

Empowering Women and their Health Care Providers: Prenatal Testing Examined

Abstract

Under the practice guidelines set by the SOGC (Society of Obstetricians and Gynaecologists of Canada) in February 2007, all physicians treating pregnant patients are now mandated to offer prenatal genetic screening. A new non-invasive prenatal genetic diagnostic test, called 'chromosomal microarray analysis,' will soon drastically increase the volume of information that is available about a fetus. However, challenges already exist with current prenatal testing in Canada. Before new testing is made available, an ethical framework needs to be developed so that parents are provided with accurate information about the conditions that may be detected through prenatal diagnosis. Additionally, an increased awareness of and access to options for improving the lives of the disabled and their families in society, will help to ensure that new prenatal genetic diagnosis technologies are used for the betterment of women, children and society.

Empowering Women and their Health Care Providers: Prenatal Testing Examined

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Under the practice guidelines set by the SOGC (Society of Obstetricians and Gynaecologists of Canada) in February 2007, all physicians treating pregnant patients in Canada are now mandated to offer prenatal genetic screening. Prenatal screening is an assessment of the developing baby to determine if there is an increased chance of chromosomal disorders or structural problems. As the impact of both the Human Genome Project and the advances in prenatal diagnosis reach from the laboratory to the doctor's office, the number of detectable conditions has increased dramatically. No longer can genetic testing identify only chromosomal anomalies, but it can also detect conditions within the fetus that may be linked to non-heritable conditions. With this increase in possible identification has come a push to expand a 'woman's right' to include prenatal testing. Where previously pregnant women over the age of 35 were the cohort targeted for such screening, the SOGC has expanded the guidelines: "all pregnant women in Canada regardless of age should be offered through an informed consent process a prenatal screening test for the most common clinically significant fetal aneuploidies in addition to a second trimester ultrasound for dating, growth and anomalies (Summers, Langlois and Wilson 2001)."

The present diagnostic procedures are capable of isolating more than 60 genetic and developmental disorders. Some of these disorders are life-limiting, while others may result in delays in physical or cognitive developmental areas or both.

Now a new non-invasive prenatal genetic diagnostic test, called ‘chromosomal microarray analysis,’ is set to once again drastically increase the volume of information that is available about a fetus. This simple blood test will be able to be done much earlier in the pregnancy, whereas currently screening is done early and diagnostic tests such as amniocentesis or chorionic villus sampling is done later.

With the dawn of these new fetal technologies the question must be raised: are we ready? And indeed, as a society we must answer that we are not ready to consent to such new advancements without considering their social and ethical implications.

What is the Purpose of the Test?

Research shows that parents and practitioners often have differing perceptions of the purpose of prenatal genetic testing. While pregnant women request diagnostic tests for reassurance that their babies are well and healthy, practitioners often offer them as a way of preventing the birth of a "defective" child (Green 1995).

The capacity to diagnose prenatally is now vastly disproportionate to the capacity to ameliorate the various genetically related conditions. Rather than preventing or treating an illness or disability, the tests are often used to prevent the birth of individuals with certain undesired characteristics. This prevention is carried out in Canada and internationally through termination of pregnancy.

Due to problems with provincial and federal surveillance and data collection, accurate Canadian statistics cannot be calculated (Lowry 2008). It has been noted, though, that:

“Prenatal diagnosis and pregnancy termination for congenital anomalies have increased in recent years and have led to marked reductions in the birth prevalence of congenital

anomalies. Widespread availability of prenatal diagnosis for severe congenital anomalies and subsequent early termination of affected pregnancies led to sharp declines in late fetal and infant deaths due to congenital anomalies... however we do not have direct information on pregnancy terminations following prenatal diagnosis of a congenital anomaly, especially terminations carried out early in pregnancy (Liu S et al. 2002).”

One example of this reduction in birth prevalence of anomalies was found by Morris et al. They determined that the birth prevalence of children with neural tube defects (NTD) has dropped from 3.6 per 1000 in 1964 to 2.31 per 1000 in 2004. This was not primarily due to increase in folic acid intake as some may suspect, but rather “due to screening and termination of affected pregnancies.” They also note that there was a 52% rate of underreporting of terminations following prenatal screening (Morris and Wald 2007).

Although prenatal screening and subsequent termination are simply choices offered to pregnant women, Montreal Pediatric Neurologist Michael Shevell warns that “reasonable concerns exist 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” (Shevell 2007). At a time when families with children with disabilities and adults with disabilities are desperately requiring greater services, should society financially gain by the elimination of these pregnancies?

Aside from the option of terminating the pregnancy, prenatal diagnosis also affords parents the opportunity to more effectively care for a disabled child, since they can prepare to accommodate a child with special needs. A mother who discovers that her child will have Down syndrome (Trisomy 21), for instance, is able then to educate herself on how to properly manage any medical issues and to seek community resources for infants and children with developmental

disabilities. Close monitoring of the pregnancy and altered birthing plans can ensure the best possible outcomes for the mother and the affected fetus. Some fetuses are also able to benefit from treatment and even surgery while still in utero (SickKids 2009).

In a minority of cases, prenatal diagnosis reveals a genetic anomaly that has potential to limit the life expectancy of the child. This occurs in some, but not all, cases of Trisomy 13 or Trisomy 18, for example. Knowledge of a life-limiting fetal abnormality can be very difficult for families to assimilate, “instead of anticipating the arrival of a new baby, there is contemplation of the impending death of a loved one (Hoeldtke and Calhoun 2001)”. However, even in circumstances where neonatal death is common, families who receive prenatal diagnosis of such a condition can benefit from perinatal palliative care. Although not yet widely available, perinatal palliative care can provide appropriate comfort care for the terminally ill child and psychological care for the family. Similar to palliative care given to the elderly at the end of life, so too, the fetus is considered to be a patient worthy of treatment. Perinatal palliative care “focuses on enhancement of the quality of life for the child and support for the family (Leuthner and Jones 2007),” which in turn, can provide families with necessary psychological relief as they are given time to bond with their dying child and say goodbye in a nurturing environment.

Choosing Not to Screen

While prenatal screening is now available to all Canadian women, it is the pregnant woman’s decision whether or not to be screened. There have been *no* studies which evaluate the outcome for mothers who decline screening, but there is nonetheless evidence of social pressure toward testing as an expected requirement of pregnancy. It is known that children are born annually with conditions that have either been a) prenatally detected but the family chose not to

abort, or b) the family chose not to submit to the testing. Nordvig et al noted that the women who declined screening accounted for only half of the children born with Down Syndrome in Denmark after an expanded screening program was implemented (Nordvig, Secher and Hjort 2005). The outcome measure for the Nordvig study considered only the reduction in number of births of children with Down syndrome. Success was defined as eliminating more disabled children from the Danish population. Nonetheless, children with Down syndrome were born both to women who were screened, and to women who declined screening.

Another study showed that, of the women whose fetuses were found to have an anomaly, 30% expressed regret about their decision to screen (Green et al. 2004) and would have preferred to have chosen not to screen.

When parents who had one child with a disability already were asked whether they would choose to be screened during a subsequent pregnancy, many did not express desire for screening. As one mother said:

“If I had went as far as to consider having another child then I would have had it in my mind that no matter what it was, what happened, it would still be my child. Just like with her, I wouldn’t have considered [prenatal testing] at all (Kelly 2009).”

Although it is unclear that prenatal screening was developed in response to women’s desire for it, the comprehensive screening that is now routinely offered to all pregnant women influence society’s perceptions of pregnancy and testing. Suter found that in California, where, like Canada, they are legally required to offer the screening, more than one-third of women interviewed believed or suspected that the state required pregnant women to be screened (Suter 1996). Women risk being labelled as irresponsible or irrational by their physician and society if they refuse the test (Seavilleklein 2008). Rothman first wrote in 1986 about the phenomenon of

the ‘tentative pregnancy’ (Katz Rothman 1996) and the view that a pregnancy must be validated through prenatal testing before it is accepted. Because abortion is a norm, pregnancy becomes conditional until the child is proven ‘normal’, and parental love moves from being unconditional to conditional. Margaret Somerville wonders whether this will lead to promoting positive eugenics: “If parental love is conditional, will we only love them if they have certain positive traits that we have chosen? (Somerville)”

Medical Professionals Have Great Influence

Why do women decide to participate in prenatal diagnosis, and how do they make their decisions after receiving the results? The influence of medical professionals on decision making around prenatal diagnosis is very significant. Yilmaz noted that “Among the factors influencing parents’ decision making, the attitude of the health care professional giving the post diagnosis counselling, seems to be the most important, next to the socio-economic and educational background of the parents (Yilmaz 2008).” Nordvig reiterates that these professionals “have significant influence upon women’s decisions to accept risk assessment and to terminate an affected pregnancy (Nordvig, Secher and Hjort 2005).”

There are grave concerns that medical professionals may be predisposed to certain approaches to counselling. They may subtly promote prenatal testing and abortion in deference to the use of medical information, and a belief that patients desire the maximum amount of information. Time constraints, fear of liability, little genetic training, and the practice of directiveness can also lead to a negative tone that medical professionals use when counselling post diagnosis (Dixon 2008). These pressures should be addressed in order to ensure proper counselling before and after prenatal testing. Research shows that 40% to 80% of parents who

are offered the option of perinatal palliative care, a supportive option for parents whose child has been diagnosed with a life-limiting anomaly, request this care and choose to continue their pregnancy (Calhoun et al. 2003) (Breeze et al. 2007). The assurance of care for the entire duration of their child's life, no matter how long or short it might be, influences parents confidence in parenting children with a genetic anomaly. In the absence of options like these and supportive care from their medical professionals, are women being offered real choices after a prenatal genetic diagnosis?

The development of prenatal screening has also increased the occurrence of wrongful birth lawsuits (Pioro et al. 2008), which are premised on the right of parents to abort a fetus due to genetic anomaly, and wrongful life lawsuits, which are premised on the right of children not to have been born. These lawsuits add additional pressure, and may lead physicians to positively encourage screening rather than neutrally offering it as an option. Autonomy of the pregnant woman and the legal protection that comes from eliciting fully informed consent often drives the process around the decision to test.

However, many have noted how difficult it is to “determine both what is material and what to disclose to each particular patient” (Polansky 2006) in order to obtain informed consent.

While the standard among health care practitioners is to offer prenatal testing in the framework of a woman's autonomy and informed consent, many are questioning whether informed consent is happening. In 78 studies, the overwhelming conclusion was that the current procedures are inadequate for achieving informed consent (Seavilleklein 2008). Challenges in disclosure due to the lack of time that physicians have to explain the test coupled with social and legal pressures that might limit the voluntariness of the decision make informed consent very difficult to achieve. Now with the new microarray test which is in development there will be an

additional level of complexity to the information that will be generated. How much of this information must be conveyed by physicians and genetic counsellors to women and their partners in order to meet the standards of fully informed consent? As a result, how much more difficult and stressful will post diagnostic decisions become?

As Chris Trevors of the Canadian Association of Genetic Counsellors warns, “the difference is the volume of information you are getting... People look for health care providers to guide them on how to interpret this info, and if we can’t, I don’t think we should be offering it (Collier 2008).”

Given the many problems with current informed consent practise, Canadian researchers Lawson and Pierson have concluded that “individual focus of rational choice models have informed counselling protocols, but these may be too narrow to encompass the social and psychological factors relevant to making a decision about testing (Lawson and Pierson 2007).”

Disability

Widespread prenatal screening also has significant implications for the disability rights movement. As a report from York University’s Roeher Institute noted, “on one hand we celebrate and broadcast the Special Olympics, on the other hand we systematically screen women for Down syndrome with the goal of preventing such births (Crawford 2002-2003).”

The social and political context in which parents make decisions around prenatal testing may also have a great influence on which choices they make. Prenatal testing offers the specific choice to not have a child with a physical and or developmental disability. One factor is whether or not there are sufficient supports for raising a child with a disability. Another is whether or not

parents are given accurate information on the nature of the disabling condition, and the level of support available to them after their child is born (Seavilleklein 2008).

Dixon states that “the premise of the disability rights movement is that persons with disabilities are disadvantaged far more by negative social attitudes than by their disabilities (Dixon 2008).”

In 2009, the Canadian Association for Community Living, Canada’s largest federation supporting people with intellectual disabilities, commented on the danger of the pressures around prenatal testing:

“The active devaluation of the lives of persons with disabilities is a disturbing trend. Misinformation about disability is a real concern for individuals and families who live with disability. The lack of public discussion about the impact of devaluation makes people with disabilities and their families extremely vulnerable... The increased demand for prenatal testing and the pressure prospective parents experience to terminate when an “anomaly” is detected risks leading us down a dangerous road reminiscent of our eugenic past (Canadian Association for Community Living 2009).”

In Germany, a nation which has suffered the effects of a eugenic mentality most drastically, ethics institutes are warning of unrealistic notions of disability that are leading parents and physicians to favour termination after a genetic anomaly is detected:

“The search for the distinctive features of the fetus is today one of the principal aims of the pregnancy precautions. Should indications of a possible disability of the unborn children be found, the pregnancy will most of the time be broken off. This is common with the socially predominant understanding that regards a life with a disabled child as

reasonably difficult. Mostly unrealistic ideas play a crucial role over the life with a disability child both with future parents and the physicians (IMEW 2009).”

Those who advocate for the disabled are concerned that the decisions after prenatal testing are often informed only by confusing medical results. They are often ill-informed about the holistic nature of the possible conditions and outcomes for the child that the tests indicate. Many have expressed disappointment that the information provided stresses only the negative aspects of having a child with such a condition. Little emphasis is placed on the possible benefits of a disabled child to the family.

The experience of parents receiving prenatal diagnosis has received little attention in research. One study of mothers who have a child with Down syndrome focussed on the prenatal testing experiences. The mothers reported that they were scared and anxious after receiving the positive test results. Their physician had not adequately explained Down syndrome to them before or after the test. In fact, most mothers reported receiving misinformation or were directed toward a termination of pregnancy. The range of ability that their child might have was not discussed, and many reported insensitive language used by the counselling physician (Skotko 2005). “Prospective parents tend to be told negative things ... like ‘this child will ruin your life ... it will be hard on your life, hard on your kids, ruin your marriage’” reiterates Krista Flint of the Canadian Down Syndrome Society. “You don't hear about those who enrich the lives of others, who go to school, get married, get jobs (Abraham 2009).”

Despite the shock and grief that many experience upon hearing the news of a fetal anomaly, the pregnant woman and her partner are usually urged to make the decision to terminate quickly (Ring-Cassidy and Gentles 2003). Very little time is allowed for couples to become informed

about parenting children born with an anomaly and to consider carrying through with the pregnancy.

Psychological Impact of Decisions Following Testing

One risk that may not be adequately disclosed to parents when they choose to undergo prenatal diagnosis is the potential for psychological distress following their decisions. As previously noted, 30% of parents who received positive test results regretted their decision to screen (Green et al. 2004).

In addition, while for many the termination of pregnancy is an attempt to eliminate suffering, research finds that 40% of women who abort for fetal abnormality suffer long-term emotional distress. In fact, research reveals that the distress does not diminish over time. A leading psychiatrist writes that "Women 2-7 years after were expected to show a significantly lower degree of traumatic experience & grief than women 14 days after termination ... Contrary to hypothesis, however, the results showed no significant intergroup differences (Kersting 2005)."

Another study found that 44% of women had posttraumatic stress symptoms, and 28% had symptoms of depression after terminating for fetal anomaly (Korenromp et al. 2007). Some women continue to grieve for years after terminating their pregnancy due to fetal abnormalities. This depression and grief can, for some women, become too much to bear. The rate of suicide after termination increases for women, while suicides actually decrease for women who carry a child to term (Gissler, Berg and Bouvier-Colle 2004).

Others, who might have made the decision to terminate, later change their mind about raising a child with a genetic anomaly. Michael Shaw, Chair of the Canadian Down Syndrome Society,

commented that if he and his wife had had prenatal testing, they would have terminated. "I know there would be no Sydney, and that tears me apart now. She's a wonderful, joyous child (The Ottawa Citizen 2008)."

The rationalization often given for termination after prenatal testing is "Maternal Necessity": that a fetal abnormality will "jeopardize her [a mother's] own health and future fertility (Jackson-Lee 1997)." However, while carrying a child with a disability might greatly influence a mother's psychological health, her physical health might not be affected. The very real risks to maternal psychological health have been discussed. Maternal physical health is sometimes cited, (United Nations Population Division Department of Economic and Social Affairs 2002) but there is no supporting scientific evidence provided that usual fetal abnormalities for which abortions are requested (Medical Practitioners Board of Victoria 1998) such as Down syndrome and cleft palate have any deleterious physical health effects on the mother.

In fact, there is no maternal medical condition that can't be treated while continuing the pregnancy, except for three rare conditions. A report on late-term abortions from the Medical Practitioner's Board of Victoria, Australia states that "There are a very small number of fetal conditions where the progression of the pregnancy may lead to significant maternal morbidity or mortality. These conditions are rare (Medical Practitioners Board of Victoria 1998)." Moreover, these conditions have available treatments for the mother with high success rates.

De Crespigny and Savulescu found in 2002 that "the current practice often appears to depend primarily on the doctor's subjective assessment of the severity of the abnormality (De Crespigny and Savulescu 2002)." Given that physicians have significant influence when consulted by parents after the detection of fetal abnormality, it is a matter of professional

responsibility for a physician not to make claims which have no supporting scientific evidence, such as recommending an abortion to preserve mother's physical health from the effects of a fetal abnormality when no relation between the two has been documented.

For the Betterment of Women

The rapid expansion of prenatal genetic testing has increased the amount of medical information that we can know about a child before birth. However, this information is both complex and overwhelming. There is no corresponding ethical framework in which these results can be placed, so that the families are dependent on the capacities of their attending physician or counsellor to interpret the myriad data and the implications surrounding the decisions that arise. Prenatal diagnosis has brought to the physician's office increasing challenges in obtaining a fully informed consent, and in respecting a woman's autonomy while giving appropriate support and information. These new technologies have raised important questions about the value of disabled people in society, and the way that we care for the disabled. Diagnostic capabilities have far surpassed our ability to improve the lives of individuals with genetic conditions. The use of prenatal testing to diagnose and eliminate individuals with certain genetic conditions is eugenics.

Additionally, many women are not fully informed of the risk of psychological distress after terminating a pregnancy. Many could be saved the trauma of abortion if given more awareness of their options. The bipartisan bill "Prenatally and Postnatally Diagnosed Conditions Awareness Act" that passed in the United States is a positive step toward ensuring that parents are provided with accurate information from appropriate sources about the conditions that may be detected through prenatal diagnosis. More co-ordinated efforts to communicate the full range

of knowledge about the genetic information to which we now have access, and increasing awareness about and access to options for improving the lives of the disabled and their families in society, will help to ensure that new prenatal genetic diagnosis technologies are used for the betterment of women, children and society.

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