'Diseases', 'Defects', 'Abnormalities', and 'Conditions': Discursive Tensions in Prenatal Screening

3 authors, including:

Meredith Vanstone
McMaster University
32 PUBLICATIONS   **276** CITATIONS

Elizabeth Anne Kinsella
The University of Western Ontario
91 PUBLICATIONS   **724** CITATIONS

Some of the authors of this publication are also working on these related projects:

Understanding the 'work' of Self-Managing Attendant Services (SMAS): A reflexive ethnographic study View project

'Diseases', 'defects', 'abnormalities' and 'conditions': Discursive tensions in prenatal screening.

Meredith Vanstone, Elizabeth Anne Kinsella, and Jeff Nisker
Running Head: Discursive tensions in prenatal screening

INTRODUCTION

Pregnant women in many industrialised countries are now offered the opportunity to receive a prenatal screening test for disability, and asked to make an informed decision about whether or not they wish to engage in this testing process, which may lead to future decisions about invasive diagnostic testing and pregnancy termination.

 In this chapter we examine the way in which choice is discursively constructed in the context of prenatal screening, contending that the terms used to describe prenatal screening and disability may have the effect of enabling certain courses of action and discouraging others, even when the test is offered under the guise of increasing individual choice. We begin by introducing our approach to discourse analysis, and outlining the context in which informed choices for prenatal screening take place in Canada. Using data from three sources collected for a related study (Vanstone, 2012), we identify two different discourses related to informed choices about prenatal screening and explore the tensions between them. After comparing the ways that these discourses operate together and in conflict with each other, we consider the understandings that these particular discourses may infer about disability, pregnancy, and motherhood. Finally, we reflect on the potential implications of dominant discourses about informed choices about prenatal screening. In this endeavour, we hope to highlight the influence of social context on choices

about prenatal screening emphasizing the importance of considering the impact of social context on reproductive choices when thinking sociologically about reproduction .

Shakespeare (1999) has written about ' 'gene rhetoric'' and disabled discourses in scholarly literature which alternately portray prenatal diagnosis as a triumph of medicine over chaos to avert tragedy and suffering or as a fascist eugenic regime. This chapter explores the more subtle points of tension in written and spoken language about prenatal screening, tensions which may be related to, but do not directly drawn upon the stronger rhetoric identified by Shakespeare (1999).

Fairclough (1995) writes about the ways in which discourses are used selectively, depending on which discourses are available to the producers and interpreters of text (written or linguistic). When multiple discourses are combined, they may be in opposition. The producer of the text makes a series of language choices or acts, and through these speech acts may resist the established discourse by using alternative language or may work with opposing discourses by borrowing from both in a form of tenuous reconciliation (Fairclough, 1995). Drawing on these ideas, we contend that discursive contradictions in women's talk about prenatal screening shows that some women struggle to articulate their thoughts and beliefs using the language afforded by dominant cultural discourses of prenatal screening. These dominant discourses may be seen to be implicitly informed by particular values and assumptions (Hodgson, Hughes et al, 2005;).   If there is a conflict between dominant cultural values and an individual woman's personal values,

it may be difficult for a woman to articulate her own perspectives and make choices concordant with her own values (Anderson, 1999).

DISCURSIVE TENSIONS

Throughout this chapter we use the term 'discursive tensions' which we hope will evoke an understanding of the ways in which different discourses can both co-exist and be in conflict with each other, such as when an individual uses a particular discourse that has inherent assumptions or values which are in conflict with the values of the speaker. We understand discourse in the Foucauldian sense, as a group of institutionalized statements (including any type of utterance) about a particular topic (or object) that function socially by forming that topic (Foucault, 1972).

According to Blood (2005), discourse is the manifestation of thought into language and can both transmit and produce power, defining the ways we can talk or think about a topic, and therefore defining the truth of that topic. Discourse shapes and constrains our ways of understanding the world, by acting as a system that structures our perceptions of reality (ibid.).

PRENATAL SCREENING AND INFORMED CHOICES

Prenatal screening is a non-invasive, non-diagnostic test performed by ultrasound measurements and a series of blood tests in the first and second trimesters (Chitayat et al., 2011). Results from these different testing modalities are combined with the mother's age to produce a numerical probability of foetal anomaly (ibid.). Prenatal screening can detect a number of chromosomal anomalies (for example, Down syndrome), incomplete neural tube defects (for example, spina

bifida), as well as an assortment of other conditions (ibid.). After receiving results from the first round of non-invasive, non-diagnostic screening tests, a woman may choose to participate in further testing which will yield a definitive diagnosis (for example, amniocentesis). While therapeutic interventions are available for a few conditions identified by prenatal screening tests, in most instances test results provide information to consider when choosing between giving birth or terminating the pregnancy.

 In Canada, as in many other countries, including the US (ACOG, 2007), the Netherlands (Health Council of the Netherlands, 2006), the UK (UK National Screening Committee, 2008), Australia and New Zealand (RANZCOG, 2010) prenatal screening is provided through a process of informed decision-making, where each woman is encouraged to make her own choice about participation in the screening and diagnostic tests, and what to do with the results. While informed decision-making does not have a single, authoritative definition (Bekker et al, 1999), the most commonly used definition describes an informed decision as one which is based on relevant knowledge, consistent with the decision-maker's values, and behaviourally implemented (Marteau, Dormandy and Michie, 2001).

When making the decision of whether or not to participate in prenatal screening, women are faced with the task of identifying their own preferences and values in order to make a decision (Vanstone, Kinsella and Nisker, 2012). These decisions may be constrained by the ' 'implicit expectations, subtle influences and restricted choices'' (Shakespeare, 2006, p.88) that shape the decision-making process. Such influences may include the particular word choices used by the

counselling health care provider (Hodgson, Hughes et al. 2005) or patient education pamphlets (Dahl, Kesmodel et al. 2006; Loeben, Marteau et al. 1998; Vanstone and Kinsella 2010); including the ways in which the test and the idea of making a choice are introduced (Pilnick 2008; Pilnick 2004). The potential influence of such aspects, and the broader social and cultural contexts they represent, may be reflected in discursive constructions. When one considers the social contexts in which women are asked to make a choice about prenatal screening, it is easy to recognize that it may be challenging for women to identify and articulate values and preferences that run counter to dominant discourses of 'healthy' pregnancy, 'normal' bodies, and 'good' mothers. This may be especially true when prenatal screening is presented without acknowledgement of the values embedded in the test (Weil, 2003). Medical discourses of objectivity may disguise the presence of embedded assumptions and values (Asch, 2000), giving them a subtle form of power, and making it more difficult for women to recognise, think beyond or resist such assumptions and values (Anderson, 1999). For these reasons, choices may be unintentionally constrained or directed by prevalent discourses, and the imperative of informed decision-making may not be met.

The emphasis on informed choice in prenatal screening is built upon the bioethical principle of autonomy (Beauchamp and Childress, 2009), but the use of this principle in prenatal screening has been problematised by feminist scholars (see Ho, 2008; McLeod 2002; Seavilleklein 2009; Sherwin, 1998). On one hand, autonomy affords protection to people who are vulnerable to coercion and other influences. Without strong respect for the principle of autonomy, patients and other vulnerable populations may be abused and exploited. On the other hand, is autonomous

decision-making really possible? When one considers the power differential between physician and patient (Bhogal and Brunger, 2010), social and political structures which oppress women (Lippman 1999) and possibly coercive or constraining contextual factors specific to prenatal screening (García, Timmermans, and van Leeuwen, 2008; Hunt and deVoogd, 2003), it is unclear if wholly autonomous decisions are possible. The question of societal constraints to autonomous choice is particularly relevant when considering the relationship between prenatal screening and disability.

Of course, there are many other extra-discursive influences on choice, such as past and present reproductive history; experience and familiarity with disability; available social and financial resources. Further consideration of the influence of these factors on choice is outside of the scope of this chapter, but interested readers may refer to a plethora of work on these topics (for example, see Hunt, de Voogd et al 2005; Rapp 1998).

METHODS

The illustrative samples of data presented in this chapter were collected and analysed as part of a larger inquiry into the process of informed decision-making about prenatal screening (Vanstone, 2012). Examples are presented here to illustrate different types of language and discursive tensions that emerged in the data. Further information about the broader study, including more detailed methodology, reflections on the process of the research, and authorial decisions about word choices, is available elsewhere (Vanstone, 2012; Vanstone, Kinsella, and Nisker, 2012; Vanstone and Kinsella, 2010).

Three sources of data were collected separately: 13 English language Canadian prenatal screening patient education pamphlets were collected by searching online, and by asking interview participants what pamphlets they had reviewed in the course of making a decision about whether or not to participate in prenatal screening; 2 Canadian policy documents (Chitayat et al, 2011; Summers et al, 2007) addressing prenatal screening were collected after a search of academic and policy databases, and contact with professional colleges and governmental agencies; 16 pregnant women were interviewed after prenatal screening was introduced to them by their family doctor, but before women who chose to participate had received their results. All women interviewed were under the age of 35, self-identified as low-risk, and were carrying their first pregnancy. Information on ethnicity was not an inclusion/exclusion criteria and was not collected.

Participants were purposively recruited through the London-Middlesex Public Health Unit's Prenatal Fair (10 women), advertisements on pregnancy and classified ad websites (four women) and through snowball sampling (two women). Women were sampled to represent a diversity of perspectives about participation in prenatal screening (see Table 1). Sampling was completed when theoretical saturation was thought to be achieved, that is, when no new categories were seen to emerge in further interviews. This study received research ethics approval from the University of Western Ontario (#16988E). In audio-taped interviews lasting between 25 and 69 minutes, women were asked about the process of being offered prenatal screening, how they came to make a decision about whether or not to participate, and their thoughts and feelings about the test.

For the purposes of this analysis, a discursive analytic perspective (Foucault, 1972; Fairclough, 1995) was adopted. This involved an analytical sensitivity to language, which in practice meant a careful comparative consideration of word choice, figurative language, and metaphors across all three data sources.

ILLUSTRATIVE SAMPLES OF DISCURSIVE TENSIONS: BIOMEDICAL AND EVERYDAY DISCOURSES

Through a comparison of the language choices from the three different sources, two distinct types of discourse were identified: a bio-medical discourse used mainly in the policy documents and some pamphlets, however also present in some of the language adopted by women; and an everyday discourse used mainly by women, but which was also identified in some phrases used in the bio-medical pamphlets, and in the earlier policy document (Summers et al, 2007). Because the intent of this chapter is to examine the way in which these discourses function and to consider the possible implications for informed decision-making, we describe our analytic findings by drawing on examples from each discourse. To describe the findings, we consider how the different discourses might be used to answer two apparently straightforward questions: 'Who' (or 'What') does prenatal screening test? 'What' (or 'Who') does prenatal screening detect?

'Who' (or 'What') does prenatal screening test?

Markers of Bio-Medical and Everyday Discourses

Analysis of the three data sources revealed that bio-medical discourse about who or what is tested by prenatal screening was frequently marked by de-personalized words such as *foetus,*

pregnancy, embryo. When words that imply personhood such as *infant* or *child* were used, they tended to be used to specifically mark the transition after birth. Sometimes the woman was named as the subject of the test (rather than the pregnancy). Bio-medical discourse used the terms *pregnant woman* or *patient* to refer to women as the subject of the test, or as the locus of biomedical risk.

Everyday discourses revealed in women's accounts of who or what is tested by prenatal screening often included terms which implied personhood, such as *baby* or *child,* many times without distinguishing between whether or not birth had taken place. Women sometimes referred to themselves or others in a similar situation as *mothers* or *parents,* even before birth had taken place.

i. Policy documents

The language in the SOGC policy documents on prenatal screening (Chitayat et al, 2011; Summers et al, 2007) is intended for health professionals, and therefore a predominant emphasis on bio-medical discourse is not surprising. In these documents, the most prevalent word used to refer to who or what is tested by prenatal screening was *pregnancy; foetus* was the second most common term. *Pregnancy* was sometimes used in place of a more specific term such as foetus or embryo: ' 'the chance of identifying a pregnancy with a specific chromosomal abnormality'' (p.738); ' 'the practice of using [technique] to identify at-risk pregnancies'' (p.739). The differentiation between *pregnancy* and *foetus* or *embryo* was sometimes ambiguous. For example, Chitayat et al (2011) refer to ' 'pregnancies' as what is conceived (p. 737), whereas

Summers et al (2007) refer to 'foetus' as the product of conception (p. 149). Ambiguity was also

found in the language used to describe who was at risk (of having a condition); sometimes the

pregnant woman was at risk (Summers et al, 2007, p.152), sometimes the pregnancy. The most

recent SOGC policy document (Chitayat et al., 2011) uses the word *woman* most frequently, and

occasionally refers to the woman as a *patient*, a word that may be viewed by some as

medicalizing pregnancy, e.g. 'patients undergoing first trimester screening' (Chitayat et al, 2011,

p.742).

Neither policy document participated widely in the everyday discourse. The term *baby* is used

only twice in both documents, once referring to a child who was born with trisomy18 (Chitayat

et al, 2011, p.742) and once referring to age-related risk of having an affected pregnancy

(Chitayat et al, 2011, p.739).

ii. Patient education pamphlets

Thirteen prenatal screening patient education pamphlets were analysed extensively elsewhere

(Vanstone and Kinsella, 2010); these pamphlets used a wide variety of terms to describe the

subject of prenatal screening, and drew on both bio-medical and everyday discourses. Seven

pamphlets were consistent in the language used throughout the publication, using *pregnancy* (1)

or *baby* (6), with the same word used before and after birth and for affected and unaffected

pregnancies; other pamphlets differentiated between *foetus* and *baby* at the point of birth.

Several pamphlets participated simultaneously in both discourses, using the terms *foetus,*

embryo, or *pregnancy* when referring to an affected pregnancy or decisions about pregnancy

termination; and the terms *baby* or *infant* or *child* when describing the reassurance that screening tests may provide, or the desire to have an unaffected child.

iii. Pregnant women

Discourses can occur in both talk and text (Mills, 2004), and examining the words women use in speech revealed tensions between discourses. Women overwhelmingly used everyday language when referring to 'who' or 'what' would be tested, however the occurrence of bio-medical language was often notable. For instance, the word *foetus* was used by only three women and only used one time by each. In each case, the woman used *foetus* when explaining medical information she had received, such as the probability of detecting Down syndrome, or what the ultrasound measured.

Pregnancy was a term that was used by every woman, mostly to describe the process of being pregnant, getting pregnant, or feeling pregnant, except, notably, when it was used to describe decisions to *terminate*, *end*, or *continue* the pregnancy. In contrast to the policy documents, most women did not talk about the pregnancy as being at risk or as being the subject of the screening tests. In almost every woman's speech, *pregnancy* referred only to the state of being pregnant, unless they were talking about abortion, in which case they used language such as *terminate the pregnancy,* a phrase which reflects a bio-medical discourse.

There were clear patterns of everyday discourse in the interviews with pregnant women; women commonly used the words *baby*, *kid*, or *child* to refer to the born and unborn, potentially affected or unaffected. *Baby* was by far the most common term used by women, usually prefaced by *a* or

11

your when speaking hypothetically, and *m*y or *the* when speaking personally. *Child* was also a common term, used in a similar way to *baby*. Seven women used the word *kid*, usually to describe what life would be like after they gave birth: '*I think I would love that kid no matter what*', or as a way of ascribing personhood to the foetus, such as one woman did when describing how it would be difficult to make a decision about whether or not to terminate an affected pregnancy because '*it is still your kid, right?*'. Women's tendency to use personal terms such as *baby, child*, or *kid* may implicitly reflect their adoption of the idea of motherhood. The use of medical discourse may be seen to distance this relationship, and is perhaps a necessary tactic to make possible the consideration of pregnancy termination.

What does prenatal screening detect?

Markers of bio-medical and everyday discourses

The distinction between bio-medical and everyday language was clear in text and talk about the conditions detected by prenatal screening; bio-medical language about conditions was marked by precise terms for specific conditions, rather than the everyday language of *problems* or *issues.* Terms such as *disorder* or *disease* participate in a general bio-medical discourse, although they are not used in the policy documents to describe the most common conditions tested for by prenatal screening (Down syndrome and incomplete neural tube closures). These terms were occasionally identified in the pamphlets and in the women's descriptions, perhaps suggesting a desire to borrow from bio-medical discourse. However, given that such terms are not regularly used in authoritative bio-medical sources in relation to prenatal screening they instead served to mark the outsider status of the user. All three data sources predominantly framed unaffected

12

pregnancies as *normal*, with many women and patient education pamphlets also using the word *healthy* to describe a foetus or person unaffected by one of the conditions screened for.

i. Policy documents
 In general, the language used in the clinical policy guidelines isspecific and scientific. For example, a commonly used term that did not occur in the other sources was *aneuploidy*, which refers to the possession of an unusual number of chromosomes and refers to conditions such as trisomy conditions, (e.g. Down syndrome) which manifest when three chromosomes exist (triploid) where two are typical (diploid). Both policy documents also refer to *open neural tube defects*, a class of conditions such as *spina bifida*, which result from incomplete neural tube closures, and *open foetal defects*, including *gastroschisis* and *omphalocele*. Neither policy document uses the word *defect* to refer generally to *birth defects*, language that was present in a few pamphlets. The word *disorder* is prevalent in both policy documents, referring to single gene disorders, autosomal recessive disorders, and 'rare disorders of cholesterol and estriol biosynthesis', 'common and mild disorder, X-linked steroid sulfatase deficiency' (Summers et al, 2007, p.151). Chitayat (2011) does use the word more generally, stating that 'screening for a disorder should be undertaken only when the disorder is considered to be serious enough to warrant intervention' (p.738). *Disability* was not used frequently in Chitayat (2011) or Summers (2007), only to state that screening programs should respect the needs and quality of life of people with disabilities (Summers et al, 2007), and to describe that particular conditions are associated with 'intellectual disability' (Chitayat et al, 2011, p.744), a move towards more politically correct bio-medical language than the alternatives used by Summers et al (2007) including 'mental handicap' (p.148) and 'mental retardation' (p.153). The word *condition* is used

four times in each document, referring to 'chromosome conditions' (Summers et al, 2007, p.148) and 'genetic conditions' (Summers et al, 2007, p.153). Both Chitayat (2011) and Summers (2007) commonly use the terms *affected* and *unaffected*, but both also equate *normal* to *unaffected*, stating that prenatal screening has the 'benefit of reducing the numbers of normal pregnancies lost because of complications of invasive procedures' (Summers et al, 2007, p. 146)

ii. Patient education pamphlets
The patient education pamphlets used many different terms to describe what the screening test detected, including *disease*, *disorder*, *defect*, *abnormality*, *anomaly*, and the names of the conditions, such as *Trisomy 18*, or *Down syndrome*. While most pamphlets had an internal consistency, there were few constant trends between all pamphlets in the types of words used to describe conditions. Some used neutral language that participated in bio-medical discourse, such as *birth anomaly*, one used the neutral, imprecise word *difference.* The majority of the pamphlets used valued terms that were more general, such as *problem* or *birth defect.* Every pamphlet named at least one specific condition.

Almost all the pamphlets placed these terms for disability in opposition to words or, in one case, *perfect*, for the purpose of stating that a negative result will lead to the birth of a healthy, normal, or perfect baby.

iii. Pregnant women

Bio-medical words were occasionally used by women; for example, *disorder* was used once each by three women and *defect* was used by six women, once or twice each. Women did tend to

adopt bio-medical language at times. For instance, four women used the term *chromosomal abnormality*. One woman used the terms *characteristics* and *disposition* to refer to the conditions tested for, but this was not common.

The most common words used by women were *problem* or *issue*, describing '*chromosomal abnormality or some other problem', 'developmental issue*', '*genetic issue*' or just generally used to state that the test would provide information about whether there was a '*problem with my baby's health*' or the baby '*has some kind of issue*'. *Disability* was also a common word, used repeatedly by four women and a few times by three others. *Condition* was the word used by the interviewer, and many women adopted that term and used it once or twice after hearing it; only two women used the word *condition* before it was introduced.   At times it was apparent that women were struggling to find the right words. In the interview transcripts there are many indications of this, for instance, 'I think it will tell you if there's a chance of some sort of problem with the baby, like some sort of defect, I don't even know if that's the right word, some sort of genetic issue with the baby' or queries such as 'is Down syndrome really a disease or is it just a defect?'

DISCUSSION

This chapter has described the presence of two distinct discourses in prenatal screening patient education pamphlets, policy documents, and pregnant women's speech. Language relating to a bio-medical discourse was identified as strongly present in clinical policy guidelines, and language related to an everyday discourse was identified as strongly present in women's speech.

These broad discourses were found to overlap in many of the prenatal screening educational pamphlets, which may be seen to act as a bridge between the two broad discourses, and serve as a means of 'educating' pregnant women into particular ways of understanding prenatal screening (Dixon-Woods, 2001). Congruent with Tom Shakespeare's writings on the subject (Shakespeare 1999; Shakespeare 2006), we do not wish to imply the presence of an intentional eugenic conspiracy, 'abetted by science, to eliminate all disabled people' (Shakespeare, 2006, p.87), or to suggest that individuals are somehow 'brainwashed or coerced' (p.101) by discourse. Rather, we wish to highlight the contexts in which decisions are made, and the potential influence of those contexts on the options which may be available or appealing.

Drawing on the ideas of medicalisation and normalisation, it is important to consider the ways in which medical discourses structure social relations and the institutional processes of prenatal screening. Disability has long been constructed as a medical issue and the ways in which it is understood and spoken about are constituted by medical discourse and action, where decisions of whom to save, treat, or abandon are 'acts and omissions serving to continually reinforce and re-create medical notions of disabled'(Shildrick and Price, 1998, p.227). Medicalisation, intentionally or unintentionally, expands the domain of medical jurisdiction (Conrad, 1972),. Morgan (1998) explains that the expansion of medical jurisdiction requires social acceptance or acquiescence, legitimizing the use of medical concepts to describe and treat life phenomena. Normalisation is related to medicine's inclination to measure and compare bodies in order to govern them, which Foucault names bio-power (Foucault, 1990). Bio-power functions by encouraging women to act, to participate in the discourse of the body as a knowable, measurable,

standardized object (Foucault, 1990). Such practices have the effect of identifying and re-categorising bodies which do not fit the medicalised ideal of normal. Through this process of identification and categorisation, individuals are encouraged to exercise their power to intervene and transform these potential people into something which would be identified as normal or acceptable (Foucault, 2003). In this conception, 'normal' is a social construct, aided by the ability of medicine to measure, count, and calculate, in order to appraise or judge ways of being as either acceptable or unacceptable.

These practices of classification and codification are central to the emergence of the concept of disability, dividing some people from others and objectifying them (Tremain, 2005). The process of classifying or coding some types of people as 'other' can be seen in the bio-medical discourse of measuring, identifying, finding, detecting, reporting, so that labels of disorder, defect, disability, abnormality, can be applied. The interview participants (Vanstone 2012) used words such as *problem* or *issue*, which participate in the categorization of an atypical person as 'other', however this language is less quick to label, and participates in a much larger category than the more heavily loaded words of *disorder*, *defect*, or *abnormality*.

We posit that informed decision-making participates in the process of bio-power by enabling women to choose to act; when participation in prenatal screening is discursively framed as enabling choice or providing reassurance it becomes more difficult to resist this process of normalisation (Seavilleklein, 2009). Belief that one is acting autonomously and making choices supports domination and normalisation by hiding the real workings of power (Dreyfus & Rabinow, 1982); a mechanism that indicates the success of power (Foucault, 1990). By cloaking prenatal screening in language of choice and autonomy, women are encouraged to participate in

the workings of this powerful apparatus, to measure and identify anomalies so they can be reported and extinguished (Lippman, 1991; Seavilleklein, 2009). Some forms of counselling to support informed decision-making may promote this emphasis; when the valued nature of prenatal screening is camouflaged under the guise of non-directive counselling, it may be more difficult for women to identify the potential for a disjuncture between their own values and the values which inform the institution of prenatal screening (Vanstone, Kinsella and Nisker, 2012).

When considering discursive imperatives to participate in prenatal testing and subscribe to medicalised ideas of 'normal', it is interesting to consider the cases of interview participants who chose to participate in prenatal screening but stated that they would not terminate their pregnancies if a condition was found (four women in the study) (Vanstone, 2012). Women who make this choice may be seen as participating in the medicalised discourse of measuring and classifying, yet simultaneously they may be seen as resisting discourses of normalisation, by stating that they would not choose to terminate their pregnancy if a condition was found. The four women who stated they would choose this approach explained their choice by stating that prenatal screening would give them a chance to educate themselves and prepare to raise a child with a disability; acknowledging that they would face additional challenges as a parent and that their child would require additional support (Vanstone, 2012). This reflects a simultaneous acknowledgement of and resistance to the medicalised discourse of normalisation. The imperative towards normalisation was acknowledged by these women as they expressed an awareness that people with disabilities may face many challenges living within a society

primarily constructed to accommodate typical people, an insight well explained by Wendell (1996). Women's unwillingness to act to ensure that their child conforms to this normalised standard may also be seen as an example of resistance with respect to the imperatives of normalisation.

The acknowledgement that people with disabilities face additional challenges was expressed by all women in the study (Vanstone, 2012). Interestingly, each woman paired this acknowledgement with a statement about how she personally would act to circumvent or mitigate these challenges. Some women stated they would take action by terminating an affected pregnancy, while other women described different courses of action such as educating themselves and securing the necessary resources to support an affected child to his or her full potential. This unquestioned adoption of personal responsibility speaks to the transfer of responsibility for health from society to the individual, a hallmark of medicalisation (Morgan, 1998). Prenatal screening presents a clear example of this principle: the onus is placed on women to detect and abort foetuses with disabilities or to provide care for children with disabilities, obscuring the responsibility of society to help all people live to their full potential. This emphasis on individual responsibility as enacted through individual choice obscures the social context within which that choice is made, and which shapes the possibilities individuals can or are willing to consider (Shakespeare, 2005).

Autonomous informed choice is the mechanism by which modern day genetics is separated from eugenics (Duster, 2003). Granting women the choice to participate in prenatal screening

empowers them to participate in governing their own bodies and families (Foucault, 1990) and disguises the workings of medicalisation and normalisation. However, what does choice really mean when the choices and the context within which those choices will be enacted are constructed by others (Beaulieu and Lippman, 1995; Lippman, 1991; Lippman and Wilfond, 1992, Shakespeare 1999, 2005, 2006)? For instance, can the choice to raise a disabled child be considered informed and autonomous when parents are not offered sufficient information (Williams et al. 2002) to combat cultural representations of people with disabilities as ' 'pathetic, medical tragedies, dependent, and unfulfilled'' (Shakespeare, 2005, p. 226)? Is it truly a choice to raise a child with a disability within a society that does not provide the necessary resources and support to ensure that child is given the opportunities of all other children? Is the choice to terminate a pregnancy after a condition is found because you cannot afford to care for that child truly autonomous (Sherwin, 1998)? When considering questions of informed choice, we must examine the context in which those choices are constructed.

CONCLUSION

Informed decision-making is built upon the concept of autonomous choice; when considering the social context of informed decision-making, specifically, the ways in which disability and normality have been constructed in our society, a significant tension emerges. When disability is so widely culturally represented as something negative that must be avoided, it becomes much more difficult to choose to a) refuse prenatal screening and assume the uncertainty of not knowing or b) decline to terminate an affected pregnancy. The discursive creation of a dichotomy between normal/disabled perpetuates the construction of a society which does not

accommodate or support the needs of people with disabilities. The discursive tensions observed

in the speech of women suggest that some women may resist this particular construction.

Without explicit acknowledgement of the values and assumptions that underpin prenatal

screening, individual women may find it difficult to locate a foothold from which to make a

decision that is not unduly influenced by dominant discourses. This may be particularly

challenging for those that might resist the social and discursive pressures to participate in

prenatal screening, and the unquestioned action to terminate an anomalous pregnancy.

REFERENCES

ACOG. (2007) 'ACOG practice bulletin no. 77: Screening for foetal chromosomal abnormalities'. The American College of Obstetricians and Gynecologists, http://www.ncbi.nlm.nih.gov/pubmed/17197615, date accessed 20 November 2012.

Anderson, G. (1999) 'Nondirectiveness in prenatal genetics: Patients read between the lines', *Nursing Ethics,* 6 (2), pp. 126-36.

Asch, A. (2000) 'Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements' In E. Parens & A. Asch (eds), *Prenatal Testing and Disability Rights,* Washington, DC: Georgetown University Press, pp.234-60 .

Beauchamp, T.L. & Childress, J.F. (2009) *Principles of Biomedical Ethics,* 6th edn, New York: Oxford University Press.

Bekker, H. L., Thornton, J. G., Airey, C., Connelly, J., Hewison, J., Robinson, M., et al. (1999) 'Informed decision making: An annotated bibliography and systematic review', *Health Technology Assessment,* 3(1).pp. 1-168.

Bhogal, A.K. & Brunger, F. (2010) 'Prenatal genetic counseling in cross-cultural medicine', *Canadian Family Physician,* 56 (10), pp. 993-99.

Blood, S. K. (2005) *Body work*. New York, NY: Routledge.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Sage Publications.

Chitayat, D., Langlois, S., & Wilson, R. (2011) 'Prenatal screening for foetal aneuploidy in singleton pregnancies', *Journal of Obstetrics and Gynecology Canada,* 33(7), pp.736.

Conrad, P. (2007) *The medicalization Of Society,* Baltimore, MD: Johns Hopkins Press.

Dahl, K., Hvidman, L., Jørgensen, F.S. & Kesmodel, U.S. (2011) 'Knowledge of prenatal screening and psychological management of test decisions', *Ultrasound in Obstetrics & Gynecology,* 38(2), pp. 152-157.

Dixon-Woods, M. (2001) 'Writing wrongs? an analysis of published discourses about the use of patient information leaflets', *Social Science & Medicine,* 52(9), pp. 1417-1432.

Dreyfus, H. L., & Rabinow, P. (1982) *Michel Foucault, Beyond Structuralism And Hermeneutics*, Chicago, IL: University of Chicago Press.

Duster, T. (2003) *Backdoor to eugenics* (2nd ed.), New York, NY: Routledge.

Fairclough, N. (1995) *Critical Discourse Analysis: The Critical Study of Language,* London: Longman.

Foucault, M. (1972) *The Archaeology Of Knowledge* (A. Sheridan, Trans.), London, UK: Tavistock Publications.

Foucault, M. (1990) *The History Of Sexuality, vol I* (R. Hurley, Trans.), New York, NY: Vintage Books.

Foucault, M. (2003) *Abnormal: Lectures at the College de France 1974-75* (G. Burchell, Trans.), New York, NY: Picador.

García, E., Timmermans, D.R.M. & Van Leeuwen, E. (2008) 'Rethinking autonomy in the context of prenatal screening decision-making', *Prenatal diagnosis,* 28(2), pp. 115-120.

Health Council of the Netherlands. (2006) 'Launching a nationwide program for prenatal screening, down syndrome and neural tube defects', [*wet bevolkingsonderzoek: Aanzet tot een landelijk programma voor prenatale screening; downsyndroom en neuralebuisdefecten]*. The Hague: Health Council of the Netherlands, Report No.: 2006/03WBO.

Hodgson, J., Hughes, E. & Lambert, C. (2005) ''SLANG'—Sensitive Language and the New Genetics—an Exploratory Study', *Journal of Genetic Counseling,* 14(6), pp. 415-421.

Hunt, L. and De Voogd, K. (2003) 'Autonomy, danger, and choice: the moral imperative of an 'at risk' pregnancy for a group of low-income Latinas in Texas', in: B. Harthorn and L. Oaks, (eds), *Risk, Culture, and Health Inequality: shifting perceptions of danger and blame.* Conneticut: Greenwood.

Hunt, L., De Voogd, K. & Castañeda, H. (2005), 'The routine and the traumatic in prenatal genetic diagnosis: does clinical information inform patient decision-making?', *Patient Education and Counseling,* 56(3), pp. 302-312.

Lippman, A. (1991) 'Prenatal genetic testing and screening: Constructing needs and reinforcing inequities', *American Journal of Law & Medicine,* 17(1-2), pp. 15-50.

Loeben, G.L., Marteau, T.M. & Wilfond, B.S. (1998) 'Mixed messages: presentation of information in cystic fibrosis-screening pamphlets', *The American Journal of Human Genetics,* 63(4), pp. 1181-1189.

Markens, S., Browner, C.H. & Preloran, H.M. (2010) 'Interrogating the dynamics between power, knowledge and pregnant bodies in amniocentesis decision making', *Sociology of Health & Illness,* 32(1), pp. 37-56.

McLeod, C. (2002) *Self-trust and Reproductive Autonomy,* Cambridge, Mass: MIT Press.

Marteau, T. M., Dormandy, E., & Michie, S. (2001) 'A measure of informed choice', *Health Expectations,* 4(2), pp. 99-108.

Morgan, K. P. (1998) 'Contested bodies, contested knowledges: Women, health, and the politics of medicalisation', in S. Sherwin (ed.), *The Politics Of Women's Health: Exploring Agency and Autonomy*, Philadelphia, PA: Temple University Press, pp.321.

Pilnick, A. (2008) ''It's something for you both to think about': choice and decision making in nuchal translucency screening for Down's syndrome', *Sociology of health & illness,* 30(4), pp. 511-530.

Pilnick, A. (2004) ''It's Just One of the Best Tests that We've Got at the Moment': the Presentation of Nuchal Translucency Screening for Fetal Abnormality in Pregnancy', *Discourse & Society,* 15(4), pp. 451-465.

RANZCOG. (2010) 'Prenatal screening for foetal abnormalities', The Royal Australian and New Zealand College of Obstetricians and Gynecologists, Report No.: C-Obs 35.

Rapp, R., (1999) *Testing Women, Testing the Fetus.* New York: Routledge.

Seavilleklein, V. (2009) 'Challenging the rhetoric of choice in prenatal screening', *Bioethics,* 23(1), 68-77.

Shakespeare, T. (2006) *Disability rights and wrongs,.* London: Routledge.

Shakespeare, T. (2005) 'The social context of individual choice', in: D.T. Wasserman, R.S. Wachbroit and J.E. Bickenbach, (eds), *Quality of life and human difference : genetic testing, health care, and disability,* Cambridge: Cambridge University Press, pp. 217-236.

Shakespeare, T. (1999) ''Losing the plot'? Medical and activist discourses of contemporary genetics and disability', *Sociology of Health & Illness,* 21(5), pp. 669-688.

Shildrick, M. & Price, J. (1998), *Vital signs: Feminist Reconfigurations Of The Biological Body,* Edinburgh: Edinburgh University Press.

Sherwin, S. (1998) 'Relational approach to autonomy in health care', in S. Sherwin (ed.), *The Politics of Women's Health: Exploring Agency and Autonomy*, Philadelphia, PA: Temple University Press, pp.7.

Summers, A., Langlois, S., Wyatt, P., & Wilson, R. (2007) 'Prenatal screening for foetal aneuploidy', *Journal of Obstetrics and Gynecology of Canada,* 29(2), pp. 146.

Tremain, S. (2005). *Foucault and the Government of Disability*. Ann Arbor, MI: University of Michigan Press.

UK National Screening Committee, Department of Health. NHS foetal anomaly screening programme, UK NSC policy recommendation 2007-2010: Model of best practice. Department of Health; 2008

Vanstone, M., & Kinsella, E. A. (2010) 'Critical reflection and prenatal screening public education materials: A metaphoric textual analysis', *Reflective Practice: International and Multidisciplinary Perspectives,* 11(4), pp. 451-465.

Vanstone, M., Kinsella, E.A., & Nisker, J. (2012) 'Information sharing to promote informed choice about prenatal screening in the spirit of the SOGC Clinical Practice Guideline: A proposal for an alternative model', *Journal of Obstetrics and Gynecology Canada, 34*(3), pp.269-275.

Vanstone, M. (2012) 'The Process of Informed Decision-Making about Prenatal Screening: Policy, Patient Education and Pregnant Women's Perspectives', PhD thesis, University of Western Ontario, London, Ontario. Viewed February 8, 2013 < http://ir.lib.uwo.ca/etd/551>.

Weil, J. (2003) 'Psychosocial genetic counseling in the post-nondirective era: A point of view',, *Journal of Genetic Counseling,* 12(3), pp.199-211.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.

Williams, C., Alderson, P. & Farsides, B. (2002) 'What constitutes 'balanced information in the practitioners' portrayals of Down's syndrome?', *Midwifery,* 18(3), pp. 230-237.