Prenatal diagnostics: an offer you can't refuse?

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Methodological considerations

The aim of this research was to investigate and present the views of women in Denmark on the human genome analysis. Its basic argument was that women's views should be separately sought as it should not be presumed that the moral basis of ethical decisions, the applications, and the implications of the human genome analysis are the same for women as for men. From our point of view, this study has a problem of methodology, as to us it represents the inversion of outdated research methods, by which researchers returned form 'X' having talked only to men, without professional comment and self-doubt. Men and women are categorised into different genders, differently located in the social decision making processes, they have different ways of experiencing their bodies and they have different ways of producing their offspring. But they still have to co-operate in the production of offspring and both men and women have vested interests in the improvement of the prospects of their offspring. Assuming different views of the Human Genome Analysis is probably correct, but as Gregory Bateson pointed out, it's the difference which makes a difference, it's a 'bit', a unit of information[1]. As men's views were not sought, it is thus not possible to detect any actual differences between the views.

The interviewees

In the abstract of the work programme it was specified that the survey and the qualitative interviews should take place with women who are most likely to have an informed opinion and women who see the programme as directly relevant to themselves through current and future medical interventions, women in the community with responsibilities for promoting and improving health care for women, women who work in the scientific field and women whose work included making views of women known to a wider public. Using these criteria, 26 women were picked out: 10 were university graduates and worked within the health sector (doctor, geneticist, psychologist), 3 had middle-range training and worked within the health sector (nurse, midwife, hospital laboratory worker), 7 had other university degrees (jurist, theologian) and 5 had other middle range training (journalist, commercial training, teachers training). One organisation had to be left out of the data sample (organisation of business women) as we were unable to locate a business woman, who could find time for an interview.

The average age of the women interviewed was, in relation to childbearing, relatively high. Only 3 of the women were under 37 years, 18 were past 40 years. Three of them had no children (one was still in graduate school and one sterile because of 'Turner's syndrome), the rest had children, maybe not in the numbers they might have wished, but as one of the women said, 'my body didn't fail me, when I wanted to be a mother'. In other words, a great majority of the interviewed women was beyond the age where prenatal screening is of personal and currently topical interest.

Regarding the question of how much autonomy and control the women had over their reproductive life, only two answered none. The rest replied that they had some, considerable degree of, or total control and autonomy. Most of the women felt that genetic manipulation of sex cells/embryos/adult bodies would in fact increase their own control and autonomy- an option, however, they felt no need for.

The interviewed group of women was, characteristically, all brought up within the Lutheran Protestant Christian tradition. For the majority, though, this didn't mean that they were Christians by conviction, rather that Christianity is a part of their cultural heritage (as well as the Vikings). To the question of identification with an ethnic/racial group, all the women replied 'none'. Developing this point of view, the women were, however, very much aware of being "white Danes', acknowledging the fact, that it certainly is a privilege to have a daily life without being confronted with questions about religious and ethnic identity.

Legislation and practice

Compared to other countries Denmark has a relatively well organised system of social security, by which, not the family unit, but each person is considered as an individual being or recipient. Denmark has relatively high divorce rates and rather progressive attitudes towards single mothers. Access to anti-con-

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ception (contraception) is free, and there is free abortion up to 12 weeks of gestation.

In this social climate, women to a large extent experience that it is possible and socially acceptable to choose if, when, and by whom they want to have children. Within the public health care system, treatment of infertility is available, e.g. IVF or donor insemination of women who are under 40 years of age. In recent years many have lived, not necessarily legally married, in a heterosexual relationship. For women past 40 years and single women (including lesbian women), private clinics offer the same range of possible treatments as the public clinics.

In 1993 an IVF treatment of a 52 years old, married, woman caused stir in the media and a member of The National Board of Ethics announced that it was never the intention, within the present legislation, that all women, irrespective of age, should be allowed to receive fertility treatment. Where and by whom the boundary is to be set, however, is still a particularly sensitive subject.

In a review of 60 scientific studies assessing the parenting ability of homosexual men and lesbian woman, Ernulf and Innala show, that sexual orientation is unrelated to the ability of man and woman to successfully rear children, and that these children are not negatively affected by growing up with homosexual parents. To deny homosexual individuals and couples the right to rear children because of their sexual orientation is therefore motivated by politics and morality, and is without scientific justification [2].

In Denmark all women past 35 years of age, women with partners past 50 years of age, or women with an increased risk of foetal chromosome defects, are automatically offered prenatal genetic screening. In practice this also covers all women who are anxious about the condition of the child. Most of the prenatal examinations are performed when there is an indication of an increased risk of chromosome defects. Of the women past 35 years, 85% accept a prenatal diagnostic examination [3]. The procedure is either an amniocentesis or a chorionic villus biopsy. It is free of charge and performed at specialised clinics and hospital wards.

In 1990 more than half of the screenings were performed on women past 35 years, and a total 12% of all live born Danish children were prenatally screened (the figures in Sweden are 4.7% and in Norway 2%). According to the National Board of Health, the higher Danish figures are not a consequence of a deliberate policy in Denmark. Between 1980 and 1990, the number of foetal chromosome examinations has more than doubled. One of the reasons could be a growing number of examinations for alpha-feto-protein. However, in the same period the increased number of examinations has not resulted in a decrease in the number of children with Down's syndrome or other serious defects [4].

Since 1973 abortion during the first trimester is legal in Denmark. It is, however, possible to obtain permission for an induced abortion till 22nd or 24th week on indication of foetal defects or on certain social indications.

In 1.9% of the Danish prenatal genetic screenings a 'positive result' was found. In case of chromosome abnormalities, after genetic counselling the decision is left to the pregnant women and in practice most women choose to abort the abnormal foetus. It is mainly in cases of sex-chromosome-linked-abnormalities that the woman chooses to continue her pregnancy. In 1990, 10 out of 22 abnormalities involved the sex chromosomes and 54 out of 55 cases of trisomies were terminated by induced abortion [3].

Perceptions of prenatal diagnostics: Data from the interviews

Of the 25 interviewed women, 13 would, in case of pregnancy, decline a prenatal genetic screening, 3 were uncertain and 9 would accept a genetic screening. Of these 9 women accepting the screening, only 6 women felt definitely positive about the choice.

The six women who were definitely positive about accepting genetic screening, were all academically educated, possessed high ranking jobs with a high degree of professional competence. They all felt they had received sufficient information on genetic screening of embryos, they were in general positive about screening of embryos and they all wanted to have the right to make a deliberate and qualified choice about which kind of abnormalities and handicaps, if the occasion should arise, they would accept for their children. "At the time of my pregnancy as I was 37 years old, I chose to have an amniocentesis. I did not want to have a child with Down's syndrome or any other genetic defects. And considering the fact that any woman can choose a legal abortion, there is no reason why we should not choose to abort genetically afflicted embryos."

Seventyfive percent of the interviewed women expressed ambivalent or explicitly negative attitudes towards the offer of prenatal, routine genetic examinations. More than half of women expressed that genetic screening of the foetus was not an option they would even consider. "I will take whatever child may come; a genetically afflicted child would be as welcome as any other child in our family". "No one can fight destiny, genetic screening is repulsive". "We get information we could easily live without". "Having a child becomes a very technical matter and if we accept screening we lose control over our reproductive life".

None of the interviewed women made explicit remarks on the 1 to 2 % risk of a miscarriage after an amniocentesis and chorionic villus biopsy. For a woman of 35 years this means that the risk of a spontaneous abortion is in fact bigger than the risk of expecting an abnormal child. This aspect was apparently not part of women's considerations about prenatal screening, implicitly showing that information about the high risk of miscarriage as a side effect of the examination is accorded a low priority in the medical information given to the public.

Among the women interviewed, only one had actually experienced a positive result after an amniocentesis. In this case the test showed a genetic inversion with unknown consequences. The woman was very alarmed and considered an abortion until a genetic test of the mother proved that she herself suffered from the affliction, a condition she was in blissful ignorance and lived without problem for 34 healthy years. She decided to continue her pregnancy.

Two of the interviewed women were by conviction against abortion, including abortion of a genetically afflicted foetus. The rest of the women considered the option of free abortion as a privilege by which women can choose if and when they want to have children. On the question whether this privilege also covers the choice of what kind of children women actually want to bear, there were disagreements. Knowing that some handicaps can be serious strains on the child and family, a burden not all families are able to cope with, the women believed that decision on them should be left to the woman alone. At the same time though, the women were aware of the fact that decisions concerning the selection of an expected child can be extremely tough, maybe so difficult that abortion of a foetus with a less significant anomalies was not to be permitted. "Less significant" for whom is of course, debatable. It suggests the paradoxical problem that within the frameworks of free abortion it is considered socially acceptable to choose not to continue a pregnancy of a normal child but is considered ethically debatable to abort a genetically afflicted foetus. And whose yardstick shall prevail when defining what is to be considered as minor or serious anomaly?

Control over reproduction is the basic argument for the women who want as well as for those who do not want prenatal genetic screening. It includes the right to get or to decline a prenatal genetic examination, the right to determine whether to terminate or continue a pregnancy of an abnormal child. One of the interviewed women characterised the offer of prenatal screening as 'getting an offer you can't refuse'. Others expressed an immanent fear of being too vulnerable at the time of pregnancy to insist on refusing the test. In other words what one fourth of the interviewed women perceived as an extension of their control over their own life, the rest of the informants perceived as an outside control of their bodies and their reproduction.

Health as a symbolic construction

As pointed out by Scheper-Huges and Lock, the politically "correct" body for both sexes in the 'healthist' and body conscious Western culture, is the lean, strong, androgenous and physically "fit" body form through which the core cultural values of autonomy, toughness, competitiveness, youth, and self-control are readily manifest[5]. Health is increasingly viewed as an achieved rather than an ascribed status, and each individual is expected to "work hard" at being strong, fit, and healthy. Conversely, ill health is no longer viewed as accidental, but is rather attributed to the individual's failure to live right, to eat well, to exercise, etc.[5] "Health" thus becomes a moral discourse, an opportunity to reaffirm the shared values of a culture, a way to express what it means to be a moral person[6].

Motherhood and children: A consumer choice?

In the industrialised society of Denmark, women's social status is not directly related to marital status or status as a mother. To become a mother is more or less considered a personal choice in line with the choice of becoming the owner of a car or a dog. In principle there is no gendered division of labour, and to men and women apply the same standards of success. Production and reproduction (production of intelligent, healthy and flawless individuals) is covered by the same standards of perfection- defective embryos relegated to the private domain as a personal problem and caring of a seriously handicapped child incompatible with an active career.

Expanding the prenatal screening programme to cover all pregnant women can thus be viewed as the manifestation of a consumer society, an extension of the freedom of choice regarding consumer goods. It is distinguishable from freedom of existence, thought and cognition. By this we don't suggest a total rejection of genetic screening. For individuals at a very high risk of serious genetic defects, screening might be a reasonable solution[7].

Perceptions of "normality" are not merely structured by biological standards but rather are reflections of the cultural/symbolic social system. With the future increase in the amount of available information concerning the possible defects of the yet unborn child, biological tests can be used to conform people to rigid institutional norms. By altering the context of defining normality and abnormality, we risk reducing social tolerance for the variation in human experience. By refusing the 'proof-reading' of the embryo women acquire the responsibility regarding the genetic conditions of their offspring. The birth of a genetically afflicted, 'non-healthy' child being is not a mere quirk of nature but a moral offence against the social codes. Prenatal diagnosis can be viewed as an extension of women's personal freedom of choice and control over their reproduction, but for the majority of the Danish informants, prenatal diagnostics were also perceived as subjection to an imposed, impersonal, symbolic, and thus much more violent, social control of their bodies and their reproduction. An offer you can't refuse!

Conclusion

Present data suggests that genome analysis opens up a deeper structural change of the cultural construction of pregnancy and motherhood. It is our opinion that most women, in their understanding of the genome analysis, distinguish between different levels of meaning. From one point of view, the genome analysis might expand the range of treatment of serious diseases, rationally perceiving prenatal diagnostics as a positive step towards fulfilling the natural wish of a normal and healthy child. In this sense it becomes a personal choice whether to accept the offer of a prenatal screening, and a personal decision with consequences the test results involve. At the same time most of the interviewed women seemed to be aware of the fact that perceptions of "normality" are not merely structured by biological standards, but rather reflections of the cultural /symbolic social system. If biological tests are used to make people conform to rigid institutional norms, we risk reducing- by altering the context for defining normality vs. abnormality- social tolerance for the variation in human experience. What is then to be defined as normal or abnormal, able or disabled, healthy or diseased? And whose yardstick should prevail? Thus, prenatal diagnostics can be viewed as an extension of women's personal freedom of choice and control over their reproduction, but for the majority of the Danish informants, prenatal diagnostics were also perceived as subjection to an imposed, impersonal, symbolic, and thus much more violent, social control of their bodies and their reproduction.

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