

CHALLENGING THE RHETORIC OF CHOICE IN PRENATAL SCREENING

VICTORIA SEAVILLEKLEIN

Keywords

prenatal screening, autonomy, choice, informed consent, relational autonomy, maternal serum screening, ethics

ABSTRACT

Prenatal screening, consisting of maternal serum screening and nuchal translucency screening, is on the verge of expansion, both by being offered to more pregnant women and by screening for more conditions. The Society of Obstetricians and Gynaecologists of Canada and the American College of Obstetricians and Gynecologists have each recently recommended that screening be extended to all pregnant women regardless of age, disease history, or risk status. This screening is commonly justified by appeal to the value of autonomy, or women's choice. In this paper, I critically examine the value of autonomy in the context of prenatal screening to determine whether it justifies the routine offer of screening and the expansion of screening services. I argue that in the vast majority of cases the option of prenatal screening does not promote or protect women's autonomy. Both a narrow conception of choice as informed consent and a broad conception of choice as relational reveal difficulties in achieving adequate standards of free informed choice. While there are reasons to worry that women's autonomy is not being protected or promoted within the limited scope of current practice, we should hesitate before normalizing it as part of standard prenatal care for all.

I. INTRODUCTION

Prenatal screening in Canada is on the verge of expanding in multiple different directions. This screening, consisting of maternal serum screening and nuchal translucency screening, is designed to identify pregnant women likely to have fetuses with chromosomal anomalies and open neural tube defects; once identified, these women can be offered further diagnostic testing with the option of abortion if test results are positive. While prenatal screening has traditionally been limited to pregnant women considered to be 'high-risk', the Society of Obstetricians and Gynaecologists of Canada (SOGC) has recently recommended that it be offered to all pregnant women regard-

less of age, disease history or risk status.¹ Similar recommendations have been made by the American College of Obstetricians and Gynecologists (ACOG).² In addition to broadening the target population of screening, the number of conditions being screened for is likely to increase. For decades, prenatal screening has been used to screen for Down syndrome, open neural tube defects, and Trisomy 18. Current studies, however, show

¹ A. Summers et al. Prenatal Screening for Fetal Aneuploidy – SOGC Clinical Practice Guidelines. *J Soc Obstet Gynaecol Can.* 2007; 29: 146–161.

² American College of Obstetricians and Gynecologists. ACOG Practice Bulletin no. 77: Screening for Fetal Chromosomal Abnormalities. *Obstet Gynecol.* 2007; 109: 217–228.

Address for correspondence: Victoria Seavilleklein, PhD, Joint Centre for Bioethics, University of Toronto, 88 College Street, Toronto, Ontario, Canada, M5G 1L4. Email: v.seavilleklein@utoronto.ca

that prenatal screens might also be used to detect conditions such as Smith-Lemli-Opitz syndrome,³ Trisomy 13, Turner's syndrome,⁴ and cystic fibrosis.⁵ Hence, this particular juncture is an ideal moment to pause and reflect on the reasons for this proliferation of screening and the values that it is deemed to support.

One of the principal values that is offered in support of prenatal screening is autonomy. The value of autonomy, often framed in terms of women's choice, is widely recognized by those who fund, research, develop, and implement prenatal screening⁶ and is central in obstetrics and genetics departments and public information pamphlets.⁷ Even those who object to some or many aspects of prenatal screening, such as disability rights activists, prioritize autonomy when they state that decisions about the kind of children one will raise – if such decisions must be made at all – are better left to individual women than to society or the medical profession.⁸ In this paper, I critically examine the value of autonomy in the context of prenatal screening to determine whether it justifies the expansion of prenatal screening to all pregnant women. I argue that current screening practice does not protect or promote women's autonomy in the vast majority of cases, either on a narrow analysis of choice reflecting individual autonomy or on a broad analysis of choice reflecting relational autonomy. Consequently, we should hesitate before expanding screening to more pregnant women.

³ Smith-Lemli-Opitz syndrome is already being screened for in some health districts, e.g. Nova Scotia.

⁴ Summers et al., *op. cit.* note 1.

⁵ The SOGC does not currently recommend prenatal screening for cystic fibrosis (R.D. Wilson. Cystic Fibrosis Carrier Testing in Pregnancy in Canada – SOGC Committee Opinion. *J Obstet Gynaecol Can.* 2002; 24: 644–647). However, it may soon be offered as part of routine screening in the US (CBC Radio One. August 15, 2007. Preparing Parents for the News: Interview with Dr. David Young. *Information Mornings*. Available at: <http://www.cbc.ca/informationmornings/interviews.html> [Accessed 1 Nov 2007].

⁶ For example, see E.M. Hutton et al. Practice Guidelines for Health Care Providers Involved in Prenatal Screening and Diagnosis. *SOGC Clinical Practice Guidelines*. 1998: 1–5.

⁷ For example, see Ontario Maternal Serum Screening Steering Committee. 2004. *Integrated Prenatal Screening (IPS): It's Your Choice*. Available at: <http://www.lhsc.on.ca/programs/rmgc/mss/pamphlet.htm> [Accessed 1 Nov 2007]; Women's and Children's Health Programs: Obstetrics/Gynaecology. *Maternal Serum Testing: A Pamphlet for Women who are Pregnant, or Planning Pregnancy*. Available at: <http://www.ahsc.health.nb.ca/prenatalscreening/PrintableMaterials6.htm> [Accessed 1 Nov 2007].

⁸ E. Parens & A. Asch. 2000. The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations. In *Prenatal Testing and Disability Rights*. E. Parens & A. Asch, eds. Washington, D.C.: Georgetown University Press: 3–43.

II. AUTONOMY AND INFORMED CONSENT

The value of autonomy is deeply entrenched in contemporary society. It is a reflection of broad social-political change brought about in the second half of the 20th century by second-wave feminism, the civil rights movement in the US, and the development of the Charter of Rights and Freedoms in the new Canadian Constitution. It also represents efforts to distance current genetics practices from the coercive and discriminatory practices of past eugenics movements and from other abuses in human experimentation and clinical medicine.

Despite its importance in society and particularly in genetics, there is incontrovertible evidence that women are not making free informed choices about prenatal screening. Autonomy is protected in health care by the theory and practice of informed consent, the most authoritative and widely disseminated theory of which is described by Tom Beauchamp and James Childress.⁹ In a specific decision-making context, informed consent is deemed to be reached if the person is competent, if adequate standards of disclosure and understanding about the intervention are attained, and if consent (i.e. authorization) is given voluntarily. According to studies conducted in North America and in the Western world, informed consent is not being met in the vast majority of cases in prenatal screening.¹⁰ In particular, a recent Health Technology Assessment, conducted by Green et al. for the UK's National Health Service, identified and surveyed 78 studies that have been conducted internationally about the psychosocial implications of prenatal screening. Most of these studies were conducted in the US and the UK, although several are from Canada and other European countries. The overwhelming conclusion drawn from all of this research concerned 'the inadequacy of current procedures for achieving informed consent'.¹¹

⁹ T. Beauchamp & J. Childress. 2001. *Principles of Biomedical Ethics*. 5th edn. New York, New York: Oxford University Press. For a thorough exploration of an earlier account, see R. Faden, T. Beauchamp & N. King. 1986. *A History and Theory of Informed Consent*. New York, New York: Oxford University Press.

¹⁰ J.M. Green et al. Psychosocial Aspects of Genetic Screening of Pregnant Women and Newborns: A Systematic Review. *Health Technol Assess.* 2004; 8: iii, ix–x, 1–109; V. Goel et al. Evaluating Patient's Knowledge of Maternal Serum Screening. *Prenat Diagn.* 1996; 16: 425–430; A.M. Jaques, L.J. Sheffield & J.L. Halliday. Informed Choice in Women Attending Private Clinics to Undergo First-Trimester Screening for Down Syndrome. *Prenat Diagn.* 2005; 25: 656–664; J. Gekas et al. Informed Consent to Serum Screening for Down Syndrome: Are Women Given Adequate Information? *Prenat Diagn.* 1999; 19: 1–7.

¹¹ Green et al., *op. cit.* note 10, p. 76.

There is no one element of informed consent that consistently fails to achieve an adequate threshold level in prenatal screening. Rather, any of disclosure, understanding, voluntariness and consent¹² can be challenged as inadequate in light of the empirical evidence of current practice. I will give some examples of each. First of all, while some pregnant women may not be competent to give informed consent, the vast majority of women are and so this pre-condition for decision-making is not a central concern in most analyses.

Disclosure is important because its quality determines women's ability to understand the test. The SOGC recommends that the following information be provided to pregnant women prior to a screening test:

details about the conditions being screened, the likelihood of detection, the method of screening, the meaning of a screen-positive result and a screen-negative result, the choices following a screen-positive result (amniotic fluid alpha fetoprotein, acetylcholinesterase and fetal karyotype, detailed ultrasound for fetal anomaly), the choices following a positive diagnosis (abortion or continuation of the pregnancy) and details as to how further information can be obtained.¹³

While full counselling is not recommended, this still encompasses a great deal of information to disclose in a short clinical encounter. Describing the details of the conditions screened for alone will take several minutes.¹⁴ Nevertheless, a 1993 report of the Royal Commission on New Reproductive Technologies revealed that physicians spent less than five minutes on average discussing maternal serum screening.¹⁵ A US study reported a discussion

time of approximately two minutes.¹⁶ This is a very limited period of time in which to disclose all the relevant material listed by the SOGC. In practice, relevant details are often disclosed incorrectly to pregnant women,¹⁷ not disclosed at all (such as the possibility of abortion if consequent tests are positive), or a discussion does not even take place.¹⁸

In health care, patients must not only be given information relevant to their decision-making, they must also understand the information that they have been given. Full understanding is not required for informed consent but patients should understand the salient aspects of the proposed procedure and the consequences of proceeding with the intervention or not.¹⁹ Studies evaluating women's knowledge and understanding of prenatal screening overwhelmingly show that women do not understand the testing, including basic facts such as why the test is being done, what conditions are being looked for, what the results mean, and what will (or may) follow after testing.²⁰ These findings are the same both for women who choose to have testing and for those who decline.²¹ Researchers of one of the most comprehensive studies done on this topic in Canada concluded that despite the high educational level of their study cohort and the existence of a well-organized provincial screening program, there were 'information gaps overall and in all domains.'²²

A contributing factor to this difficulty in comprehension may be that probabilities are very difficult for people to understand. For example, when women are told that they have an increased risk of having a fetus with Down syndrome, some women think this means a) that they

¹² 'Consent' should not be confused with 'informed consent'. Consent is one of the elements of informed consent, and simply refers to the decision that is made to accept or decline a medical intervention. For example, agreeing to a procedure *without proper discussion or understanding* would satisfy the criterion of consent, but informed consent would not be achieved because adequate threshold levels of the other three elements would not also have been met.

¹³ J. Johnson & A. Summers. Prenatal Genetic Screening for Down Syndrome and Open Neural Tube Defects Using Maternal Serum Marker Screening. *SOGC Clinical Practice Guidelines: Committee Opinion*. 1999: 4.

¹⁴ For example, Down syndrome, Trisomy 18, and open neural tube defects are all known by other names (Trisomy 21, Edwards' syndrome, spina bifida, myelomeningocele) and each is distinct and variable in terms of clinical outcomes and clinical expression. It is also important to clarify the non-medical aspects of the conditions.

¹⁵ B.N. Chodirker & J.A. Evans. 1993. Maternal Serum AFP Screening: The Manitoba Experience. In *Current Practice of Prenatal Diagnosis in Canada: Research Studies of the Royal Commission on New Reproductive Technologies*, Vol. 13. Royal Commission on New Reproductive Technologies, ed. Ottawa, Ontario: Canada Communications Group: 535–610.

¹⁶ N. Press & C. Browner. 1994. Collective Silences, Collective Fictions: How Prenatal Diagnostic Testing Became Part of Routine Prenatal Care. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. K.H. Rothenberg & E.J. Thomson, eds. Columbus, Ohio: Ohio State University Press: 201–218.

¹⁷ Chodirker & Evans, *op. cit.* note 15, pp. 577–582; J.C. Carroll et al. Ontario Maternal Serum Screening Program: Practices, Knowledge and Opinions of Health Care Providers. *Can Med Assoc J*. 1997; 156: 775–784.

¹⁸ Of almost a thousand women surveyed in Ontario just before many of them were about to undergo maternal serum screening, almost half (48%) reported that they had not discussed the screen with their health care provider (Goel et al., *op. cit.* note 10.)

¹⁹ Beauchamp & Childress, *op. cit.* note 9; Faden & Beauchamp, *op. cit.* note 9.

²⁰ Green et al., *op. cit.* note 10; Goel et al., *op. cit.* note 10; Jaques et al., *op. cit.* note 10; Gekas et al., *op. cit.* note 10; Press & Browner, *op. cit.* note 16.

²¹ Goel et al., *op. cit.* note 10; Press & Browner, *op. cit.* note 16.

²² Goel et al., *op. cit.* note 10, p. 428.

have a fetus with Down syndrome²³ or b) that their chance of having a child with Down syndrome is 50-50.²⁴ This reaction reflects the difficulty in applying a population statistic at an individual level; after all, a chance of 1 in 250 of having a child with a certain condition is meaningful when considering a group of 250 women, but it does not say anything specific about the child of any particular woman in that group.

Once the relevant information has been disclosed and understood, a decision must be made voluntarily, or in the absence of a substantially controlling influence.²⁵ Whether an act is controlled, non-controlled, or somewhere in between depends on the degree to which a patient acts on the basis of her own will. The most obvious cases where voluntariness is undermined are when women are not asked for their authorization at all or when they believe that testing is mandatory. Screening was originally performed frequently without giving women the ability to consent or decline. For example, in the first Canadian prenatal screening program, established in Manitoba in 1985, only 38% of clinicians asked for women's express consent for maternal serum alpha-fetoprotein (AFP) screening while more than 40% incorporated the test into routine blood work without asking for consent.²⁶ A more recent prospective study performed in Ontario in 1996 found that 360 out of 941 respondents reported that they had not been given a choice about having maternal serum screening.²⁷ Their belief that they did not have a choice about testing is sufficient to undermine voluntariness.

The influence that a health-care provider has on a woman's decision-making is widely recorded in the literature on prenatal diagnosis,²⁸ with decision-making correlating with factors such as the provider's approach, gender, and specialty (i.e. obstetrician versus general practitioner).²⁹ This same trend has been observed in prenatal screening. Nancy Press and Carole Browner found

that the very diverse group of women in their study – who almost unanimously accepted screening – were influenced primarily by the way in which the screening was described to them by their health-care provider and in patient information pamphlets (both of which were biased in favour of screening).³⁰ Diane Paul goes so far as to say that the strongest determining factor in whether women choose to have screening is not in the attitudes of the women but in the approach taken by their health-care provider.³¹ Whether this influence is sufficient to undermine voluntariness may be debated. However, in some cases, health-care providers may use their influence to more directly determine the choices of pregnant women. For instance, concerns about litigation, if women do not have screening and end up having a child with a disability, may cause some physicians to err on the 'safe' side and convince women to have screening in a way that may be regarded as substantially controlling.³²

Consent, the final element, refers to the authorization given for a specific procedure or intervention to be performed. It can be express, tacit (given through silence or by omission), implicit or implied (when consent is interpreted by certain actions), or presumed (based on assumptions of what a person will or should do).³³ It is clear from documents on prenatal screening that the form of consent considered to be appropriate is express consent. For example, the SOGC Practice Guidelines for maternal serum screening state that 'The decision whether or not to have testing may be verbally communicated between the woman and her health care provider but, ideally, should be recorded.'³⁴ The empirical evidence discussed above shows that express consent for prenatal screening is not always asked for or given by women undergoing the testing.

Hence, while some health-care providers may be very skilled at clearly disclosing the relevant information and some pregnant women may understand the test sufficiently to provide express voluntary consent (or refusal), in the majority of cases adequate levels of informed consent are not being achieved. Given the importance of autonomy in our society and in genetics in particular, it is essential that efforts be made to improve the process of informed consent in order to protect free informed choice for pregnant women. The fact that reproductive autonomy is not being well protected in current prenatal

²³ M. Garel et al. Ethical Decision-Making in Prenatal Diagnosis and Termination of Pregnancy: A Qualitative Survey Among Physicians and Midwives. *Prenat Diagn.* 2002; 22: 811–817.

²⁴ Gekas et al., *op. cit.* note 10.

²⁵ Beauchamp & Childress, *op. cit.* note 9; Faden et al, *op. cit.* note 9.

²⁶ Chodirker & Evans, *op. cit.* note 15.

²⁷ Goel et al., *op. cit.* note 10.

²⁸ R. Rapp. 1994. Women's Responses to Prenatal Diagnosis: A Socio-cultural Perspective on Diversity. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. K.H. Rothenberg, E.J. Thomson, eds. Columbus, Ohio: Ohio State University Press: 219–233.

²⁹ L. Stranc. 2000. *Patterns of Referral and Invasive Prenatal Diagnosis in Women of Advanced Maternal Age: Manitoba 1990–1995*. Doctoral Dissertation. University of Manitoba, Winnipeg, Manitoba; J. Rothchild. 2005. *The Dream of the Perfect Child*. Bloomington, IN: Indiana University Press.

³⁰ Press & Browner, *op. cit.* note 16.

³¹ D.B. Paul. 1998. *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*. Albany, NY: State University of New York Press.

³² Press & Browner, *op. cit.* note 16.

³³ Beauchamp & Childress, *op. cit.* note 9.

³⁴ Johnson & Summers, *op. cit.* note 13, p. 4.

screening practice should also make us wary about expanding the scope of screening to pregnant women population-wide.

III. A RELATIONAL APPROACH

Even if the process of informed consent were improved, however, this theory reflects a very narrow conception of choice; it reflects a bias in the literature about choice traditionally understood as individual choice, or individual autonomy, in a specific decision-making context. An analysis of women's choice is thereby restricted to their ability to accept or decline a particular option that is offered to them. It allows no room for reflection on the *practice* that is making those particular choices available or on other contextual influences outside the clinic that may not qualify as coercive or substantially controlling but may nevertheless have a significant impact on women's decision-making. If prenatal screening is intended to represent something more than an additional consumer choice for women, then a broader conception of choice is required.

A broader conception of choice requires a different kind of theory. In traditional theories of autonomy, persons are characterized as independent, self-sufficient, rational decision-makers who can receive information and make decisions by weighing the costs and benefits of various options. By contrast, in theories of relational autonomy, persons are viewed as relational beings embedded within and shaped by a web of interconnected relationships.³⁵ As a result of this conception of selves, persons, and their values, desires, etc. are seen as constructed in part by their social environment.³⁶ Relational autonomy (understood in a broad sense) has a much larger scope than informed consent, or individual autonomy. It explicitly includes consideration not only of women's decision-making in the clinic, but also of the social and political context in which practices develop and choices are offered;³⁷ it is not just the quality of the information disclosed to pregnant women that matters but the kinds of choices that are available, how these

choices are framed, and what opportunities or pressures women experience as a result. These contextual features, illuminated by a relational approach, provide additional reason to challenge the claim that prenatal screening should be promoted and expanded on the basis of autonomy.

Contextual factors, such as the research agenda, political and economic interests, and historical circumstance, are worth exploring because they provide insight into the practice of prenatal screening and determine the choices that women will face in the clinic.³⁸ Carine Vassy argues that in the UK prenatal screening was not developed in response to the demands of women, as is often claimed, but that programs were initiated by government organizations, interested sectors of the medical profession, and the medical supply industry for their own purposes.³⁹ In France, she notes the role of biomedical researchers in implementing and expanding screening services. While there were undoubtedly numerous factors and actors influencing the initial developments and implementations of screening programs, Vassy claims that testing is established to suit particular interests in society – but not directly those of pregnant women – and that women are then screened without much attention to informed consent. Citing various studies, she argues that most women in France simply followed along with offers of testing and did not make engaged, informed decisions to be tested.⁴⁰ As we have seen, there was a similar lack of express consent sought by health-care providers in Canada in the early years of screening.⁴¹ Since the number of women being screened increases when informed consent is not a priority, Vassy argues that institutions and organizations involved in the screening receive the false impression that women want the testing and therefore invest more resources into expanding the services. Expanded services result in more women being tested, and so the cycle continues. At some point during this feedback loop, however, the testing becomes normalized as part of routine prenatal care, such that women come to expect it; stopping the programs then becomes

³⁵ S. Sherwin. 1998. A Relational Approach to Autonomy in Health Care. In *The Politics of Women's Health: Exploring Agency and Autonomy*. S. Sherwin, ed. Philadelphia: Temple University Press: 19–47.

³⁶ Ibid.

³⁷ For a thorough exploration of theories of relational autonomy, see C. Mackenzie & N. Stoljar, eds. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford: Oxford University Press. For an example of relational autonomy applied to the health care context, see Sherwin, *op. cit.* note 35.

³⁸ For an exploration of the contextual factors influencing the development of prenatal diagnostic technologies, see R. Rapp. 1999. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York, NY: Routledge.

³⁹ C. Vassy. From a Genetic Innovation to Mass Health Programmes: The Diffusion of Down's Syndrome Prenatal Screening and Diagnostic Techniques in France. *Soc Sci Med*. 2006; 63: 2041–2051. These purposes include the costs that would be saved by having fewer children with Down syndrome and spina bifida to care for and the money that could be made from the sale of obstetric ultrasound equipment and the testing kits for the screens.

⁴⁰ Ibid.

⁴¹ Chodirker & Evans, *op. cit.* note 16.

perceived as removing choice even though women's wishes about screening may never have been established.

Similarly, despite the rhetoric of choice in screening programs and the conviction of clinicians that 'women want this testing' and that 'we are just offering women what they want', there is little support in the literature for women driving the initiative to develop and implement prenatal screens; this creative impetus seems to have come from elsewhere. There is some information collected on the wishes of couples regarding future use of prenatal genetic testing when they have already had a child with a particular condition,⁴² but there is not much evidence available regarding the wishes of low-risk populations for screening services. Some of the evidence that does exist does not provide much clarity. For example, the health technology assessment by Green et al. reports that most women seem to have favourable attitudes towards the screening although they have 'ambiguous or conflicting evaluations of the role of screening and the information it provides to the individual and society'.⁴³ Moreover, the authors found that efforts to study the desires of women were inconsistent, that some perspectives were likely misrepresented in the data, and that others were affected by 'cognitive readjustment' or post-choice bias.⁴⁴ Another complicating factor was that women's choices were not fully informed and relied mostly on wishes for reassurances and/or on the recommendations of their health-care provider.⁴⁵

Once prenatal screening is established, its implementation and uptake may be propelled by cultural attitudes about the value of information and of science. 'Information is power', 'more information is better than less', and 'information increases choice' are all familiar mantras. The emphasis on informed choice that is pervasive in prenatal screening seems to reinforce this view. For example, in a study conducted by Press and Browner of Catholic pregnant women, the participants thought it was better to have the information about a positive screen result despite the fact that nothing could be done about it (or would be done about it, since most did not want to abort).⁴⁶ Moreover, the belief appeared to be unanimous

that scientific information 'could not, or should not, be refused'.⁴⁷ Similarly, a study conducted for the late onset condition of Alzheimer's found that, despite most participants remembering almost nothing about their genotype or risk factors for the condition, they all stated that they would recommend testing to their friends and relatives partly because they thought it would 'provide useful information'.⁴⁸ Hence, whether women want genetic or biological information is debatable. For those who do come to value it, it is not clear why they value it; in the latter case, for instance, the information was prized even though it was not fully understood or needed for decision-making.

Whether more information, obtained via new screening options, will increase choice is also unclear. Barbara Katz Rothman explains that sometimes new options quietly foreclose on old possibilities.⁴⁹ She gives the example of contraception. When it was first introduced, it was hailed as a tool of liberation – especially for the middle classes – because women were able to control the size of their families and have fewer children. A consequence of this choice, especially when it came to be made by more and more women, was that it became socially difficult to have large families. She notes the difficulty of finding apartments and even vehicles large enough to accommodate a family with more than two or three children, not to mention the wealth that is necessary to make large families feasible.⁵⁰ Women on welfare who have 'too many children' have been threatened at various times in the past with a loss of welfare payments if they have any more.⁵¹ This example demonstrates a 'narrowing and structuring of choices'.⁵² According to Ruth Hubbard, '[a]s choices become available, they all too rapidly become compulsions to 'choose' the socially endorsed alternative'.⁵³

who would not consider an abortion may not pursue this option and be left instead with the uncertain probability assessment from a prenatal screen result.

⁴⁷ Ibid: 213.

⁴⁸ M. Lock. 2006. *Grappling with a Shape Shifter: Social Repercussions of Genetic Testing for the APOE Gene*. Public Lecture. Dalhousie University, Halifax, Nova Scotia, Canada.

⁴⁹ B.K. Rothman. 1986. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York, New York: Viking Penguin, Inc.; D. Davis. 2001. *Genetic Dilemmas: Reproductive Technologies, Parental Choices, and Children's Futures*. New York, NY: Routledge.

⁵⁰ Rothman, *op. cit.* note 49.

⁵¹ Ibid. Having too few children can also be a problem, however, as developed countries with falling birth rates have begun to discover, or in populations that feel culturally threatened, such as Quebec. In these social and/or political circumstances, some countries may offer incentives for having more children.

⁵² Ibid: 13.

⁵³ Ibid: 12.

⁴² For example, see T. Dudding et al. Reproductive Decisions after Neonatal Screening Identifies Cystic Fibrosis. *Arch Dis Child – Fetal Neonatal Ed.* 2000; 82: F124–F127.

⁴³ Green et al., *op. cit.* note 10, p. 55.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ Press & Browner, *op. cit.* note 16. Advance knowledge of a child with disabilities can allow women the opportunity to prepare for this outcome. However, this knowledge can only be achieved through the pursuit of an additional, diagnostic, test such as amniocentesis. Because of the risk of miscarriage associated with this procedure, some women

When the focus of society is on a new option, such as prenatal screening, other possibilities might become harder to choose or may silently disappear. In other words, once women exercise their ability to make the choice to use prenatal screening, they might lose their ability *not* to choose it. For instance, increased use of maternal serum screening enabled the SOGC to recommend that amniocentesis only be routinely offered to pregnant women over the age of 40; this strategy assumes that all women aged 35 to 39 who are interested in amniocentesis will make use of maternal serum screening, as indeed they must in order to have access to amniocentesis. The testing pathway that older pregnant women can take has been re-shaped by these new recommendations and their option to choose amniocentesis directly (or at all, if they receive a negative screen result) has disappeared.⁵⁴

Social-political forces and entrenched cultural assumptions can also affect how choices are framed and how free women may feel to make certain decisions. For instance, recommendations for the widespread offering of amniocentesis were instigated by two major lawsuits filed (and won) by women who had not been offered testing and had given birth to children with disabilities.⁵⁵ Because of the fear that any problems with a newborn must be assigned a culprit, clinicians may be worried that even if a woman does not wish for screening *now*, in retrospect, she *might* have wanted it, in which case clinicians may be liable.⁵⁶ As a result, health-care providers may be more persuasive when offering a test than strict standards of disclosure would allow⁵⁷ and make it hard for women to decline screening.⁵⁸

The language used to describe the screening may also affect choice. For example, disability rights activists have challenged the use of language such as 'abnormalities', 'defects', and 'risks' because they are normative and have

⁵⁴ In many cases, the option of maternal serum screening will be a benefit because it may avoid the need for invasive testing. However, for some women who are particularly anxious about their fetus, not having direct (or possibly any) access to amniocentesis may be considered an unwelcome restriction of autonomy.

⁵⁵ R.S. Cowan. 2001. Medicine, Technology, and Gender in the History of Prenatal Diagnosis. In *Feminism in Twentieth-Century Science, Technology, and Medicine*. A. Creager, E. Lunbeck & L. Schiebinger, eds. Chicago, US: The University of Chicago Press: 186–196.

⁵⁶ For example, health-care providers interviewed in the US when maternal serum AFP screening was first offered reported feeling required to test all their patients because of liability concerns (Press & Browner, *op. cit.* note 16).

⁵⁷ D.B. Paul. 1994. Eugenic Anxieties, Social Realities, and Political Choices. In *Are Genes Us?: The Social Consequences of the New Genetics*. C. Cranor, ed. New Brunswick, NJ: Rutgers University Press: 142–154.

⁵⁸ Press & Browner, *op. cit.* note 16.

built-in negative connotations.⁵⁹ Women's decisions may be subtly influenced by how they interpret these terms. Language may also mislead when comments referring to screening as a way to 'make sure your baby is healthy' imply that testing is meant to ensure health rather than to detect certain conditions.⁶⁰ Also, any comments that suggest directiveness are influential to some degree. Statements like 'when a screening test is positive, further investigation is *usually recommended*' and 'If the test shows a higher risk, it can also cause a lot of worry until *we can find out for sure* if there really is a problem'⁶¹ imply that further testing should or will normally follow after a positive screen result instead of emphasizing that it is up to the woman whether she chooses to pursue the results further.

Entrenched cultural assumptions about the roles and responsibilities of women and mothers may increase the difficulty women face in refusing screening. Abby Lippman argues that claims that women themselves *need* or choose prenatal screening is something constructed by the context of testing.⁶² The fact that women are generally responsible for the health of the family and that screening is often portrayed as part of routine prenatal care makes screening seem like the responsible course to take.⁶³ The commonly expressed belief that testing is reassuring goes hand-in-hand with this assumption, since it builds on the belief held by some women that testing will somehow promote the birth of a healthy child, such that a caring woman is not doing her motherly duty if she foregoes this testing. The framing of screening in this way makes the refusal of screening seem irresponsible or irrational.

⁵⁹ E. Parens & A. Asch, eds. 2000. *Prenatal Testing and Disability Rights*. Washington, DC: Georgetown University Press; R. Grant & K. Flint. Prenatal Screening for Fetal Aneuploidy: A Commentary by the Canadian Down Syndrome Society. *J Obstet Gynaecol Can.* 2007; 29: 580–582.

⁶⁰ Press & Browner, *op. cit.* note 16; E. Gates. 1994. Prenatal Genetic Testing: Does it Benefit Pregnant Women? In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. K.H. Rothenberg & E.J. Thomson, eds. Columbus, Ohio: Ohio State University Press: 183–200.

⁶¹ Women's and Children's Health Programs: Obstetrics/Gynaecology. Prenatal Screening & Prenatal Diagnosis: Basic Information; my emphasis. Available at: <http://www.ahsc.health.nb.ca/prenatalscreening/index.htm> [Accessed 1 Nov 2007]. Interestingly, this site was developed by Maritime women, their partners, and health-care providers so this phrasing might reflect the perception of pregnant women of their experiences.

⁶² A. Lippman. Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequalities. *Am J Law Med.* 1991; 17: 15–50.

⁶³ Gates, *op. cit.* note 60; S. Sherwin. 2001. Normalizing Reproductive Technologies and the Implications for Autonomy. In *Globalizing Feminist Bioethics: Crosscultural Perspectives*. R. Tong, with G. Anderson & A. Santos, eds. Boulder, Colorado: Westview Press: 96–113.

The labelling of pregnant women as 'at-risk' is also likely to construct a perceived need for testing according to Lippman. A woman labelled 'high-risk' may feel that she requires testing in order to reduce her risk, whatever her actual risk figure.⁶⁴ Indeed, in pregnancy, everyone is categorized as 'at-risk'; they are either low or high risk, at least until all the results are in. No one is 'no-risk'⁶⁵ despite the fact that the vast majority of children are born healthy and at term.⁶⁶ Because of the negative and fearful connotations of risk, the label of risk may make women feel more dependent on technology for their pregnancies to reduce this risk and to provide reassurance that their pregnancy is progressing normally.⁶⁷ The impact of risk labels can be demonstrated by looking at the uptake of prenatal screening in the Netherlands where pregnancy is considered natural and not medicalized to anywhere near the degree that it is in North America.⁶⁸ In a study of 1400 pregnant women who received the offer of screening along with detailed information about the advantages and disadvantages of screening, 35% declined screening did so on the basis of the fact that they believed testing to be unnecessary; one of the primary reasons given for this judgment was that they were not categorized as belonging to a risk group.⁶⁹ In North America, every pregnant woman is categorized as belonging to a risk group, thereby eliminating the reasonableness of declining screening based on lack of need.

The very offer of screening, however it is framed, may create a perceived need for testing, especially when screens have been selected and implemented by the medical system; this decision establishes screening as a legitimate use of scarce medical resources and thereby surreptitiously underlines its importance. The offer of screening is widely recognized to raise anxiety levels in pregnant women, in addition to positive screen results.⁷⁰ Susan Sherwin argues that the medicalization of preg-

nancy elevates the importance of medical interventions and distances women from their own pregnancies; this distance increases their anxiety and causes women to rely even more on medical expertise to assure them that everything is progressing normally, thus reinforcing the cycle of dependence.⁷¹ Indeed, reassurance is one of the primary reasons for which women pursue prenatal screening.⁷² In the same Dutch study described above, where pregnancy is not medicalized and prenatal screening is not routine, pregnant women do not feel these levels of anxiety about their pregnancies. Of the 1400 pregnant women offered prenatal screening in the study, 'reassurance' was almost insignificant (8%) as a contributing factor for accepting testing.⁷³

Hence, the existence of the technology and the way it is portrayed creates the perception that it is a necessary part of prenatal care, not merely an optional one. Once screening becomes even more normalized, it may not even be reassuring to be in a low risk bracket or to have one's risk reduced; the impetus for testing may remain due to the fact that fears over the conditions being screened for may become enhanced due to the constant public focus created by prenatal screening and diagnosis.⁷⁴ Also, as tests become more normalized, they become harder to question or decline and they become part of the care that is desired by women and expected of women.⁷⁵ Ultrasonography is a classic example of a technology that was adapted for pregnancy and increasingly became offered to assess gestational age, detect fetal anomalies and monitor fetal development.⁷⁶ This technology is now entrenched in prenatal care and has come to play an important social and emotional role in pregnancy because of its ability to visualize the fetus.⁷⁷ This role has been fulfilled despite a continued lack of evidence as to its clinical efficacy.⁷⁸ Regardless of its clinical import, ultrasound is so central to the pregnancy experience and so widely valued that most women who are offered it have difficulty refusing it at the risk of being judged to be

a negative screen result, anxiety levels either return to their pre-test level or continue to stay at a residual, elevated level throughout the pregnancy and even after birth.

⁶⁴ Lippman, *op. cit.* note 62.

⁶⁵ *Ibid.*

⁶⁶ R. Kohut & I.D. Rusen. 2002. *Congenital Anomalies in Canada – A Perinatal Health Report, 2002*. Ottawa, Canada: Minister of Public Works and Government Services Canada.

⁶⁷ Lippman, *op. cit.* note 62; T. Pearce. July 10 2007. 40 is the New 35 When it Comes to[*sic*] High-Risk Pregnancy. *Globe and Mail*. Available at: <http://www.theglobeandmail.com/servlet/story/RTGAM.20070710.wlamnio10/BNSStory/lifeFamily/home> [Accessed 1 Nov 2007].

⁶⁸ For instance, midwives perform most of the prenatal care, there are high rates of home births and low rates of epidurals (M. van den Berg et al. Accepting or Declining the Offer of Prenatal Screening for Congenital Defects: Test Uptake and Women's Reasons. *Prenat Diagn.* 2005; 25: 84–90).

⁶⁹ *Ibid.*

⁷⁰ Green et al., *op. cit.* note 10; Carroll et al., *op. cit.* note 17; J.M. Green. Serum Screening for Down's Syndrome: Experiences of Obstetricians in England and Wales. *BMJ.* 1994; 309: 769–772. In the event of

⁷¹ Sherwin, *op. cit.* note 63.

⁷² Green et al., *op. cit.* note 10.

⁷³ van den Berg et al., *op. cit.* note 68.

⁷⁴ Lippman, *op. cit.* note 62.

⁷⁵ Sherwin, *op. cit.* note 63.

⁷⁶ R. Kohut, D. Dewey & E.J. Love. Women's Knowledge of Prenatal Ultrasound and Informed Choice. *J Genet Couns.* 2002; 11: 265–276.

⁷⁷ As an example, in some baby books the spot for 'baby's first picture' is designated as the place to put the fetus' ultrasound photo (Anna Sheridan-Jonah, personal communication).

⁷⁸ B.G. Ewigman et al. Effect of Prenatal Ultrasound Screening on Perinatal Outcome. *N Engl J Med.* 1993; 329: 821.

irrational or irresponsible.⁷⁹ In prenatal interventions that are as normalized as ultrasound, to decline their use poses an ‘enormous burden of proof’ on those who might want to challenge the norm.⁸⁰

Ultrasonography also presents an example of how familiarity with a technology and its routinization or normalization in prenatal care can reduce the impact of choice and even the perceived need to ask for authorization. Informed consent in relation to ultrasonography as a screening test is significantly below any reasonable threshold⁸¹ and counselling women prior to screening is no longer even a standard of practice.⁸² A study conducted in Canada in 2002 found that out of 113 women surveyed before undergoing their 18 week ultrasound, 55% had not received any information about ultrasound screening from their health-care provider, 46% did not understand the ultrasound to be a screen for anomalies, and 26% were unclear about its diagnostic capabilities.⁸³ Hence, the widespread desire for and use of ultrasound screening is not accompanied by any significant level of understanding about the meaning or implications of the screen, at least relative to the purpose for which the technology has been medically justified.⁸⁴ Since pre-test counselling for ultrasound is no longer a standard of practice, it is naïve to suppose that informed consent will increase with more widespread use of prenatal screening if it is not even being satisfied now. In fact, as a practice becomes more accepted, it often ceases to become a focus of critical attention.⁸⁵

A framework of relational autonomy also allows us to look beyond the available choices to consider other possibilities. The choice that is being offered with prenatal screening is not the choice to have a blood test but the choice to avoid having a child with a certain condition, primarily one that could result in a disability. Prenatal screening is the first step in offering women *this* choice. Why is this choice being supported and not others? For example, women can choose to abort a fetus with Down syndrome or spina bifida at 20 weeks gestation but they cannot choose to abort a fetus at 20 weeks based on fetal sex (in the absence of a sex-linked disorder). Abortions on the basis of fetal sex are considered to be morally objectionable because of entrenched sex discrimination

against female fetuses; hence, abortions based on *this* trait are not supported by the medical profession. Nor is it widely supported for women to choose to give birth under water or using a birthing stool, to give birth at home,⁸⁶ or to stay several days in the hospital after labour in order to have time to rest and adjust to being a mother. In other words, it is only possible to make choices about a narrow range of options that are defined by the medical system. Whether certain options will be available to pregnant women depends on the eligibility criteria set by the medical system, and these occasionally shift in light of professional practice guidelines as is the case with prenatal screening. Likewise, prenatal technologies are not freely available for women to choose but can only be accessed through the medical system acting as gatekeeper.

Interestingly, part of the emphasis on prenatal screening over the last several years has been due to the fact that women are having children later in life. Since the risk of chromosomal anomalies increases with age, the incidence of Down syndrome is suspected to have increased dramatically in correlation.⁸⁷ This suspicion has been used in part to justify widescale implementation of prenatal screening and to motivate the case to secure provincial funding for these programs.⁸⁸ While prenatal screening, diagnosis, and abortion have been targeted as a means by which to counter this increasing incidence, alternatives such as creating more possibilities for women to have children earlier have not been sufficiently promoted or endorsed. While women may delay childbirth for many reasons, the fact that having a child early in a woman’s career may be damaging to her chances of success is a significant reason to postpone pregnancy. Increased acceptance in the workplace of child care demands and maternity leaves might remove some of the social pressure that encourages some women to put their childbearing plans on hold until their career paths are secure.

A societal commitment to support children with disabilities is another option that is often not given as much attention as prenatal screening, diagnosis and abortion options. For instance, it is hard to make a free choice about pursuing prenatal screening options when there are

⁷⁹ Sherwin, *op. cit.* note 63.

⁸⁰ Ibid: 104.

⁸¹ Kohut et al., *op. cit.* note 76.

⁸² Garel et al., *op. cit.* note 23; R. Kohut. 2000. *Prenatal Services Report, 2000: National Survey*. Personal Communication: 1–22.

⁸³ Kohut et al., *op. cit.* note 76.

⁸⁴ Pregnant women may, of course, understand it perfectly well in terms of the ability of ultrasound to provide her with a visual of her fetus and a picture to take home.

⁸⁵ Green et al., *op. cit.* note 10.

⁸⁶ Some of these possibilities may be options for women who are able to access the services of a midwife in provinces where midwifery is accepted and available.

⁸⁷ Kohut & Rusen, *op. cit.* note 66. This statement cannot be confirmed, however, since abortion rates for fetuses with Down syndrome is also suspected to have increased, thereby keeping the live birth rate of children with Down syndrome approximately the same.

⁸⁸ For example, see Alberta Public Health Association. 2004. *Support for a Provincially Funded and Centrally Organized Maternal Serum Screening Program*. Available at: <http://www.apha.ab.ca/Resolutions/2004res01.html> [Accessed 11 Apr 2006].

not adequate socially-supported alternatives, such as social supports, that would make the decision to raise a child with disabilities easier and/or when the availability of these services is not known to women during pregnancy. Social and economic pressures (in addition to pervasive discrimination) may make a woman feel that she is not able to care for a child with disabilities and turn to screening options as a result.⁸⁹ Hence, improved social supports and the communication of these supports to pregnant women may have an impact on some women's reproductive decisions.⁹⁰ While many pregnant women may still choose to pursue screening, diagnosis, and abortion even when social supports are very good and known to them during pregnancy (or before), knowing that there are adequate supports available may enhance the ability of some women to make the choice to continue a pregnancy if the choice to do so might otherwise have been restrained by a concern about resources.

In summary, there are a multitude of factors in society that might influence women's choices in the clinical context; while these factors might not be characterized as coercive or substantially controlling, as described in the theory of informed consent, they may nevertheless restrict the ability of women to make a free choice in the face of screening options. These forces include the normalization of technology combined with a cultural desire for information, cultural assumptions about women and mothers being responsible for health combined with the misperception of medical technology as promoting the birth of a healthy child, the categorization of pregnant women into risk categories with technology offering risk reduction and reassurance, and medical and societal values that determine which choices will be supported and made available to pregnant women. Hence, a broader conception of choice using a relational framework reveals additional reasons to worry that the expansion of prenatal screening may undermine women's autonomy.

To be clear, I am not advocating that prenatal screening be withheld from pregnant women. Reproductive autonomy is highly valued in our society and is important because of past coercive practices in reproduction and continued gender oppression. Because having a child with

a disability may have a significant impact on a woman's life (depending on the severity) and because she is more likely to be responsible for the care work, she is in the best position to judge whether having a child with a disability is something that she could manage. However, it is not clear that women *are* being given the opportunity to make informed choices about screening. Some women are being subtly directed down a path that, given greater understanding, they might not have chosen. Increased normalization through the continued expansion of prenatal screening will extend these concerns to all pregnant women. In order to promote reproductive autonomy for women who want testing while protecting the autonomy of women who may not, alternative means of implementing prenatal screening should be pursued. One possibility that I explore elsewhere is to make screening available to all women who want it without routinely offering it as part of standard prenatal care.⁹¹

IV. CONCLUSION

In short, whether choice is interpreted narrowly as informed consent or broadly as relational, there are reasons to worry that women's autonomy is not being protected or promoted by the routine offer of screening. At minimum, efforts must be made to improve the process of informed consent, which is no easy task. Steps should also be taken to address some of the contextual factors that restrain choice. In the meantime, however, incorporating the offer of prenatal screening into routine prenatal care for all pregnant women is not supported by the value of autonomy and ought to be reconsidered.

Acknowledgements

I would like to thank Dr. Susan Sherwin, Dr. Françoise Baylis, and Dr. Lisa Gannett for helpful comments on earlier versions of this paper. I am also grateful for the following financial support: a Social Sciences and Humanities Research Council Doctoral Fellowship, an Izaak Walton Killam Memorial Doctoral Fellowship, a Canadian Institutes of Health Research Strategic Training Program in Health Ethics and Policy Doctoral Fellowship, a Nova Scotia Health Research Foundation Student Research Award, and particularly an Associated Medical Services Bioethics Internship which inspired me to pursue this topic.

Victoria Seavilleklein PhD. is a Fellow in Clinical and Organizational Ethics at the Joint Centre for Bioethics at the University of Toronto, Toronto, Ontario, Canada. Her research interests include applied ethics, bioethics, and healthcare policy.

⁹¹ V. Seavilleklein. 2007. *The Values and Practice of Prenatal Screening in Canada*. Doctoral Dissertation. Dalhousie University, Halifax, Nova Scotia.

⁸⁹ Philip Ferguson, Alan Gartner, and Dorothy Lipsky propose that many of the difficulties reported from raising a child with disabilities in the 1950s and 1960s may have had more to do with the complete lack of social supports available to families than any other features of raising a disabled child per se (P.M. Ferguson, A. Gartner & D.K. Lipsky. 2000. *The Experience of Disability in Families: A Synthesis of Research and Parent Narratives*. In *Prenatal Testing and Disability Rights*. E. Parens & A. Asch, eds. Washington, DC: Georgetown University Press: 72–94).

⁹⁰ Parens & Asch, *op. cit.* note 8.