic screening while opposing sex-selective abortion? The juxtaposition of these 2 practices raises questions of how they compare and whether there is a credible, ethical basis for endorsing one while condemning the other. We hope to encourage this conversation without raising broader questions about the morality of abortion, or about whether human rights should be considered applicable to fetuses. Our objective is to point out the differences in how the selective abortion of different kinds of fetuses is viewed and to explore if it is ethically defensible to treat them in radically different ways.

If we agree to prohibit parents from knowing the sex of their child before birth, we do so in order to prevent discrimination based on sex. We seek to affirm the equality of both males and females and agree to limit the rights of women when they trend toward clear, purposeful "socially repugnant" sexism. We refuse to allow a practice that clearly furthers a mindset of female inferiority. In doing so, we seek to cultivate a society that furthers the United Nations principles of human rights in declaring the following:

All individuals are equal as human beings and by virtue of the inherent dignity of each human person. No one, therefore, should suffer discrimination on the basis of race, colour, ethnicity, gender, age, language, sexual orientation, religion, political or other opinion, national, social or geographical origin, disability, property, birth or other status as established by human rights standards.1

The widespread practice of prenatal genetic screening and diagnosis, with an outcome that can lead to termination of pregnancy, does nearly the opposite. While medical practitioners seem uncomfortable with women terminating pregnancies for the reason of sex selection, they remain accepting, and at times encouraging, of a woman's choice to end a pregnancy when she receives an unexpected prenatal genetic diagnosis. Our society appears to stand firmly against discrimination based on

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sex, but fails to uphold the spirit of the United Nations human rights code when we endorse policy promoting discrimination based on ability. Leaving aside the question of whether the code applies to fetuses, it does seem to regard differences of sex and ability in a similar way.

Sex-selective abortion

There has recently been much discussion about the practice of sex-selective abortion. This practice is rampant in China and India and has led to an estimated 61 to 80 million "missing" females. The CMAJ drew attention to this issue in an article detailing this common practice and postulating potential consequences of a class of single, less wealthy men unable to find wives.2 While the authors are also in part optimistic that this paucity of females will give rise to an increasing sense of empowerment for women, emerging case reports from India of women forced to bear children for entire families of brothers suggest the exact opposite might be true 3

Historically and universally, there has been a remarkably constant ratio of approximately 105 male births for every 100 female births.4 This number is known as the sex ratio at birth (SRB), and is defined as the number of males born for every 100 females. In China, this number has been steadily increasing during the past 30 years to a high of more than 130 in parts of the country.⁵ India is close behind with SRBs of up to 125 in certain states.6,7

As similar trends are emerging in the West, governing medical associations are speaking out against the practice of sex-selective abortions. A recent ethical policy released by the Society of Obstetricians and Gynaecologists of Canada (SOGC) noted an imbalance in the ratio of male to female births in immigrantrich pockets of South Asians in Canada.8 While the SRB remains normal with first births, numbers begin to favour males in second births after 1 female child (SRB=117). The imbalance is particularly strikingly in third births when the first 2 children have been females (SRB=151).9 The SOGC and an editorial in the CMAI suggest that this practice ought to be curtailed, and propose withholding disclosure of fetal sex until the pregnancy has reached a stage at which abortion for nonmedical purposes would be difficult to attain.8,10 In a guideline, the College of Physicians and Surgeons of British Columbia agreed that revealing fetal sex for nonmedical

purposes was "unethical" and mandated that physicians withhold this information given the potentially socially repugnant consequences.11

Similar policies are emerging internationally, with the Council of Europe encouraging member states, particularly Albania, Armenia, Azerbaijan, and Georgia, to enact legislation forbidding this practice and to take practical steps to limit the growing imbalance in male and female births. 12 Likewise, American and Australian states have enacted guidelines and legislation to prohibit the facilitation of sex-selective abortion. 13,14

The overwhelming condemnation of this practice from both medical and political authorities in the developed world highlights an apparent, widely held opposition to any form of discrimination on the basis of sex. Interestingly, this same opposition does not seem to be present for certain other forms of discrimination.

Ability-selective abortion

Prenatal genetic screening is now considered the standard of care in most Western countries. The lead author of the American College of Obstetricians and Gynecologists practice bulletin on prenatal genetic screening, Dr Deborah Driscoll, stated, "Physicians are ethically obligated to fully inform our patients of their health care options, including prenatal testing," requiring that all pregnant women be offered invasive and noninvasive tests to screen for genetic anomalies. 15 Likewise, the SOGC is in agreement that testing options must be offered to all pregnant women as the standard of care for Canadian patients.¹⁶ A report of prenatal tests and recommendations in European states reveals that most European countries are also offering nationwide screening programs to all interested women.¹⁷

Trisomy 21, also known as Down syndrome (DS), is the most common condition screened for and detected prenatally in Europe and North America. 18-21 A 2009 report from the United Kingdom demonstrated that 92% of pregnancies in which DS is prenatally diagnosed are terminated, while approximately 2% end in miscarriage and 6% in live births.²² These statistics are fairly consistent with those in North America, where it is reported that up to 90% of such pregnancies in Canada and 84% to 91% in the United States are terminated.²³⁻²⁶

Analysis

It is worth considering if there is an important distinction between sex-selective and ability-selective abortion that allows a philosophical justification of one and prohibits the other. We will identify some possible distinctions that can be drawn, but ultimately argue that none of them are satisfactory, and therefore no philosophically substantial distinction can be drawn. In our analysis, the term ability-selective abortion will be used to describe the practice of screening for and terminating

pregnancies on the basis of genetic anomalies. Most of our arguments and examples about this practice will focus on DS given that it is the most commonly detected genetic anomaly.

Perceived burden. One common reason given to justify the termination of pregnancies in which genetic anomalies are prenatally diagnosed is an alleviation of the perceived future burden of a child with a disability. However, in certain cultures, sex-selective abortion is done for the very same reason. For some, the birth of a female child requires the parents to accumulate a large sum of money to facilitate the marriage of their daughter. Further, females might not always have the right to inherit honestly earned land or wealth from their parents, nor can they expect to be regarded as equal to their male counterparts in the workplace or society at large.²⁷ From a purely cost-benefit perspective, a female child is indeed a substantial burden.

It could be argued that, instead of allowing sexselective abortion, societies should adapt their cultural practices in order to reduce the social inequalities that lead women to be a burden. Changing the expectations around dowries and addressing workplace inequality would be good steps. Further, additional accommodations for the unique challenges women face, such as paid maternity leave and more widely available child care, would make it easier for women to work and therefore reduce the burden associated with having female children. Of course, the same argument could be used for persons with disabilities—additional governmental support and programs aimed at integrating people with disabilities into the work force would reduce the extent to which they impose an economic burden. Therefore, the economic burden argument does not seem to provide a clear basis for distinguishing between sexselective and ability-selective abortion.

Suffering. A second possible way of distinguishing between sex-selective and ability-selective abortion is to say that people with disabilities might suffer to a degree that makes their lives not worth living and abilityselective abortion is done for their own good. In some sense, the same response can apply here—women also experience more suffering than men. In the developed world, they are more vulnerable to physical and sexual assault, they face systemic inequalities, and they uniquely experience the physical pain associated with childbirth. In the developing world, things are often much worse. Perhaps steps can be taken to address that suffering, but things can also be done to address the suffering of people with disabilities. Additionally, the "suffering" argument does not apply to DS, the most commonly detected disability, but rather to a limited subgroup of prenatally diagnosed conditions.

The natural, the necessary, and the useful. A third way of distinguishing between sex-selective and ability-selective abortion might be in an appeal to the natural, the necessary, and the useful. Natural in this sense is often invoked in public debates to imply that a thing or state is the way it was originally supposed to be, without some improper intervention or distortion. Necessary means that the continuation of human life would not be possible without it, and useful implies that a thing contributes in some meaningful way to human well-being.

In considering the natural, it is clear that 2 distinct sexes have always been a part of humanity and are undeniably necessary for its perpetuation. As identified earlier, an imbalance in the male-to-female ratio substantially greater than the usual 5% disparity seems to be associated with considerable social problems. Conversely, genetic anomalies are often described as diseases. People (and even people with disabilities) seem culturally inclined to suppose that, unlike in the case of femaleness, a disability is a case in which "something has gone wrong." For whatever reason, the problems with a society without people with DS do not immediately spring to mind as clearly as the problems with a society without females do.

We reject this distinction for 2 reasons. First, we believe that defining people's social usefulness, their "necessary-ness," or the naturalness of their state and valuing them based on that is a flawed and dangerous project. Second, even if one does wish to consider individuals' value based on their social usefulness, people with disabilities have unique and invaluable social contributions to make.

It can be fairly easily demonstrated that there is variation in the general usefulness of individuals. Individuals are generally paid for the work they do based on the value of that work to those who benefit. A doctor tends to be paid more than a painter because those who are served by the physician value his work more than those who benefit from the work of the painter do. (It might seem strange that a professional hockey player is paid more than a doctor, but this is because an individual player can provide benefit to a large number of people all at once. A doctor, while providing a much greater benefit to each individual he helps, can generally help only one person at a time. If a doctor were more socially useful than a hockey player, then he would be able to demand more for his services than a hockey player can.) With some exception (services provided to children or others who lack the capacity to pay for things they value), we can generally see that people in a capitalist society are paid based on the usefulness of their actions. There is variation in the amount of money people are paid, and there is variation in the usefulness of individuals.

In light of this variation, valuing individuals based on usefulness seems like a very dangerous project. It has as the obvious conclusion that killing a professional athlete is a much graver crime than killing a painter. If salary is indeed a good indication of usefulness, then killing an athlete might in fact be 100 times worse than killing a painter. Perhaps playwrights are not necessary for the continuation of the human species, but we certainly are a lot better off for the past existence of Shakespeare and George Bernard Shaw (although Shaw might not have agreed). If necessary-ness is the metric, then how many homeless people would you sacrifice to save a doctor? Merely asking the question elucidates the problem with this kind of thinking.

Our modern systems of ethics are based on valuing individuals as having absolute worth and not as means to other ends. In medical ethics, doctors are expected to treat patients as individuals with equal and noninterchangeable value. Withholding lifesaving treatment from a "less-valuable" patient in order to use his or her organs to save the life of another more "useful" person is clearly unacceptable. Therefore, to distinguish between ability-selective and sex-selective abortion by comparing the usefulness or necessary-ness of females with people with disabilities is not only dangerous, but inconsistent with the way we consider other questions in medical ethics.

Leaving aside usefulness, what about valuing people based on the naturalness of their condition? Perhaps being female is natural and having a disability is not. This might seem intuitively reasonable, but it is based on a wholly arbitrary distinction between what is natural and what is unnatural. An appeal to naturalness might have some social currency, but it is impossible to define objectively whether a thing is part of the way the natural world is "supposed to be" or whether it represents a distortion. Further, even if we could clearly distinguish between the natural and the unnatural, who is to say that something is more valuable because it is natural? There are plenty of synthetic pharmacologic products that are much more useful and valuable than natural herbal products. Distinguishing between sex-selective and ability-selective abortion based on the naturalness of such conditions is therefore quite arbitrary and relies on an unjustified assumption that natural is better.

Down syndrome: But even if one does not accept the foregoing arguments, can we be so sure that disability cannot be useful, necessary, or natural? We have good reason to believe that people with DS, for example, are indeed all of the above.

Down syndrome was first formally described in 1866 by John Langdon Down; however, history suggests that this syndrome has been a part of the human family for thousands of years.²⁸ In Central America between 1500 BC and

300 AD lived a tribe called the Omecs. Remnants of their statues depict overweight children with round faces, palpebronasal folds, slanted eyes, a short nose with a flat bridge, and shortened limbs-classic DS phenotypes.²⁹ Given the persistent presence of trisomy 21 for more than 3500 years, the possibility that people with DS play an important role in society ought to be considered. Although not all things that are persistent have value, evident persistence seems a good reason to carefully consider if value might indeed be present. Either way, 3500 years of existence does bolster the claim of DS being natural.

In interviews with mothers whose children have DS, they repeatedly highlighted the children's "ability to relate to others and their sense of humour, cheerfulness, and insightfulness."30 Several commented that, compared with their normally developing children, DS kids were more attuned to their parents' efforts, emotions, and needs that their siblings were oblivious to, and showed genuine gratitude and affection.30 A recent research paper titled "It's not what you were expecting, but it's still a beautiful journey" presents an insightful narrative of mothers' experiences giving birth to and raising children with DS.31 In a particularly relevant comment, one mother said,

If we had known [about his diagnosis] early enough, we would've faced a difficult decision whether to terminate him or not. I'm very glad that we weren't given that option because it would've been the biggest mistake of my life if I had.31

Another mother commented, "[Ella] is easily the best thing that's ever happened to me, to the power of a thousand. Easily the best thing."31 Without minimizing the challenges that necessarily come with raising a child with a disability, it is crucial that we also recognize their unique contributions to families and society at large. The mothers interviewed concluded that having a child with DS strengthened relationships in the family; led to personal growth, compassion, and greater acceptance; and strengthened them emotionally. Although many of the interviewed mothers had other children, they found that raising their children with DS led to substantial development that they might not have otherwise experienced.³¹

In the 2010 Olympics, downhill skier Alexandre Bilodeau was the first Canadian to ever win an Olympic gold medal on Canadian soil. As he crossed the finish line, his younger brother Frédéric cheered wildly from the bottom of the hill. When Alexandre was asked how much of the gold medal belonged to his brother, who was diagnosed with cerebral palsy, the skier reportedly said, "My brother is my inspiration. Growing up with handicapped people puts everything back in

perspective and he taught me so many things in life."32 Spectators worldwide commented that seeing the brothers together after Alexandre's victory was one of the highlights of the Olympics.

In considering the stories and comments of those who walk closely with those with disabilities, it appears quite reasonable to suppose that people with disabilities are natural, necessary, and indeed useful.

Conclusion

Medical and political authorities currently appear quite comfortable in their promotion of ability-selective abortion while adamantly opposing sex-selective abortion. Through broad analysis, it is not clear that a defensible basis for this distinction exists. Therefore, in the absence of such a distinction, medical and political authorities should seek to address this inconsistency. There are 2 options to attain consistency. Either seek to minimize the occurrence of both sex-selective and abilityselective abortion, or allow completely unrestricted access to abortion services, with no consideration of motivation. Given the above analysis, the authors believe that the former is the ethical choice to make. "

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Competing interests

None declared

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