

From Iran to Latin America: Must Prenatal Diagnosis Necessarily Be Provided With Abortion for Congenital Abnormalities?

Daniel Sperling, Hebrew University of Jerusalem

Prenatal diagnosis and antenatal screening (PND/S) refer to various methods to identify before birth or conception the genetic conditions known to affect the neonate. In their recent article, Angela Ballantyne and colleagues examine a disturbing practice taken place in the Latin American region, according to which PND/S are offered despite legal prohibitions to terminate pregnancy in case of severe genetic abnormalities. The following article examines the question of whether it is ethical to introduce and provide prenatal diagnosis and antenatal screening in areas where termination of pregnancy for congenital abnormalities is legally prohibited. The article further explores the various reasons according to which people seek prenatal genetic information and the factors affecting their decision to continue pregnancy despite congenital abnormalities. It concludes that with a proper emotional support and cultural sensitivity it is ethically justifiable to introduce prenatal diagnostic tests and screening, and that taken as a whole, the benefits of such an introduction outweigh the general harm already associated with restrictive abortion laws.

Resting on a disputed assumption that these services are offered for every woman upon request (Penchaszadeh and Beiguelman 1998; Rivera-Lopez 2002, 16), it is argued that the introduction of such tests appears to harm poor women of that region by forcing them to carry a fetus with congenital conditions to full term (Ballantyne et al. 2009). As it was previously illuminated in the context of Sri Lanka (Simpson 2007), the discussion of such a practice reflects how essential it is to evaluate technology in its action and to regard it as one actor among many in changing and coordinating clinical and organizational aspects of health care (Latour 1987). It also sheds light on the false assumption that detection of disease is and should be separable from designing a treatment or a medical course for such a disease, including the termination of pregnancy, thereby freeing the first from pragmatic considerations such as social factors, values, culture, religion and so forth (Mol and Elsmann 1995). Although the authors' ambition seems worthy of consideration their only practical conclusions are to argue for a "greater attention" (Ballantyne et al. 2009, 48) to such a practice and encourage geneticists, physicians and policy makers to "represent the plight of [these] poor women"

(48). While this political agenda may be legitimate and in need, the actual recommendation derived from it is far from clear.

Three forms of harm are identified with offering PND/S in the absence of safe and legal abortion: psychological trauma to and disempowerment of affected women who are forced to continue pregnancy; violation of procreative autonomy and disproportionate and unjust burden of unsafe abortions falling mostly on poor women; and placing of financial strains on poor families and overburdened public health systems by raising and supporting children with genetic and congenital conditions (Ballantyne et al. 2009). Nevertheless, the attributed harm—despite its forceful merit—does not appear to be special to the 'therapeutic gap', namely the gap between availability of prenatal screening and diagnosing and the legal prohibition to terminate pregnancy based on fetal abnormalities. Such harm may be attributed—as it is frequently referred—to the more general situations where access to safe and legal abortions in case of serious fetal abnormalities is lacking or prohibited. Indeed, when access to abortions is limited, the proportion of unsafe and illegal abortions increases, leading to higher health risks and maternal mortality. Even if such harm is exacerbated as a result of genetic testing—and this has to be tested empirically—there may still be some benefits that outweigh the harm already associated with restrictive abortion laws.

It is believed that the main reason for screening and diagnostic testing in pregnancy is to detect genetic abnormalities and to allow women to choose whether continue or terminate pregnancy. However, empirical data examining such a belief mainly relate to hypothetical statements made by individuals and hardly represent people's actual decisions which may be affected by a varied group of factors and considerations, including but not limited to the expected prognosis, societal acceptance of the disability, parental perceptions, environmental familiarity with the disability, orientation of the medical team, maternal age, self/medical referral, social stigma and isolation associated with abortion procedures, single/multiple gestation with different result in each fetus, etc. (Quadrelli et al. 2007).

Address correspondence to Daniel Sperling, Federmann School of Public Policy and Government; Braun School of Public Health and Community Medicine, Hebrew University of Jerusalem, Mount Scopus, Jerusalem 91905, Israel. E-mail: dsperling@mscc.huji.ac.il

Indeed, there are many other advantages and potential benefits of detecting fetal abnormalities beforehand, all of which are found empirically significant even within regions or among cultures where termination of pregnancy is illegal or unacceptable. Early detection of diseases or being a carrier may provide prospective parents with valuable and requisite information concerning the health of their future child. Receiving such information, which may be supported by the parents' / pregnant woman's rights to personal autonomy and the more specific medico-legal "right to know", avoids unnecessary obstetrical intervention and reassures parents when pregnancy is normal. In case of positive finding, it may also better prepare for the malformed child, reduce fear and anxiety, allow obstetrician to follow better the pregnancy and the delivery itself (where congenital disorders may cause risk during delivery), and provide better health care to the newborn (Gadow et al. 2006). When *in utero* gene therapy is or will be available, early diagnosis will also prevent the development of severe manifestations of early or late onset diseases in the affected child. Other than that, screening may still be valuable in such regions if introduced to teenagers for the purpose of successful matching, like it is practiced today in Iran (Saniei et al. 2008) and—with the help of an organization called "Dor Yeshorim"—by Ultra Orthodox Jews throughout the world. Last, but not least, future parents to a child suffering from a serious congenital abnormality (eg, anencephaly) may still want to be informed about this condition in advance. Such parents can choose to deliver this child, and once dead donate her organs to save the lives of other children, thereby fulfilling—through the act of donation—the child's interest in her symbolic existence after death (Sperling, 2008a; Sperling, 2008b).

Hence, it is not surprising that attitudes towards genetic testing need not coincide with those relating to termination of pregnancy. A study performed in Argentina and Uruguay found, for example that only 68.2% of couples would consider termination of pregnancy if a serious fetal anomaly was diagnosed yet 88.8% regarded genetic testing very or extremely important (Gadow et al. 2006). Another study based in Argentina demonstrated that although none of the 165 respondents who were parents to children with non-syndromic oral cleft (NSOC) would terminate a pregnancy because the ultrasound revealed NSOC, and only 9% would terminate for early diagnosis of Down syndrome, 83.4% of them said they wished they had known about such conditions before the child was born and 53.2% considered prenatal diagnosis extremely important (Wyszynski et al., 2003). Same tension between strong acceptance of the idea of prenatal diagnosis and salient refusal of abortion is also evidenced in Saudi Arabia (Alkuraya and Kilani, 2001) and among Pakistani pregnant women living in the UK (Ahmed et al. 2006; Hewison et al. 2007).

Arguing unfavorably against the introduction of genetic tests and screening in areas where abortions for congenital abnormalities are prohibited also rests on simplistic assumptions on individuals' choices and beliefs concerning

termination of pregnancy. It assumes that the only, or most dominant, impediment for termination of pregnancy is legal. However, empirical data reveal that there are many factors influencing the decision to continue pregnancy, most dominantly women's "inner voice" and personal feelings, religion, partner's opinion, relevant material they find on their own, discussion with other parents to a child suffering from the disease, and positive images of persons living with that disease (Skotko 2005; Moyer et al. 1999). The legal official position on abortions—unfortunately or not—hardly receives any meaningful weight in shaping individuals' behaviors and decisions of whether to cease or continue pregnancy. Furthermore, the law may still be open to more liberal interpretations by courts in individual cases, like it is practiced in Brazil and other parts of Latin America, and following influential public debate, be changed or partly reversed, like in Iran or Argentina (Ballantyne et al. 2009). More generally, and regardless of the formal legal position on abortions for congenital abnormalities, one has to carefully consider whether the law should play a central role in determining the ethical obligations of physicians and geneticists concerning PND/S. Although law has contributed significantly to reasoning and discourse in bioethics by shaping and constraining duties and responsibilities of the medical professions, it has done so with considerable troubling implications (Sperling 2008c).

It follows that Ballantyne and colleagues (2009) main arguments rest on problematic assumptions concerning the reasons for consuming genetic services and the factors leading to termination of pregnancy. Paradoxically, if one takes these arguments seriously, they may not have much convincing power in areas where it is reasonable to assume that restrictive abortion laws (resting on a forceful Catholic moral doctrine) will hardly be transformed (Cook and Dickens 2002, 73–74). As this article showed, one's decision to seek prenatal genetic information and to manage such information are affected by a variety of aspects that cannot and should not be reduced to the question of whether selective abortions are legally prohibited or not. At times, and as demonstrated in Iran for example, the introduction of such tests results in more liberated laws, diminishing the harm associated with selective abortions. At other times, and when no change in the law is apparent, there is still considerable value in their introduction. Hence, it is ethical to provide, with proper emotional support and cultural sensitivity, prenatal diagnosis and antenatal screening in such areas where abortions for congenital abnormalities are legally prohibited, if people consuming them are—on the whole—more likely to benefit from these services than be harmed by them in pursuance with their own ideologies, values, religions and cultures, which may—but not necessarily—be reflected in their laws.

REFERENCES

- Ahmed, S., J. M. Green, and J. Hewison. 2006. Attitudes towards prenatal diagnosis and termination of pregnancy for thalassaemia

- in pregnant Pakistani women in the north of England. *Prenatal Diagnosis* 26(3): 248–257.
- Alkuraya, F. S. and R. A. Kilani. 2001. Attitudes of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling, ed. Fatwa. *Prenatal Diagnosis* 21: 448–451.
- Ballantyne, A., A. Newson, F. Luna, and R. Ashcroft. 2009. Prenatal diagnosis and abortion for congenital abnormalities: Is it ethical to provide one without the other? *American Journal of Bioethics* 9(8): XX–XX.
- Cook, R. J. and B. M. Dickens. 2002. Law and bioethics: The injustice of unsafe motherhood. *Developing World Bioethics* 2(1): 64–81.
- Gadow, E., F. Petracchi, L. Igarzabal, A. Gadow, R. Quadrelli, and H. Krupitzki. 2006. Awareness and attitude toward prenatal diagnosis of chromosomal abnormalities in patients with no access to legal termination of pregnancy. *Prenatal Diagnosis* 26: 885–891.
- Hewison, J., J. M. Green, S. Ahmed, H. S. Cuckle, J. Hirst, C. Hucknall, et. al. 2007. Attitudes to prenatal testing and termination of pregnancy for fetal abnormality: A comparison of White and Pakistani women in the United Kingdom. *Prenatal Diagnosis* 27(5): 419–430.
- Latour, B. 1987. *Science in Action: How to Follow Scientists and Engineers Through Society*. Cambridge, MA: Harvard University Press.
- Mol, A. and Elsmann, B. 1995. Detecting disease and designing treatment: Duplex and the diagnosis of diseased leg vessels. *Sociology of Health & Illness* 18(5): 609–631.
- Moyer, A., B. Brown, E. Gates, M. Daniels, H. D. Brown, and M. Kuppermann. 1999. Decisions about testing for chromosomal disorders: Perceptions of a diverse group of pregnant women. *Journal of Women's Health & Gender-Based Medicine* 8(4): 521–531.
- Penchaszadeh, V. B. and B. Beiguelman. 1998. Medical genetic services in Latin America: Report of a meeting experts. *Revista Panamericana de Salud Publica* 3(6): 409–420.
- Quadrelli, R., A. Quadrelli, B. Mechoso, M. Laufer, C. Jaumandreu, and A. Vaglio. 2007. Parental decisions to abort or continue a pregnancy following prenatal diagnosis of chromosomal abnormalities in a setting where termination of pregnancy is not legally available. *Prenatal Diagnosis* 27: 228–232.
- Rivera-Lopez, E. 2002. Ethics and genetics in Latin America. *Developing World Bioethics* 2(1): 11–20.
- Saniei, M., E. J. Mehr, S. Shahraz, L. N. Zahedi, A. M. Rad, S. Sayar, et al. 2008. Prenatal screening and counseling in Iran and ethical dilemmas. *Community Genetics* 11: 267–272.
- Simpson, B. 2007. Negotiating the therapeutic gap: Prenatal diagnosis and termination of pregnancy in Sri Lanka. *Journal of Bioethical Inquiry* 4(3): 207–215.
- Skotko, B. G. 2005. Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics and Gynecology* 192: 670–677.
- Sperling, D. 2008a. Me or mine? On property from personhood, symbolic existence, and motivation to donate organs. In *Organ Transplantation: Ethical, Legal, and Psychological Aspects—Towards a Common European Policy*, eds. W. Weimer, M. A. Bos, and J. J. van Busschbach/Lengerich, UK: PABST Science Publishers, 463–470.
- Sperling, D. 2008b. *Posthumous Interests: Legal and Ethical Perspectives*. Cambridge, UK: Cambridge University Press.
- Sperling, D. 2008c. Law and bioethics: A rights-based relationship and its troubling implications. *Current Legal Issues* 11: 52–78.
- Wyszynski D.F., Perandones, C. and Bennun, R.D. 2003. Attitudes toward prenatal diagnosis, termination of pregnancy and reproduction by parents of children with nonsyndromic oral clefts in Argentina. *Prenatal Diagnosis* 23: 722–727.

An Unjustified Exception to an Unjust Law?

David Wasserman, Yeshiva University
Adrienne Asch, Yeshiva University

Ballentyne and colleagues (2009) describe the cruel dilemma faced by poor women in developing countries permitted to test for congenital disabilities but not permitted to abort if such disabilities are detected. These women, the authors argue, are placed

in the position of making an unjust choice: a choice between continuing with a pregnancy they do not want and cannot afford...or exposing themselves to the legal, financial, social, emotional, and physical risks of an unsafe abortion...It is unjust to allow those who already enjoy socioeconomic

Acknowledgment: The authors gratefully acknowledge the support of NIH/NHGRI Grant No: 1R03HG004249-01 for work on this commentary.

Address correspondence to David Wasserman, Center for Ethics at Yeshiva University, 917 Belfer Hall, 2495 Amsterdam Ave. New York, NY 10033. E-mail: dwasserm@yu.edu