Prospective parents and decisions concerning nuchal translucency screening

Helga Gottfreðsdóttir

Supervisors:
Kristín Björnsdóttir
Jane Sandall

PhD Thesis
in Midwifery
University of Iceland
Faculty of Nursing
2009

Prospective parents and decisions concerning nuchal translucency screening

Helga Gottfreðsdóttir

Supervisors:

Kristín Björnsdóttir

Jane Sandall

Doctoral Committee:

Kristín Björnsdóttir

Jane Sandall

Marga Thome

Reynir Tómas Geirsson

Vilhjálmur Árnason

Printed in Háskólaprent ehf.
Reykjavík, Iceland 2009

ISBN 978-9979-9702-2-4

To Þórir, Magnús and María Soffía

"... what we measure, identify and manage as risks are always constituted via pre-existing knowledges and discourses."

(Lupton, 1999, p. 29)

PREFACE

In my work as a midwife in an antenatal clinic in Iceland, I observed the introduction and implementation of nuchal translucency screening. This screening is a probability test performed at the end of the first trimester of pregnancy. Its use was initiated in late 1999 and quickly became a norm among the majority of parents who visited the specialized clinic which provided care to women in high-risk as well as low-risk pregnancies. This development is clearly reflected in the statistics, since in 2007 three quarters of pregnant women in Iceland accepted the test and in the capital area, where access is easy, the uptake was almost 90%.

It was not until some years after the introduction of the screening that clinical guidelines concerning its use were formed. Observing this development, I came to the conclusion that an open discussion was needed about the benefits and possible drawbacks of routine use of screening in antenatal care. I felt that the role of professionals in introducing screening had to be clarified. At that time, I was starting my academic career and, as my interest lay primarily in pregnancy and service delivery, the idea of this study began to develop. As time progressed, I became aware of the interplay of a number of social and medical factors that affect the introduction of new technique. In the literature, the point was raised that fetal screening is an area in which unrealistic expectations are rife. Furthermore, in a 'screening for all' policy, its use firmly maintains the emphasis on individualized risk assessment in pregnancy for all women. Several studies had been published in the United Kingdom on this subject and in the following years research from other countries became apparent.

Nuchal translucency screening has not received much research attention in Iceland, but policy on its use is reflected in the current guidelines on antenatal care for low-risk women. Several authors have suggested that placing nuchal translucency screening within traditional antenatal care can result in its use being experienced as a routine part of antenatal care and not

an actual choice. Therefore, there is a growing awareness of the need to increase knowledge of what influences the experience of screening in early pregnancy among prospective parents.

The present study was developed from the perspective that pregnancy and childbirth are transformative life events and socially managed in all societies. The study therefore rests on a combination of *midwifery*, *social science* and *ethics,* and presents a combination of theoretical reflections and empirical writing concerning this issue. The overall aim of the study was to describe and explain what contributes to the process of decision making concerning the use of nuchal translucency screening among prospective parents and the four papers presented in chronological order later in this dissertation are devoted to that aim.

ÁGRIP

Samþætt líkindamat hefur verið innleitt í meðgönguvernd í mörgum löndum með það að markmiði að finna frávik í fósturþroska, svo sem Downs heilkenni og bjóða verðandi foreldrum aukið val um áframhald meðgöngunnar. Þrátt fyrir að slík rannsókn auki öryggi sumra kvenna ætti það að vera íhugunarefni fyrir þá sem bjóða slíka rannsókn öllum barnshafandi konum að rannsóknin er þess eðlis að nálgast þarf konur í upphafi meðgöngu og að fleiri konur munu fá svar um auknar líkur á fráviki. Á Íslandi hefur öllum verðandi mæðrum verið boðið samþætt líkindamat frá 2001 og þiggja nú nærri 90% kvenna á höfuðborgarsvæðinu það boð.

Innleiðing samþætts líkindamats fyrir allar konur hefur verið tengd þeirri stefnu sem leiðir til arfbóta, hvert svo sem markmið skimunarinnar er. Þrátt fyrir áhrif þessarar skimunar hafa fáar rannsóknir beinst að því að skoða beint reynslu og ákvarðanaferli sem tengjast þessari tilteknu skimun frá sjónarhorni kvenna og engar rannsóknir hafa verið birtar um þetta efni sem byggja á gögnum sem safnað hefur verið í upphafi meðgöngu. Jafnframt hefur lítil athygli beinst að því hvort um sameiginlega ákvörðun sé að ræða meðal verðandi mæðra og feðra og hvort sjónarhorn kynjanna séu á einhvern hátt ólík.

Markmið þessarar eigindlegu rannsóknar var að skoða ákveðna þætti í íslensku umhverfi meðal heilbrigðra kvenna og maka þeirra til þess að skilja hvernig ákvörðun um að þiggja eða hafna skimun verður til. Safnað var efni frá fjölmiðlum sem innihélt umræðu um samþætt líkindamat frá árinu 2000 til 2005 og orðræðugreining (sifjafræði) notuð við úrvinnslu. Einnig voru tekin viðtöl við verðandi mæður (n=20) og verðandi feður (n=20), sitt í hvoru lagi, á 7.–11. og 20.–24. viku meðgöngu. Niðurstöður orðræðugreiningar sýndu að það var aðallega starfsfólk fósturgreiningardeildar, þar sem skimunin var boðin, sem talaði fyrir innleiðingu hennar, og fjótlega náði hún mikilli útbreiðslu. Þrátt fyrir að nokkrir aðilar settu fram spurningar um arfbótastefnu sem í skimuninni gæti falist og áhrif hennar á það gildismat

sem lagt væri á líf fatlaðra einstaklinga, þá voru viðbrögð samfélagsins fremur lítið áberandi. Viðtöl við verðandi foreldra sýndu að nánast öllum konunum fannst þær byggja ákvörðun sína á eigin vali. Margar þeirra kvenna sem ákváðu að þiggja skimunina höfðu töluverðar væntingar og auðsýndu fylgispekt við reglubundna notkun hennar. Ákvörðun karlanna í þeim hópi mótaðist fremur af því að hafa stjórn á meðgöngunni, að fá fullvissu, og af efnahagslegum ástæðum. Konunum fannst ákvörðun um að þiggja skimun vera sameiginleg, en mökum þeirra fannst konan taka ákvörðunina. Meirihluti þeirra þátttakenda sem hafnaði skimun reyndist hafa reynslu af eða þekkingu á fötlun og meiri sveigjanleika varðandi fjölbreytileika mannlífs. Þau höfðu jafnframt áhyggjur af því að skimunin væri óáreiðanleg og hjá parinu var að jafnaði gagnkvæmur skilningur á skimuninni. Almennt voru þátttakendur sama sinnis síðar á meðgöngunni.

Gagnrýnin skoðun á því hvort bjóða eigi verðandi foreldrum samþætt líkindamat þarf að eiga sér stað í íslensku samfélagi og aðgengi kvenna og karla að upplýsingum og úrræðum sem auka möguleika þeirra til umræðu um skimunina þarf að vera auðsætt. Þverfagleg samhæfing á þjónustu í upphafi meðgöngu er nauðsynleg, bæði hvað varðar þær leiðir sem standa til boða í heilbrigðiskerfinu og skipulag og innihald upplýsinga sem ætlað er verðandi foreldrum.

Lykilorð: *fósturskimun, samþætt líkindamat, foreldrar, reynsla, val, ákvarðanataka***.**

ABSTRACT

Nuchal translucency (NT) screening has been implemented as a routine part of antenatal care in many countries. Its aim is to detect fetal abnormalities such as Down's syndromes and provide prospective parents with more choices in pregnancy. Although this test does create certainty and reassurance for some women, it can also lead to uncertainty since it is a probability test. Routine use of NT screening also requires a change in pattern of care. Pregnant women need to be approached earlier in pregnancy and inevitably, since all women are offered screening, the number of women being screened will increase. Therefore more women will be identified high-risk with a resulting sequel for management of the ongoing decision making process. In Iceland, NT screening has been offered to all pregnant women since 2001 and the uptake is now almost 90% in the capital area.

The introduction of NT screening for all women has been related to a policy that could be said to be eugenic in impact if not in intent. Despite the social, organisational and ethical implications of screening, few studies have explored the experience of NT screening and decision-making processes from the woman's standpoint, and there is a paucity of published work that has explored this in very early pregnancy. Additionally, little attention has been paid to differences in attitude between men and women in relation to NT screening and whether the decision to accept or decline is a joint one.

The aim of this qualitative study was to explore issues within the Icelandic context among low-risk women and their partners, particularly with reference to understanding processes of accepting or declining the screening offer. The data included a genealogical analysis of public media items on the introduction of NT screening in Iceland between 2000 and 2005 and semi-structured interviews conducted with prospective mothers (n=20) and fathers (n=20) separately, in weeks 7–11 and weeks 20–24 of pregnancy. The findings show that NT screening was mainly promoted by staff at the specialized clinic where the test was offered, and that soon after its initiation

in 2001 the screening became widespread. Although some persons who appeared in the media questioned the eugenic policy implications of screening and its impact on the value placed on the lives of disabled people, the societal response was fairly muted. Interviews with parents show that almost all women experienced their decision as a choice, where those who accepted screening had high expectations and showed compliance with a routine offer. Men's decisions were more framed by control, a search for certainty and economic considerations. Women felt that the decision to accept screening as a joint decision, but their partners experienced it more as a decision made by the woman. Many of the women and their partners who declined screening had more personal experience or knowledge of disability and more tolerance for diversity. Some of them were concerned about unreliability of the NT screening. In general, all the couples' decisions remained consistent later in pregnancy.

A critical examination of the provision of screening needs to take place in the Icelandic context. Women's and men's access to resources that impact on opportunities to discuss NT screening need to be improved by multidisciplinary coordination of early pregnancy care, both regarding the pathway of care and the management of adequate information to prospective parents.

Key words: *prenatal screening, Nuchal translucency screening, parents, experience, choice, decision making.*

ACKNOWLEDGEMENTS

This work would not have been possible without the support of a number of people. I would first like to thank my supervisors who guided me through this process and gave me the opportunity to do this work in the way presented in this thesis. Kristín not only guided me academically but provided me with great personal support and encouragement. She respected my need for independence, but was always prepared to provide feedback and engage in challenging discussions. I thank Jane for her extraordinary kindness during the periods I spent in the UK and constructive teaching which helped me to focus more clearly and inspired me to embrace the importance of a scientific approach in midwifery. I also wish to express special thanks to other members of my doctoral committee, to Reynir for his enthusiasm, endless generosity of his time and constructive criticism, Vilhjálmur for his challenging discussions and thoughtful advice, and Marga for her motivating discussion.

There are number of colleagues who, throughout the years, have encouraged me and I am grateful to every single one of them, although their names are not mentioned here. Still, I can not but especially thank Ólöf Ásta Ólafsdóttir, Árdís Ólafsdóttir and Hildur Kristjánsdóttir who have stepped in and helped me with teaching when I needed to create space for this work.

The Faculty of Nursing at the University of Iceland and The Primary Health Care in Reykjavík are thanked for allowing me the flexibility to devote extra time to this work.

This study would not have been possible without the women and men who agreed to participate and the midwives who, during their busy working day, recruited participants. Special thanks go to the staff at the Prenatal Diagnosis Unit at LUH for their assistance and cooperation.

Margrét Lúðvíksdóttir is thanked for her encouragement and proofreading of the thesis.

Most of all I need to mention and thank a few people in my life, for they have each provided different types of support throughout the years leading up to the final stages of this thesis. My parents, Ásdís and Gottfreð, are thanked for their constant interest and for being there for my children when I was away.

In particular I would like to thank my children whom I dedicate this work. Þórir, Magnús and María Soffía, thank you for your endless patience and for supporting me in such a loving way through this process.

This work was supported by the Icelandic Science Foundation and the Association of Midwives in Iceland. Finally, a Visiting Research Fellowship in the Florence Nightingale School of Nursing and Midwifery, Kings College in London is acknowledged.

CONTENTS

LIST OF FIGURES AND TABLES

Figures:

Tables:

ABBREVIATIONS

AC: Abdominal circumference, a parameter used to evaluate growth retardation.

AD: Abdominal diameter of the fetus used for detecting fetal growth and disproportion.

AFP: Alfa- fetal- protein. A protein produced by the fetal liver.

ART: Assisted reproductive technology

BPD: Biparietal diameter used to estimate gestational length and follow fetal growth.

hCG: Human chorionic gonadotropin, produced first by the embryo then by the placenta.

CRL: Crown-rump length.

CVS: Chorion villus sampling.

EFM: Electronic fetal monitoring

IVF: In-vitro fertilization.

LUH: Landspítali University Hospital.

NT: Nuchal translucency.

NTD: Neural tube defect.

PAPP-A: Pregnancy associated plasma protein-A.

LIST OF PAPERS

This thesis is based on the following original papers:

Gottfreðsdóttir, H., & Björnsdóttir, K. (in press). 'Have you had the test?': A discourse analysis of media presentation of prenatal screening. Accepted for publication in *Scandinavian Journal of Caring Sciences.*

Gottfreðsdóttir, H., Sandall, J., & Björnsdóttir, K. (doi:10.1016/j.midw. 2007.12.004). 'This is what you do when you are pregnant': A qualitative study on prospective parents who accept nuchal translucency screening. *Midwifery.* Available online March 4, 2008.

Gottfreðsdóttir, H., Björnsdóttir, K., & Sandall, J. (in press). How do prospective parents who decline prenatal screening account for their decision? A qualitative study. Accepted for publication in *Social Science & Medicine.*

Gottfreðsdóttir, H. & Árnason, V. The meaning of ethical concepts and their reflection in the context of fetal screening. (Submitted)

The papers are reprinted with permission from the respective publishers.

Other relevant publications:

Helga Gottfreðsdóttir. (2006). Breyttar áherslur í meðgönguvernd í ljósi nýrra aðferða til fósturgreiningar og skimunar [Change in emphasis in antenatal care following new technique in fetal screening and diagnosis]. In H. Jónsdóttir (Ed.) *Frá innsæi til inngripa. Þekkingaþróun í hjúkrunar og ljósmóðurfræði* (pp. 145–163). Reykjavík: Hið íslenska bókmenntafélag and University of Iceland, Faculty of Nursing.

Helga Gottfreðsdóttir. (2009). Samskipti verðandi foreldra við heilbrigðisstarfsfólk í upphafi meðgöngu og fræðsla um skimun fyrir fóstur-göllum. [Prospective parents and professionals communication in early pregnancy and information on fetal screening] (Submitted)

INTRODUCTION

Screening for anomalies in pregnancy has become widespread. Over recent years, advances in both ultrasound technology and biochemistry and the combination of both have facilitated a trend towards earlier screening for Down's syndrome among all pregnant women. Nuchal translucency screening (NT) developed in the early 1990's. It is based on the discovery that increased fluid in the fetal neck area is associated with chromosomal abnormality. Therefore, a measurement of increased fluid indicates a heightened risk for Down's syndrome and other fetal abnormalities. The risk score from an NT screening provides a numerical ratio for every woman. Within the biomedical context the focus has been on improving the sensitivity and effectiveness of prenatal screening, but other disciplines have identified ethical dilemmas associated with the implementation of the screening such as stigmatization of disability.

NT screening is performed near the end of the first trimester of pregnancy. Therefore, the woman needs to make her decision in very early pregnancy. The offer of NT screening also places new responsibilities on professionals who introduce the possibility to undergo screening. They must be prepared to present and discuss complex ethical issues involving having a child with some anomalies or choosing abortion. The question of how the decision to undergo screening is presented to prospective parents has repeatedly been brought up. For example, this was reflected in an editorial in the *British Medical Journal* more than ten years ago:

> While health care professionals in maternity services are good at giving some sorts of information to patients – for example, on nutrition during pregnancy – they may fail to consider the issues of informed consent raised by the use of such a powerful diagnostic tool during routine antenatal care. (McFayden, Gledhill, & Whitlow, 1998, p. 694)

This is the issue being addressed in this study. In many settings it is the midwife who is the first professional that prospective parents contact, and the widespread use of screening and diagnostic tests has led to an increased need for midwives to have knowledge and skills regarding the implications of this technology. Indeed, new developments, such as NT screening, do go beyond the conventional confines regarding normal pregnancy and communication of risk and uncertainty becomes more complex. Decision-making concerning prenatal screening can not be separated from the social context that the woman belongs to. Therefore, a greater understanding of how decisions emerge in early pregnancy and the complex interaction between the individual woman and the health care system is of importance. As such, knowledge development around decision-making on fetal screening has connections with ethical, social and medical aspects. The overarching aim of the work presented here is to contribute to knowledge of the process of decision making among prospective parents regarding undergoing screening, with respect to the provision of information to prospective parents in clinical and social context. The study developed in midwifery and was designed to address difficult issues that midwives are confronted with in their everyday practice.

The implementation of fetal screening and diagnosis and the social response to the offer vary between countries. This variation is based on a number of policy and practice-related factors such as the availability and access to antenatal care, the technology, abortion policy, the conceptualization of health and risk and the social construction of disability. Due to a relatively small population, the development in Iceland provides a good opportunity to explore how the interaction between the healthcare policy, clinical professionals and prospective parents has evolved. However, the aim of this thesis is not to explain in depth why or how the uptake of fetal screening has become as high as seems to be the case. That is a complex issue linked to multi-disciplinary work within sociology,

bieoethics, law, medicine, midwifery and health policy. The concern here is to understand how parents´ decisions regarding undergoing screening emerge within a particular socio-cultural context. All new technology in pregnancy affects the attitude and experience of women and it is of importance for midwives to understand the effects of this change. Viewing pregnancy and childbirth as a socially managed process, therefore, calls for an exploration of the social and political context in which those decisions are made (Wrede, Benoit & Sandall, 2001). Thus, the *theoretical perspective* chosen here has connections with two viewpoints. On the one hand, this thesis rests on the approach described Page & McCandlish (2006), that pregnancy and birth are far more than a physical experience as the social and emotional adaption that is required with the transition to a new role and responsibility is one of the most crucial aspects of human life. On the other hand, it draws on social constructionism as its theoretical orientation offers an appropriate feature for understanding decisions and choice as constituted in existing knowledge and discourses (Burr, 2003). Our constructions of the world are founded upon language, and language underpins the form of action that we take. Addressing social constructionism, my attempt is to draw on the 'critical stance toward taken for granted knowledge' which underpins much of technological development and implementation around fetal screening. As such, the focus is on the societal context that may shape the views and practices of prospective parents and of practitioners around fetal screening. It developed from the assumption that the way in which things are discussed, i.e. the language used to describe social life is also an active force in shaping it (Fraser & Gordon, 1994).

Antenatal Care

Historical perspective.

As fetal screening is an integral part of antenatal care, it is of importance to be aware of how and why care of that kind spreads and what it incorporates. Antenatal care as a term started to develop around the turn of the twentieth century. At that time, infant and maternal mortality and morbidity were high, which had its roots in a number of socio-economic and health related factors, such as poverty, malnutrition and poor housing, added to a lack of skilled professionals to attend women in pregnancy and birth (Garðarsdóttir, 2002; Williams, 1997). By assessing pregnant women it was hoped that factors contributing to health risks might be found and addressed and that by this the situation could be improved (Boyle, 1996).

Antenatal care developed slowly in the first decades of the twentieth century in Western Europe. The first antenatal clinics in England opened in 1915 for young unmarried women, where they could rest and have access to medical supervision and good food (Baird, 1960; Tew, 1995). In 1918, The Act on Maternity and Child Welfare in the UK advocated that the clinics should be staffed by midwives and doctors (Currell, 1992; Tew, 1995). After the First World War, many countries in Europe were confronted with a huge loss of lives. Therefore, in health policy, many nations placed an emphasis on preventive health care and childbirth education. This understanding was as an encouragement for organized care during pregnancy, along with discoveries such as the development of the sphygmomanometer and the knowledge that eclampsia in women during pregnancy could be decreased by routine testing of blood pressure, urine and weight (Ondeck, 2000). The first official framework for antenatal care was issued in the UK by the Ministry of Health in 1929 (Field, 1999). In the United States, nurse-midwives began to provide antenatal care in 1925 with the establishment of the Frontier Nursing Service (Baird, 1960; Lehrman, 1981). However, there

were very few educational opportunities for midwives in the USA at that time, and obstetricians became nearly the sole profession attending women in pregnancy and birth in the country (Arney, 1982; Ondeck, 2000). In the Scandinavian countries, the structure of antenatal care was based on the British pattern, although each country has developed its own set of guidelines (Bondas, 2002).

After the Second World War, when new possibilities for diagnosis and intervention in pregnancy were established, care continued to develop. Today, the objectives of antenatal care can be seen to rest on two main components. The former is to detect deviations in growth and development of the fetus and to identify maternal diseases by clinical investigation; the latter is on comprehensive information and support to prospective parents, including parenthood education (Boyle, 2003 in Maye's; NICE, 2008a). It has been concluded that the outcome of pregnancy and birth is, however, not least depended on the health condition of the pregnant woman and how she makes use of the service options provided in the society as antenatal care (Enkin et al., 2000).

Many studies have been published on the experience of pregnant women and what they consider to be the main purpose of antenatal care. Women value physical assessment such as blood and urine tests, estimation of fetal growth and auscultation most (Bondas, 2002; Ladfors et al., 2001). Few studies have actually explored the interaction between the pregnant woman and the midwife during antenatal visits. In an ethnographic study the interaction between 40 women and their midwives during the first antenatal visit was mainly reflected in risk assessment, providing information, and establishing relationship with the pregnant women (McCourt, 2006).

The context of reproduction and antenatal care in Iceland.

The development of maternity care in Iceland followed the main trends seen in many European countries and the US, such as the move of birth from

home to hospitals and the rise of caesarean deliveries (Arney, 1982; Wrede et al., 2001). Hence, the organization of maternity care in Iceland is similar to the many European countries where women seek antenatal care within health care centres and the majority gives birth in hospitals.

Iceland shares the Nordic identity of a welfare state and Icelanders have come to expect high-quality health services. The health policy in the country is characterized by strong state involvement, which means that the majority of health care institutions and community centres are governmentally run. Some services are privately run although the cost is covered to a variable extent by national health insurance. Private practice provided by obstetricians exists for reproductive health, but in the context of maternity care it more or less centres on initial pregnancy assessment and most parents use the services provided at the community centres when pregnancy has been established. One clinic in Iceland provides assisted reproduction. The clinic was privatized in 2004 (Nordic Council, 2006). Over the past years, assisted reproduction has become relatively common in Iceland compared to many neighbouring countries. About 3-4% of babies are born annually after assisted reproduction, with the highest rate (4.2%) in 2006 (Bjarnadóttir, Garðarsdóttir, Smárason & Pálsson, 2007).

There are around 4200 births annually in Iceland. Childbearing is highly valued in the country as seen by the fact that the birth rate is the highest in Europe (Bjarnadóttir, 2003; Ólafsson, 1998). Interestingly though, Icelanders also have a liberal view toward abortion. As in the other Nordic countries, the laws on abortion were liberalized in Iceland in the 1970's. Contrary to the other countries where the rate of abortion decreased after the law was enacted, the rate in Iceland increased. Although this difference is based on a complex interplay of a number of factors, it has been highlighted that the emphasis on preventive care and access to contraception is organized differently in those countries (Knudsen et al., 2003).

Midwifery has a strong tradition in Icelandic maternity care (Ólafsdóttir, 2006) and the professional role of midwives covers care of all women during pregnancy, birth and postpartum. Hunt and Symonds (1995) have pointed out that the meaning of the word midwife is socially constructed. The term or name used for a midwife in Icelandic is *ljósmóðir,* which translates as 'mother of light', a term which became well known in the language in the fourth decade of the 20th century. Before that time, the term *yfirsetukona* was used (Einarsdóttir, 1982). The midwife is the main care giver in the 'normal' process of pregnancy and childbirth, and all Icelandic midwives are licensed to practice independently (Act on Midwives, 1984). Hence, most midwives in Iceland either work within the primary health care system or at a particular department within a hospital. Unlike in some of the neighbouring countries, contraception and family planning has not been within the remit of midwifery, although there is an interest to develop that aspect within the profession.

The organization of antenatal care.

Antenatal care in Iceland was initiated by the charity organization *Líkn* in 1928, and care during pregnancy gradually evolved from then on. In the seventies and eighties, the organization of antenatal care slowly shifted from hospital-based service to antenatal care provided within health care centres around the country (Magnúsdóttir, 1985; Pétursdóttir, 1969). Today, antenatal care is provided free of charge to all women/prospective parents in Iceland, which has been the policy in the country for the past decades (Act on Health Care, 2007; Regulation on Health Care Centres, 2007):

> Antenatal care shall be provided at health care centres or under their supervision by a midwife if at all possible. Antenatal care refers to the monitoring of the mother's and the fetus' health during pregnancy, i.a. to detect risk factors at an early stage and intervene. In antenatal care it should be endeavoured to enhance the safety and well-being of parents and to

> prepare them for their parental role by providing antenatal education and counselling on pregnancy, birth and post partum care. (Regulation on Health Care Centres, 2007, § 13).

In uncomplicated cases, the antenatal care consists of a series of consultations with a midwife at a health care centre at a community health care centre, sometimes in cooperation with general practitioners or an obstetrician if needed. Each health care centre has one to four midwives who all provide antenatal care and some continue to provide care to the family after the time of birth. According to the national guidelines issued by the Directorate of Health (2008), which provide information on evidence-based care for professionals and pregnant women, the recommended number of visits is ten for first time mothers and seven for subsequent pregnancies. It is assumed that consultation on screening takes place in the first antenatal visit, which can now be booked from the 8th week of gestation. However, in the capital area, many women have their pregnancy confirmed by an obstetrician, at a private clinic, before signing up for antenatal care. This relates to the general understanding which has prevailed, that publically funded maternity care starts at 12 weeks.

The majority of midwives working in Iceland belong to the Association of Midwives in Iceland, which is instrumental in developing the ideology upon which midwives base their services. As articulated by the association, the practice of midwifery is women centred, meaning that women are supported to make their own decision in relation to care. In addition, the association stresses that having a baby is a normal process and all intervention should be based on knowledge obtained from studies of women's views and experience parallel to clinical studies on effectiveness of new procedures (Einisdóttir, 1998).

Although the reproductive process has been studied to a considerable extent in Iceland, very little is known about the views and experience of pregnant women and their partners. In a qualitative study, eight Icelandic women

described their experience of the care they received from a midwife during pregnancy and in their view the physical assessment was of most importance (Gottfreðsdóttir, 2001). They related physical assessment to the perception of safety and reassurance, where safety was the most prominent concept in the interviews. In their experience, less time was spent on other issues, especially psychosocial issues, although it was clear that all the women valued the importance of continuity of carer. The same study showed on the other hand, that the four midwives interviewed considered support to be the main component of antenatal care, although in the interviews they spent much more time discussing issues that were related to physical assessment. It can be speculated that the emphasis which is placed on risk assessment within antenatal care can result in that more women feel unsafe or at risk. Reassurance and personal communication with a midwife whom they know was also strongly emphasized in another Icelandic study (Kristjánsdóttir, 2009). This implies that women value the personal relationship with a midwife they know and her expertise as a competent clinician. The trust that women place in the midwife is equally related to clinical competence and personal acquaintanceship with the midwife. In the same study, women also seemed to consider antenatal care as a self-evident act, not as an actual choice.

Technology Diffusion and Implications

Although antenatal care still follows the basic schedule introduced in the 1930's, new technologies such as fetal screening and diagnosis have gradually been added to the standardized part of care during pregnancy. As scientific evaluation of the efficacy of a new technique is not a necessary precondition for the introduction of that technique into routine practice, there is a need to provide insights into understanding of how new technology becomes a norm in various systems in health care (Wrede et al., 2001).

Various writers have attempted to explain how new technology becomes part of health care. Banta (1983) suggested that a number of factors affect this process, e.g. characteristics of the technology, the complexity of understanding and using it, and observability or visibility of the result. He introduced the term diffusion to describe how technology enters and becomes part of the health care system (Banta, 1983). More recent literature within the 'Studies of Technological Science' (STS) have explored how expectations act as a driving force for the adoption of new technologies concerning both the ones which encourage the uptake of new procedures and the public users (Brown & Webster, 2004). Other issues which promote new technology and organize practice refer to whether the innovation of new technologies is relatively established or newly emergent (Brown & Michael, 2003; Brown et al., 2005). Therefore, analysing how the future was presented in the discourse in the past – and comparing that to more recent presentations of the future – illuminates how high optimistic expectation is discursively correlated with a technology in its infancy. 'Hype is about the future and the new – not about the past' (Brown et al., 2005, p. 3). This also implies that the role of different actors engaged in implementing new technologies varies according to their different positioning, i.e. correlation between closeness to the point of knowledge production and uncertainty. For those closely involved in the production of knowledge, uncertainty will be more acute than for the users of that knowledge, who will be more certain that it is the truth. Hence, one of the best predictors of public acceptance is the strong institutional or provider support to medical technology (Brown et al., 2005). A study on diffusion of Down's syndrome screening in France shows how biomedical researchers took the initiative and promoted the innovation to political and administrative decision makers (Vassy, 2006). Within the clinical context, terminology such as evidence based practice has been applied, where an attempt has been made to introduce new methods and procedures on proven evidence and knowledge (McLaughlin, 2001).

Screening is an area within health care where unrealistic expectations dominate the scene (Marteau, 2002). Many studies show that pregnant women have limited knowledge of what the screening can do and high expectations that it will reassure them about the health of their baby (Dahl, Kesmodel, Hvidman & Olsen, 2006; Favre et al., 2006). Few studies have explored the level of acceptability of innovative health-care technologies among the public users and how their concerns are reflected about the technology in general. A survey by Calnan, Montaner and Horne (2005) on this issue shows a complex picture of views, where women seem to hold more consistent beliefs about the negative value of modern scientific treatment and technological development. In general, the acceptance depended on the technology's perceived utility value in terms of treating specific diseases. Additionally, although genetic technologies were not perceived as problematic, the findings raise concerns about its interference in the natural processes from the user's perspective.

Throughout history, in relation to reproductive technologies such as ultrasound, women's consent, experience and opinion have rarely been taken into consideration in the provision of care (Dodds, Goodman & Tyler, 1996; Green, Hewison, Bekker, Bryant & Chuckle, 2004). In the review by Green and colleagues, it is pointed out that there are several angles from which ultrasound needs to be considered which have been neglected in previous research. There, the issue of unmet needs of women who receive false-positive result and the inadequacy of current procedure for achieving informed consent are of importance. With the development of new technology in antenatal care and the increasing capacity of the ultrasound techniques to allow detection of anomalies in relatively early pregnancy, the implications of ultrasound screening have become more complex and new concerns have emerged which called for attention. Another classical example is the use of electronic fetal monitoring (EFM) applied to monitor the fetus during labour and delivery. EFM diffused very rapidly into practice

in the 1970's and is now a standard of care despite the arguments that auscultation is an acceptable alternative to EFM in low-risk birth (Banta & Stephen, 2001). In England, the guidelines for intrapartum care recommend that EFM is not to be used for low-risk women. Here, the issue is how many hospitals implement the national guidelines; how research findings inform practice (NICE, 2008b).

Innovation of prenatal screening.

Technological innovation is influenced by systemic factors, expectations and small events, but its existence also depends on the historical path of its development. As medical and genetic technology evolved during the last part of the 20th century and the beginning of the 21st, it was gradually incorporated in various ways into antenatal care. Apart from the driving forces behind the spread of new technology in health care which were previously described, few issues serve to illuminate how risk assessment became established in the wider context. Referring to the work of Beck-Gernsheim (2002), the modernization which accompanies industrial societies creates not only the production of 'goods' but also the prevention or minimization of bads, i.e. risks. In contemporary societies, we have come to interpret our health in the context of risk where the term is generally used to relate only to negative or undesirable outcome. Similarly, risk and uncertainty have come to mean the same thing, implying that what is risky is that which is unknown (Lupton, 1999). Elevated levels of expectations and confidence in technology serve to increase public concerns about risk (Brown et al., 2005).

In relation to pregnancy, an added awareness of risk became evident in the medical and public domain, where statistical representation of possibilities further stimulated the risk discourse and linked risk and technology (Solbekken, 1995). From this techno-scientific perspective, risk could be calculated based on existing data. Within this framework,

pregnancy and childbirth became defined as a period of risk, since the outcome is not known until the end and, as such, normality was only allowed in retrospect. Epidemiological methods and diagnostic technologies which followed, further served to strengthen this development (Cartwright & Thomas, 2001). The relation between epidemiology and the delivery of antenatal care became real in relation to screening for raised AFP (alfa-fetal protein), although that marker turned out to be weak for detection of Down's syndrome (Cuckle, 2001). With the introduction of ultrasound in the 1980's, and with the special position that it holds in antenatal care, screening procedures performed by ultrasound became a trend which further created a society norm of acceptance (Getz & Kirkengen, 2003). With the focus on individual choice in the context of reproduction as presented in the discourse, the attention has been taken away from the social context in which these technologies emerge and are sustained. Hence, professionals' and policy-makers' choices tend not to come under scrutiny (Kerr, 2004).

Screening and diagnosis – historical path.

The use of ultrasound in obstetrics in the mid-1950's can be defined as a starting point for fetal screening and diagnosis. The initial aim of its use was to detect anomalies and measure gestational age. The Scotsman, Ian Donald, who introduced diagnostic ultrasound to obstetrics and gynecology in 1958, was the first to perform fetal head measurements and relate them to gestational age and birth weight in an article published in the *Lancet* in 1958 (Donald, Macvicar & Brown, 1958). In 1961, Donald and Brown (in Campell, Johnstone, Holt & May, 1972) described a detection of hydrocephalus by ultrasound, but the first termination of pregnancy as a result of ultrasound detection of anencephaly was reported by Campbell and co-workers in 1972 (Campbell et al., 1972). In the following years, several new methods and parameters for examining the fetus and measure the length of pregnancy using ultrasound were introduced (Campbell & Wilkin, 1975;

Robinson & Shaw-Dunn 1973). During this time, studies focused on the possibilities of ultrasound examination and it use was not monitored by routine data-collection systems, which make it hard to say when and how the technology actually escalated (Oakley, 1986).

The adoption of ultrasound in maternity care in the Nordic countries can be said to start with Bertil Sundén in Sweden, but his work was inspired by Ian Donald (Tegnander, 2006). The first systematic screening program for use in pregnancy was one ultrasound examination at 28 weeks implemented in Sweden by Persson and colleagues in 1974 (Persson, Grennert & Gennser, 1978). Gradually, ultrasound spread in all the Nordic countries although the pattern of use is different for each country (Eik-Nes, Okland, Aure & Ulstein, 1984; Jörgensen, 1999; Kjaergaard et al., 2007; Saari-Kemppainen, Karjalainen, Ylöstalo & Heinonen, 1990). In the 1980's in Iceland, one examination at around 18–19 weeks was implemented (Geirsson, 1987). The use of ultrasound developed differently in the USA, England and Scotland compared to the Nordic countries, depending on service delivery and insurance arrangements in the health services in those countries.

Invasive diagnosis and biochemical testing.

Following the discovery by the French cytogeneticist Jerome LeJeune in 1959, that Down's syndrome is due to an extra chromosome number 21, amniocentesis was developed. The procedure is invasive where a small amount of amniotic fluid is withdrawn in the 14-16th week of pregnancy. In 1968, the first prenatal diagnosis of Down's syndrome by amniocentesis was reported (Valenti, Schutta & Kehaty, 1968). This diagnostic test came to be offered widely to all women of reproductive age who were between 35-37 years of age and older and for women at higher risk because of previous history. In this context it must be emphasized that development in fetal diagnosis such as amniocentesis was based on increased flexibility in abortion policy at that time in a number of countries, such as US, UK and

Canada (Louhiala, 2004). Chorion villus sampling (CVS) was first performed in the late 1960's and had the same purpose as amniocentesis but could be offered earlier in pregnancy, at about 10-12 weeks (Skirton & Patch, 2002). The chorionic villi are the part of the placenta that attaches into the wall of the uterus. As the placenta and the fetus arise from the same fertilized embryo, they essentially share the same genetic and chromosomal material (Skirton & Patch, 2002). The incidence of fetal loss following both amniocentesis and CVS is considered to be around 1% (Caughey, Hopkins & Norton, 2006).

Calculation of the prevalence of Down's syndrome in a society depends on several factors, such as maternal age, timing of diagnosis during the pregnancy and the number lost due to termination (Morris, Mutton & Alberman, 2002). Therefore, with increased mean age of mothers' the number of conceived Down's fetuses, increases, but at the same time the prevalence of Down's syndrome births has decreased in some countries, such as Denmark, Australia and Germany (Cheffins et al., 2000; Kjaergaard et al., 2007; Rösch, Steinbicker & Kropf, 2000). Boyd and colleagues estimate in a recent survey in Europe that 68% of Down's syndrome cases were detected prenatally, of which 88% resulted in termination of pregnancy. Countries with a first trimester screening policy had the highest proportion of prenatally diagnosed Down's syndrome cases. The survey was based on data from the EUROCAT database which contains information from 12 countries (Boyd et al., 2008).

The use of alfa-fetal protein (AFP) to screen for neural tube defects (NTD) has been offered from the 1970's in the UK. The incidence of those defects, however, varies between countries, regions of countries and also over time, according to different emphasis in practice (Skirton & Patch, 2002). The use of AFP was extended in the late 1980's and early 1990's to detect Down's syndrome, and soon other biochemical markers, such as hCG

(either free-β or total) and pregnancy associated plasma protein (PAPP-A), were added to the risk estimation (Skirton & Patch, 2002; Spencer, 2000).

Development and implementation of nuchal translucency screening.

The use of nuchal translucency screening (NT), with or without a combination of maternal serum biochemical markers, has been gradually established in obstetric care in several countries. The method is based on measuring the space between the skin and the cervical spine of the fetus in a sagittal view. An increased NT is associated with a raised risk of trisomy 21 as well as other chromosomal abnormalities, major heart defects and a wide range of skeletal dysplasias and genetic syndromes (Nicolaides, Heath & Liao, 2000; Spencer, Spencer, Power, Moakes & Nicholaides, 2000). Although the term 'trisomy' includes in clinical practices trisomies 13 and 18 as well as trisomy 21, the prevalence of trisomies 13 and 18 is far smaller than that of trisomy 21, and the rate of fetal death between 12 and 40 weeks of those fetuses is approximately 80% (Nicholaides, 2003). The findings from a cohort study with a large sample size showed that the current most effective method of screening for chromosomal defects is by combining maternal age, fetal NT, and maternal serum-free β-hCG and PAPP-A at 11 to 13+6 weeks. The detection rate for Down's syndrome by this method was about 92.6% and the false-positive rate 5.2%. A slightly lower detection rate for trisomy 18 or 13 and other chromosomal anomalies was reported (Nicolaides, Spencer, Avgidou, Faiola & Falcon, 2005). An association between the absence of the nasal bone at 11 to 14 weeks of pregnancy and trisomy 21 has also been reported. The nasal bone was absent in 1.4% of normal fetuses compared to 69% in fetuses with trisomy 21 (Nicholaides, 2004). The uptake of invasive testing following NT screening has been lower in twin pregnancies which are of importance as twin pregnancies have increased in many countries as a result of assisted reproduction and increased maternal age (Spencer & Nicholaides, 2003). There is a variety in

findings of studies on the diagnostic value of NT screening to detect other malformations, such as cardiac anomalies, although in general the technique seems to have a poor value in detecting cardiac anomalies of low-risk population (Westin, 2006).

Following the introduction of NT screening, ultrasound examination at 12 weeks has been offered in some clinics to women who decline NT screening. Evidence of the effectiveness of a routine first-trimester scan to detect major fetal malformation as compared to a routine second-trimester scan in a chromosomally normal fetuses is however limited. The sensitivity of detecting fetuses with a major malformation was 38% in the first trimester scan but 47% in the second trimester scan in a trial involving 39,572 pregnancies of unselected women (Saltvedt, Almstrom, Kublicas, Valentin & Grunewald, 2006). The sensitivity for detecting fetuses with a major heart malformation was 11% in the examination around 12 week, while it was 15% in the 18 week ultrasound examination in the same trial (Westin et al., 2006). Despite the higher detection rate of fetuses with a lethal anomaly at the 12 week ultrasound scan, the evidence showed no difference in any clinical outcomes. As a high uptake is needed if screening programmes such as NT screening are to have a significant population impact for reducing mortality and/or morbidity from a disease or condition, the issue of choice can in this context be seen as contradictive (Jepson, Forbes, Sowden & Lewis, 2001).

Fetal screening and diagnosis in Iceland.

The use of ultrasound was initiated at the Women's Clinic at LUH in 1975 and in 1978, amniocentesis became available for women aged 35 and over (Hreinsdóttir & Guðmundsdóttir, 2009). In 1984-86, ultrasound examination around 18-19 weeks became a standard procedure in antenatal care in Iceland (Geirsson, 1987) and today, nine units in the country offer a 19-20-week scan for all women, free of charge.

In 1999, NT screening was introduced as a new screening method for women over 35 years of age in order to reduce the use of amniocentesis. The development of its use in Iceland is reported in Table 1. In its first year of use, 10.6% of pregnant women underwent NT screening, while in 2002 the proportion had increased to 30%. At the same time, the number of amniocentesis tests performed dropped from 497 in 1998 to 158 in 2002 at the LUH clinic (Geirsson, Garðarsdóttir, Pálsson, Bjarnadóttir & Harðardóttir, 2003), but CVS started to increase as can be seen in the table below. Since 2004, NT screening has also been offered at a clinic in Akureyri, in the north of Iceland. By 2005, NT screening had become established practice in Iceland with about 84.5% of prospective mothers opting for it in the capital area, i.e. where there is easy access, and a total of 66.5% of all pregnant women in the country. At that time (2004 and 2005), all fetuses identified with Down's syndrome following screening were aborted (Geirsson, Garðarsdóttir, Pálsson, & Bjarnadóttir, 2005).

Table 1. ***Development of NT screening and amniocentesis in Iceland. From 2004 two places offered NT screening in the country, LUH and Akureyri (Bjarnadóttir et al., 2007).***

Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
NTscreening	477	418	610	1194	2194	2358	2820	3071	3332	3629
Amniocentesis	377	296	234	170	118	90	34	40	30	31
Chorion villus biopsy	33	42	41	47	67	58	62	85	96	101
No of births	4054	4269	4043	3977	4080	4187	4241	4344	4496	4766

Preliminary findings from an ongoing Icelandic study show a trend towards fewer children being born with Down's syndrome in the past ten years compared to the decade before (Figure 1). Figure I show the number of children with Down's syndrome who have been diagnosed at The State Diagnostic and Counselling Centre in Iceland in the past 25 years.

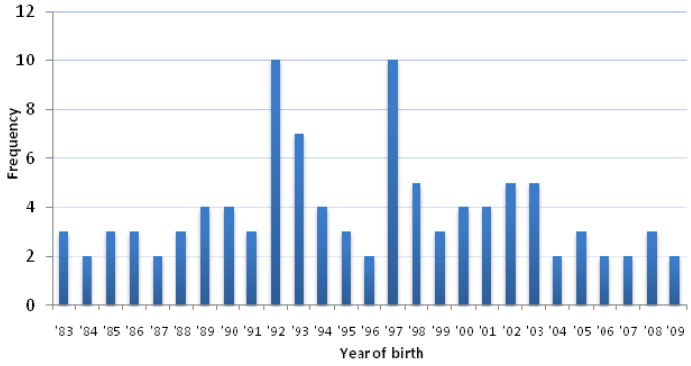

Figure 1. Children diagnosed with Down's Syndrome according to GRR
*****_The State Diagnostic and Counselling Centre_

The authors speculate that this is related to the policy in the country where there is both easy access to fetal screening and diagnosis along with the liberal abortion policy (I. Einarsson, personal communication, May 2, 2009; see also Einarsson, 2006). Figure 2 shows the number of pregnancy terminations of fetuses diagnosed with Down's syndrome following NT screening.

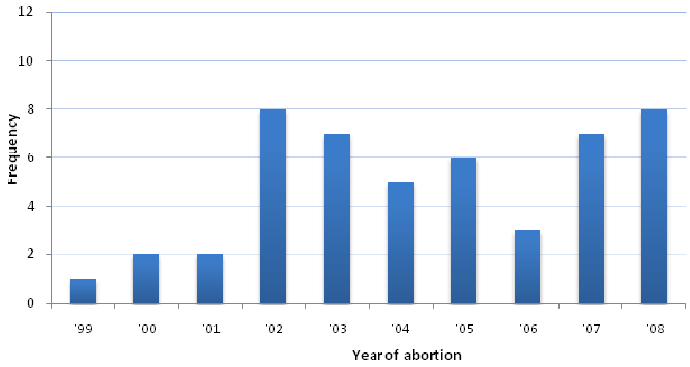

Figure 2. Aborted fetuses diagnosed with Down's syndrome following NT screening
*****_Figures retrieved from the Women´s Clinics at the LUH and in Akureyri._

Although the offer of NT screening had been discussed at conferences and among professionals, it was not until 2006 that official recommendations on the screening were issued by the Director of Health. There it was emphasized that the screening should be presented as an informed choice (Directorate of Health, 2006). With the clinical guidelines from 2008 this is further confirmed.

Social and ethical implications of screening.

Medical geneticists, epidemiologists, public health professionals and policy makers all play a part in an attempt to bring about the most beneficial engagement of public health. This challenge also relates to managing the controversial topics such as genetic technologies, for example prenatal genetic diagnosis (Raz, 2009), that have eugenic implications. The word eugenics is etymologically derived from Greek words meaning 'good in birth', but since the foundation of the Third Reich it has among other things been shaped by the meaning 'discrimination against minorities'. In the second half of the last century, the eugenics movements were influential in some countries, i.e. USA, UK and some parts of Scandinavia (Kerr, 2004).

Disability groups argue that selective abortion on the grounds of a genetic condition not only amounts to negative eugenics which aim to eliminate or reduce the incidence of particular genetic disorders in society, but is also morally unacceptable as it is based on and implicitly encourages discrimination against people already born with a condition for which such abortion is available (Gillon, 1998). Raz argues that the role of the state in modern societies where liberal eugenics is promoted is merely to facilitate rather than to impose eugenic choices. By focusing on individual choice rather than governmental coercion, it has been framed as 'sneaking in through the backdoor' (Raz, 2009). Routine screening of chromosomal abnormalities does not usually provide information that could lead to fetal therapy (Parens & Asch, 2000). Therefore, the ethical dilemma that arises

around screening has connections with eugenic implications of screening and its connection with selective abortion. Although eugenic implications of screening can often be seen as a relief of unnecessary suffering, pain and limitation of freedom, the idea that decision to continue a pregnancy should be based on assurance that no deviances have been identified has been objected to by many people.

Fetal screening has been around since the 1970's and from the mid-1980's both proponents of disability rights and feminists have made important contributions to the discussion. In disability studies, the argument is commonly made that policy which encourages routine screening during pregnancy ignores the social implications that accompany it. Such policy is based on the assumption that disability is a problem to be eliminated, rather than focusing on improving the medical and social situation of disabled people. Abortion is clearly not of benefit to Down's syndrome children, but when born, their physical condition can be counteracted with modern technique and they themselves do not seem to suffer (Ford, 2002). Following this argument, it has been said that routine screening may have a detrimental effect on the lives of existing disabled people, whereas collective responsibility for differences in ability would be more helpful for this group (Parens & Asch, 2000; Shakespeare, 1998). This is probably a result of stereotypic thinking of what disability means for individuals, families and societies, which is often contradictory to what research on the life satisfaction of people with disabilities and their families has actually shown (Blaymore Bier, Liebling, Morales, & Carlucci, 1996; Parens & Asch, 2000). Although individuals with Down's syndrome have a wide range of problems, some of them are treatable, and, in the past decade and a half, studies have reported on substantial improvement in the life expectancy of those individuals. Approaches, standard of care and outcomes differ throughout the world, but positive improvement in the quality of life of

individuals with Down's syndrome depends on the support parents are provided with in each community (Roizen & Patterson, 2003).

The prevailing ideology in each social context affects technology development during pregnancy in that community (Rothman, 2001). New screening methods prescribe for action to be put into practice, and, as Tremain argues, each testing and screening technology contributes to the naturalization and materialization of impairment (Tremain, 2006). Within antenatal care in the Netherlands, this was clearly visible where new imported technology encouraged new speculations on the meaning of disability and normal pregnancy among midwives and women who then had to act and reconsider their values and apply the new technology to their understanding of pregnancy and birth (Rothman, 2001). There is a well developed and growing body of knowledge on social and ethical implications of screening arising from multidisciplinary work in the social sciences (Alderson, 2001a; Kerr, 2004; Raz, 2009), disability studies (Parens & Asch, 2000; Shakespeare, 1998), feminism (Beckett, 2005; Oakley, 1986; Rothman, 1986; Zechmeister, 2001) and bioethics (Alderson, 2001a; Beauchamp & Childress, 2001). Those studies serve to inform, by one way or another, how implementation of a new screening technology will change the management of pregnancy care, the professional role of midwives, and affect conceptualization of disabled people. As such, they highlight the need to reconsider and develop care which is organized and informed to meet the needs of women.

Some authors also argue that with constant new technology and 'screening for all' policy, self-determination of reproductive choices for individual women will in fact decrease and the women will be left to confront moral decisions on their own (Tremain, 2006; Williams, 2006; Williams et al., 2005). This practice echoes the 'autonomy model', as decision is made with little or no discussion with a health professional. The earlier work of Foucault has been used by a number of authors to explain

how power operates in modern societies in order to understand the nature and diffusion of screening in prenatal care (Helén, 2002; Koch & Svendsen, 2005; Tremain 2006). One of his main ideas is that power is present in all social relations (Foucault, 1991). As Foucault (1977) explained, since the 18th century, the authorities have increasingly taken on the task of managing life by enhancing the health, welfare, prosperity and happiness of the population as a whole. A system developed where knowledge about strategies to enhance life was of key importance. This knowledge, or forms of rationalities, then comes to manifest itself as true and proper ways of acting and thinking (Koch & Svendsen, 2005). The normalization of antenatal care can be seen as a good example of this process. Arney describes, in Foucault's tradition, how surveillance extended into the community through epidemiological analysis. With the development of sophisticated technology, the fetus became more like a patient which was a new order of control (Arney, 1982).

Autonomy.

The ethical implications of fetal screening are diverse and its effect on pregnant women has been discussed (Garcia et al., 2002; NICE, 2008a). I have chosen, however, to focus on the issue of autonomy because of its predominant role in the discourse of decision making. Similar to laws in many other countries, Icelandic laws and regulations emphasize patients' autonomous informed decision making (Chadwick et al. 1998; Act on the Rights of Patients no.74/1997). This has been in line with a general agreement within the literature on increased patient autonomy. Although the resources lie in the construction of the Nuremberg Doctors' Code from 1947, change in the context of social and health care in the past decades can be seen as an impetus for this evolvement (O'Neill, 2002). With a more recent social change, the introduction of the new liberalism, an atomistic sort of autonomy emerged. "It created a self determinative euphoria, where speech

and rhetoric about ‘rights’ have supplanted a notion of social responsibility and the collective good of society.” (Dunne & Warren, 1998, p. 168).

Much of the contemporary writing on autonomy has its roots in the four principle approach developed by Beauchamp and Childress (2001). Those four principles are: beneficence, non-maleficence, autonomy and justice, where, according to Beauchamp and Childress, respect for autonomous choices is given equal weight to the other principles. In the context of decision making in health care, autonomy is most often analyzed in terms of self-determination, but the authors reject the criticism that their interpretation of the concept is too individualistic, excessively focused on reason, and not unduly legalistic (Beauchamp and Childress, 2001, p. 57). In summary, they highlight that their interpretation refers to the right to choose, not to the duty to choose. Although this understanding has been applied within studies in health care, such as nursing, midwifery and medicine, some writers claim that proponents of autonomy force choices on patients and do not pay attention to the web of relationships that people belong to (Callahan, 2003; Frank, 2004; Struhkamp, 2005). One of the key dimensions of autonomy is in fact how it is realized in relationship with others, and in pregnancy, the perception of the fetus and then the intimate relationship between mother and child make it difficult to view autonomy as a rational concept (Erich, Farsides, Williams & Schott, 2007; Rothman, 1986). People are always dependent on each other and the social context they belong to, and in the context of health care, an individualistic model of autonomy can be problematic, even though one values informed and uncoercive choice. Situations can in principle create a paradox if emphasis is first and foremost on autonomy and choice as Rose (1999) argues:

> …modern individuals are not merely ‘free to choose’ but *obliged to be free*, to understand and enact their lives in terms of choice. (Rose, 1999, p 87)

Informed choice – informed decision.

The literature shows that the different degrees of autonomous decision making are dependent on the relationship between the woman and the professionals who attend her. Theoretically, to be able to experience autonomy, informed choice or informed decision making must fulfil certain characteristics. The conditions or arguments for making an autonomous decision or choice are, however, complicated. According to one definition, evaluating the conditions, voluntariness, having alternatives, competence and adequate information, has been seen as a foundation for making an autonomous choice (Green, 1999; Huibers & Spijker, 1998). Here, voluntariness refers to the one who seeks it and having alternatives is the presentation of all options. Competence refers to the client's ability to make a decision. The last precondition, adequate information, means that the information should be given up to a level that a reasonable medical practitioner would apply under the same circumstances, the need for information of every individual is satisfied and notice should be taken of the level of information which a reasonable person would deem relevant to the decision at hand (Green, 1999; Huibers & Spijker, 1998). Several approaches have been developed as to how an informed decision is best achieved. From the educational perspective, there are three domains of competence: knowledge, skills and attitude (Amin & Eng, 2003). It is of importance to be aware of this variation when measurement of informed choice or informed decision is considered.

Although there has been a strong emphasis on the information part of the term informed choice or informed decision, which in fetal screening means that a certain amount of information has been disclosed to becoming parents (Marteau, Domandy og Michie, 2001), it appears to play limited role in whether women undergo screening or not. A handful of studies show that decisions on screening are not based on knowledge although it is seen as the key component within informed choice (Jaques, Sheffield & Halliday, 2005;

Michie, Dormandy & Marteau, 2005). Attitude seems to be a stronger predictor of uptake, and knowledge and attitude appear to be independent of each other (Michie, Dormandy & Marteau, 2002). Marteau et al. (2001) define three variations of informed choice, informed decision, evidence-informed decision, and effective decision. In the first and third variation, the individual's value is of importance and in the third it is also behaviourally implemented (Marteau et al., 2001). A number of authors have emphasized the value-based nature of the concept which incorporates patients' preferences as well as knowledge of a patient's clinical state (O'Connor, Llewellyn-Thomas & Flood, 2004). This is interpreted differently by other researchers who consider that pregnant women exercise their autonomy and informed choice in relation to invasive testing as there is a correlation between estimated risk for Down's syndrome and the decision to have an invasive test (Nicolaides, Chervenak, McCullough, Avgidou, & Papageorghiou, 2005). It might be simplistic to interpret such a complex term as informed choice within this form as it has a number of psychological and ethical dimensions which are not taken into consideration in this context. Informed decision is constructed within particular epistemological frameworks and is therefore contingent on them (McLaughlin, 2001). Therefore, professionals' understanding of informed decision is important as their interpretation is reflected in everyday practices. Vilhjálmur Árnason points out the importance of promoting mutual responsibility between professionals and clients in order to avoid either one-sided patient autonomy or professional paternalism; hence, he argues for a model of shared decision-making (Árnason, 1994, 2000, 2003).

Some feminists argue that, in the context of screening performed within ultrasound environment, informed choice is perhaps not possible as women have been 'socialized' into a certain role and argue that the situation requires visual proof of pregnancy. Nicol draws on a gender belief theory which means that women have moved their knowledge base from feelings and

intuition to such actual proof as ultrasound (Nicol, 2007). She also points out that, as ultrasound is performed within the hospital environment where technology and expertise are 'male prototypes', it creates a barrier in communication.

Many feminists have identified with the 'natural childbirth movement' which similarly criticizes the understanding of pregnancy and childbirth as pathological. Services offered during pregnancy and birth have been seen as overly technological, fragmented, inhumane and impersonal, with the woman as a passive recipient rather than active participant. Hence, technology such as ultrasound could be described as a different trigger of prenatal bonding as the woman becomes attached to the visual image of the fetus which can influence her compliance (Rothman, 1986; Zechmeister, 2001). Referring to the discussion of Foucault above, the emerging relation between the pregnant women and reproductive technology can be explained by the strategy of biopower as a form of modern governance (Tremain, 2006). Other feminists object to this negative view of reproductive technology, arguing that it could just as well be seen as a way for women to gain more control over their body, thus liberating them from their biology (Beckett, 2005). In summary, the existing literature acknowledges that ultrasound has a powerful effect on the meaning and experience of pregnancy among pregnant women and their partners. Ultrasound is highly accepted as a technical procedure, where the visual confirmation and reassurance about the well-being of the fetus is of most importance. NT screening is strongly related to ultrasound and it may be expected that many women see the two as related. Therefore, despite the considerable knowledge on informed decision making and autonomy in the context of fetal screening that has been briefly described, it is important in the context of the present study to understand the positive views or attitudes that seem to have developed towards screening.

Women's Attitudes towards Screening

In a review of 64 studies (Bricker et al., 2000), it was shown that there is a deficit in women's knowledge of ultrasound screening and another review published two years later came to the same conclusion (Garcia et al., 2002). Some studies also showed that women experienced increased anxiety concerning their unborn child which the authors relate to the strengthened maternal-infant bonding as part of the ultrasound use (Garcia et al., 2002).

As suggested by the NICE guidelines, more findings of uncertain clinical importance have become evident with recent trends in the use of ultrasound which is likely to have psychological and social consequences for women and their partners. The included studies were not able to identify positive health behaviour among women during pregnancy as a consequence of the routine use of ultrasound (NICE, 2008a). As NT screening is performed in the context of ultrasound, it is likely, however, that this positive attitude towards ultrasound may augment the uptake of first trimester screening (Dahl et al., 2006; Mulvey & Wallace, 2000; Williams et al., 2005).

Women's preferences of NT screening.

Most women favour the offer of screening regardless of their decision to accept or decline (Gourounti & Sandall, 2008; Jaques et al., 2005; Muller, Bleker, Bonsel & Bilardo, 2006a). Similarly, women prefer the screening early in pregnancy (Pilnik, Fraser & James, 2004). In a survey performed to determine whether women prefer to have a screening test with a higher detection rate or a lower false-positive rate, the majority of participating women preferred a screening test with the lowest false-positive rate to minimize the risk of a miscarriage of a normal baby if a positive result led to diagnostic testing. Older women in that study (age 37 or more) chose the test with the highest detection rate despite a higher screen-positive rate. They expressed as the reason that they would prefer to miscarry a normal baby as

a result of a diagnostic procedure rather than miss the diagnosis of Down's syndrome (Mulvey, Zachariah, McIlvaine & Wallace, 2003).

Few studies have been able to explore in advance the preferences of women regarding NT screening before its implementation. In the Netherlands, the offer of amniocentesis has traditionally been aimed at women aged 36 and older. However, around 60% of both high-risk and low-risk age of Dutch women thought that invasive tests should be offered to all women, and 77% felt that serum screening and ultrasound should be offered to all women. In the same study, a large number of women preferred NT screening combined with biochemical measurements as a routine offer (de Graaf, Tijmstra, Bleker & Lith, 2002). Similarly, findings from an Icelandic study showed that 96% of pregnant women were interested in NT screening and would accept the test if offered. The study consisted of one hundred eighty two women who were asked to complete a questionnaire at the Department of Fetal Diagnosis at the LUH following their 19–20th week scan in the beginning of 2001. They were not informed in particular about NT screening in advance (Haraldsdóttir, 2001). Those findings were used in the discourse around screening in Iceland and encouraged the implementation of the screening.

Women's knowledge and understanding of NT screening.

As previously described, the visual confirmation of the pregnancy and reassurance about the wellbeing of the baby seems to be of most importance to women and therefore can override that women seek useful information about ultrasound. As NT screening is a relatively recent phenomenon, there is a lack of research looking at its actual implementation in countries where the screening has been introduced. Already in 1992, Marteau and colleagues stated that making choices about screening is meaningless if women are likely to have little understanding about the screening and its implications (Marteau, Slack, Kidd & Shaw, 1992). Knowledge and understanding of

screening for Down's syndrome has been of concern in a number of studies since the study by Marteau and colleagues in 1992. As acknowledged in the NICE guidelines, the levels of knowledge adequate for decision making of screening have not been achieved. Although leaflets seem to improve knowledge, substantial gaps in understanding remain (NICE, 2008a), partly because the delivery of information is poor (Kohut, Dewy & Love, 2002). Dahl and colleagues (2006) showed in their review that knowledge varies; most pregnant women are able to explain the more uncomplicated purposes such as the estimated date of birth and a number of fetuses, only a small portion of women are familiar with terms such as false-negative or false-positive result (Dahl et al., 2006).

Knowledge seems to be higher among women with higher education and income status, which is reflected in that more women with lower income and educational level are more likely to make an uninformed choice (Gourounti & Sandall, 2008; Jaques et al., 2005; Santalahti, Hemminki, Latikka & Ryynänen, 1998; van den Berg, Timmermans, ten Kate, van Vugt & van der Wal, 2005). In a Swedish study, one in five women was unaware that the risk score was noted in her record after NT screening and about one-third of those who actually said that they had been informed of their risk score did not know the figure when asked in mid-pregnancy. Women's perception of risk does not always reflect the calculated risk as some women interpreted their risk as very high or rather high when more than half of them were actually at calculated low-risk. In addition, a woman's perception of being at high-risk seemed to affect her emotional well-being, at least in mid-pregnancy (Georgsson Öhman, Grunewald & Waldenström, 2007).

Partners' views.

It is known that ultrasound can potentially change the experience of pregnancy and strengthen the father's perception about the unborn child (Draper, 2002; Ekelin, Crang-Svalenius & Dykes, 2004; Gottfreðsdóttir,

2005). Women have identified that their partner has a strong influence on the decisions they make on antenatal screening (Jacques, Bell, Watson & Halliday, 2004). Studies have also demonstrated that women want the decision to be made by both parents (van Berkel & van der Wele, 1999). As such, it is important to listen to men's direct account, but studies where men are the main subject are limited. The study by Locock and Alexander showed that men's involvement in the process was based on the information passed on by their partner. Although the men felt that the attendance at the ultrasound examination was a positive experience, some men felt left out in the process, especially if the pregnancy was not progressing normally (Locock & Alexander, 2005). However, in their study, only two men were interviewed alone, the others were with their partner. In a study on men's and women's values in relation to accepting or declining amniocentesis, it was shown that spouses are particularly vulnerable to moral tension because they anticipate that differences in their beliefs may not be resolved if disclosed. This keeps them from opening up to each other and the professional. Some couples, who declined testing, exercised autonomy by choosing not to know about prenatal testing (Anderson, 2001a). Other studies, performed in the 1980's in relation to genetic testing, showed that the difference could be striking, as the study of Sorenson and Wertz on 699 couples demonstrated. There, a significant proportion disagreed on major issues such as reasons for seeking genetic counselling and differences in perceptions of the level of risk of having an affected child (Sorenson & Wertz, 1986).

Decision making and NT screening.

The understanding of decision making and NT screening partly rests on findings from studies on ultrasound and AFP screening where some of the same concerns are shared. As discussed previously, amniocentesis and AFP was used routinely in the USA and some Western/European countries in the

early 1980's, and from there the first research of decision-making under conditions of uncertainty emerged (Press & Browner, 1997; Rapp, 1999; Rothman, 1986). The study performed by Press and Browner is highly relevant in the context of this thesis, not only as one of the first studies to include contextual factors, but also because the study was performed in the state of California which in 1986 implemented public policy on offering AFP screening to all pregnant women. The study showed how alternate discourses about AFP screening were constructed among pregnant women and professionals and how institutional factors encouraged the uptake of screening as the practitioners interpreted the offer of 'screening for all' as a policy to mean that a high uptake of screening should be the standard of care. Of the 110 women interviewed in the study, 85% said that they did not give the screening much consideration before deciding, but the 10% of women who declined had thought a lot about their decision. A minority of women were aware of pregnancy termination as an option in the context of screening (Press & Browner, 1997). In an interventional study, group counselling was used for 271 women, who were all 35 years of age or older, before they underwent NT screening. The study showed that the group counselling with a preclinical information package did not change anxiety scores, but there was decreased decisional conflict for the majority of women. However, despite the improvements in knowledge regarding prenatal diagnosis, there was a lack of knowledge on NT screening which also indicated that communication about NT screening was clearly lacking. It was speculated that, as NT screening was a relatively new technique in the setting where the study was performed, it was perhaps not yet integrated into clinical discussion at that time (Kaiser et al., 2002).

Several studies have looked at whether the decision to accept NT screening is based on an informed choice. Ekelin and Crang-Svalenius (2004) claim that the presentation of information prior to screening is constructed by midwives as an obvious decision to make but not as an actual

choice. As previously described, the ethical principle of autonomy is respected by means of informed choice and it has even been argued that better psychological outcome could be achieved (van den Berg et al., 2005). Knowledge on its own does not predict decision outcome, which emphasizes the importance of incorporating attitude towards decision options into any definition and measure of informed choice (Michie, Dormandy, & Marteau, 2002). Most women in the study by Gourounti and Sandall (2008) had a positive attitude towards screening for Down's syndrome and their attitude was not associated with demographic features. However, the low level of knowledge was reflected in that the majority of participants (56%) made an uninformed choice. This is relatively low compared to studies from the UK (Michie et al., 2002), Australia (Jaques et al., 2005) and the Netherlands (van den Berg et al., 2005). Informed choice is valued differently among the general population across countries and appears to be more favoured in Northern European countries than Southern European and Asian, i.e. in Chinese and Indian populations. The variations reflect broad cultural orientations, and disability, for example, is perceived more negatively in Asian countries, where many consider the birth of a disabled child to be irresponsible to both the family and the society. Acknowledging different value systems is of importance in modern societies with a wide ethnic variation (van den Heuvel et al., 2009).

The term disability has a short history in Icelandic law and the first law on disability rights was issued in 1983. The law of 1983 have been reformed but reflect a commitment to provide comprehensive services that will allow the disabled to live independently (Act on the Disabled, 1992, § 7). An ongoing study on how parents of children with Down's syndrome in Iceland experience service delivery shows that parents emphasize that care provided by the state should be better organized and preliminary findings also indicate that the majority of the mothers worked part time in order to be able to take care of the child (I. Einarsson, personal communication May 2, 2009).

Many additional factors have been addressed in earlier studies which have relevance in the context of NT screening and decision-making. For example, most women in the study by Santalahti and collegues found the decision to accept screening easy. However, the decision was experienced as less easy if the screening was presented as an actual choice. Although the majority of women considered participation as a self-evident act and did not describe in particular their motives or reasons for participation (Sanatalahti et al., 1998), ambivalence towards decision making was more frequent among women who had waited to become pregnant for over a year and acquaintance with a person with congenital disability was also negatively associated with participation in serum screening (Santalahti, Hemminki, Aro & Helenius, 1999). From the technical perspective, speculations have been on the effect of assisted reproductive technology (ART) on the first trimester screening markers, which is of relevance in countries where ART is high. This was especially related to PAPP-A which was decreased in pregnancies after ART compared to controls that conceived spontaneously and therefore recommended to develop median curves for pregnancies after ART (Gjerris, Loft, Pinborg, Christiansen & Tabor, 2009).

Management of NT screening.

Few studies have assessed whether the pathway of care is of importance to ensure that decision making is informed. It has been speculated that the uptake of screening is higher when it is offered at the same time as other antenatal care procedures (Dormandy, Michie, Weinman & Marteau, 2002), but it is still uncertain how much of the variance in informed choice is explained by the way that Down's syndrome screening is conducted. One trial with informed choice as an outcome measure showed that a similar proportion of women made an informed choice to accept Down's syndrome screening when it was offered at a combined visit and a separate visit (Dormandy, Michie, Hooper & Marteau, 2006). About 30% of participants

in a cohort of 325 pregnant women considered that any delay in getting the screening result made a difference to them, but 70% indicated that it made no difference if the result was not available at the same visit. A service which provides a result the same day would satisfy the majority of participants and about 20% considered a delay of more than one day to be as good as same day service (Chan et al., 2005). Women's experience of the service in a small UK survey with 10 women indicated that women had different access to resources and this impacted on opportunities to discuss NT screening options (French, 2000).

Policy of Nuchal Translucency Screening

The policy of the state and the social organization of maternity care have the greatest influence on what kind of service is available (Wrede et al., 2001). It differs between countries whether the policy-making on fetal screening is behind or ahead of the implementation of screening, but the literature relating to women's knowledge and experience of screening is hardly incorporated when policy recommendations are taken forward (Bryant, Green & Hewison, 2001). Women's choices are in each context limited by intersections of ideology, resources, class and race, all factors over which they have little control (Cartwright & Thomas, 2001; Kirkham 2004; Press & Browner, 1997). Therefore, good intentions in health care do not always lead to good results and not all policies which have been put in place promote equality between different social groups. For example, in societies which consist of a multicultural population, there is evidence that the uptake of screening for Down's syndrome is lower in some ethnic minority groups and among socioeconomically deprived women when compared with Caucasian and socially advantaged women (Dormandy, Michie, Hooper & Marteau, 2005; Ford et al., 1998; Rowe, Garcia & Davidson, 2004). Alderson argues, for example, that what can be seen to be the main encouragement for the shift from age-based screening to a 'screening for all'

policy in many European countries after 1990 was the development of NT screening as a non-invasive method and an emphasis on the prevention of suffering and reduction in the cost of care of disabled children in the community. If the policy and counselling on fetal screening is, however, to become evidence based, still more knowledge is needed on people who have congenital condition (Alderson, 2001b). Gilbert and colleagues (2001) argue that the risk of babies with Down's syndrome being missed and the miscarriage rate due to amniocentesis and CVS should be in focus in policy-making on screening, in addition to cost-effectiveness.

Although insignificantly explored it is speculated that there is inconsistency between policy makers' and professionals' roles in implementing the new genetics. The general practitioners in the study by Kumar and Gantley (1999) emphasized the need to build on current practice, whereas policy makers focused on transforming practice to include new knowledge in the area. As the holistic model of health underpins the work of GPs, they might find it contradictive to integrate such information as genetics which undermine the consideration of other dimensions of health, such as the social and psychological dimensions. In the context of fetal screening, the policy on screening is enacted through conversation between the pregnant woman and professionals. There is, however, a discrepancy in the actual consultation and the experience of women who are being informed, which indicates complexity of the interaction between women and midwives. Although midwives highlight the issue of choice they need to discuss what kind of choices there are to be made (Pilnick, 2008). Kirkham (2004) points out that the power imbalance that is in place in most situations where information is being delivered in maternity care results in that women are being 'helped' to make choices that practitioners feel comfortable with and are perceived as accepted by society.

A number of studies have been done that are highly relevant to informing-policy and practice around screening on a macro level. A few

years ago, a project was launched to identify the main ethical, legal and social issues related to the development of prenatal screening in Europe. The main aim was to inform policy makers in public health and biomedicine (http://www.valt.helsinki.fi/sosio/pnse/) for the sake of future development of practice. The research issues were approached by theoretical analysis, interviews and questionnaire surveys in a cross-cultural comparison of four countries, i.e. Finland, the Netherlands, the UK and Greece. In summary, the published reports based on this project showed that there had been a different development of fetal screening in each country, which indicats that availability of screening is bound to cultural and political norms. Furthermore, it was demonstrated that women lacked knowledge of screening and its implications (Dormandy et al., 2006; Muller, Bleker, Bonsel & Bilardo, 2006a; Santalahti et al. 1998). A more recent survey on prenatal screening policies in 18 countries showed that 10 countries had a national country-wide policy for Down's syndrome and 14 for structural anomaly scanning (Boyd et al., 2008). This result shows more clearly that despite the available techniques, considerable variation in cultural factors between countries results in that some countries have not yet implemented a national policy on fetal screening.

To follow the recognition that patients should be involved in their own care, special organizations have been established to conduct research on patients' perspectives towards service delivery with the aim to contribute information for use in formulating healthcare (Hasman, Coulter, & Askham, 2006). The notion of patients to be both informed and active participants in their own care has been highlighted as fundamental in future planning (Coulter & Ellins, 2006). In fetal screening this is particularly important as a number of concerns have been raised following the introduction of a 'screening for all' policy. For example, some evidence suggests that following increased termination of pregnancy for fetal abnormality, which is an inevitable result of a such a policy, more women will experience coping

difficulties and be in need for special attention (Bryant et al., 2001; Zeanah, Dailey, Rosenblatt & Saller, 1993). It is also of concern that women who undergo serum screening for Down's syndrome may develop less attachment for the baby owing to the uncertainty surrounding interpretation of the test result (NICE, 2008a).

As has been introduced, the history of the current policy on NT screening in Iceland is short. The national guidelines recommend that parents should be informed of the NT screening before the 12th week of pregnancy and it should be stressed that the screening is an informed choice. In the past 4–5 years the two clinics in Iceland that offer NT screening have charged for the test by a decree from the Ministry of Health. This decision was partly introduced to cover the cost of the tests, but also to emphasize over for prospective parents that this form of testing is optional in maternity care and that it demanded thought about whether the parents really wanted to avail themselves to the offer (Directorate of Health, 2006).

Implications for professionals.

Constantly, new techniques involving extraction of fetal cells from a maternal blood sample are being developed. These techniques will give parents the option of knowing their expected baby karyotype without invasive tests (Skirton & Patch, 2002). This development, along with the discourse on individual autonomy in the context of 'screening for all' policy, calls for the need to provide information on genetics or matters concerning specialized prenatal assessment by professionals who are not specialized in this area (Dunn & Warren, 1998). In the context of screening, the midwife has to bring together different threads of knowledge, linking to the biomedical, technical and bioethical perspectives. Optimally, the midwife would use nondirective counselling philosophy when discussing fetal screening with prospective parents (Zindler, 2005). However, in this context, consultation is problematic as screening and diagnosis quickly become part

of social norms and expectations. Therefore, its use was reflected in the professional attitude as well as that of the expectant parents as has been reported in a number of cross-cultural studies following the implementation of AFP and amniocentesis in the USA in the 1980's (Press & Browner, 1997; Rapp, 1999; Rothman, 1986). Findings from the UK study by Marteau and colleagues in 1992 highlighted that during consultation little information was provided about AFP screening, the conditions screened for and the meaning of a positive and negative result. Both doctors and midwives in the study rather encouraged the women to take part in the screening and the issue of choice or limitations of the screening were hardly discussed. The uptake rate at the study hospital was 90% and the possible factors influencing the presentation of screening in this context could therefore have been the perception of professionals of the screening as a routine procedure, as well as the women's attitude and behavior (Marteau et al., 1992). Many studies have since reported similar findings when it comes to consultation on screening in the clinical context. Recent studies have, however, shown a paradox in the view of professionals on developments in genetics on the one hand, and moral beliefs and values on the other, when the centrality of informed choice in fetal screening came to the fore. Professionals seem to have doubted whether informed choice can be achieved in practice and to have seen the expansion of screening as an inevitable development over which they have little if any control (Williams, Alderson, & Farsides, 2002). Similarly, Ryder (1999) identified professional and personal conflicts in her study on midwives and, despite the small sample and the fact that her study was done 10 years ago, it points out the many aspects of the procedures and the dilemma midwives face when working in this field. Midwives are concerned about protecting the women in their care, as well as themselves, when women make choices during pregnancy. Levy identified 'protective steering' to be the main category in her study, which refers to facilitating

informed choice and attempting to meet the wishes of women and steering their way through several dilemmas (Levy, 1999).

The notion that screening is part of traditional antenatal care has raised the issue of compliance, but change in a screening provision to a separate visit to undergo screening does not seem to increase women's informed choice as mentioned previously (Dormandy et al., 2006). However, reluctance by policy makers and professionals to accept studies that have shown inadequate knowledge of fetal screening among midwives, doctors and other counsellors inhibits shared decision making and deprives women of information and counselling on screening (Bramwell, West & Salmon, 2006; Ladfors et al., 2001; Santalahti et al., 1998, 1999). Although midwives have been shown to be in general positive towards screening, they have identified a need for continuous education, standardized policy and ethical debate (Ekelin & Crang-Svalenius, 2004).

SUMMARY – RATIONALE FOR THE STUDY

Improved ultrasound techniques and the advent of biochemical markers led to the development of NT screening in the early 1990's. The introduction of NT screening, as a late first trimester screening, is now part of the history of antenatal care inspired by the ideology of prevention in modern health care. Recent research continues to identify methods of prenatal screening, with first trimester screening being the biggest area of change.

While the use of these techniques has created certainty for some women and has lead to fewer invasive diagnostic tests, it has at the same time created uncertainty for at least some women. This is because the result obtained is based on prediction in the context of "risk", which calls for the need for parents to understand meaning of false-negative and false-positive terminology. For society, maybe the uncomfortable collective impact of personal decisions can result in a policy that could be said to be to some degree eugenic in impact if not in intent. In some countries, this has led to fewer children being born with Down's syndrome, although there is still a debate about whether the technique will decrease perinatal mortality. Following NT screening in Iceland in 1999, the use of amniocentesis has decreased but CVS has increased compared to when the screening was implemented (Table 1). An overview of the number of children with Down's syndrome being born in Iceland shows a tendency towards fewer births of children with Down's syndrome (Fig. 1).

In general the rapid development of fetal screening technology has not been accompanied by a concurrent public debate of the social and ethical implications. Some social scientists have questioned the 'principalist approach' which has informed the moral discourse around screening. The four principles, beneficence, no harm, justice and autonomy, have informed regulations and guidelines on screening with the main emphasis on autonomy. The individualistic interpretation of the principles has become the common understanding and affected the content and format of delivery of

information. In Iceland, NT screening gained popularity within a short period of time. Counselling, or providing parents with information, is an important part of midwifery care during pregnancy and the midwife, as the main care-giver in low-risk pregnancies, will need to inform prospective parents in a way that facilitates their decision and answers their questions, not least when the result is inconclusive. The value-based nature of informed decision making in the context of screening has been shown to play a role in the decision making process, although very few intervention studies have been developed. Much of our current knowledge on NT screening and decision making rests on findings from studies related to ultrasound and serum screening in the 1990's. In general, those studies showed lack of knowledge among professionals accompanied by a positive attitude towards the offer of screening. Similarly, parents' satisfaction regarding the provision of information was low and lack of knowledge of the meaning of screening in particular was apparent. More recent studies on NT screening show that prospective parents are positive towards first trimester 'screening for all', but that there is an indication that risk is constrained by a medical structure that limits reflection on the issue. Although women see their partner to be their main supporter during pregnancy, information on the needs and views of fathers-to-be in the context of screening is still scarce. It is insufficiently explored if the decision to decline or accept screening is a joint decision made by both parents, but there is an indication that some women make their choices in early pregnancy in their own situated context, even before they contact a health professional. Therefore, so far, there is insufficient information on how decisions on whether to accept or decline screening emerge in very early pregnancy, and on the processes women and men go through as they make these decisions.

Icelanders have come to expect high-quality services, but each technological advance calls for new questions on service delivery and professionals' roles. Limited knowledge and understanding of the process

and implications of prenatal screening affects rational development in the clinical and social context. The decision making of fetal screening is strongly connected to the health care system and thereby the society in which it is enacted (see Figure 3). The purpose of the present study was to understand better how prospective parents perceive choices of NT screening in early pregnancy and how that perception develops as the pregnancy continues. A deeper knowledge about what affects the decision-making process during pregnancy will contribute to an understanding of the situation that prospective parents are confronted with and what motives and values are specific to each parent-to-be. The discussion of choice is such that it is difficult to argue against it without unintentionally giving the impression of arguing against individual rights. In this regard it is important to understand the context in which choices is made. Therefore, the media discourse in Iceland around NT screening provides a background for understanding how information on screening dissipates through society and thus to prospective parents and professionals.

In practice, knowledge of women's and men's attitude toward screening will help professionals to facilitate the discussion on how to ensure that women have a choice. Counselling parents during the first trimester of pregnancy is of key importance in midwifery practice; hence, this study may be of value in enhancing the knowledge base of midwives in this important area.

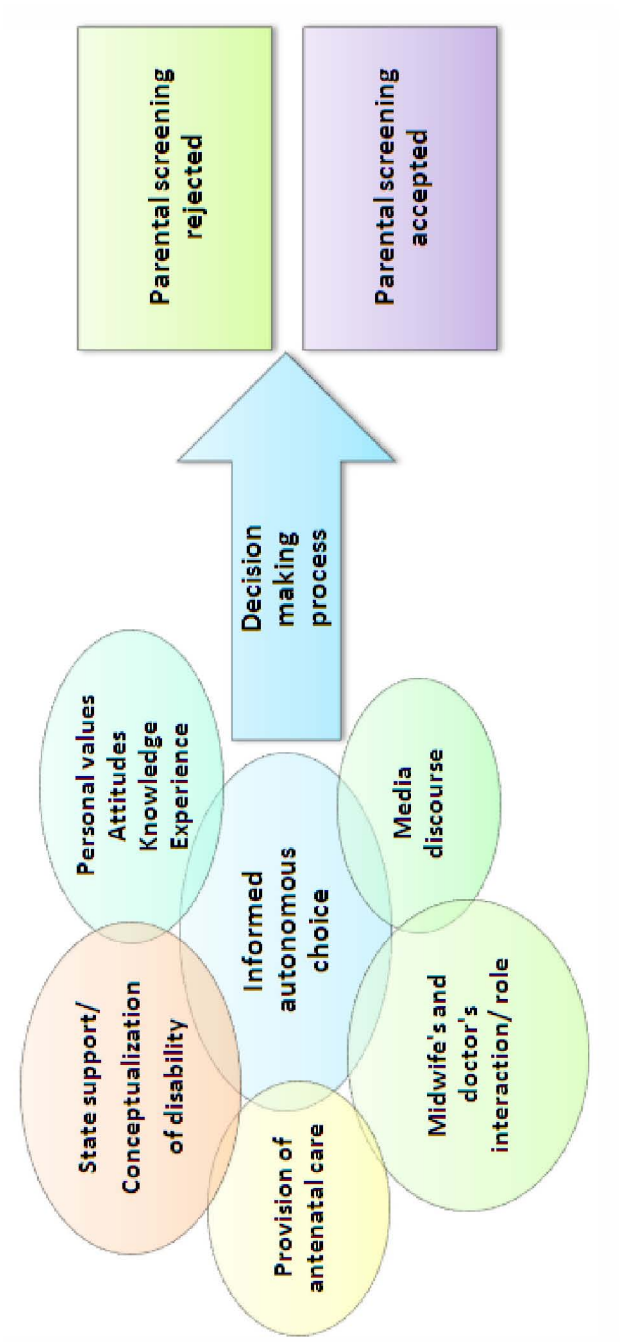

Figure 3. **NT screening and prospective parents´ decision making. Conceptual framework of main study items.**

AIMS

The main aim of this study was to describe and explain how prospective parents experience the process of decision making concerning the use of nuchal translucency screening in early pregnancy in Iceland. The focus was on decision making among prospective parents who accept and who decline screening and how they reflect on their choices as the pregnancy proceeds. Specific issues that were explored included: how the process of decision making is experienced among prospective parents who accept and decline screening; how parental reflection on the decision may change as the pregnancy proceeds; and the interplay between women and their partners' perception, professional views and the social discourse in Iceland. It was expected that the findings would provide a greater understanding of the dynamics of decision making among prospective parents and would inform the development of policy and practice around screening. The overall aim was met by fulfilling the following specific objectives.

Objective 1

To describe the discourse around fetal screening as reflected in the public media in Iceland. This was considered important to illuminate the social context within which prospective parents make their decisions. All items related to fetal screening that appeared in the public media from 2000 to 2005 were evaluated. This data was analyzed using discourse analysis and the result is presented in Paper I.

Objective 2

To study how prospective low-risk mothers and fathers experience the decision making process around accepting NT screening in early pregnancy and to understand what influences their choice in relation to the interplay between women and their partners', professionals' views and the discourse in Iceland.

Also and more specifically, to study prospective parents who accept and decline NT screening and how they experience decision making around NT screening in early pregnancy.

This was done by gathering data from twenty couples, prospective parents who accepted and declined screening in early pregnancy. Interviews were conducted with men and women separately, twice during pregnancy, first in the 7-11th week and again in the 20-24th week, a total of 80 interviews. The findings are presented in Papers II and III.

Objective 3

To discuss the meaning and origin of decision making and autonomy in relation to ethical considerations in the literature and how those concepts are reflected in the Icelandic media and the experience of prospective parents in early pregnancy. The focus is on the relationship between the concepts used in ethical discourse about prenatal screening and the Icelandic media and experience of prospective parents. Those findings are presented in Paper IV.

MATERIAL AND METHODS

This thesis was developed within a qualitative tradition of enquiry, where the aim is to expand understanding of the process and the meaning of interventions for those receiving them (Green & Thorogood, 2004). The contribution of qualitative studies to policy or practice within health care is most obvious in the area of health service, health service planning and policy, and public health and health promotion (Green & Thorogood, 2004).

The study design was based on a philosophical and theoretical framework which is rooted in ontology, where the implication for practice can be that "the researcher uses quotes and themes in words of participants and provides evidence of different perspectives" (Greswell, 1998, p. 75).

The sets of data upon which this thesis was based were designed to complement each other using three qualitative methods. The first method (Paper I) was a discourse analysis. In this data set the public media discourse on nuchal translucency screening (NT) in Iceland was explored over five years. It provides a broader context for other data in the project. In the second study (Papers II & III), data collection was based on interviews with 40 prospective parents. This analysis formed the central part of the thesis, where the aim was to explore how prospective parents experienced the process of decision making concerning NT screening (Kvale, 1996; Miles & Huberman, 1994; Ritchie & Lewis, 2003). The interviews were conducted in 2006 and 2007, with 20 couples, i.e. 10 who accepted screening and 10 who declined. Each participant was interviewed twice, first in the 7-11th week and again in the 20-24th week, making a total of 80 interviews. The purpose of the second interview was to explore if the perception of screening changed as the pregnancy proceeded. The third method (Paper IV) was an analysis of ethical concepts, where it was explored how these concepts are reflected in the discussion in the public media, as well as in the experience of parents-to-be. The interrelatedness of those three studies was explained in the analytical framework following the Introduction of the thesis.

Discourse Analysis (I)

The method chosen in the first part of the study was discourse analysis, which provided opportunity to study linguistic usage. A number of approaches to discourse analysis have been developed where the analytic commitment of the method is to study texts and talks in social practice. The focus is on language as the medium for interaction. An analysis of discourse becomes analysis of how people talk and how they act (Silverman, 2006). The term discourse has been defined in different ways, but in this study it is understood as 'historically specific, socially situated, signifying practices' (Fraser & Gordon, 1994). This definition highlights the understanding that discourse reflects both the historical time and the social context in which it developed and is used.

Studies of discourses depend on the theoretical formulation being used. Genealogy was the method chosen here to illuminate how NT screening, as a new form of practice, emerged and was taken up within the Icelandic context (Foucault 1977, 2003). Foucault suggested genealogy as a fruitful means of studying how new forms of practice emerge historically. He outlined the approach further in his lectures at the Collège de France (Foucault, 2003). The genealogist is interested in knowing how things happen and develop, for example how certain practices become routine or norms. The method highlights complexities and local knowledge that has been silenced by the disciplinary power of scientific discourse. Studying the genealogy of the emergence of fetal screening as a routine part of antenatal care in Iceland means studying the historicity of social conduct via its own particular set of ethical and political concerns ‘grounded in the present’ (Dean, 1999, p. 41). By studying the different discourse on fetal screening that developed among different social groups in Iceland, an attempt was made to explore the sometimes hidden and multi-dimensional influences of power that influence the decision to offer and undergo fetal screening.

Applying Foucault's idea that power is present in all social relations, reflects a system where knowledge about strategies to enhance life is of key importance. This knowledge, or forms of rationalities, then manifests themselves as true and proper ways of acting and thinking (Koch & Svendsen, 2005). Foucault coined the term *governmentality* to describe the strategies and techniques that authorities employ to influence conduct in this way (Rose, 1993, 1999). Based on his theory of the power/knowledge relationship, the study of governmentality looks at the production of truth and knowledge and its impact on conduct or regimes of practices (Dean, 1999, p. 18). This study focused on the representation of screening in the media, based on the assumption that the view of prospective parents has, at least to some extent, been influenced by the public discussion.

Material and analysis.

The data included all newspaper articles, news reports, editorials, feature articles in magazines, and radio and television programmes published or broadcast in the period from the beginning of year 2000 until the end of 2005, in all 53 items (Table 4, a-c). The items were obtained through a media database and selected with the help of specific key words. In addition, policy documents, such as a recommendation from Directorate of Health, and information brochures for prospective parents were analysed. This aimed to provide a snapshot of prevailing ideas, understanding and practices around fetal screening in Iceland.

Each text item was closely read for its portrayal of screening by both of the authors who participated in this part of the study. Content categories were formed and patterns of discourse identified. This means that the categories were developed through repeated coding of the 53 items. The questions that guided the analysis were: How was the discussion presented? Who contributed to the debate and what was their argumentation? All the items were categorized after they had been carefully evaluated and assigned

to a particular discourse, which led to the identification of three main themes.

Qualitative Study (II & III)

Design in qualitative research is a continuous process where unknown issues are recognized and attended to as they emerge (Lewis, 2003; Strauss & Corbin, 1998). The analysis which is used throughout this part of the thesis is Framework analysis, developed during the 1980's at the National Centre for Social Research in the UK (Richie & Lewis, 2003). Applying this approach, rigorous and transparent data management is facilitated such that all the stages involved in the analytical 'hierarchy' can be systematically conducted.

As the study is influenced by constructionism, its significance is that the experience of participants is embedded in the social context where the language is the central fountain (Burr, 2006). In this thesis, a critical stance towards 'taken-for-granted knowledge' is applied for understanding processes of accepting and declining the offer of screening. I did not seek to provide a comprehensive overview of a situation in health care, but rather to illuminate examples that provide illustrations for decision-making in the context of fetal screening.

Setting.

Choosing a setting and participants is fundamental to the study design (Marshall & Rossman, 2006). The decision was made to recruit participants from one large department, operating at that time within the primary health care in Reykjavík, providing midwifery and obstetric care to both low- and high-risk women. In the beginning of the study period, however, this department was closed and antenatal care for women with low and moderate risk transferred to the primary health centres located in the different neighbourhoods in Reykjavík. To continue the data collection, the study was

introduced to midwives at four health care centres who agreed to participate in selecting participants when the pregnant women booked time for their first interview. The midwives were informed about the background, aims and method being used and were asked to introduce the study to eligible women when they phoned to book their first visit. When participation had been agreed upon, a letter of introduction was sent. The expectant mothers were asked to inform their partners about the study.

Sample design and inclusion criteria.

This part of the study draws also on social constructionism, and the central point was to study language to gain understanding of how people construct their meaning and how social norms are created (Burr, 2003). The sample size should vary enough as to be representative for the phenomenon under study (Denzin, & Lincoln, 2000; Marshall & Rossman, 2006) The number of participants in qualitative studies is often considered adequate when the collected data reach saturation. A common number may be 10–15 participants (Kvale, 1996), although it depends on the focus of the study. In this study, 20 couples participated, a total of 40 individuals. The selection of participants was purposive, meaning that "members are chosen with a 'purpose' to represent a location or type in relation to a key criterion" (Richie, Lewis & Elam, 2003, p. 79). Here, the key criterion was weather parents accepted or declined screening. The inclusion criteria can be seen in Table 2. Those reflect the aim of the study, to explore the decision making process in relation to NT fetal screening among low- risk women and their partners.

Table 2. ***Inclusion criteria for participants in the study***

Prospective mother	**Prospective father**
Speaks Icelandic	Speaks Icelandic
Length of pregnancy at first interview 7-11 weeks	Willing to participate
No previous history that might increase the probability of genetic anomaly during this pregnancy	
Decided on accepting/declining NT screening	
Cohabitation	Cohabitation with the mother to be

Participation included two interviews with each prospective mother and father in early pregnancy (7-11 weeks gestation) and after the 19-20 week ultrasound, between 20-25 weeks gestation. To investigate if there was a gender difference in the perception of screening and attitude towards fetal abnormality, it was considered important to conduct separate interviews for men and women. Although insignificantly explored, studies are inconsistent regarding men's involvement in an interview in the presence of their partner (Anderson, 1999; Reed, 2009). Five women who intended to undergo screening, and were approached, rejected participation because of lack of time or interest by their partner. All the women who declined screening accepted participation.

The participants were given the option to choose a place for the interview and all decided to be interviewed at home.

Ethical considerations.

The study design was approved by the Icelandic National Bioethics Committee (05_125-S1) and the Data Protection Authority (S2702/2005). The studies on parents' decision making were approved by the Medical

Director and the Nursing Director of the Primary Health Care Services in Reykjavík and the Clinical Director and the Head of Nursing and Midwifery at the Landspítali University Hospital. Written informed consent was obtained from all participants.

As research during this period in pregnancy can lead to additional worries by women and issues can be raised which cause anxiety, I spent time as necessary after the interviews to listen and reflect on the discussion, and offered the participants the opportunity to contact me if needed. They were also offered to talk to another health professional with experience and knowledge in fetal screening. None of the participants took up this offer.

The interviewer.

I was aware of the importance of respecting each participant, and let each interviewee speak for him- or herself. There are advantages and disadvantages of conducting research in one's 'own setting', and my background in midwifery shaped the perspective in this research and the data generated. The advantage was my knowledge of what screening involves and experience in discussing issues related to screening in the clinical context. I have criticized the way in which NT screening was implemented in Iceland and the lack of knowledge and understanding of the decision making process, both among clinicians who introduce the option to undergo screening and among the general public. This may at times have come through in the interviews, but I tried to create an atmosphere where the participants could express their views freely. It is acknowledged that the interview is a collaborative process where interviewers and interviewees are actively engaged in constructing meaning (Kvale, 1996). In this respect, constructionism has something in common with research in feminism; where the emphasis is to *share* and the researcher must therefore, in the beginning, give an insight to her/his background (Ribbens & Edwards, 1998). The goal is to establish a collaborative relationship and to place the researcher within

the study as to avoid/minimize objectification and to conduct a study with transferability (Creswell, 2007). The way in which I have dealt with that in this data collection and analysis was to provide the participants with an opportunity to reflect at the end of each interview and I discussed the content of the interviews with my supervisors.

Forming the interview schedule.

An interview schedule was developed based on semi-structured interviews which are characterized by limited formality and where the interactive nature of the conversation is emphasized. The topics which form the center of the interview were outlined, but flexibility was emphasized (Ritchie & Lewis, 2003). In such circumstances, the interviewer, who creates and negotiates the interviewee's stories, is therefore in the forefront and the emphasis is on the knowledge constructed in the interview (Fontana & Frey, 2000; Kvale, 1996). The first step was to define the purpose of the study, which was to explore the experience of prospective parents of being offered an opportunity to undergo NT screening. In developing the interview schedule, the topics which were chosen for discussion were thought to illuminate the phenomenon under study and to ensure coherence between research aims and methods. These topics were based on an extensive and thorough literature review. The area that was covered reflected fetal screening and technology, women's and men's views and experience of screening, and literature on bioethics and fetal screening. The literature review covered material published in midwifery, medicine, sociology and ethics. The interview schedule was verified beforehand with the supervisors. The schedule for the first interview, conducted in the 7-11 week, is shown in Table 3 below. This schedule was used both in the interviews with participants who accepted and those who declined screening. The second interview, conducted after the 20th week ultrasound, was based on the first

interview and reflected experience of the decision making process and the content of the former interview.

Table 3. Topics discussed in the interviews

Topics discussed with prospective mothers and fathers with previous experience of pregnancy and childbirth
Experience of pregnancy and childbirth. Previous communication with professionals during pregnancy and birth. Did you have access to the necessary information during that time? Describe your experience of previous screening if any. Are your children born healthy?
Topics discussed with all participants: (Rephrasing of some questions in the interviews with fathers)
Is this a planned pregnancy? Can you tell me how you have been feeling during the past weeks? Tell me about the experience of pregnancy and childbirth in your family. Have you communicated with health care professionals during those past weeks? Could you describe if and how they provided you with information about nuchal translucency screening? Describe your views on the purpose and meaning of the screening. Would you say that the information you have is sufficient for you, or would you have liked more information? Describe how you made your decision to accept/decline screening. Would you describe it as an easy or a difficult decision? Was it a joint decision and, if so, how did you discuss it with your partner? How is the discussion around nuchal translucency screening in the context of your family and friends? Is there anyone close to you who has a disabled child? Do you have experience of disability? Describe your views on abortion. Referring to your age, your risk is X of having a child with Down's syndrome. Could you comment on that? How would you describe Down's syndrome? Will the acceptance of screening affect your wellbeing?– Describe how.

Data collection.

The original intention was to approach prospective parents before they had any contact with the health care system during the current pregnancy other

than the phone call to decide on their first antenatal visit to give a 'clearer' picture of how decisions emerge around screening. However, due to the context in which this study took place, it varied at what time in pregnancy women phoned to book the first antenatal care visit. As previously discussed, the general understanding has been, that publicly funded maternity care starts at 12 weeks but many women book a visit at a private clinic with their obstetrician to have the pregnancy confirmed. Therefore, screening had already been introduced to them when they made contact to start the public antenatal care and most of them had decided what they were going to do.

I contacted the women and explained in more detail the purpose of the study and the possible length of interviews. If the woman and her partner were both willing to participate, a time was arranged for the interviews. Before the first interview, an informed consent form was signed and information on characteristics of the participants was collected. The interviews lasted from 15 min (an exceptional case; a father who could hardly express himself on the matter) to 1 hour and 30 min. The atmosphere was made as relaxed as possible and most participants spoke openly about their speculations on screening.

Data analysis.

The data analysis was conducted following the framework analysis and was informed by the background literature. Apart from the actual transcribed interviews (almost 350 pages), research notes developed at the time of data collection were used. The first step, *familarization with the data,* involves listening to tapes and re-reading field notes or transcripts. After reviewing the interviews, the foundation for the next steps was formed by identifying recurrent themes or ideas which include views, attitude or motivations. Then, a conceptual framework or index was devised using the recurrent themes and topics incorporated in the interview schedule. This is what is referred to as *indexing*; an index shows which theme or concept is being mentioned or

referred to within a particular section of the data, described in a similar way as an index at the back of a book (Ritchie & Lewis, 2004). To organize the data within this index, I had to read every sentence and paragraph in the interviews and ask myself: What is it about? Where can I place this? For large and complex interviews like in this study, to make them more amenable for analysis, it is helpful at this stage to use computer packages. Therefore, the transcripts were structured and clarified using NVivo Version 7 (di Gregorio, 2003).

The thematic framework did change on re-reading the interviews, as in a few cases missing index categories were found. Some of the material was brought together into 'sets' where the index categories were interconnected. The final stage of data management involved synthesising the original data, which in this study meant to ensure that all the content had been considered. The next task was to 'unpack' the content, to display the data in a meaningful and illuminating way. This involved *detection,* in which substantive content and dimensions of a phenomenon were identified; *categorization,* in which categories are refined and descriptive data assigned to them; and *classification* in which groups of categories were assigned to 'classes' usually at higher level of abstraction (Ritchie & Lewis, p. 237). The categorization is the actual form of presentation of the data synthesized.

All the transcripts were analyzed in Icelandic to maintain meaning. The complexities of analysing semi-structured interviews that require translation for the purpose of data analysis have been highlighted (Esposito, 2001; Twinn, 1997). Quotes used in the papers were translated into English by the author, but to maximize reliability, all quotes were reviewed by a professional translator who is familiar with the phenomenon under study.

Reliability and validity.

The meaning of reliability depends on the consistency of the categorization of data by different actors (Silverman, 2006). The topics that were brought

up and the experience of participants were consistent, which showed that an adequate number of participants had been chosen and the findings could have meaning within a wider perspective. Validity is the main criterion of credibility within qualitative studies. Therefore the guidance put forward by Kvale (1996) was followed by checking and adopting a critical outlook on the analysis and emphasizing different views to avoid *anecdotalism*, since only few examples could be shown to highlight the issue raised. After each interview, it was emphasized to get a feedback from the participants to gain more confidentiality (respondent validation).

Exploration of Ethical Concepts in Theory and Practice (IV)

In this part of the study, a focus was set on how certain topics were presented in the bioethical literature, in the public media discourse, and among prospective parents. Hence, the material reflects a review of the literature that combines bioethics, social science, midwifery and fetal screening. Additionally, the items that were used to illuminate the discussion of fetal screening in the Icelandic context were based on the two sets of data previously described. The former data set was obtained from the public media from 2000–2005. After a reading of all items with the focus of this study in mind, an analysis of the data developed. As the aim was also to search for conceptualization of those specific topics among individuals who participated in this study, a fresh exploration of the interviews was needed. The main steps described for analysis in study II were applied. I explored the ethical concepts and from that standpoint I examined whether the notion of informed decision making and autonomous choice had the same significance in the social and clinical context versus the moral theory.

Methodological Considerations

A few limitations need to be mentioned. The first regards the first part of this study, the media discourse, where the researcher used material that had been

published or broadcast. Discussion which took place at meetings or conferences could not be included, although some of those discussions would have been important contribution to the debate. Secondly, in interviews studies in general, the participants are aware that they are participating in a research. Therefore, they may have adapted their answers to what they considered important from the researcher's perspective. This is difficult to avoid, but the former interviews were recorded and discussed before the second interview with each participant to get a clearer understanding about some statements from the first interview. The third issue of concern is the pre-understanding that the researcher had in this context, which could be seen as strength and/or weakness in the study. Sandelowski argues that there is a risk that the interviewer dominates the conversation with personal experience if he is familiar with the topic under study (Sandelowski, 1986). Although there is probably no way to fully circumvent this problem, I have described my point of view which the reader can keep in mind when going through the findings. Also, as the aim was that the participants would be able to talk freely during the interview process, the researcher took up time to discuss and explain the screening and answer questions that were of concern to the prospective mothers or fathers after some of the interviews.

RESULTS

The results of the three studies are presented separately. The conceptual framework presented in the final section of the introduction presents the main study items (Figure 3). It informs the understanding that fetal screening is part of the social and medical context at large, and the findings must be seen from that standpoint. First, the way in which fetal screening was presented in the Icelandic media is described, then the parents' experience around the decision to undergo screening, and in the final section, the findings on the ethical issues involved in the implementation and adoption of screening in early pregnancy.

The Media Discourse of Screening (I)

The main objective of the first paper was to illuminate the context in which parent's decisions on screening emerge. The data collection and analysis was organized around two questions: How was the discussion presented? Who contributed to the debate and what was their argumentation? The data consisted of 53 items altogether, 46 media items, as described in Table 4, and 7 handouts and booklets. Table 4.a provides an analysis of the different kinds of articles published in newspapers and magazines. Table 4.b gives an overview of radio and TV programs and Table 4.c gives an overview of who contributed to the debate around screening.

Table 4. a-c.

a. *Newspapers and magazines*

News article	Feature article	News bulletins	News reports	Interviews	Commentaries
4	11	4	4	2	3

b. *TV* *Radio*

Special programmes	Studio based	Outside broadcast	News	Special programmes
2	2	6	4	4

c. *Different actors contributing to the debate**

Obstetricians	GPs	Midwives	Priests	Parents	Others**
14	11	7	4	3	16

* Quotation or an interview with respective

** Politicians, Director of Health, Proponents of Disabled people etc. In some cases the same person is interviewed or quoted several times.

Three main themes could be recognized: NT as a technological advance, questioning of screening, and screening as a technical or ethical issue. The first theme reflected the view that NT screening will lead to positive benefits for the public. The discussion in the first two years after the implementation of screening focused on advantages of NT screening over amniocentesis, and at the same time it was indicated that it was intended for all pregnant women. As is reported in Paper I, this view was represented by the staff working at the Prenatal Diagnosis Unit at the LUH. Another perspective became visible in the early stages of the introduction of screening, which was framed in a few news reports, articles and radio and TV broadcasts. That represented concerns about the screening for-all policy and the issue that the screening was first and foremost aimed at eliminating fetuses with Down's syndrome. This point was left unattended by the public media at that time

with few exceptions. The third theme represents the discussion that was promoted by a theology student in the beginning of 2004. That discussion was taken further in a studio based TV programme and in a special radio programme where spokespersons for children with Down's syndrome came forth with more force and claimed that a rational debate was needed and the way issues were presented to parents-to-be in early pregnancy needed reconsideration. Paper I presents examples of these findings. Key questions which relate to health care and scientific benefits were brought up, but at that time two thirds of pregnant women in Iceland already underwent screening.

The Experience of Parents Who Accept and Decline Screening (II & III)

Results from the interview study were addressed in two papers. The former (Paper II) described the experience of parents who decided to accept screening and the latter (Paper III) reported on parents who declined. The whole sample will be described here below and then the discussion will move on to the two papers.

Characteristics of the sample.

All participants spoke openly and did not decline to answer any of the questions. Compared to the 10 women who accepted screening, the 10 women who declined were more likely to have had a previous pregnancy and birth, and a slightly higher mean age was seen among both men and women in the latter group. Within the group of prospective parents who declined screening, thirteen participants had university education, but among the participants, who accepted screening, nine had a university degree but three were university students. Based on the inclusion criteria of cohabitation, ability to express oneself in Icelandic and no previous history of genetic anomaly as discussed previously, the sample can not be defined as representative of the population. Table 5 shows some of the characteristics of the women.

Table 5. ***Characteristics of the women participating in the study***

Women no	NT screening	No. of previous pregnancies	Previous NT screening	Experience with disability/Down's syndrome
Woman no 1	yes	2	yes	no
Woman no 2	Yes	1	yes	no
Woman no 3	Yes	0	no	no
Woman no 4	No	1	no	no
Woman no 5	Yes	1	yes	yes
Woman no 6	Yes	1	no	yes
Woman no 7	Yes	0	no	yes
Woman no 8	Yes	2	yes	yes
Woman no 9	Yes	0	no	no
Woman no 10	No	1	no	yes
Woman no 11	Yes	1	yes	no
Woman no 12	No	1	no	yes
Woman no 13	No	1	no	yes
Woman no 14	No	1	yes	no
Woman no 15	Yes	0	no	no
Woman no 16	No	0	no	no
Woman no 17	No	0	no	yes
Woman no 18	No	0	no	no
Woman no 19	No	1	no	no
Woman no 20	no	2	no	yes

Parents who accept screening.

The second paper presents findings on the experience of prospective mothers (n=10) and prospective fathers (n=10) who accepted screening. Seven of the women in this group of participants had their pregnancy confirmed by their obstetrician in early pregnancy and five booked their NT screening following that visit. Three had been to see their GP at a community health centre and one booked her NT screening after that visit. Therefore, six of the ten women made an appointment for NT screening before their booking visit

at a health care centre. Two prospective fathers accompanied their partner to the physician in early pregnancy, one to an obstetrician and one to a GP. The former waited outside the consultation room, the other was present when the screening was discussed. The mean age in this study group was 28.6 years among the women (age range 19- 35 years) and 31.7 among the men (age range 22-52 years). Four of the women were expecting their first child. Five of the parous women had had NT screening in previous pregnancy. The one parous woman who had not undergone screening was not told about the option at the health care centre. One woman described ambivalence towards the screening, but all the other women in the study explained the screening as their choice.

The reasons for accepting NT screening was explained differently by the men and women. As can be seen from examples in Paper II, the women framed their explanations more in line with *compliance*, i.e. you accept what is offered because you assume that health professionals offer the best care.

The acceptance of screening was also seen as a way to confirm the health of the fetus. Five women explained how their obstetrician informed them in a way that further encouraged them to accept screening. The following description is from one of those women:

> He spoke like it was just to show me that there was a fetus. It was more as to confirm that I was pregnant and that everything was all right. Of course that was what I was searching for and perhaps that is the reason why he did not explain it further (Woman no. 6).

The men, on the other hand, used a different dialogue. Words such as *control and certainty* were more apparent, along with issues that related to technical advantages of the screening procedure. They experienced the screening as a way to control and manage the pregnancy. Further arguments for the screening were expressed differently among men and women. Four of the men were outspoken about the *financial burden* of having a disabled

child and the *negative attitude* of the society towards disabled children. The women saw having a disabled child more as a *burden* for the family. They also mentioned some positive sides of disability, for example that children with Downs's syndrome are often happy and affectionate. No one in this part of the study had clear ideas about what the screening might detect, although most knew that the screening was for Down's syndrome. None of the participants had knowledge of what a false-positive or false-negative result were, although two women and one man with a background in health sciences had some understanding of diagnostic tests as a possibility if the screening result was positive as the following example shows;

> Of course they are just telling you the probability of something….. I understand the NT screening as an evaluation of risk and if you screen high-risk then you have the option of amniocentesis… (Man no 5).

There were descriptions of a *joint decision* by many women when they explained how they along with their partner had decided on screening. The men, on the other hand, explained that the woman had informed them that they were going to undergo screening and they most often experienced that in a positive way. If the couple had experience of screening from a previous pregnancy the decision was experienced as a self-evident act.

When the participants were interviewed for the second time later in pregnancy (week 20-24), after they had all received a negative result, three women and four men brought up the subject that they would have liked to know more about the screening. Two of the four men and one woman discussed that they were not sure if they felt that the screening should be offered to all parents, both because it did not provide them an assurance and also because of the decision that they might have to face if they would have received a positive result. Reflecting on the process, some of the prospective fathers felt that they had not been part of the discussion around screening and they saw participation in this study as an opportunity to create a dialogue

on the matter. In this part of the study there was a variation in the length of interviews as the first interview lasted longer.

Parents who decline screening.

In the third paper, experience of the 10 couples who declined screening was explored. The mean age of the women was 32.5 years (age range 23-39 years) and 32.7 (age range 24-38) for the men. Four of the women had seen their private obstetrician to have their pregnancy confirmed, and three had seen their GP. In addition, one woman had tried to make an appointment with an obstetrician without success. The two remaining women did not feel a need to see a physician. The interviews varied in length from 45 min. to 1hr and 35 min with no difference in the length of interviews conducted with the men (n=10) and women (n=10). On average, the interviews with parents in this group lasted longer as they in general had more to say. Six of the seven women who had been in contact with doctors stated that the information they received on NT screening were limited. Although all the participants had decided against screening, six of the ten women had planned to have a 12-week dating scan which is offered to parents who do not wish to have NT screening. The results from the interviews are presented in three categories: *personal philosophy of Down's syndrome, tolerance for diversity* and *an unreliable test* (see paper III).

Of the twenty men and women, eleven had previous experience with disabled people through their work or personal acquaintanceship and, therefore, the issue of disability was reflected in the discourse around decision making. Some of them were quite familiar with Down's syndrome and the services that are provided to those individuals by the community. Although all the participants except one man supported the offer of NT screening for all parents, six women and seven men had decided against screening because, for them, Down's syndrome was not severe enough as a disability to terminate pregnancy. Other deviances that the screening might

detect were not mentioned except by two participants who were aware of other trisomies that the screening might detect. That did however not affect their perspective. Therefore, those participants framed their view as their *personal philosophy of Down's syndrome,* but at the same time they respected prospective parents with different decisions. It was strongly emphasized by eight participants, three men and five women that all parents want a healthy child and they felt that levels of health should be maintained in society although they respected *variability* and *complexity in ability*. As such, they saw their role as *caring* for their unborn child. However, all, except one man, supported termination of pregnancy as a free option.

Another reason for declining screening was lack of trust in the screening method, i.e. they saw it as an *unreliable test*. As it did not give them accurate answers, it brought up feelings which inhibited some participants from deciding on screening. Lack of knowledge of the screening was apparent in some interviews and five women referred to cases they knew of, where either healthy fetuses were lost following amniocentesis or children with Down's syndrome were born after a negative screening result:

> I know this woman who had the screening and they [the midwife and GP] said to her that something was wrong and after that she had amniocentesis. Something was wrong there as well, but she decided to proceed with the pregnancy and gave birth to a normal child. I mean, I could not decide to have an abortion with such information (Woman no 19)

Four women felt that they had to justify their decision, both within their context of family and friends and with professionals in the antenatal care. They felt that the use of screening was experienced as routine by the majority of individuals as it was offered within the traditional antenatal care system, which made them have to argue more for their decision. One couple explained how they were offered screening during the 12-week scan. However, most participants emphasized their free uncoercive choice. The

decision to decline screening was experienced as a joint decision made by both parents-to-be, and it was considered important by both the women and the men to have a mutual understanding of the screening as described by a prospective father, expecting his second child:

> As I see it and we have discussed, I am prepared to support a child with disabilities. She is focused on, as far as I understand, that she does not want to have an abortion and that is a very valid argument. For her to have an abortion or not is something that I am not able to control .... (Man no. 19)

In the second interview (week 20-24), their decision remained strong; however, one woman with a previous experience of miscarriage said that perhaps it would have made her more secure to have had the screening.

Ethical Concepts in Theory and Practice (IV)

Autonomy is the leading principle within bioethics. In health care, autonomy is understood as the right to self-determination. In the context of decision making, it has been seen as the right to informed decision making, where several preconditions have been put forth. The model of professional-patient communication affects how those topics are experienced. Fetal screening holds a unique moral position as its implementation relates to selective abortion and the conceptualization of health and risk. As such, the conceptualization of autonomy and informed decision making has been questioned by several authors as being too individualistic. The findings describe how parents-to-be experience the key ethical terms and how they are reflected in the public media. *Autonomous choice* was significant in most of the interviews, meaning that deciding for oneself is of importance. However, within the description of parent- professional communication it did rarely incorporate explanation of information and knowledge provided by the professional. As such, the communication reflected that parents are often left to decide on their own. It was also visible in some interviews that

parents wanted others to decide for them; they expressed a wish for supervision. There is a consistency in the media discourse and the discussion in the interviews, where the concept of autonomous choice is promoted by a number of actors who contributed to the discussion.

DISCUSSION

Antenatal care is increasingly shaped by the use of different screening methods that aim at ensuring the birth of a healthy baby. The dissemination of screening into antenatal care has been driven by new knowledge in medical genetics (Skirton & Patch, 2002; Valenti et al., 1968), improved ultrasound technique (Donald et al., 1958; Eik-Nes et al., 1984; Jörgensen, 1999; Nicholaides et al., 2000; Persson et al., 1978; Robinson & Shaw-Dunn, 1973), and the development of biochemical markers (Spencer, Souter, Tul, Snijders & Nicholaides, 1999). There are strong indications that non-invasive prenatal detection of Down's syndrome will become a reality in many countries in the coming decade (Hahn & Chitty, 2008). The above interventions and ongoing developments reflect expectations and optimism in a technocratic society (Brown & Webster, 2004).

The main aim of this study was to explore parents' decisions concerning undergoing or declining NT screening. It was conducted in the capital area of Iceland, where the uptake of screening is high. When work on this thesis began, the authorities had not developed a policy on NT screening and official guidelines for NT screening had not been issued by the Director of Health. The topic had not been studied in the Icelandic context, except for one survey, conducted by the staff at the Prenatal Diagnosis Unit at LUH on the views of women toward screening. Very limited knowledge could be found in the international literature on what contributes to prospective parents' decision making in relation to undergoing screening in early pregnancy, and men's experience of screening had hardly been studied. Knowledge of women's views and understanding of screening rested mainly on studies of 2nd trimester screening. Theses studies showed that women were generally in favour of the technique (Marteau, 2002; Press & Browner, 1997). The more recent studies show limited knowledge and understanding of screening among women (Jaques, 2005; Michie et al., 2002; van den Berg et al., 2005) although their views are positive.

This study demonstrates how NT screening was introduced as a technological advancement for prospective parents in the Icelandic media, while critical questions related to the implication of the adoption of fetal screening in general were largely avoided. In light of the rapid development of knowledge and technology in this area, it may be expected that, even in the near future, screening for an array of anomalies will be possible. Therefore, a further implementation of screening technique might suffer from lack of discussion on how this development should progress in this country. The study indicates an association between acceptance of NT screening and support at a macro level, although this is insignificantly explored. Most parents remain content with their decision both to accept and decline screening, although some parents did describe unmet needs to reflect on their decision later in pregnancy. The parents who declined screening were more knowledgeable and more likely to have made a joint decision. The study also highlights that men would like to be more involved in the decision making process and they describe their views towards topics such as disability differently than the women. Those issues are of importance and should be of concern in further development of policy and practice in the context of screening.

The Media as a contributing Factor in the Social Discourse of Screening

As is reported in Paper I, the Icelandic media introduced NT screening simultaneously as a choice and as an integral part of antenatal care. This was especially apparent in the first years after the screening was introduced. Soon after its introduction, the uptake of the screening in Iceland became widespread, which may at least partly be explained by the understanding which was common among the parents, that screening was something that one does when pregnant. This is consistent with Beck-Gernsheim's writing (2002) referring to the ready acceptance of knowledge and technology, such as screening for genetic abnormalities, as voluntary compulsion. As this

study showed, parents are certainly not forced to comply with any rule or law, but they do behave in a suggested way nonetheless. This is what Foucault referred to as governmentality (Foucault, 1991; Rose, 1993). Through their free choice parents make the 'right' decision. As such, individuals in modern liberal societies are not forced or coerced to behave in a certain way; they are governed through their freedom (Foucault, 1991). Fetal screening has been seen as a way to benefit women by giving them more control over their own bodies and protecting them from risk, but it has also been understood from the perspective that it is there more for the fetus. That is what Arney described as a new order of control (Arney, 1982). In newspaper interviews, the obstetricians that came forth emphasised that the screening provided prospective parents with increased opportunities to make informed choices regarding the continuation or termination of pregnancy. This is similar to the argument made by geneticists, who identify enhanced reproductive choices as the main benefits of screening (Koch & Svendsen, 2005). The possible downsides of screening, such as the psychological impact of the uncertainty involved in screening, the influence on the lives of disabled people, the eugenic implications, risk of miscarriage (Getz & Kirkengen, 2003), and the difficult decisions that sometimes need to be made, were rarely brought up. The exceptions to this were views of parents of children with Down's syndrome and some healthcare workers, who raised critical questions about the routine use of screening. Their arguments were certainly given space in the media, but the views they represented did not seem to have the impact at the policy level to develop or to start a critical debate among the public, and health authorities were slow to develop guidelines regarding screening.

The assumption that these procedures generate positive feelings in pregnant women has, however, hardly been questioned (Eurenius, Axelsson, Gallstedt-Fransson & Sjöden, 1997; Lippman, 1999). Instead, the sense of optimism that is implicit in the development of new technologies seems to

act as a force for securing acceptance of new procedures (Beck-Gernsheim, 2002), and this has arguably been predominant in the development in Iceland as in other countries.

The way in which screening is conceptualized and performed is based on a differentiation between the technical responsibility of healthcare workers, i.e. their responsibility for providing information regarding the risk of anomalies, and the ethical responsibility of the prospective parents regarding the continuation of the pregnancy (Helén, 2002, 2004). The ethical dilemmas which may arise have thus been individualised, left to the parents who must then also shoulder the responsibility for their decision. This view was clearly reflected in the discussion about screening in Iceland: since the parents have to take care of disabled children, the decision on the continuation of the pregnancy must be theirs. In the current ethos, there seems to be little collective responsibility for the potential implications of screening for the identity of the disabled and societal views toward them. Fetal screening is perceived as a private matter, and neither a public health issue nor a political issue to be dealt with as such. It may also be speculated that the debate may reflect the limited cultural objection to selective abortion in Iceland, which seems to be accepted by the public in general, and the positive view towards the use of reproductive technology.

Although a comparison of results between countries is problematic, up to a certain point, due to variations in practice around screening in different cultures, a recent study of the initiation of screening in France revealed considerable controversy on the negative impact of screening, although it has become widely accepted (Vassy, 2006). In that case, screening was introduced and encouraged by biomedical researchers, while front-line health practitioners and prospective parents were prevented from full participation in the decision making. What the Icelandic and French examples seem to demonstrate is the need for an open discussion with front-

line providers and users on the use of new technologies, particularly when serious ethical considerations are involved.

The Experience of Parents Who Accept Screening

The study shows that the decision to accept screening lies with the women in the majority of cases, although all the women in the study described the decision as a joint one. The majority of their partners claimed that it was for the woman to decide and they respected that decision. Their knowledge was usually dependent on information that the woman had provided as has been seen in other studies on prospective fathers in a broader spectrum (Donovan, 1995; Gottfreðsdóttir, 2005; Zechmeister, 2001). In a very recent study, it was discussed that midwives can only include prospective fathers in the discussion on screening if they are present at the booking visit (Skirton & Barr, 2009). In the present study, the prospective fathers were in some cases willing to take on responsibility in the screening process, which was more demonstrated later in pregnancy, i.e. in the second interview. The gendered nature of responsibility is, however, complex in antenatal screening and diagnosis, as brought up by Reed (2009). Hence, women are generally the primary recipients of information about screening and diagnostic tests in early pregnancy, and male partners are unlikely to be present at the first contact when women have their pregnancy confirmed. This is similar to contraception and family planning. Only one partner was present when the discussion of screening took place in the present study. The study also revealed different experiences of men and women, where the importance of control, emphasized by men, is in line with findings from studies on men's educational needs and experience during pregnancy. Studies have shown that men just like women, value being in control, but pregnancy is a time, and may be the first time in their lives, when they feel the opposite (Gottfreðsdóttir, 2005). Accepting screening can be a way to fulfil this need and thereby decrease uncertainty. The difference between men and women

in perception of disability in the context of screening has not been raised previously, to our knowledge. That, however, is important as the aim of screening in the first place is to detect anomalies and provide prospective parents with more accurate information of their risk status. The study reveals that men were more direct in their description of disability, and more outspoken in their discussion of disabled people in society. Their motivations, that disabled children are a financial burden on the family, are related to findings of studies on fathers who had a child with Down's syndrome which showed that their greatest concern was the long-term provision for their children (Hornby, 1995; Trute, 1995). In the recent study by Hawthorne and Ahern (2008), women's expression of disability was in line with our findings, as they described that they were not rejecting the child, but rather they were not prepared for being a mother to a disabled child and could not cope with a baby with Down's syndrome (Hawthorne & Ahern, 2008). Although it is difficult to predict how different perceptions of disability and expectations between men and women add to the decision making process, these findings draw attention to these issues. In the ongoing Icelandic study on service delivery for parents who have children with Down's syndrome, 65% of the participants had fairly limited or no knowledge of Down's syndrome before they had their child. The authors speculate that this is similar among parents in general (Einarsson, 2006). It should also be of interest in the context of reproduction in Iceland whether those views encourage a high screening uptake and high termination rate.

The intention was to approach prospective parents in this study before they had had any communication with a health professional, apart from a telephone call to arrange their booking interview. This way, it was hoped, that the process of decision making could be studied from the very beginning. However, as the data collection unfolded, it became apparent that all the women who underwent screening had been to see a physician, most often an obstetrician, before they contacted the public care system, where

recruitment took place. The information on the pathways of care is important as it affects further planning and provision of information in early pregnancy (French, 2000; Jaques et al., 2005). Although the Icelandic guidelines on antenatal care draw on the responsibility of professionals to provide information and indicate that decisions should be based on informed choice, it is not necessarily assumed that care in the first trimester should be provided within the traditional public system. Among 42 Icelandic women who participated in a very recent pilot study on sources of information before NT screening, 76.2% had met a midwife before they underwent screening, 71.4% an obstetrician and 21.4% had meet a GP. Almost half of the women, 47.6%, had met both an obstetrician and a midwife but among 23.8% of the women, the obstetrician was the only professional they had meet (Jónasdóttir, 2009).

The factors which influence the decision of parents-to-be who accept screening may be the presentation of NT screening, both in the social context and the media, and interaction with professionals whom the women assume to offer the best care (Porter & Macintyre, 1984). In the present study, some women felt obliged to follow the advice of accepting the screening as for many of them it seemed to be an obvious option supported by the attitude of their obstetrician. As such, the health professional that the woman meets in the beginning of her pregnancy is influential. In some of the interviews with the parents, communication with professionals was described in a way that seemed to indicate a reluctance to explain the parent's risk status after the screening, meaning that the midwife who provided antenatal care did not discuss the result of neither the screening nor the 20th week ultrasound scan. This is consistent with the findings of the review by Skirton and Barr (2007) which showed that both professionals and parents experienced screening as a routine and therefore, the need to have a discussion was not obvious. It is of concern that, although screening has been on offer for a number of years, there is a considerable gap in midwives' and doctors' knowledge on what the

screening might detect, and studies show a strong indication for further education on screening in some countries (Ekelin & Crang-Svalenius, 2004; Skirton & Barr, 2009). This research topic has, however, not been brought up in Iceland, but views and knowledge on screening among professionals involved in antenatal care is one of the main issues in the management of pregnancy care.

Previous studies highlight that offering screening in a traditional antenatal care system can result in placing a moral responsibility to accept screening (Williams et al., 2005), and although insignificantly explored, it can be speculated whether both lay groups and health professionals influence the decision that women make by making judgements about women's responsibilities in the birth of children with disabilities (Marteau & Drake, 1995). The explanation of how medical technology has changed women's knowledge base regarding the confirmation of pregnancy from feelings and touch to visualisation can probably be applied to screening in very early pregnancy.

Compliance has been described as one of the main components in coping with the decision to undergo ultrasound in early pregnancy (Nicol, 2007). It is tempting to apply that to NT screening in our study context with the uptake of screening being almost 90% where the access is best. In the present study, most women had already decided to accept screening before they had any contact with a health professional. This finding is similar to what has been seen in other studies, although it is insignificantly explored (Pilnik, Fraser & James, 2004). When contemplating on NT screening, the women's decision to accept screening was in general promoted by their fear of having an abnormal baby and, for them, their risk level had no meaning in the decision making process. Those women were much more influenced by their friends than by their own mother, professionals or even their partner (Hawthorne & Ahern, 2009). One could speculate that the fact that many participants in our study showed lack of understanding about what screening

could and could not do, could affect uptake in the setting and reinforce screenings as a component of routine care. The presentation of NT screening in the context of this study, as our analysis of the media discourse shows in Paper I, is highlighted by emphasis on choice at the cost of important information about the implication of screening. As we were able to follow prospective parents through the process, it was found that they had not been given explanations about their risk status in the antenatal care setting, with the result that high expectations remained or they were left with unanswered questions and concerns. Some participants, especially men, explained in the second interview that they would have liked more time to discuss the screening and its implications. This could be explained by the fact that by the 20-24th week when the second interview was conducted they are more involved in the pregnancy, and at that time all of them had been present during the 20th week scan.

To Decline Screening

This part of the project aimed to explore how people who decline screening experience their choice and how they account for their decision. The findings draw on the relation between the participants´ experience of disability, risk and the context of antenatal care. Since the argument for NT screening is stated to be enhancement of reproductive choices based on information, the approach of the participants in this study is of interest. When the results from the NT screening indicate a possibility of Down's syndrome, a great majority of women will have a diagnostic test and termination of pregnancy if the result is positive. In general, there are relatively few studies on how decisions emerge among prospective mothers who decline NT screening in early pregnancy, and a literature search revealed no published studies exploring prospective fathers' view on this issue in particular. The contextualization of Down's syndrome as a condition seems to be the main prediction for the participant's decision. As such, they

did not experience Down's syndrome severe enough for termination of pregnancy. Their knowledge of cognitive and physical abilities of people with Down's syndrome and the support provided to this group within the community is considerable and contributes to their view in a positive way. Several authors have raised the issue that acquaintance with a disabled person has an important implication for the attitude towards screening. The majority of prospective parents and professionals in the study by Skirton and Barr (2009) confirmed that experiential knowledge of Down's syndrome was important, but only 50% of participants in the study had ever known a person with that condition (Skirton & Barr, 2009). The greatest distinction among participants in the study by Bryant, Green and Hewison (2006) was reflected in beliefs about the quality of life of the individual with Down's syndrome and that of their families, where personal experience of the condition was linked to positive attitude. In addition, personal experience with a family member with Down's syndrome can override socio-economic variables influencing attitudes towards prenatal diagnosis and termination (Bryant, Green & Hewison, 2005). In our study, overall, it is of interest that the majority of parents supported the availability of abortion and, as such, their views towards abortion were not related to whether they accepted screening or not. In fact, all participants favoured and respected the freedom of choice regarding the use of NT screening, although parents-to-be who declined screening emphasized that life is a complex phenomenon where diversity should be accepted. In some interviews it was discussed that all parents wanted their child to be healthy, but at the same time the issue was raised that health is a complex concept and that screening was not aimed at the most serious anomalies. This was, however, not necessarily related to their perception of technology, as for example most women who declined screening wanted to have an ultrasound to confirm pregnancy.

The effect of the screening as a probability test was described as inhibiting in accepting the test. Looking across the data, this view was more

reflected by those who were less likely to have experience with disabled people. In recent studies, this has been seen to be the main argument why women choose not to have screening (Muller, Bleker, Bonsel, & Bilardo, 2006a). Some of the participants, however, overestimated the risk of abortion after amniocentesis. In this study, although the sample size poses limitations on the generalization of results, it is of interest to speculate if age and parity differ between those who accept screening and those who decline. This may illustrate that the experience people gain with age and childbearing and rearing can serve to reinforce their perception and views of concepts such as health and risk. In general, we are able to say that some participants had good knowledge and understanding of disability and of the screening. On the other hand, some participants would have preferred more information from the health care professionals, either in the private or the public system. This was more reflected in the latter interview as with the parents who accepted screening.

Our findings suggest that the majority of this group of parents experience their choice as a free and uncoercive. Their considerations consist of many factors rooted in their values and beliefs as well as their knowledge of disability and perception of risk. In this regard our findings are in line with studies on women who refuse amniocentesis and form their own 'embodied knowledge' (Lippman, 1999; Press & Browner, 1996, 1997) meaning that they weave together various threads of understanding, experience and feelings.

Ethical Concepts in Today's Antenatal Care

The meaning of the bioethical concepts, autonomy and informed decision making is well defined and understood in ethics (Beauchamp & Childress, 2001). Attention has turned to the issue of autonomous decision making in health care, and it is questioned if the principalist approach is suitable (Callahan, 2003; Frank, 2004). This study reveals that both prospective

parents and the public media include ethical terms in their rhetoric around fetal screening. Many of the prospective parents are explicit about the choice they made, which must be considered a positive finding. There were, however, interesting differences in how that was explained between the two groups of prospective parents. The main difference can be seen in those who accept screening, who were less clear about their moral values and beliefs, which indicates that their experience of the screening was more characterized by compliance. Thus, one could argue that their values were more in line with the norms that prevail within the society in general. As such, their autonomy to make an informed choice should not be seen as restricted, but affected by a number of factors. The value component was less visible in the interviews among participants in this group and, as such, it was difficult for them to recognize that there were other choices to be considered in the situation. Among individuals who refused, moral values and beliefs were more visible in the discussion. This is understandable because their decision is in conflict with the prevailing social norm and, thus, they become more aware of the values upon which it is based. This does not necessarily mean that a decision to decline is more autonomous than a decision to accept, but it can be regarded as requiring more independent judgment (Dworkin, 1988).

Marteau and Dormandy claim that in the context of screening, the notion of informed choice has to refer to knowledge as well as values and beliefs of prospective parents (Marteau & Dormandy, 2001). However, it was hardly described in the interviews that the participants were confronted with a discussion of informed choice of this kind by professionals. It is recognized that professionals in the context of screening find it difficult to construct the discussion of informed choice and, although they recognise the centrality of the concept in fetal screening, they have many doubts whether it could be achieved (Alderson, Farsides & Williams, 2002; Williams, Alderson, Farsides, 2002). Drawing on the three models of patient-professional

relation, only in a small number of interviews was it actually possible to describe the discussion as cooperative or shared decision in the context of professional-parent relationship (Paper IV). One has to bear in mind, however, that those interviews are only with prospective parents and reflect on their experience of the situation. However, there was a positive presentation of screening in the media which was reflected in two main issues: scientific achievement and the expansion of choice for prospective parents. Much of the items, however, frame choice and decision making in an idealistic way, sometimes superficial and lacking connection with real situations, which corresponds to the autonomy model where the right to make an autonomous choice is highly emphasized. There, the responsibility rests with the parents first and foremost. This may damage other important aspects of patient-professional relationship. Furthermore, arguments do not have equal strength in the discourse nor do they act in the same manner on an audience. As others have noted, it is difficult to make generalizations about the impact of the media on public opinion and public policy (Kitzinger & Williams, 2005; Petersen & Bunton, 2002) and this is truly the case in the Icelandic media. However, the correlation between the views in the media and in the interviews suggests that the understanding of bioethical concepts is socially constructed. It is difficult to speculate if this actually promotes autonomy or facilitates informed choice in the context of screening in general, but it indicates that there is a considerable gap in the interpretation of those ethical concepts in the interviews and the media on the one hand, and in theory on the other. These are complex effects of screening implementation which need to be incorporated in the discussions, both on the levels of policy and practice.

GENERAL SUMMARY AND CONCLUSIONS

NT screening has become a routine procedure in antenatal care in Iceland as in some of its neighboring countries. Implementation of new technology such as NT screening, affects service delivery, social management of pregnancy and professional roles. It is forecast that noninvasive tools may soon be used to detect a number of fetal abnormalities.

There is a general understanding that informed decision and autonomy in the context of fetal screening is of importance. It is also acknowledged that the decision to accept or decline screening is, at the same time, affected by a number of issues on the macro and micro level (see Figure on page 35) which supports the need to explore this research topic in each socio-cultural context. Studies on prospective parents' decision making regarding in the context of fetal screening have been limited in Iceland. Although the findings of this study echo to some extent of other studies regarding prospective parents' decision making in relation to NT screening, they also brought out some new issues which have implication in the wider context.

- The findings show that choice in relation to undergoing NT screening was highly valued in the social context in Iceland. This was echoed both in the public media and in the interviews with the prospective parents. The media study made it possible to speculate on how the society at large evaluates new technology. That information is of importance as both the professionals and prospective parents belong to that context.

- The media discourse mainly draws on two opposite opinions. NT as a technological advance and the question of screening as an ethical issue. There was a considerable tension between the two views and a balanced discussion did only take place in a limited way.

- In this study, most participants felt that it was up to them to decide whether to accept screening or decline. Prospective parents who accept

screening make their decision in early pregnancy, most often before they have any contact with professionals. It is the woman's decision which is supported by their partner. The descriptions of their understanding of the implications of NT screening reveal that there is a lack of communication between women and professionals in the context of screening in early pregnancy.

- As we were able to follow prospective parents through half of the pregnancy, it was found that they had not been given explanations about their risk status, with the result that high expectations remained or they were left with unanswered questions and concerns. Some participants, especially men, explained in the second interview that they would have liked more time with the health professional to discuss the screening and its implications

- Prospective parents who decline screening know more about the screening and more experience with disabled people. The study findings showed, however, that in this group there was a misunderstanding of the accuracy of the procedure as some participants overestimated the risk of abortion following amniocentesis.

- The prospective fathers who belonged to the group of parents who accepted screening had been informed about the screening by their partner. Some related their reason to economic factors, i.e. that it is a financial burden to have a disabled child in the society. Many would have liked more information about the screening. The study findings indicate that men's actual involvement in pregnancy does not start until after the ultrasound at 20th week of gestation.

- The findings show a variation in the pathway of care in early pregnancy, although the majority of participating women had been to see their obstetrician to have their pregnancy confirmed. It is of importance to

coordinate antenatal care in early pregnancy and follow the clinical guidelines where it is suggested that antenatal care should start after the 8th week of pregnancy. Furthermore, provision of fetal screening should be subject to regular audit with reference to explore how the offer of screening and informed choice is experienced among prospective parents.

IMPLICATIONS FOR PRACTICE AND RESEARCH

As the aim of this study was to develop an understanding that could be of use for improvement in a particular field of practice and for future research within midwifery, the thesis should be judged in terms of practical utility as much as by the theoretical knowledge.

As with all sound research, the thesis raises many questions which indicate a need for further research on the decision making process that takes place in early pregnancy in relation to fetal screening and diagnosis. There are several gaps in this research field:

- From the practice perspective, this study has highlighted the role and importance of good information in early pregnancy. Hence it calls for a need to explore professional's knowledge and views on early screening and come up with a suitable educational program.

- There is a lack of research on how prospective parents use the sources of information already available and how they would like to be approached in this context.

- Sense of control and ability to make decisions in the context of birth is reflected in higher satisfaction and feeling of confidence. This is insignificantly explored in relation to pregnancy related issues such as prenatal screening.

- Knowledge about how to enact guidelines on screening in practice to meet the needs of prospective parents is limited. An evaluation should be performed on the impact of specific guidelines and recommendations in this area and about what should be disclosed in the discussion with prospective parents.

- It is insignificantly explored why there is a difference in the uptake of screening around the country. Research is required on if there are barriers in the offer of screening at institutional and professional level.

REFERENCES

Act on Health Care no. 40/2007 [Lög um heilbrigðisþjónustu nr. 40 frá 2007].

Act on the Disabled no. 59/1992 [Lög um málefni fatlaðra nr. 59 frá 1992].

Act on Midwives no. 67/1984 [Ljósmæðralög nr. 67 frá 1984].

Act on the Rights of Patients no. 74/1997 [Lög um réttindi sjúklinga nr. 74 frá 1997].

Alderson, P. (2001a). Prenatal screening, ethics and Down's syndrome: A literature review. *Nursing Ethics*, *8*, 360–374.

Alderson, P. (2001b). Down's syndrome: Cost, quality and value of life. *Social Science & Medicine*, *53*(5), 627–638

Alderson, P., Farsides, B., & Williams, C. (2002). Examining ethics in practice: Health service professionals' evaluation of in-hospital ethics seminars. *Nursing Ethics, 9*(5), 508–521.

Amin, Z., & Eng, K.H. (2003). *Basics in medical education*. Shanghai: World Scientific Publishing.

Anderson, G. (1999). Nondirectiveness in prenatal genetics: Patients read between the lines. *Nursing Ethics*, *6*(2), 126–136.

Árnason, V. (1994). Towards authentic conversations. Authenticity in the patient-professional relationship. *Theoretical Medicine*, *15*, 227–242.

Árnason, V. (2000). Gadamerian dialogue in the patient-professional interaction. *Medicine, Health Care and Philosophy*, *3*, 17–23.

Árnason, V. (2003). *Siðfræði lífs og dauða* [Ethics of life and death] (2nd ed.). Reykjavík: Siðfræðistofnun and Háskólaútgáfan.

Arney, W.R. (1982). *Power and profession of obstetrics*. London: University of Chicago Press.

Baird, D. (1960). The evolution of modern obstetrics. *Lancet*, *2*(7151), 609–614.

Banta, H.D. (1983). Social science research on medical technology: Utility and limitations. *Social Science & Medicine, 17*(18), 1363–1369.

Banta, D., & Stephen, T. (2001). Historical controversy in health technology assessment: The case of electronic fetal monitoring. *Obstetrical & Gynecological Survey*, *56*(11), 707–719.

Beaukamp, T.L., & Childress, J.F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.

Beck-Gernsheim, E. (2002). Health and responsibility: From social change to technological change and vice versa. In B. Adam, U. Beck, & J. Van Loon (Eds.), *The risk society and beyond* (pp. 122–135). London: Sage Publications.

Beckett, K. (2005). Choosing caesarean: Feminism and the politics of childbirth in the United States. *Feminist Theory*, *6*(3), 251–275.

Bjarnadóttir, R.I. (2003). Burðarmálsdauði á Íslandi. Getum við enn lækkað tíðnina? [Perinatal mortality in Iceland. How low can we go?] (Editorial). *Læknablaðið*, *10*, 745–746.

Bjarnadóttir, R.I., Garðarsdóttir, G., Smárason, A.K., & Pálsson, G.I. (Eds.) (2007). *Skýrsla frá fæðingaskráningunni fyrir árið 2006* [The Icelandic birth registration – Report for 2006]. Reykjavik: Landspítali-háskólasjúkrahús (LUH).

Blaymore Bier, J.A., Liebling, J.A., Morales, Y., & Carlucci. M. (1996). Parents' and pediatricians' views of individuals with meningomyelocele. *Clinical Pediatrics*, *35*(3), 113–117.

Bondas, T. (2002). Finnish women's experience of antenatal care. *Midwifery*, *18*, 61–71.

Boyd, P.A., DeVigan, C., Khoshnood, B., Loane, M., Garne, E., & Dolk, H. (2008). Survey of prenatal screening policies in Europe for structural malformations and chromosome anomalies, and their impact on detection and termination rates for neural tube defects and Down's syndrome. *BJOG*, *115*(6), 689–696.

Boyle, M. (1996). *Fetal assessment: An overview*. Cheshire: Books for Midwives Press.

Boyle, M. (2003). Antenatal investigations. In C. Henderson & S. Macdonald (Eds.), *Maye's midwifery: A textbook for midwives* (13th ed., pp. 312–327). London: Bailliére Tindall.

Bramwell, R., West, H., & Salmon, P. (2006). Health professionals' and service users' interpretation of screening test results: Experimental study. *British Medical Journal*, *333*(7562), 284.

Bricker, L., Garcia, J., Henderson, J., Mugford, M., Neilson, J., Roberts, T., et al. (2000). Ultrasound screening in pregnancy: A systematic review of the clinical effectiveness, cost-effectiveness and women's views. *Health Technology Assessment*, *4*(16), i–vi, 1–193.

Brown, N., Douglas, C., Eriksson, L., Rodrigues, E., Yearley, S., & Webster, A. (2005, June). *Researching expectations in medicine, technology and science: Theory and method*. Position paper for the York Workshop of the Expectations Network 2005, June 23rd . University of York, UK.

Brown, N., & Michael, M. (2003). A sociology of expectations: Retrospecting prospects and prospecting retrospects. *Technology Analysis and Strategic Management*, *15*(1), 3–18.

Brown, N., & Webster, A. (2004). *New medical technologies and society: Reordering life*. Cambridge: Polity.

Bryant, L.D., Green, J.M., & Hewison, J. (2001). Prenatal screening for Down's syndrome: Some psychosocial implications of a 'screening for all' policy. *Public Health*, *115*, 356–358.

Bryant, L.D., Green, J.M., & Hewison, J. (2006). Understanding of Down's syndrome: A Q methodological investigation. *Social Science & Medicine*, *63*, 1188–1200.

Bryant, L., Hewison, J.D., & Green, J. (2005). Attitudes towards prenatal diagnosis and termination in women who have a sibling with Down's syndrome. *Journal of Reproductive and Infant Psychology*, *23*, 181–198.

Burr, V. (2003). *Social constructionism*. (2nd ed.). London: Routledge.

Callahan, D. (2003). Individual good and common good: A communitarian approach to bioethics. *Perspectives in Biology and Medicine, 46*(4), 496–507.

Calnan, M., Montaner, D., & Horne, R. (2005). How acceptable are innovative health-care technologies? A survey of public beliefs and attitudes in England and Wales. *Social Science & Medicine*, *60*(9), 1937–1948.

Campbell, S., Johnstone, F.D., Holt, E.M., & May, P. (1972). Anencephaly: Early ultrasonic diagnosis and active management. *Lancet*, *2*(7789), 1226–1227.

Campbell, S., & Wilkin, D. (1975). Ultrasonic measurement of fetal abdomen circumference in the estimation of fetal weight. *British Journal of Obstetrics and Gynaecology*, *82*(9), 689–697.

Cartwright, E., & Thomas, J. (2001). Constructing risk. Maternity care, law and malpractice. In R. DeVries, C. Benoit, E. VanTeijlingen, & S. Wrede (Eds.), *Birth by design: Pregnancy, maternity care and midwifery in North America and Europe* (pp. 218–228). London: Routledge.

Caughey, A., Hopkins, L., & Norton, M. (2006). Chorionic villus sampling compared with amniocentesis and the difference in the rate of pregnancy loss. *Obstetrics & Gynecology*, *108*(3 Pt.1), 612–616.

Chadwick, R., ten Have, H., Husted, J., Lewitt, M., McGleenan, T., Shickle, D. et al. (1998). Genetic screening and ethics: European perspectives. *Journal of Medicine and Philosophy*, *23*(3), 255–273.

Chan, L.W., Chau, M.C., Leung, T.Y., Fung, T.Y., Leung, T. N., & Lau, T.K. (2005). Expectation and knowledge of women undergoing first-trimester combined screening for Down syndrome in a Chinese population. *Prenatal Diagnosis*, *25*, 1248–1252.

Cheffins, T., Chan, A., Haan, E.A., Ranieri, E., Ryall, R.G , Keane, E.J. et al. (2000). The impact of maternal serum screening on the birth prevalence of Down's syndrome and the use of amniocentesis and chorionic villus sampling in South Australia. *BJOG*, *107*(12), 1453–1459.

Coulter, A., & Ellins, J. (2006). *Patient-focused interventions: A review of the evidence*. London: The Health Foundation. Retrieved August 10, 2008 from http://www.pickereurope.org/Filestore/Downloads/QEI-Review-intro.pdf.

Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). London: Sage Publications.

Cuckle, H. (2001). Time for a total shift to first-trimester screening for Down's syndrome. *Lancet*, *358*(9294), 1658–1659.

Currel, R. (1992). The organization of midwifery care. In J. Alexander, V. Levy & S. Roch (Eds.), *Antenatal care: A research-based approach.* London: Macmillian Press Ltd.

Dahl, K., Kesmodel, U., Hvidman, L., & Olsen, F. (2006). Informed consent: Attitudes, knowledge and information concerning prenatal examination. *Acta Obstetricia et Gynecologica Scandinavica*, *85*, 1414–1419.

Dean, M. (1999). *Governmentality: Power and rule in modern society*. London: Sage Publications.

de Graaf, I.M., Tijmstra, T., Bleker, O.P., & van Lith, J.M. (2002). Womens' preference in Down syndrome screening. *Prenatal Diagnosis*, *22*(7), 624–629.

Denzin, N., & Lincoln, Y. (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage Publications.

di Gregorio, S. (2003). Teaching grounded theory with QSR NVivo. *Qualitative Research Journal*, *3*, 79–95.

Directorate of Health (2006). *Tilmæli um fósturskimun á meðgöngu.* [Request regarding nuchal translucency screening during pregnancy]. Dreifibréf nr. 9 [Bulletin no. 9 of the Directorate of Health]. Retrieved Nov. 14, 2008 from http://www.landlaeknir.is/Pages/207.

Directorate of Health (2008). *Meðgönguvernd heilbrigðra kvenna í eðlilegri meðgöngu. Klíniskar leiðbeiningar* [Antenatal care in normal pregnancy. Clinical guidelines]. Retrieved January 5, 2009 from http://landlaeknir.is/Uploads/FileGallery/Kliniskar%20leidbeiningar/Medgonguvernd_KL_nov.2006.pdf.

Dodds, R., Goodman, M., & Tyler, S. (Eds.). (1996). *Listen with mother: Consulting users of maternity services*. Hale, Cheshire: Books for Midwives Press.

Donald, I., Macvicar, J., & Brown, T.G (1958). Investigation of abdominal masses by pulsed ultrasound. *Lancet*, *7*(7032), 1188–1195.

Donovan, J. (1995). The process of analysis during a grounded theory study of men during their partners' pregnancies. *Journal of Advanced Nursing*, *21*(4), 708–715.

Dormandy, E., Michie, S., Hooper, R., & Marteau, T.M. (2005). Low uptake of prental screening for Down syndrome in minority ethnic groups and socially deprived groups: A reflection of women's attitude or failure to facilitate informed choices. *International Journal of Epidemiology*, *34*(2), 346–352.

Dormandy, E., Michie, S., Hooper, R., & Marteau, T.M. (2006). Informed choice in antenatal Down syndrome screening: A cluster-randomised trial of combined versus separate visit testing. *Patient Education and Counseling*, *61*(1), 56–64.

Dormandy, E., Michie, S., Weinman, J., & Marteau, T. (2002). Variation in uptake of serum screening: The role of service delivery. *Prenatal Diagnosis*, *22*, 67–69.

Draper, J. (2002). It was a real good show. The ultrasound scan, fathers and the power of visual knowledge. *Sociology of Health & Illness, 24*(6), 771–786.

Dunne, C., & Warren, C. (1998). Lethal autonomy: The malfunction of the informed consent mechanism within the context of prenatal diagnosis of genetics variants. *Issues in Law & Medicine*, *14*, 165–202.

Dworkin, G. (1988). *The theory and practice of autonomy*. Cambridge: Cambridge University Press.

Eik-Nes, S.H., Okland, O., Aure, J.C., & Ulstein, M. (1984). Ultrasound screening in pregnancy: A randomized controlled trial. *Lancet*, *1*(8390), 1347.

Einarsdóttir, B. (Ed.). (1982). *Ljósmæður á Íslandi* [Midwives in Iceland]. Reykjavík: Ljósmæðrafélag Íslands.

Einarsson, I. (2006). Downs heilkenni. *Þroskahjálp, 28*(4), 15–18.

Einisdóttir, I.S. (1998). *Ljósmæðrafélag Íslands. Hugmyndafræði og stefna* [The Icelandic Association of Midwives: Philosophy and policy] Reykjavík: Ljósmæðrafélag Íslands.

Ekelin, M., & Crang-Svalenius, E. (2004). Midwives' attitudes and knowledge about a newly introduced foetal screening method. *Scandinavian Journal of Caring Sciences, 18*, 287–293.

Ekelin, M., Crang-Svalenius, E., & Dykes, A.K. (2004). A qualitative study of mothers' and fathers' experiences of routine ultrasound examination in Sweden. *Midwifery*, *20*(4), 335–344.

Enkin, M., Keirse, M.J.N.C., Neilson, J., Crowther, C., Duley, L., Hodnett, E. et al. (2000). *A guide to effective care in pregnancy and childbirth* (3rd ed.) Oxford: Oxford University Press.

Erich, K., Farsides, B., Williams, C., & Schott, R. (2007). Testing the embryo, testing the fetus. *Clinical Ethics*, *2*, 181–186.

Esposito, N. (2001). From meaning to meaning: The influence of translation techniques on non-English focus group research. *Qualitative Health Research*, *11*(4), 568–579.

Eurenius, K., Axelsson, O., Gallstedt-Fransson., & Sjöden, P. O. (1997). Perception of information, expectations and experiences among women and their partners attending a second-trimester routine ultrasound scan. *Ultrasound in Obstetrics and Gynecology*, *9*, 86–90.

Favre, R., Moutel, G., Duchange, N., Vayssiére, C., Kohler, M., Bouffet, N. et al. (2006). What about informed consent in first-trimester ultrasound screening for Down syndrome? *Fetal Diagnosis and Therapy*, *23*, 173–184.

Field, P.A. (1999). Effectiveness and efficacy of antenatal care. *Midwifery*, *6*, 215–223.

Fontana, A., & Frey, J.H. (2000). The interview: From structured questions to negotiated text. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Ford, N.M. (2002). *The prenatal person: Ethics from conception to birth*. East Melbourne: Blackwell Publishing.

Ford, C., Moore, A.J., Jordan, P.A., Bartlett, W.A., Wyldes, M.P., Jones, A.F. et al. (1998). The value of screening for Down's syndrome in a socioeconomically deprived area with a high ethnic population. *British Journal of Obstetrics & Gynaecology*, *105*(8), 855–859.

Foucault, M. (1977). Nietzsche, genealogy, history. In D.F. Bouchard (Ed.), *Language, countermemory, practice: Selected essays and interviews* (pp. 139–164). Ithaca: Cornell University Press.

Foucault, M. (1991). Governmentality. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 87–104). Chicago: University of Chicago Press.

Foucault, M. (2003). *Society must be defended: Lectures at the Collége De France 1975–1976* (D. Macey, Trans.). New York: Picador.

Frank, A.V. (2004). Ethics as process and practice. *Internal Medicine Journal*, *34*(6), 355–357.

Fraser, N., & Gordon, L. (1994). A genealogy of dependency: Tracing a keyword of the U.S. welfare state. *Signs*, *19*(2), 309–336.

French, S. (2000). Perceptions of routine nuchal translucency screening. *British Journal of Midwifery*, *8*(10), 632–638S.

Garcia, J., Bricker, L., Henderson, J., Martin, M., Mugford, M., Nielson, J. et al. (2002). Women's views of pregnancy ultrasound: A systematic review. *BIRTH*, *29(*4), 225–250.

Garðarsdóttir, Ó. (2002). *Saving the child: Regional, cultural and social aspects of the infant mortality decline in Iceland, 1770–1920*. Umeå: Umeå University.

Geirsson, R. (1987). Leiðbeiningar um ómskoðun á meðgöngu [Guidelines on ultrasound in pregnancy]. *Hjúkrun*, *63*, 14–16.

Geirsson, R.T., Garðarsdóttir, G., Pálsson, G., Bjarnadóttir, R., & Harðardóttir, H. (Eds.) (2003). *Skýrsla frá fæðingaskráningunni fyrir árið 2002* [The Icelandic birth registration – Report for 2002]. Reykjavík: Landspítali-háskólasjúkrahús (LUH).

Geirsson, R.T., Garðarsdóttir, G., Pálsson, G., & Bjarnadóttir R. (Eds.) (2005). *Skýrsla frá fæðingaskráningunni fyrir árið 2004* [The Icelandic birth registration – Report for 2004]. Reykjavík: Landspítali-háskólasjúkrahús (LUH).

Georgsson Öhman, S., Grunewald, C., & Waldenström, U. (2007). Perception of risk in relation to ultrasound screening for Down's syndrome during pregnancy. *Midwifery,* (in press), doi: 10.1016/j.midw.2007.04.007.

Getz, L., & Kirkengen, A. (2003). Ultrasound screening in pregnancy: Advancing technology, soft markers for foetal chromosomal aberrations, and unacknowledged ethical dilemmas. *Social Science & Medicine*, *56*, 2045–2075.

Gilbert, R.E., Augood, C., Gupta, R., Ades, A.E., Logan, S., Sculpher, M. et al. (2001). Screening for Down's syndrome: Effects, safety, and cost effectiveness of first and second trimester strategies. *British Medical Journal, 323*(25), 1–6.

Gillon, R. (1998). Eugenics, contraception, abortion and ethics (Editorial). *Journal of Medical Ethics, 24,* 219–220.

Gjerris, A.C., Loft, A., Pinborg, A., Christiansen, M., & Tabor, A. (2009). First-trimester screening markers are altered in pregnancies conceived after IVF/ICSI. *Ultrasound Obstetrics & Gynecology*, *33*, 8–17.

Gottfreðsdóttir, H. (2001). Hvað felst í mæðravernd? Viðhorf kvenna og ljósmæðra. [What is the content of antenatal care? Views of women and midwives] *Ljósmæðrablaðið, 79*(2), 5–15.

Gottfreðsdóttir, H. (2005). Prospective first time fathers and their views on fatherhood in the context of new policy on parental leave in Iceland. *Birth Issues*, *14*(4), 128–134.

Gourounti, K., & Sandall, J. (2008). Do pregnant women in Greece make informed choices about antenatal screening for Down's syndrome? A questionnaire survey. *Midwifery*, *24*, 153–162.

Green, R.M. (1999). Genetic medicine and the conflict of moral principles. *Families, Systems & Health*, *17*(1), 63–73.

Green, J.M., Hewison, J., Bekker, H.L., Bryant, L.D., & Cuckle, H.S. (2004). Psychological aspects of genetic screening of pregnant women and newborns: A systematic review. *Health Technology Assessment*, *8*(33), 1–109.

Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London: Sage Publications.

Greswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications.

Hahn, S., & Chitty, L.S. (2008). Noninvasive prenatal diagnosis: Current practice and future perspectives. *Current Opinion in Obstetrics and Gynecology*, *20*, 146–151.

Haraldsdóttir, K. (2001). Áhugi kvenna á ómskoðun, upplýst val og ráðgjöf [Women's interest in ultrasound, informed choice and counselling]. *Læknablaðið*, *87* (Suppl. 42), 44–46.

Hasman, A., Coulter, A., & Askham, J. (2006). *Education for partnership: Developments in medical education*. Retrieved September 2, 2007 from http://www.pickereurope.org/page.php?id=23.

Hawthorne, F., & Ahern, K. (2009). "Holding our breath":Tthe experience of women contemplating nuchal translucency screening. *Applied Nursing Research,* doi:10.1016/j.apnr.2008.02.007

Helén, I. (2002). Risk and anxiety: Polyvalence of ethics in the high-tech antenatal care. *Critical Public Health*, *12*(2), 119–136.

Helén, I. (2004). Technics over life: Risk, ethics and the existential conditions in high-tech antenatal care. *Economy & Society*, *33*, 28–51.

Hornby, G. (1995). Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies*, *4*, 103–117.

Hreinsdóttir, M.J., & Guðmundsdóttir, Ó.M. (2009). Ljósmæður við ómskoðanir í 25 ár [Midwives performing ultrasound over 25 years]. *Ljósmæðrablaðið, 87*(1) (in press).

Huibers, A.K., & Spijker, A. (1998). The autonomy paradox: Predictive genetic testing and autonomy: Three essential problems. *Patient Education and Counseling, 35*, 53–62.

Hunt, S., & Symonds, A. (1995). *The social meaning of midwifery*. London: Macmillian Press.

Jacques, A., Bell, R., Watson L., & Halliday, J.L. (2004). People who influence women's decisions and preferred sources of information about prenatal testing for birth defects. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, *44*, 233–238.

Jaques, A.M., Sheffield, L.J., & Halliday, J.L. (2005). Informed choice in women attending private clinics to undergo first-trimester screening for Down syndrome. *Prenatal Diagnosis, 25*(8), 656–664.

Jepson, R.G., Forbes, C.A., Sowden, A.J., & Lewis, F.A. (2001). Increasing informed uptake and non-uptake of screening: Evidence from a systematic review. *Health Expectations*, *4*, 116–130.

Jónasdóttir, H.R. (2009). Upplýsingaöflun verðandi mæðra um fósturskimun/sónar á fyrsta þriðjungi meðgöngu [Prospective mothers and sources of information on fetal screening/ultrasound in the first trimester]. Unpublished dissertation in midwifery , University of Iceland, Reykjavík .

Jörgensen, F.S. (1999). Epidemiological examinations of obstetric ultrasound examinations in Denmark 1989–90 versus 1994–95. *Acta Obstetricia et Gynecologica Scandinavica*, *78*, 305–309.

Kaiser, A.S., Ferris, L.E., Pastuszak, A.L., Llewellyn-Thomas, H., Johnson, J., Conachier, S. et al. (2002). The effects of prenatal group genetic counselling on knowledge, anxiety and decisional conflict: Issues for nuchal translucency screening. *Journal of Obstetrics and Gynaecology, 22*(3), 246–255.

Kerr, A. (2004). *Genetics and society: A sociology of disease*. London: Routledge.

Kirkham, M. (2004). *Informed choice in maternity care*. London: Palgrave Macmillan.

Kitzinger, J., & Williams, C. (2005). Forecasting science futures: Legitimising hope and calming fears in the embryo stem cell debate. *Social Science & Medicine, 61*, 731–740.

Kjaergaard, S., Hahnemann, J.M., Skibsted, L., Neerup, L., Sperling, H., Zingenberg, A. et al. (2007). Prenatal diagnosis in Denmark after the introduction of nuchal translucency screening. *European Journal of Human Genetics, 15* (Supplement 1).

Knudsen, L.B., Gissler, M., Bender, S.S., Hedberg, C., Ollendorff, U., Sundström, K. et al. (2003). Induced abortion in the Nordic countries: Special emphasis on young women. *Acta Obstetricia et Gynecologica Scandinavica, 82*(3), 257–268.

Koch L., & Svendsen, M.N. (2005). Providing solutions—defining problems: The imperative of disease prevention in genetic counselling. *Social Science & Medicine, 60*(4), 823–832.

Kohut, R., Dewey, D., & Love, E. (2002). Women's knowledge of prenatal ultrasound and informed choice. *Journal of Genetic Counseling, 11*, 265–276.

Kristjánsdóttir, H. (2009). Svo maður sé öruggur. Fyrsta koma kvenna í meðgönguvernd. [In order to be safe. Women's first antenatal visit]. In H. Gottfreðsdóttir & S.I. Karlsdóttir (Eds.), *Lausnarsteinar: Ljósmóðurfræði og ljósmóðurlist* (pp. 21–37). Reykjavík: Hið íslenska bókmenntafélag.

Kumar, S., & Gantley, M. (1999). Tensions between policy makers and general practitioners in implementing new genetics: Grounded theory interview study. *British Medical Journal, 319,* 1410–1413.

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. London: Sage Publications.

Ladfors, L., Eriksson, M., Mattsson, L.A., Kyleback, K., Magnusson, L., & Milson, I. (2001). A population based study of Swedish women's opinions about antenatal, delivery and postpartum care. *Acta Obstetricia et Gynecologica Scandinavica*, *80,* 130–136

Lehrman, E.J. (1981). Nurse-midwifery practice: A descriptive study of prenatal care. *Journal of Nurse Midwifery*, *26*, 27–41.

Levy, V. (1999). Protective steering: A grounded theory study of the processes by which midwives facilitate informed choices during pregnancy. *Journal of Advanced Nursing, 29*(1), 104–112.

Lewis, J. (2003). Design Issues. In J. Richie, & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 47–76). London: Sage Publications.

Lippman, A. (1999). Embodied knowledge and making sense of prenatal diagnosis. *Journal of Genetic Counseling*, *8*, 255–274.

Locock, L., & Alexander, J. (2005). ‘Just a bystander’? Men’s place in the process of fetal screening and diagnosis. *Social Science & Medicine*, *62*, 1349–1359.

Louhiala, P. (2004). *Preventing intellectual disability*. Cambridge: Cambridge University Press.

Lupton, D. (1999). *Risk*. London: Routledge.

Magnúsdóttir, I. (1985). *Heilsugæslustöðvar* [Health care centres]. Rit heilbrigðis- og tryggingamálaráðuneytisins [Bulletin of the Ministry of Health and Social Security]. Reykjavík: Heilbrigðis- og tryggingamálaráðuneytið.

Marshall, C., & Rossman, G. (2006). *Designing qualitative research* (4th ed.). London: Sage Publications.

Marteau, T. (2002). Prenatal testing: Towards realistic expectations of patients, providers and policy makers. *Ultrasound in Obstetrics and Gynecology*, *19*, 5–6.

Marteau, T., & Dormandy, E. (2001). Facilitating informed choice in prenatal testing: How well are we doing? *American Journal of Medical Genetics, 106*, 185–190.

Marteau, T., Dormandy, E., & Michie, S. (2001). A measure of informed choice. *Health Expectations, 4*(2), 99–108.

Marteau, T., & Drake, H. (1995). Attributions for disability: The influence of genetic screening. *Social Science & Medicine*, *40*(8), 1127–1132.

Marteau, T., Slack, J., Kidd, J., & Shaw, R. (1992). Presenting a routine screening test in antenatal care: Practice observed. *Public Health*, *106*, 131–141.

McCourt, C. (2006). Supporting choice and control? Communication and interaction between midwives and women at the antenatal booking visit. *Social Science & Medicine, 62*, 1307–1308.

McFayden, A., Gledhill, J., & Whitlow, B. (1998). First trimester ultrasound screening carries ethical and psychological implications (Editorial). *British Medical Journal*, *317*(7160), 694–695.

McLaughlin, J. (2001). EBM and risk. Rhetorical resources in the articulation of professional identity. *Journal of Management in Medicine*, *15*(5), 352–363.

Michie, S., Dormandy, E., & Marteau, T. (2002). The multi-dimensional measure of informed choice: A validation study. *Patient Education and Counseling, 58,* 87–91.

Michie, S., Dormandy, E., & Marteau, T.M. (2005). Informed choice: Understanding knowledge in the context of screening uptake. *Patient Education and Counseling, 55*(2), 218–222.

Miles, M., & Huberman, A. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage Publications.

Morris, J.K., Mutton, D.E., & Alberman, E. (2002). Revised estimates of the maternal age specific live birth prevalence of Down's syndrome. *Journal of Medical Screening*, *9*(1), 2–6.

Muller, M.A., Bleker, O. P., Bonsel, G.J., & Bilardo, C.M. (2006a). Women's opinions on the offer and use of nuchal translucency screening for Down syndrome. *Prenatal Diagnosis, 26*, 105–111.

Muller, M.A., Bleker, O. P., Bonsel, G.J., & Bilardo, C.M. (2006b). Nuchal translucency screening and anxiety levels in pregnancy and puerperium. *Ultrasound in Obstetrics & Gynecology, 27*, 357–361.

Mulvey, S., & Wallace, E.M. (2000). Women's knowledge of and attitudes to first and second trimester screening for Down's syndrome. *BJOG*, *107*, 1302–1305.

Mulvey, S., Zachariah, R., & McIlwaine, E.M. (2003). Do women prefer to have screening tests for Down syndrome that have the lowest screen-positive rate or the highest detection rate? *Prenatal Diagnosis, 23,* 828–832.

National Institute for Health and Clinical Excellence [NICE] (2008a). *Antenatal care: Routine care for the healthy pregnant woman*. *NICE clinical guideline 62.* Retrieved April 10, 2008 from http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf.

National Institute for Health and Clinical Execellence (NICE) (2008b). *Intrapartum care: Care of healthy women and their babies during childbirth. NICE CG55*. Retrieved April 10, 2008 from http://www.nice.org.uk/guidance/index.jsp?action=download&o=36275.

Nicol, M. (2007). Vulnerability of first-time expectant mothers during ultrasound scans: An evaluation of the external pressures that influence the process of informed choice. *Health and Care for Women International*, *28*, 525–533.

Nicolaides, K.H. (2003). Screening for chromosomal defects. *Ultrasound in Obstetrics & Gynecology*, *21*, 313–321.

Nicolaides, K.H. (2004). Nuchal translucency and other first-trimester sonographic markers of chromosomal abnormalities. *American Journal of Obstetrics and Gynecology*, *191*, 45–67.

Nicolaides, K., Chervenak, F., McCullough, L., Avgidou, K. & Papageorghiou, A. (2005). Evidence-based obstetric ethics and informed decision-making by pregnant women about invasive diagnosis after first-trimester assessment of risk for trisomy 21. *American Journal of Obstetrics and Gynecology*, *193*, 322–326.

Nicolaides, K.H, Heath V., & Liao, A.W. (2000). The 11–14 week scan. *Bailliere's Best Practice and Research. Clinical Obstetrics & Gynaecology*, *14*, 581–594.

Nicolaides, K.H., Snijders, R.J., Gosden, C.M., Berry, C., & Campbell, S. (1992). Ultrasonographically detectable markers of fetal chromosomal abnormalities. *Lancet*, *340*(8821), 704–707.

Nicolaides, K., Spencer, K., Avgidou, K., Faiola, S., & Falcon, O. (2005). Multicenter study of first-trimester screening for trisomy 21 in 75 821 pregnancies: Results and estimation of the potential impact of individual risk-orientated two-stage first-trimester screening. *Ultrasound in Obstetrics and Gynecology*, *25*(3), 221–226.

Nordic Council of Ministers (2006). *Assisted reproduction in the Nordic countries. A comparative study of policies and regulations. Thema Nord, 505.* Copenhagen: Nordic Council of Ministers.

Oakley, A. (1986). The history of ultrasonography in obstetrics. *Birth*, *13* (Suppl.), 5–10.

O'Connor, A.M., Llewellyn-Thomas, H.A., & Flood, A.B. (2004). Modifying unwarranted variations in health care: Shared decision making using patient decision aids: A review of the evidence base for shared decision making. *Health Affairs* [Online, web-exclusive] Retrieved Oct. 10, 2008 from http://content.healthaffairs.org/cgi/reprint/ hlthaff.var. 63v1.pdf.

Ólafsdóttir, Ó.A. (2006). *An Icelandic midwifery saga – Coming to light: "With woman" and connective ways of knowing*. Unpublished PhD thesis, Thames Valley University, London.

Ólafsson, Ó. (1998). *Health in Iceland.* Reykjavík: Director of Health.

Ondeck, M. (2000). Historical development. In F.H. Nichols & S.S. Humenick (Eds.), *Childbirth education*: *Practice, research and theory* (2nd ed., pp. 18–31). New York: Saunders Company.

O'Neill, O. (2002). *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.

Page, L., & McCandlish, R. (2006). *The new midwifery: Science and sensitivity in practice.* (2nd ed.). Netherlands: Churchill Livingstone, Elsevier.

Parens, E., & Asch, A. (2000). *Prenatal testing and disability rights*. Washington, DC: Georgetown University Press.

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.) Thousand Oaks, CA: Sage Publications.

Persson, P.H., Grennert, L., & Gennser, G. (1978). Ultrasound screening in pregnancy: Methodology and significance. *Acta Obstetricia et Gynecologica Scandinavica*, *78* (Suppl.), 40–48.

Petersen, A., & Bunton, R. (2002). *The new genetics and the public's health*. Routledge: London.

Pétursdóttir, M. (1969). *Hjúkrunarsaga* [History of Nursing]. Reykjavík: Höfundur.

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), 511–530.

Pilnick, A.M., Fraser, D.M., & James, D.K. (2004). Presenting and discussing nuchal translucency screening for fetal abnormality in the UK. *Midwifery*, *20*, 82–93.

Porter, M., & Macintyre, S. (1984). What is, must be best: A research note on conservative or deferential responses to antenatal care provision. *Social Science & Medicine, 19*(11), 1197–1200.

Press, N., & Browner, C.H. (1997). Why women say yes to prenatal diagnosis. *Social Science & Medicine*, *45*(7), 979–989.

Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America*. New York: Routledge.

Raz, A.E. (2009). Eugenic utopia/dystopias, reprogenetics, and community genetics. *Sociology of Health & Illness, 31*(4), 602–616.

Reed, K. (2009). 'It's them faulty genes again': Women, men and the gendered nature of gentic responsibility in prenatal blood screening. *Sociology of Health & Illness, 31*(3), 343–359.

Regulation on Health Care Centres no. 787/2007. [Reglugerð um heilsugæslustöðvar nr. 787/ 2007]. Retrieved April 14, 2008 from http://www.heilbrigdisraduneyti.is/log-og-reglugerdir/reglugerdir/nr/787.

Ribbens, J., & Edwards,R. (1998). *Feminist dilemmas in qualitative research: Public knowledge and private lives.* London: Sage Publications.

Richie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. London: Sage Publications.

Richie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In J. Richie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 77–108). London: Sage Publications.

Robinson, H.P., & Shaw-Dunn, J. (1973). Fetal heart rates as determined by sonar in early pregnancy. *Journal of Obstetrics & Gynaecology of the British Commonwealth*, *80*(9), 805–809.

Roizen, N., & Patterson, D. (2003). Down's syndrome. *Lancet*, *361*(9365), 1281–1289.

Rose, N. (1993). Government, authority and expertise in advanced liberalism. *Economy & Society*, *22*(3), 283–299.

Rose, N. (1999). *Powers of freedom: Reframing political thought*. Cambridge: Cambridge University Press.

Rösch, C., Steinbicker, V., & Kropf, S. (2000). Down's syndrome: The effects of prenatal diagnosis and demographic factors in a region of the eastern part of Germany. *European Journal of Epidemiology*, *16*(3), 627–632.

Rothman, B.K. (1986). *The tentative pregnancy: Prenatal diagnosis and the future of motherhood.* New York: Viking Press.

Rothman, B.K. (2001). Spoiling the pregnancy: Prenatal diagnosis in the Netherlands. In R. DeVries, C. Benoit, E. Van Teijlingen, & S. Wrede (Eds.), *Birth by design: Pregnancy, maternity care and midwifery in North America and Europe* (pp. 180–198). New York: Routledge.

Rowe, R. E., Garcia, J., & Davidson, L.L. (2004). Social and ethnic inequalities in the offer and uptake of prental screening and diagnosis in the UK: A systematic review. *Public Health: Journal of the Royal Institute of the Public Health, 18*, 177–189.

Ryder, I.H. (1999). Prenatal screening for Down syndrome: A dilemma for the unsupported midwife? *Midwifery*, *15*(1), 6–23.

Saari-Kemppainen, A., Karjalainen O., Ylöstalo P., & Heinonen, O.P. (1990). Ultrasound screening and perinatal mortality: Controlled clinical trial of systematic one-stage screening in pregnancy. The Helsinki Ultrasound Trial. *Lancet*, *336*(8712), 387–391.

Saltvedt, S., Almstrom, H., Kublicas, M., Valentin, L., & Grunewald, C. (2006). Detection of malformations in chromosomally normal fetuses by routine ultrasound at 12 or 18 weeks of gestation - A randomised controlled trial in 39,572 pregnancies. *BJOG*, *113*(6), 664–674.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27–37.

Santalahti, P., Hemminki, E., Aro, A.R., & Helenius, H. (1999). Participation in prenatal screening tests and intentions concerning selective termination in Finnish maternity care. *Fetal Diagnosis and Therapy*, *14*(2), 71–79.

Santalahti, P., Hemminki, E., Latikka, A.M., & Ryynänen, M. (1998). Women's decision making in prenatal screening. *Social Science & Medicine, 46*, 1067–1076.

Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability & Society*, *13*(5), 665–681.

Silverman, D. (2006). *Interpreting qualitative data*. London: Sage Publications.

Skirton, H., & Barr, O. (2007). Influences on uptake of antenatal screening for Down syndrome: A review of the literature. *Evidence Based Midwifery*, *5*, 4–9.

Skirton, H., & Barr, O. (2009). Antenatal screening and informed choice: A cross-sectional survey of parents and professionals. *Midwifery*, doi:10.1016/j.midw.2009.01.002.

Skirton, H., & Patch, C. (2002). *Genetics for healthcare professionals: A lifestage approach*. Oxford: BIOS Scientific Publishers Limited.

Solbekken, J.A. (1995). The risk epidemic in medical journals. *Social Science & Medicine*, *40*, 291–305.

Sorenson J.R., & Wertz, D.C. (1986). Couple agreement before and after genetic counseling. *American Journal of Medical Genetics*, *25*(3), 549–555.

Spencer, K. (2000). Second-trimester prenatal screening for Down's syndrome and the relationship for maternal serum biochemical markers to pregnancy complications with adverse outcome. *Prenatal Diagnosis*, *20*, 652–656.

Spencer, K., & Nicholaides, K.H. (2003). Screening for trisomy 21 in twins using first trimester ultrasound and maternal serum biochemistry in a one-stop clinic: A review of three years experience. *British Journal of Obstetrics and Gynaecology*, *110*, 276–280.

Spencer, K., Souter, V., Tul, N., Snjiders, R.J., & Nicholaides, K.H. (1999). A screening program for trisomy 21 at 10–14 weeks using fetal nuchal translucency, maternal serum free beta-human chorionic gonadotropin and pregnancy-associated plasma protein-A. *Ultrasound in Obstetrics & Gynecology*, *13*(4), 231–237.

Spencer, K., Spencer, C.E., Power, M., Moakes, A., & Nicolaides, K.H. (2000). One stop clinic for assessment of risk for fetal anomalies: A report of the first year of prospective screening for chromosomal anomalies in the first trimester, *BJOG*, *107*(10), 1271–1275.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). London: Sage Publications.

Struhkamp, R.M. (2005). Patient autonomy: A view from the kitchen. *Medicine Health Care, and Philosophy, 8*, 105–114.

Tegnander, E. (2006). *Detection of congenital heart defects in a non-selected population of 42,381 fetuses*. Doctoral thesis. Norwegian University of Science and Technology, Faculty of Medicine, Department of Laboratory Medicine, Children's and Women's Health, Trondheim.

Tew, M. (1995). *Safer childbirth? A critical history of maternity care*. (2nd ed.). London: Chapman & Hall.

Tremain, S (2006). *Foucault and the government of disability*. Ann Arbor: University of Michigan Press.

Trute, B. (1995). Gender differences in the psychological adjustment of parents of young, developmentally disabled children. *Journal of Child Psychology and Psychiatry, 36*(7), 1225–1242.

Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing*, *26*(2), 418–423.

Valenti, C., Schutta, E.J., & Kehaty, T. (1968). Prenatal diagnosis of Down's syndrome. *Lancet*, *2*(7561), 220.

van Berkel, D, & van der Weele, C. (1999). Norms and prenorms on prenatal diagnosis: New ways to deal with morality in counseling. *Patient Education & Counseling*, *37*(2), 153–163.

van den Berg, M., Timmermans, D., ten Kate, L., van Vugt, J.M., & van der Wal, G. (2005). Are pregnant women making informed choices about prenatal screening? *Genetics in Medicine, 7*(5), 332–338.

van den Heuvel, A., Chitty, L., Dormandy, E., Newson, A., Attwood, S., Masturzo, B. et al. (2009). Is informed choice in prenatal testing universally valued? A population-based survey in Europe and Asia. *BJOG*, *116*(7), 880–885.

Vassy, C. (2006). From a genetic innovation to mass health programmes: The diffusion of Down's syndrome prenatal screening and diagnostic techniques in France. *Social Science & Medicin*e, *63*, 2041–2051.

Westin, M. (2006). Is measurement of nuchal translucency thickness a useful screening tool for hearth defects? A study of 16,383 fetuses. *Ultrasound in Obstetrics and Gynecology, 27*(6), 632–639.

Williams, S. (1997). *Women & childbirth in the twentieth century*. Cornwall: Sutton Publishing Ltd.

Williams, C. (2006). Dilemmas in fetal medicine: Premature application of technology or responding to women's choice? *Sociology of Health & Illness*, *28*(1), 1–20.

Williams, C., Alderson, P., & Farsides, B. (2002). Is nondirectiveness possible within the context of antenatal screening and testing? *Social Science & Medicine, 54*, 17–25.

Williams, C., Sandall, J., Lewando-Hundt, G., Heyman, B., Spencer, K., & Grellier, R. (2005). Women as 'moral pioneers'?: Experiences of first trimester nuchal translucency screening, *Social Science & Medicine*, *61*(9), 1983–1992.

Wrede, S., Benoit, C., & Sandall, J. (2001). The state and the birth/the state of birth: Maternal health policy in three countries. In R. DeVries, C. Benoit, E. Van Teijlingen, & S. Wrede (Eds.), *Birth by design: Pregnancy, maternity care and midwifery in North America and Europe* (pp. 28–50). New York: Routledge.

Zeanah, C.H., Dailey, J.V., Rosenblatt, M.J., & Saller, D.N. Jr. (1993). Do women grieve after terminating pregnancies because of fetal anomalies? A controlled investigation. *Obstetrics & Gynecology*, *82*, 270–275.

Zechmeister, I. (2001). Foetal images: The power of visual technology in antenatal care and the implications for women's reproductive freedom. *Health Care Analysis*, *9*(4), 387–400.

Zindler, L. (2005). Ethical decision making in first trimester pregnancy screening. *The Journal of Perinatal & Neonatal Nursing, 19*(2), 122–131.

Paper I.

ORIGINAL ARTICLE doi: 10.1111/j.1471-6712.2009.00727.x

Have you had the test?' A discourse analysis of media presentation of prenatal screening in Iceland

Helga Gottfreðsdóttir MA, RN, RM (Assistant Professor, Doctoral Student)[1] and **Kristín Björnsdóttir** EdD, RN (Professor)[2]

[1]Department of Midwifery and [2]Department of Nursing, Faculty of Nursing, University of Iceland, Reykjavik, Iceland

Scand J Caring Sci; 2009

Have you had the test?' A discourse analysis of media presentation of prenatal screening in Iceland

Nuchal translucency (NT) screening has come to be widely used in antenatal care in many countries. In the capital area of Iceland, which is the focus of this study, 84% of pregnant women underwent screening in 2005. At the time no official policy had been formulated regarding the use of this screening, and very limited public discussion had taken place on the ethical issues related to its use. Although screening has been widely welcomed as a scientific and technological improvement, it may also have unintended consequences, both for practitioners and prospective parents, and for particular groups such as the disabled, which have not been fully explored. The purpose of this study was to examine how NT screening was introduced as a new practice and came to be adopted in prenatal care in Iceland. Using a genealogical approach, we explored the way in which the value and potential drawbacks of NT screening were presented to the public. The data used in the analysis comprised material published from the beginning of 2000 until the end of 2005, such as television programmes, newspaper and magazine articles and booklets written for prospective parents. The findings reveal that the screening was mainly promoted by staff at the specialized clinic where the test was offered, and that soon after its initiation screening became widespread. In interviews, both practitioners and parents of children with Down's syndrome questioned the eugenic implications of screening and its impact on the lives of the disabled and their relatives. However, the societal response was fairly muted and a critical debate regarding the routine use of NT screening can hardly be said to have taken place. These findings alert us to the importance of promoting critical discussion of new knowledge and technology in health care, particularly when serious ethical issues are involved.

Keywords: fetal screening, public policy, ethics, governmentality, prenatal care, media, midwifery, nuchal translucency screening.

Submitted 14 August 2008, Accepted 12 May 2009

Introduction

Screening for Down's syndrome and other trisomies during the first trimester of pregnancy, or nuchal translucency (NT) screening, has become a routine part of antenatal care in many countries. In Iceland, which is the focus of this study, 84% of pregnant women in the capital area opted for screening in 2005. Statistics for 2004 and 2005 show that all fetuses identified with Down's syndrome following screening were aborted. This development raises ethical questions, both for practitioners in maternity care and for the public in general, which this paper will address.

Correspondence to:
H. Gottfredsdottir, Faculty of Nursing, University of Iceland, Eirberg, Eiriksgata 34, 101 Reykjavik, Iceland.
E-mail: helgagot@hi.is

NT screening is performed in the 11–14th week of pregnancy. It is based on an evaluation of the space between the skin and the cervical spine of the fetus as measured by ultrasound. Increased NT is associated with a heightened risk of trisomy 21, as well as other chromosomal abnormalities, major heart defects and a wide range of skeletal dysplasia and genetic syndromes (1, 2). Based on the results of screening, the probability of a chromosomal deviation can be calculated but an amniocentesis is needed for confirmation.

The introduction of screening for fetal anomalies was part of a trend in the late 20th century, when pregnancy came to be regarded as a period of risk. The widespread use of screening is an attempt to manage and reduce the risk of unwanted illness or disability. With the help of scientific knowledge and advanced technology, possible deviances can be assessed, analysed and calculated in each pregnancy. The use of such technologies tends to foster the idea

that perfection can be expected in all pregnancies. By submitting to screening, pregnant women are implicitly offered a healthy baby (3–5). Yet, although screening may be seen as a relief from unnecessary suffering, pain and limitation of freedom, there has been criticism of the idea that the decision to continue a pregnancy should be based on the assurance that no deviances have been identified. Among many religious groups, for whom preservation of and respect for human life are fundamental, the routine use of fetal screening is opposed. Proponents of disability rights have pointed out that a policy which encourages routine screening during pregnancy ignores its social implications. They maintain that such policy is based on the assumption that disability is a problem to be eliminated, rather than finding ways to improve the medical and social situation of disabled people. Their view is that focusing on collective responsibility for differences in ability in society would be more helpful (6, 7).

The main argument for the use of fetal screening is that it enhances parental choice. However, while informed, uncoerced parental choice regarding screening is usually seen as the hallmark of quality prenatal care, in reality choices may be limited. As Beck-Gernsheim points out, although screening may be framed within a liberal ideology of freedom to choose, the pressure to undertake screening is intense (8). Through the media, and possibly through interaction with family, friends and health professionals, parents-to-be may have developed a sense of responsibility for assuring the normality of their fetus (9).

Studies have found that women make decisions about first-trimester screening before their initial visit to the antenatal clinic (10). The inference is that the media are of key importance in providing prospective parents with the knowledge and understanding upon which they base their decisions regarding undergoing screening. Studies have also indicated that the media tend to portray a positive picture of new technology. In their analysis of the way in which the media take up and report on new scientific information, Petersen and Bunton (11) came to the conclusion that when reporting on the development of new scientific knowledge and technology, particularly in the area of genetic knowledge, the media tend to emphasize the positive impact of the findings on the maintenance and promotion of health, while avoiding focusing on possible downsides. A recent study of media coverage of new knowledge in relation to stem cells in the UK demonstrated that the media tended to emphasize the positive impact of the new discoveries, while at the same time revealing inadequate knowledge and failing to ask critical questions (12).

The aim of this study was to explore how first-trimester screening for Down's syndrome and a number of other anomalies came to be represented as a routine part of prenatal care in Iceland. It focused on the way in which the value and potential drawbacks of the adoption of NT screening as a routine feature of antenatal care in the first trimester were constructed in the media, policy documents, leaflets and handouts written for prospective parents in Iceland. We developed the study as a genealogy which we will be described later. It allowed us to study how different discourses around screening developed within particular contexts or social practices. In the next section we will describe the theoretical background informing the study and then we outline the context of prenatal care in Iceland.

Theoretical background

A number of authors have used Foucault's delineation of the way in which power operates in modern societies to understand the nature and easy spread of screening in prenatal care (13–15). One of his main ideas is that power is present in all social relations (16). As Foucault (17) explained, since the 18th century the authorities have increasingly taken on the task of managing life by enhancing the health, welfare, prosperity and happiness of the population as a whole. A system developed where knowledge about strategies to enhance life was of key importance. This knowledge, or forms of rationalities, then come to manifest themselves as true and proper ways of acting and thinking (15). Foucault coined the term governmentality to describe the strategies and techniques authorities employ to influence conduct in this way (18, 19). Based on his theorization of the power/knowledge relationship (20), 'the study of governmentality looks at the production of truth and knowledge and its impact on conduct or regimes of practices' (21: 18). Knowledge, developed through science, is reflected in different discourses that have come to be regarded as representing the right ways of acting and thinking. Foucault defined discourse as 'practices that systematically form the objects of which they speak' (22: 49). As Mills pointed out in explaining his understanding of discourse:

> In this sense, a discourse is something which produces something else (an utterance, a concept, an effect), rather than something which exists in and off itself and which can be analysed in isolation. A discursive structure can be detected because of the systematicity of the ideas, opinions, concepts, ways of thinking and behaving which are formed within a particular context, and because of the effects of those ways of thinking and behaving (23: 17).

As Foucault pointed out, individuals in modern liberal societies are not forced or coerced to behave in a certain way. Rather, they are governed through their freedom. By voluntary self-discipline we behave in the 'correct' way (16). Those who deviate from the norm and do not adopt expected behaviour are, on the other hand, said to be at risk.

Based on the above understanding of the operation of power, Tremain (13) described how prenatal screening, based on scientific knowledge about a normal fetus and

possible deviances from the norm, constitute prenatal impairment. Following her argument it may be said that screening methods contribute to the naturalization and materialization of impairment. Based on findings from the screening, the risk of deviances from the norm is calculated and presented to prospective parents for consideration.

The Icelandic context

As in the other Nordic countries, public policy in Iceland has been aimed at promoting social equality among individuals. Consequently, health care has been mostly free of charge and readily accessible. Icelanders have come to expect high-quality services and access to the newest technology. Assisted reproduction has become relatively common in the country, but in contrast to the other Nordic countries the rate of abortion has seen an increase after abortion law was liberalized in the 1970s (24, 25). Antenatal care is organized within the primary healthcare system (26). Midwives, in cooperation with GPs and obstetricians if necessary, attend almost all pregnant women throughout pregnancy, although it should be noted that before signing up for antenatal care many women have had their pregnancy confirmed by their obstetrician at a private clinic.

In 1999, NT screening was introduced by the staff at the Prenatal Diagnosis Unit at Landspitali University Hospital as a new screening method for women over 35 of age, in order to reduce the use of amniocentesis, which carries a risk of miscarriage. In its first year of use, 10.6% of pregnant women in Iceland underwent NT screening, while in 2002 the proportion was 30%. At the same time, the number of amniocentesis tests performed dropped from 497 in 1998 to 158 in 2002 (27). By 2005, NT screening had become established practice in Iceland; about 84.5% of prospective mothers in the capital area, and 66.5% of all pregnant women in the country, had the test (28). During this time, no official policy or recommendations regarding the use of this screening existed, but in the autumn of 2006 a National Committee appointed by the Director of Health formulated new guidelines for prenatal screening, which were posted on the website of the Director of Health for review.

At the Prenatal Diagnosis Unit at Landspitali University Hospital it was felt that women in general, and not only those at risk, showed a keen interest in screening. This view was, among other things, based on a survey conducted by the hospital staff in 2001, where women, following their 19–20th week scan, were asked about their views on first-trimester screening. Of the 182 women who responded to a questionnaire, 96% said that they were interested in NT screening and would accept the test if it were offered (29).

Methods

A number of approaches to discourse analysis have been developed, of which genealogy seemed the most helpful for the present study. Foucault (17) suggested genealogy as a fruitful means of studying how new forms of practice emerge historically. He outlined the approach further in his lectures at the Collège de France (30). Through the study of buried and disqualified knowledge, genealogies make struggles and oppositions visible. They highlight complexities and local knowledges that have been silenced by the disciplinary power of scientific discourses. The genealogist is interested in knowing how things happen and develop, for example how certain practices become norms. Studying the genealogy of the emergence of fetal screening as a routine part of antenatal care in Iceland means studying the 'historicity of social conduct via its own particular set of ethical and political concerns 'grounded' in the present' (21: 41). By studying the different discourses on fetal screening that developed among different social groups, we have tried to uncover the sometimes hidden and multi-dimensional operations of power that influence the decision to offer and undergo fetal screening. Our aim was to provide a critical reading of the material under consideration, rather than a detailed description.

The texts generated for this study were published and broadcast materials that addressed fetal screening in Iceland, such as newspaper articles, news reports, editorials, feature articles in magazines and radio and television programmes, published or broadcast in the period from the beginning of 2000 until the end of 2005. In addition, policy documents, such as recommendations from the Directorate of Health and information brochures for prospective parents, were analysed. It should be noted that the media in Iceland comprise a relatively small number of key players. Although there were three nationally distributed newspapers in circulation at the time of the study, one of them, Morgunbladid, was unquestionably dominant when it came to addressing issues relating to health. The two television channels which carry news and news-related programmes, i.e. RUV National Broadcasting and one independent channel, are included in the evaluation, as is one radio station, also operated by RUV.

In all, 53 items were found addressing the issue of fetal screening during the period under consideration. This material was critically analysed, focusing on ideas, understandings and practices regarding fetal screening as reflected in the discourses identified. The analysis was informed by the theoretical literature on fetal screening and by the context of prenatal care in Iceland. Each text item was closely read for its portrayal of screening. Content categories were formed and patterns of discourses were identified. The questions that guided our analysis were: How was the discussion presented? Who contributed to the debate and what was their argumentation? Table 1 gives an overview of the different actors who contributed to the discussion on fetal screening and the content of the discussion. All the items were categorized after they had

Type	Agent	Quantity
TV programmes/radio	Interview with professionals (doctors/midwife) others[a]	10
	Programmes addressing issues related to children with Down's syndrome	2
Newspapers (articles/editorials)	Doctors	21
	Midwives	3
	Priests	4
	Parents of children with Down's syndrome	2
	Politicians	1
Magazines	Parents of children with Down's syndrome	2
Handouts/booklets		8

[a]Politicians, Director of Health, advocates of disabled people, etc.

Table 1 Overview of media items and different actors contributing to the discussion

been carefully evaluated and assigned to thematic focus of the discourses. Examples from the data were used to clarify and support the thematic analysis.

Results

The results were organized based on three different discourses identified in the data. The first discourse reflects the view that *NT screening is a technological advance* that will lead to largely positive results for the public. This view was mainly represented by the staff working at the Prenatal Diagnosis Unit. We then follow the discussion, highlighting oppositions and resistance and the second discourse *Screening questioned* reflects the views of those who question the ethics of screening. The third discourse *Technical or ethical issue?* Further highlights the dilemmas entailed by the routine use of screening.

NT presented as a technological advance

NT screening was first presented to the public as a new method of fetal screening in one of Iceland's main daily newspapers, Morgunbladid, in August 2000. In an interview with the paper one of the obstetricians at the Prenatal Diagnosis Unit described a new technology that would reduce the need for amniocentesis, a practice which carries considerable risk of miscarrying a healthy fetus. The article explained that women over 35 years or believed to have a heightened risk of carrying fetuses with Down's syndrome, had been offered the option of amniocentesis for over 20 years, but were now offered NT screening. The obstetrician explained that this was a new technology developed in the UK, which enables doctors to diagnose abnormal pregnancies earlier than before. The technology will provide information about possible genetic and heart defects as early as the 11–13th week of gestation (rather than the 19th, as the current ultrasound screening does). The article proceeded to describe the test and its advantages over amniocentesis. The technology was already in use and, according to the obstetrician, had proved successful: 'We have used it for over a year, but only in the case of this particular group [women over 35]. We intend to make the test available to all pregnant women, of all ages. There is a great deal of interest in the screening among pregnant women.' The obstetrician explained that professionals at the clinic had undergone special training abroad to learn how to perform the procedure, although a lack of facilities had prevented universal utilization of the screening: 'The reason we have not been able to offer NT screening to all expectant mothers is that the accommodation for the fetal screening department is too small' (Morgunbladid, August 29, 2000).

In the article, routine screening at an early stage of pregnancy was presented as a matter of technological progress, devoid of ethical considerations. This publication did not provoke public debate on the consequences of NT as a routine screening procedure.

A further argument in favour of NT screening appeared in the same newspaper in 2003. In a news story, based on the annual report on births in Iceland, entitled 'Most pregnant women undergo NT screening' (Morgunbladid, September 24, 2003), it was claimed that the use of NT screening had led to a reduction in perinatal mortality:

> About two-thirds of all pregnant women in the capital and in the northeast of Iceland underwent NT screening last year. The report of Landspitali University Hospital and the Children's Hospital on births last year states that the decline in the number of stillbirths is linked to NT screening. So-called perinatal mortality has never been lower than in the last year, when there were 12 stillbirths, and six infants who died in the first week after birth (Morgunbladid, September 24, 2003).

In this article the routine use of NT screening was related to improved clinical outcome in perinatal mortality. It is not unlikely that this report may have encouraged parents to undergo screening.

Screening questioned

Fetal screening was brought up in the media in relation to news coverage from a symposium organized by the

Icelandic Medical Association in collaboration with the Icelandic Midwives' Association in January 2001. The symposium addressed the ethics of early fetal screening and was prominently reported in the middle section of Morgunbladid. Ten speakers addressed the symposium. The first speaker, a professor of general practice who opened the symposium, pointed out that the motivation for holding the symposium had arisen from the Association of Obstetricians' suggestion to the Directorate of Health that NT screening should be offered to all pregnant women in Iceland. He went on to point out that this was not only an issue for healthcare workers or obstetricians, but an interdisciplinary issue that called for debate. He discussed the possible eugenic implications of the test, stating that in some countries a decision may be made to abort a fetus because it is of the wrong sex or has a minor physical defect such as a cleft lip, and that we must decide where the line should be drawn. A general practitioner made the point that the aim of fetal screening, i.e. to detect deviances so that they can be eliminated, is contrary to the medical principle of preserving life. An ethicist and a midwife participating in the symposium discussed the impact of screening on parents, both in terms of stress, which may be severe when results call for further investigation, and also in relation to the difficult decision facing them after the discovery of a fetal defect. They both spoke of the need for comprehensive support, the careful provision of information, and respect for parental decisions. It should be noted that, although some of the speakers championed the value of screening, the journalist chose to quote those who suggested caution in its routine inclusion in prenatal care.

In June of 2001 the Icelandic Midwives' Association issued a statement in Morgunbladid advising caution in the use of NT for early screening. The midwives pointed out the need for a critical debate to take place before the decision was made to adopt NT as routine screening, and stressed that an adequate counselling service must be made available to all parents who wished to seek advice.

Although the complex ethical issues surrounding the use of fetal screening were brought up at the above-mentioned symposium and taken up in the media, this did not lead to any generalized public debate. Later that year the papers presented at the symposium were published in a supplement to the Icelandic medical journal (Læknabladid supplement 42, 2001). Following the publication, one of the authors, a physician, was interviewed in a news article in Morgunbladid (Morgunbladid, October 25, 2001). Similarly, RUV state television station broadcast a panel discussion in which different views were presented.

Apart from the above items, very little public discussion took place during this period, and nothing can be found at the policy level. In interviews in magazines, the parents of children with Down's syndrome criticized the way in which the discussion had changed people's perception of particular conditions. From their perspective it was unjustified to lump Down's syndrome together with other trisomies, thus implying that it is a major abnormality.

Screening for fetal anomalies was also brought up within the Lutheran state church. A member of the clergy wrote an article in Morgunbladid warning of eugenic tendencies in the use of screening (Morgunbladid, May 18, 2001). The then newly elected bishop of Iceland published a declaration in the form of a Pastoral Letter in 2001. In the letter he argued that routine fetal screening might lead to selective abortion, which in his view was contrary to Christian beliefs, with very few exceptions. As the bishop explained:

> This technology also makes it possible to weed out 'unwanted' individuals at the fetal stage, and prevent them from living; individuals who would possibly be a burden on society. We must pay heed to this and ask: Do we want the kind of society where only the ideal is allowed to live? Where only the 'physically sound' and 'healthy' are given life? And are we ready to face the next step? (Pastoral Letter, 2001: 183).

Here, the bishop associated the use of fetal screening with eugenic implications, to which he clearly objected. At the time of the Pastoral Letter's publication, however, the bishop's views on screening did not provoke any public debate in the country, nor was there any impact on the introduction of screening as a routine procedure in antenatal care in Iceland.

Although a handful of professionals publicly objected to the routine use of screening, their criticism was not taken up in the media for any in-depth analysis and critical scrutiny. An interview with a professor of general practice, entitled 'Prevention gone too far,' highlighted the possible downsides of screening. He pointed to the figures on the risk of miscarrying a healthy fetus following amniocentesis as a result of first-trimester screening:

> Historically, for every two fetuses that are diagnosed with Down's syndrome, one healthy fetus is sacrificed. This applies to Iceland just as it does to other Western countries where there is increased emphasis on prevention … What we need is education, so that people can base their decisions on information and then make their choices (Fréttabladid, November 12, 2003).

A few days later an interview was published under the heading 'Dispute over prevention', where a chief obstetrician stated that the figures quoted above were inaccurate, and claimed that for every six fetuses diagnosed with a chromosomal defect, one healthy fetus is lost.

A technical or an ethical issue?

Apart from the public discussion on fetal screening that took place in relation to the symposium in 2001, as described above, the routine use of NT screening was hardly mentioned publicly until 2004. In an interview with a theology student that appeared in Morgunbladid under the heading

'Ethical debate far behind the technology' (Morgunbladid, January 4, 2004), the ethical issues concerning screening were raised. The student had recently completed a thesis in which she addressed this topic, and the newspaper was interested in knowing more about her arguments. As she observed, there had been no public discussion in Iceland of the ethical issues associated with screening during pregnancy. She also pointed out that the technology already offers a choice as to which fetuses should be allowed to live, and will do so to an even greater extent in the future; her point was that this should raise ethical questions.

In response to the interview with the theology student, a senior obstetrician from the Prenatal Diagnosis Unit at Landspitali University Hospital wrote an article to 'provide information on fetal screening and fetal diagnosis as currently practised.' In the article she presented the view that NT screening should be part of routine prenatal care and thus made available free of charge to all prospective parents, adding that:

> In my opinion, it is the undisputed right of prospective parents to choose or reject fetal screening, since it is they who will ultimately care for their child. Parents' situations vary, and some are better equipped than others to deal with the difficulties that arise from the serious illness or disability of their children. … It is not for me or others to decide [for them] (Morgunbladid, January 11, 2004).

A few days later an interview with the father of a child with Down's syndrome was published in the same paper, entitled 'Should children be commodities?' (Morgunbladid, January 8, 2004). In this interview he made the point that parents of children with Down's syndrome had already expressed their views on routine screening for Down's syndrome several times in magazine and television interviews since 2000. He argued that rather than seeing children with Down's syndrome as a burden, parents see them as a gift, just like any other children. He further pointed out that with the right social support they can live happy and fruitful lives. In the interview, the father talked of a film that was to be shown on national television about the reality of the lives of children with Down's syndrome. The idea for the film was suggested by a state television employee who had presented a programme discussing the implications of the routine use of NT screening in 2001.

Once again, critical issues had been brought up regarding the routine use of fetal screening, but did not provoke a public debate on its justification. Although two-thirds of all pregnant women in Iceland underwent NT screening at the time, no official policy had been introduced on its use, and no guidelines were available on how the test should be presented to women. In a news item in Morgunbladid the Minister of Health was asked to comment on the proposal to make screening a routine feature of prenatal care (Morgunbladid, January 14, 2004). He explained that it was a delicate matter and that a number of issues had to be considered, and that he hoped a decision whether or not to include NT screening in prenatal care would be made shortly.

Again fetal screening emerged in the media in 2005. The annual report from 2005 on births in Iceland in 2004 reveals that all fetuses diagnosed with Down's syndrome that year had been aborted (23). These figures provoked some public discussion about the implications of routine screening. The issue of parents' informed choice dominated the discussion, both among healthcare professionals and spokespeople for the disabled, with a number of those participating in the discussion warning of the possible consequences of routine screening. A mother of a Down's syndrome child, interviewed on a television programme, said:

> I did not have to face these choices. This situation was not yet possible when I had my child. My perspective reflects my experience. But what impression does it give people if all fetuses diagnosed with Down's syndrome are aborted? For us, the parents of these children, it raises the question … is society departing from the basic principle of diagnosing defects which are so serious that it is not worth living with them? (Kastljós, August 11, 2005)

The matter was also discussed among members of the National Federation for People with Disabilities, Throskahjálp, and a statement was posted on the Federation's website. In an interview on state television the chair of the Federation said:

> It is deplorable that every [fetus] diagnosed [with Down's syndrome] is aborted in this country. Insufficient research has been done on the individuals who live with the defect or the views of their parents. This information has to be available before a decision is made (Chair of Throskahjálp, August, 12, 2005).

These quotations encapsulate the views of parents and spokespeople for the disabled, who express the fear that routine screening will become the norm, with unforeseen consequences. The next day a representative of the Directorate of Health, interviewed on national radio, announced that the Directorate had decided to endorse the use of NT screening for those parents who wished to undergo the procedure. The rationale behind the decision was that, since the technique is available and has been implemented, screening should continue to be carried out as hitherto. However, in order to emphasize it as a choice, people would have to pay for the screening, unlike other prenatal care.

Discussion and conclusion

This study has described how NT screening was introduced and promoted as an integral part of antenatal care in the media in Iceland. In newspaper interviews obstetricians

emphasized that the test provided prospective parents with increased opportunities to make informed choices regarding the continuation or termination of pregnancy. This view is consistent with the arguments made by geneticists, who identify enhanced reproductive choices as the main benefits of screening (15). The possible downsides of screening, such as the influence on the lives of disabled people, the eugenic implications, risk of miscarriage, the psychological impact of the uncertainty involved in screening (31), and the difficult decisions that sometimes need to be made, were, on the other hand, rarely brought up. Noticeable exceptions to this were views of parents of children with Down's syndrome and a few healthcare workers, who raised critical questions about the routine use of screening. Although their arguments were given space in the media, the views they represented did not seem to have the impact needed at the policy level, or to start a critical debate among the public. Health authorities were slow to develop guidelines regarding screening and did not initiate or encourage public discussion on the routine use of screening.

Soon after its introduction, the uptake of NT screening in Iceland became widespread. Beck-Gernsheim (8) referred to the ready acceptance of knowledge and technology, such as screening for genetic abnormalities, as voluntary compulsion. Parents are not forced to comply with any rule or law, but behave in a suggested way nonetheless. This can be understood as governmentality, defined by Foucault (18, 19). Through their free choice parents make the 'right' decision, or to use Tremain's (32) phrase: 'For power functions best when it enables subjects to act in order to constrain them' (p. 46). As Beck-Gernsheim pointed out, we have come to value health above all else, both for ourselves and for our children. During pregnancy, women become socialized into certain roles and behaviour rituals. Prenatal screening is designed to benefit women by giving them more control over their own bodies and protecting them from risk. The assumption that these procedures generate positive feelings in pregnant women has, however, rarely been questioned (33, 34). Instead, the sense of optimism that is implicit in the development of new technologies seems to act as a force for securing acceptance of new procedures (8), and this has arguably been predominant in the development in Iceland.

As Helén (14, 35) points out, the way in which screening is performed is based on a differentiation between healthcare workers' technical responsibility and the ethical responsibility of the prospective parents. The healthcare worker is responsible for providing information regarding the risk of deviances, based on the results from the tests, while the ethical decision on the continuation or termination of pregnancy is left to the parents. The ethical dilemmas which may arise have thus been individualized, left to the parents who must then also shoulder the responsibility for their decision. This view was clearly reflected in the discussion about screening in Iceland. Since the parents have to take care of disabled children, the decision on the continuation of the pregnancy must be theirs. In the current ethos, there seems to be little collective responsibility for the potential implications of screening for the identity of the disabled and societal views toward them. Fetal screening is perceived as a private matter, and neither a public-health issue nor a political issue to be dealt with as such. It may also be speculated that the uncritical debate may reflect the limited cultural objection to selective abortion in Iceland and the positive view towards the use of reproductive technology.

Screening has been taken up in a number of Western countries, although more critical debate may have taken place than in Iceland. A recent study of the initiation of screening in France revealed considerable controversy on the negative impact of screening, although it has become widely accepted (36). In that case, screening was introduced and encouraged by biomedical researchers, while front-line health practitioners and prospective parents were prevented from full participation in decision-making. What the Icelandic and French examples seem to demonstrate is the need for an open discussion on the use of new technologies, particularly when serious ethical considerations are involved.

A number of authors have called for a critical discussion regarding the use of screening in pregnancy (37). The findings of this study certainly support that call, and highlight the unreflective and unethical way in which screening may be taken up. It seems imperative to initiate a public discussion on the extent to which new technologies will or should be used in clinical practice, and how they may impact the lives of particular members of society, such as the disabled.

Acknowledgements

This study was supported by grants from the Research Fund at the University of Iceland, The Icelandic Science Foundation and from the Icelandic Midwifery Association.

Author contributions

This paper is a cooperative work, with equal contribution of both authors. The design of the paper was outlined by both authors, the data were collected by the first author, the data was analysed by both authors and the writing was done in cooperation.

Funding

This study was supported by grants from the Research Fund at the University of Iceland, The Icelandic Science Foundation and from the Icelandic Midwifery Association.

References

1 Nicolaides KH, Heath V, Liao AW. The 11–14 week scan. *Baillieres Best Pract Res Clin Obstet Gynaecol* 2000; 14: 581–94.
2 Spencer K, Spencer CE, Power M, Moakes A, Nicolaides KH. One stop clinic for assessment of risk for fetal anomalies: a report of the first year of prospective screening for chromosomal anomalies in the first trimester. *BJOG* 2000; 107: 1271–5.
3 Zechmeister I. Foetal images: the power of visual technology in antenatal care and the implications for women's reproductive freedom. *Health Care Anal* 2001; 9: 387–400.
4 Rapp R. *Testing Women, Testing the Fetus*. 2000, Routledge, New York.
5 Rothman BK. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. 1986, Viking Press, New York.
6 Shakespeare T. Choices and rights: eugenics, genetics and disability equality. *Disability & Soc* 1998; 13: 665–81.
7 Parens E, Asch A. *Prenatal Testing and Disability Rights*. 2000, Georgetown University Press, Washington, DC.
8 Beck-Gernsheim E. Health and responsibility: From social change to technological change and vice versa. In *The Risk Society and Beyond* (Adam B, Beck U, Van Loon J, eds.), 2002, Sage, London, 122–35.
9 Williams C, Sandall J, Lewando-Hundt G, Heyman B, Spencer K, Grellier R. Women as moral pioneers? Experiences of first trimester antenatal screening. *Soc Sci Med* 2005; 61: 1983–92.
10 Pilnick AM, Fraser DM, James DK. Presenting and discussing nuchal translucency screening for fetal abnormality in the UK. *Midwifery* 2004; 20: 82–93.
11 Petersen A, Bunton R. *The New Genetics and the Public's Health*. 2002, Routledge, London.
12 Kitzinger J, Williams C. Forecasting science futures: legitimising hope and calming fears in the embryo stem cell debate. *Soc Sci Med* 2005; 61: 731–40.
13 Tremain S. *Foucault and the Government of Disability*. 2005, University of Michigan Press, Ann Arbor.
14 Helén I. Techniques over life: risk, ethics and the existential conditions in high-tech antenatal care. *Econ Soc* 2004; 33: 28–51.
15 Koch L, Svendsen MN. Providing solutions defining problems: the imperative of disease prevention in genetic counselling. *Soc Sci Med* 2005; 60: 823–32.
16 Foucault M. Governmentality. In *The Foucault Effect: Studies in Governmentality* (Burchell G, Gordon C, Miller P, eds), 1991, University of Chicago Press, Chicago, 87–104.
17 Foucault M. Nietzsche, genealogy, history. In *Language, Countermemory, Practice: Selected Essays and Interviews* (Bouchard DF, ed.), 1977, Cornell University Press, Ithaca, 139–64.
18 Rose N. Government, authority and expertise in advanced liberalism. *Econ Soc* 1993; 22: 283–99.
19 Rose N. *Powers of Freedom: Reframing Political Thought*. 1999, Cambridge University Press, Cambridge.
20 Foucault M. *Power/Knowledge: Selected Interviews and Other Writings 1972–1977*. 1980, Pantheon Books, New York.
21 Dean M. *Governmentality: Power and Rule in Modern Society*. 1999, Sage, London.
22 Foucault M. *The Archeology of Knowledge* (Translated by Sheridan Smith). 1974, Tavistock, London.
23 Mills S. *Discourse*. 1997, Routledge, London.
24 Geirsson RT, Gardarsdottir G, Palsson G, Bjarnadottir RI, Hardardottir H. *Skýrsla frá fæðingaskráningunni fyrir árið 2004 [Registration of Births in Iceland in 2003]*. 2005, Landspitali-háskólasjúkrahús, Reykjavik.
25 Knudsen LB, Gissler M, Bender SS, Hedberg C, Ollendorff U, Sundstrom K, Totlandsdal K, Vilhjalmsdottir S. Induced abortion in the Nordic countries: special emphasis on young women. *Acta Obstet Gynecol Scand* 2003; 82: 257–68.
26 Reglugerðir < Lög og reglugerðir < Heilbrigðisráðuneyti (2007) http://www.heilbrigdisraduneyti.is/log-og-reglugerdir/reglugerdir/nr/787
27 Geirsson RT, Gardarsdottir G, Palsson G, Bjarnadottir RI, Hardardottir H. *Skýrsla frá fæðingaskráningunni fyrir árið 2002 [Registration of Births in Iceland in 2002]*. 2003, Landspitali-háskólasjúkrahús, Reykjavik.
28 Geirsson RT, Gardarsdottir G, Palsson G, Bjarnadottir RI, Hardardottir H. *Skýrsla frá fæðingaskráningunni fyrir árið 2005 [Registration of Births in Iceland in 2005]*. 2006, Landspitali-háskólasjúkrahús, Reykjavik.
29 Haraldsdóttir K. Áhugi kvenna á ómskoðun, upplýst val og ráðgjöf [Women's interest in ultrasound, informed choice and counselling]. *Laeknabladid* 2001; 87: 44–6.
30 Foucault M. *Society Must be Defended: Lectures at the Collège De France 1975–1976*. 2003, Picador, New York.
31 Getz L, Kirkengen AL. Ultrasound screening in pregnancy: advancing technology, soft markers for fetal chromosomal aberrations, and unacknowledged ethical dilemmas. *Soc Sci Med* 2003; 56: 2045–75.
32 Tremain S. Reproductive freedom, self-regulation, and the government of impairment in utero. *Hypatia* 2006; 21: 35–53.
33 Lippman A. Embodied knowledge and making sense of prenatal diagnosis. *J Genet Couns* 1999; 8: 255–74.
34 Eurenius K, Axelsson O, Gallstedt-Fransson I, Sjoden PO. Perception of information, expectations and experiences among women and their partners attending a second-trimester routine ultrasound scan. *Ultrasound Obstet Gynecol* 1997; 9: 86–90.
35 Helén I. Risk and anxiety: Polyvalence of ethics in the high-tech antenatal care. *Crit Publ Health* 2002; 12: 119–36.
36 Vassy C. 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: 2041–51.
37 Williams C. Dilemmas in fetal medicine: premature application of technology or responding to women's choice? *Social Health Illn* 2006; 28: 1–20.

Paper II.

Midwifery (▮▮▮▮) ▮, ▮▮▮–▮▮▮

ELSEVIER

midwifery

www.elsevier.com/locate/midw

'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening

Helga Gottfredsdóttir, BSc, MA, RM, RN (Assistant Professor)[a,*], Jane Sandall, BSc, MSc, PhD, RM, RN, HV (Professor)[b], Kristín Björnsdóttir, BSc, MSc, PhD, RN (Professor)[c]

[a]*Department of Midwifery, Faculty of Nursing, University of Iceland, Reykjavik, Iceland*
[b]*Health and Social Care Division, King's College, London, UK*
[c]*Department of Nursing, Faculty of Nursing, University of Iceland, Reykjavik, Iceland*
*Corresponding author. *E-mail address:* helgagot@hi.is (H. Gottfredsdóttir).

Received 13 July 2007; received in revised form 14 November 2007; accepted 20 December 2007

Abstract

Background: nuchal translucency (NT) screening, mainly for Down's syndrome, in the first trimester of pregnancy is becoming an established practice in many countries. However, very little is known about parents' knowledge and beliefs prior to undergoing screening. Such information is essential to form guidelines regarding informed decision-making.

Objectives: to explore the influences on prospective parents' decision-making in relation to NT screening in early pregnancy, and to gain insight into how the views of prospective mothers and fathers towards the benefits and implications of screening may differ.

Design: a qualitative study using framework analysis based on a grounded theory approach.

Participants: 10 couples, who had decided to have NT screening, were recruited from four community health centres in Iceland. All pregnancies were defined as 'low risk' for fetal anomaly.

Data collection: semi-structured interviews were conducted separately with each prospective mother and father at 7–11 weeks and again at 20–24 weeks of gestation. In total, 40 interviews were conducted.

Findings: the majority of prospective mothers in this study had already decided to accept NT screening before they entered the public antenatal care system. The decision to accept screening seemed to lie with the prospective mother and had hardly been discussed by the couple. Differences between prospective mothers and fathers were observed in relation to the expression of expectations towards the benefits of screening and the perception of disability, which is of interest in the context of information provided to prospective parents.

Conclusions and implications: the findings from this study are of interest to clinicians and policy makers forming future guidelines for antenatal care both in Iceland and further afield. It highlights the need for information for prospective parents to be in the public domain prior to their contact with maternity services. Additionally, findings add to knowledge of prospective fathers in early pregnancy regarding how their perceptions of disability may contribute to the couple's decision to accept screening.

Keywords Pregnancy; Nuchal translucency screening; Decision-making; Fathers; Down's syndrome

0266-6138/$ - see front matter © 2008 Elsevier Ltd. All rights reserved.
doi:10.1016/j.midw.2007.12.004

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

Introduction

Nuchal translucency (NT) screening has been introduced in several countries for the detection of Down's syndrome, other trisomies, and a wide range of skeletal dysplasias and genetic syndromes (Nicholaides et al., 2000). There is some evidence that this test provides prospective parents with earlier and more accurate information regarding the risk of a baby being born with Down's syndrome and other fetal anomalies than previous screening procedures (Nicholaides, 2004). However, implementation of screening in the first trimester presents ethical issues that need to be considered. It has also been argued that the existence of such technologies places a moral responsibility on prospective parents, particularly mothers, to comply with screening for fetal anomalies (Williams et al., 2005). Therefore, comprehensive and timely consultation, and availability of good information and support is essential.

Studies have shown that when new screening technologies and tests become available within the health-care system, there is a tendency to incorporate them rapidly as routine practice. For example, Press and Browner's (1997) study on the uptake of maternal serum alpha-fetoprotein screening in California in the 1990s indicated that, when provided within the antenatal care system to women at low risk, women tend to experience the offered screening as a recommended part of routine care, which they believe is essential. Making decisions in health care is not familiar to most women, and studies show that their view (logically) is that whatever is offered must be the best option (Porter and Macintyre, 1984; van Teijlingen et al., 2003). Brown and Webster (2004) have demonstrated that public expectations can act as a driving force in the implementation and funding of new procedures, depending on whether technologies are relatively established or newly emergent. In relation to this, involvement of key actors such as scientists and health professionals in the development and implementation of new screening and testing technologies provides authoritative endorsement to technologies that provide people with the hope and promise of a healthy baby if they submit to medical surveillance. As such, providers and managers carry a heavy responsibility to ensure that the screening services they provide are ethical, and that prospective parents have access to information in a timely and appropriate manner and do not feel subject to undue pressure.

Feminist critique of reproductive technologies has highlighted how the culture and institutionalisation of hospitals make women feel vulnerable and their behaviour and choices restricted by rigid rules (Davis-Floyd, 1994; Zechmeister, 2001). In the context of ultrasound, the issue has been raised regarding whether women are complying rather than making a choice (Nicol, 2007), and Lalor and Devane (2007) found that the majority of women who underwent second trimester routine ultrasound in Ireland had expectations that exceeded the purpose and technological capacity of the ultrasound examination. Although their study was performed in a context that does not support termination of pregnancy, the majority of participating women thought that the scan would provide them with information that the baby was healthy. Other studies have shown that the high acceptance of ultrasound relates to the need for reassurance and a confirmation of a healthy baby (Santalahti et al., 1998; Ekelin et al., 2004). Williams et al. (2005) raised the issue of the increasing responsibility that women might encounter as a consequence of being offered screening technology. This seems to be reflected in societies where screening and tests are available, and women who decline screening and give birth to children with genetic disabilities are seen to be responsible for their birth (Marteau and Drake, 1995).

Little research has focused on the views of prospective parents in very early pregnancy. It has been found that although people have limited knowledge of prenatal screening, both before conception and during pregnancy (Heyman et al., 2006; Skirton et al., 2007), there is an indication that women have already decided whether to have screening before their first antenatal visit (Pilnik et al., 2004; Heyman et al., 2006). Studies of women later in pregnancy have shown that, in general, women are in favour of screening, but have limited knowledge of the condition being screened for and the meaning of the results (Michie et al., 2003; Dormandy et al., 2006).

In this respect, it is of interest to consider the interplay between the couple in the first trimester of pregnancy, and what influences them in their decision-making process. Some studies have indicated that the majority of women perceive their partner to have a strong influence on their decision (Jacques et al., 2004), although few studies have explored decision-making regarding fetal screening from the prospective fathers' perspective. Locock and Alexander (2005) pointed out that as early screening becomes a standard component of antenatal care, men may be left out of the discussion. They stated that although efforts were made to involve men in the routine scan, their ability to take part fully was sometimes constrained.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

In situations when the screening identified potential problems, some of the men saw themselves as bystanders and their individual feelings overlooked. In other cases, men became the main channel of communication with the professional, acting as protector of their partner in a difficult situation. Other studies have argued that the emphasis on men's role as the main support person for the woman during pregnancy ignores their psychosocial aspects and emotions (Beardshaw, 2001; Schott, 2002; Gottfredsdóttir, 2005).

In a review of studies in the context of reproduction, Becker (1996) argued that biomedical research and programmes in family planning have traditionally focused on women. One could speculate that this could be translated to pregnancy care in general. The few studies that have been conducted on couple's decision-making in terms of fetal testing indicate disagreement on the issue, with more men in favour of accepting amniocentesis (Sorenson and Wertz, 1986; Kolker and Burke, 1994; Browner and Preloran, 1999).

The question arises whether these differences are maintained when it comes to perceptions of disability, which may affect men's approach to decision-making around screening; an issue that also appears to be under-explored. Studies of fathers' perspectives of the effects of having a child with Down's syndrome have reported that the greatest concern expressed by fathers is the long-term provision for their children (Hornby, 1995; Trute, 1995). Sullivan (2002) concluded, from his study on gender differences in coping strategies of parents of children with Down's syndrome, that men demonstrate no more negative traits, such as denial, than women, and record a high level of acceptance, similar to women. Regarding these studies, it is of relevance that they were conducted among fathers who already had children with Down's syndrome.

In summary, few studies have accessed prospective mothers and fathers in early pregnancy before their first formal contact with health providers, and followed couples through their pregnancy journey. This paper uses the introduction and wide uptake of NT screening in Iceland as an opportunity to explore decisions around the acceptance of fetal screening among prospective parents. It is hoped that the findings can be used to develop policies and practice guidelines in this area.

The context of antenatal care in Iceland

Iceland is one of the Nordic countries and shares their tradition of providing comprehensive welfare services at no or very low cost. Perinatal mortality in Iceland is now among the lowest in the world, while the birth rate has been the highest in Europe (Ólafsson, 1998; Bjarnadóttir, 2003). Icelanders have come to expect high-quality reproductive services based on the newest technology. Assisted reproduction is relatively common, while the rate of induced abortion in Iceland has seen an increase compared with countries with comparable legislation (Knudsen et al., 2003; Nordic Committee on Bioethics, 2005).

All women in Iceland have access to antenatal care, which from September 2007 has involved regular visits to midwives at community health-care centres and general practitioners (GPs) and obstetricians if needed. A new policy was passed on the operation of health-care centres which assumes that all women have access to antenatal care (Regulation on Health Care Centres, 2007). However, before signing up for antenatal care in the public system, especially in Reykjavik, the capital of Iceland, the majority of women (58%) have their pregnancy confirmed by a private obstetrician, where their partners are less likely to accompany them (unpublished data, collected in cooperation with the Prenatal Diagnostic Unit at Landspitali University Hospital). That appointment has not been defined as part of the antenatal care programme and usually takes place before 12 weeks of gestation.

NT screening was introduced in Iceland in 1999 for women over 35 years of age, with the aim of decreasing the use of unnecessary amniocentesis. NT screening gained popularity within a few years and is now offered to all women. In 2006, uptake was 90% in Reykjavik, where access to screening clinics is easy. Thus, it can be argued that this screening technology became part of routine antenatal care before official policy or clinical guidelines were published (Gottfredsdóttir and Björnsdóttir, in review).

In 2006, draft antenatal guidelines were introduced in Iceland, which were adapted from the UK National Institute for Clinical Excellence guidelines (Directorate of Health, 2006). The draft highlights that the decision to undergo screening should be an informed choice, and underlines the responsibility of the health professional providing care to the woman to explain all available options in a non-directive way and, furthermore, encourages the first antenatal visit to the traditional public health system before 12 weeks of gestation.

In general, it is not known what influences the decision-making process in terms of screening, and the experience of prospective parents is under-explored in Iceland. As the use of fetal screening

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

has increased and can be expected to increase further, the issue of how to give information most effectively to assist men and women to make the decision they want is of importance. This paper attempts to fill some gaps in knowledge by putting forward two research questions:

(1) What influences prospective parents to accept NT screening in very early pregnancy?
(2) How do prospective mothers and fathers experience decision-making?

Methods

This paper reports one part of a larger study addressing prospective parents' decision-making concerning the use of NT screening in the first trimester of pregnancy. A qualitative approach was chosen to further understanding of the process and the meaning of interventions for those receiving them (Green and Thorogood, 2004). The findings presented in this paper are drawn from data collected from March to September 2006, using semi-structured interviews with 10 couples. Each prospective mother and father was interviewed separately at 7–11 weeks and again at 20–24 weeks of pregnancy. In total, 40 interviews were conducted. Data collection was conducted in cooperation with four community health centres in Reykjavik. Formal ethical approval was obtained from the National Bioethical Committee in Iceland (05-125-S1), and permission to access the participants was also given by the head of midwifery and the medical director at each clinic.

Participants

The participants included both prospective parents who decided to accept NT screening and prospective parents who declined, although this paper draws on interview data from women and their partners who accepted screening. Midwives, who booked the first antenatal visit by phone, selected the participating women. The inclusion criteria were: age of mother between 18 and 35 years; and ability to express themselves in Icelandic. In addition, as the focus of the study was, amongst other things, to gain insight into how a couple without defined risk experienced this particular screening, the prospective parents had to have no previous history that might increase the probability of genetic anomaly during this pregnancy. The midwives introduced the study to the eligible women, and if they agreed to participate, a letter of introduction was sent which was followed-up by a telephone call from the researcher. If both prospective parents agreed to participate, a time and place for an interview were agreed. As the purpose of the study was exploratory, the size of the sample for this part of the study was based on Kvale's arguments that 10–15 interviews are sufficient to reach the point of saturation (Kvale, 1996). In this study, there was no intention to reach quantitative conclusions, but after conducting interviews with 10 couples twice during their pregnancy, similar clarification and threads were visible; these formed the framework for the analysis. There was considerable variation in the demographic background of participants; six of the couples had had children previously and four were expecting their first child. The women were aged 22–35 years and their partners were aged 23–50 years. The educational levels of participants ranged from basic schooling to university education.

Data collection

The first author conducted the interviews in this study. She worked for many years in the largest antenatal clinic in Iceland, where she observed the implementation of NT screening in the community. The interviews, which were in the form of guided conversation, covered topics such as: description of previous pregnancy and screening, if any; description of the meaning of NT screening; description of Down's syndrome; and views on abortion (see Table 1 for a list of topics and questions). During the second interview, which was conducted after the 20-week scan and was, on average, much shorter, both parents were asked to reflect on their experience of the screening process. The content of the first interview was agreed with the interviewee in the second interview following a description of the experience of screening. During the interview, several participants raised issues that were causing anxieties and dilemmas. These were attended by the researcher, who spent time as necessary after the interview to listen and reflect on the discussion, and offered the participants the opportunity to contact her if they needed. However, none of the participants took up this offer. The first interviews were held at 7–11 weeks of gestation and they lasted from 15 mins (an exceptional case; a father who could hardly express himself concerning the matter) to 1 hour 20 mins. All the interviews were tape recorded and transcribed verbatim by the first author and a secretary.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

Table 1 Interview guide (first interview)

Topics discussed with prospective mothers and fathers with previous experience of pregnancy and childbirth
Tell me about your experience of pregnancy and childbirth.
How was your communication with professionals during that time?
Did you have access to the necessary information during that time?
Describe your experience of previous screening if any.
Were your children born healthy?
Topics discussed with all participants (rephrasing of some questions in the interviews with fathers)
Is this a planned pregnancy?
Can you tell me how you have been feeling during the past weeks?
Tell me about the experience of pregnancy and childbirth in your family.
Have you communicated with health-care professionals during the past weeks?
Could you describe if and how they provided you with information about nuchal translucency screening?
Describe your views on the purpose and meaning of the screening.
Would you say that the information you have is sufficient for you, or would you have liked more information?
Describe how you made your decision to accept the screening.
Would you describe it as an easy or a difficult decision?
Was it a joint decision and, if so, how did you discuss it with your partner?
Describe the discussion around nuchal translucency screening among your family and friends.
Is there anyone close to you who has a disabled child?
Do you have experience of disability?
Describe your views on abortion.
Referring to your age, your risk is X of having a child with Down's syndrome. Could you comment on that?
How would you describe Down's syndrome?
Will the acceptance of screening affect your well-being? Describe how.

Data analysis

Framework analysis was used to analyse the data. This approach 'facilitates rigorous and transparent data management such that all the stages involved in the analytical hierarchy can be systematically conducted for ordering and synthesising data' (Ritchie and Lewis, 2003, p. 220). The first step was familiarisation by listening to tapes and re-reading fieldnotes or transcripts. In the second phase, the development of a coding scheme took place. Next, a comparison was made both within and between cases, following charting or re-arranging of the data according to its thematic content, either case by case or by theme. The identification of recurrent themes was compared between participants, followed by categorisation which is the actual form of presentation of the data in this paper. The transcripts were structured and clarified using NVivo Version 7, which is helpful for large and complex interviews, making them more amenable for analysis (Di Gregorio, 2003). As with all qualitative results, no claim to generalisability can be made. However, the reader is invited to make decisions about the transferability of findings to their own context.

All the transcripts were analysed in Icelandic in order to maintain meaning in the analysis, as the complexities of analysing semi-structured interviews that require translation for the purpose of data analysis have been highlighted (Twinn, 1997; Esposito, 2001). Quotes used in this paper were translated into English by the researchers, but, to maximise reliability, all quotes were reviewed by a professional translator who is familiar with the phenomenon under study.

Findings

Seven of the female participants had their pregnancy confirmed by their obstetrician at a private clinic, and three by their GP at a community health centre. One of the men had accompanied his partner to the GP and one to an obstetrician, but decided to wait for his partner in the waiting room. Six of the women made an appointment for NT screening before their first antenatal visit in the public health system; five of these women had been to a private obstetrician initially and one had visited her GP. Five of the multiparous women had had an NT screening in a previous pregnancy and screened low risk at that time, and all the women in the sample were screened low risk for Down's syndrome during this study. None of the participants had a close relationship with a person with Down's syndrome.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

Language of compliance vs control

As in previous work, the findings show that parents' expectations and hopes seem to influence the acceptance of screening. However, interestingly, in this study, expectations of screening emerged from two different perspectives among men and women. On the one hand, men's expectations related to technical effectiveness, providing them with feelings of control and reduced uncertainty. The women's expectations, on the other hand, reflected a wish for a healthy baby.

The following example from the first (7–11 week) interview with a prospective first-time mother illustrates her expectations of screening and the implications of accepting the test:

> This is, of course, not an invasive procedure, and as such, to me, not a harmful one. It gives me, well perhaps I do not look at it the right way... it confirms that everything is all right. But I haven't thought it through. However, the doctor felt it was somehow a self-evident act and because of that I just made the appointment for the screening. She said that I should do that and I didn't think about it further. I just thought, well, this is just something you do when you are pregnant. (Prospective mother 9, Interview 1)

This woman raised the issue twice in this part of the interview that perhaps she had not thought enough about her decision to accept screening. She felt strongly, however, that she should opt for the screening as it was seen as part of routine care and would confirm and reassure her that everything was all right and her baby was healthy. Six of the seven women who had their pregnancy confirmed at a private clinic described their obstetrician's attitude in favour of the screening, stating 'He just handed the form for the screening to me before I left' and 'He did not talk about it at all—just assumed that it was something for me'.

The expectations expressed by the prospective fathers were demonstrated more directly. The following quotation is from a man who already had three children.

> Everything that you can explore in advance is positive. It reduces uncertainty and increases your certainty. Then you know at least that there is no sign of any abnormality. (Prospective father 2, Interview 1)

His use of words to articulate and rationalise his acceptance of the screening is rather different from that of the women. He used words such as 'safety' and 'risk' more often than the women, and his motives referred to managing and controlling the process. Analysis of the interview data revealed that the majority of the men framed their description in this way. The following quotation is from an interview with one of the two men who were not as direct in their description and did not have much to say about the screening:

> I don't have much knowledge of all this. From my perspective, the term [nuchal fold screening] is negative. Of course, it is there to evaluate your risk status but in fact I know so little. I do not even know what it tells you. (Prospective father 7, Interview 1)

The perception of expectations changed as the pregnancy continued, revealing a greater variation in expression in the second interview. Expectations of screening remained high among many participants, but only three of the ten women had been given an explanation about the screening results. Some described how unanswered questions raised uncertainty and fostered speculations that caused anxiety. The experience of the ultrasound examination did affect their perception of screening, where some participants described how it made them more confident when information was delivered in a clear way. The only woman in the sample to describe ambivalence to screening in the first interview explained, in her second interview, how the midwife at the ultrasound clinic made her more at ease during the examination by providing information in a calm way.

To alleviate burden and optimise ability

The prospect of disability was viewed differently by prospective fathers compared with prospective mothers in this study. Four of the men raised issues related to the financial burden of having a disabled child, and expressed concerns about the impact on them of negative attitudes of society towards disability. The only similarity in the background information of these four men was that they all had children already.

> Most people want to have healthy children and that is the way the evolution goes. There are always complaints in our society that we do not support disabled, sick and old people well enough. It is very expensive to provide service for everybody like that and that is my main point. There is always this ongoing discussion that it is so expensive and we cannot afford it. (Prospective father 8, Interview 1)

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

However, no such arguments were raised in the interviews with women. This attitude towards disability was not necessarily based on knowledge of the conditions screened for, and, in fact, hardly any of the participants had clear ideas about what the screening might detect. For the few who had some experience with disability, it did not seem to alter their attitude or their perception of screening. However, none of the participants had a close relationship with a person with Down's syndrome.

The description of Down's syndrome and disabilities was also framed differently among the women in general.

> I do not know what to say. I, from my point of view, if I would have a child with Down's syndrome without knowing in advance, I would be devastated for a long time. I would probably experience a shock. I know it is a burden for the whole family, and particularly for mothers, but the children themselves are often happy. Well it depends on how you look at it.... I really don't know what to say any more. (Prospective mother 2, Interview 1)

Some of the women had thought about disability in relation to screening, but in more general terms. They talked more positively about disability than the men, and said that children with disabilities were affectionate and had a big need for love.

During the second interviews, when the participants had all received a negative screening result, some of them raised the subject that they were not sure what should be offered to parents during pregnancy in general. One of them said that it was easy to say that all people wanted NT screening, but it was not as certain that they knew what to do with the result if it turned out to be positive.

Mutual acceptance of screening?

Most of the couples claimed that the decision to accept screening was mutual. This was particularly emphasised by the women. However, the men, when asked how they talked about the decision and how they understood the screening, claimed that it was the woman who had decided to undergo screening. Some of them also described how it was the woman who had provided them with information about the screening. None of the men had sought information on their own initiative, and none of them had discussed the screening or the pregnancy with anyone other than his partner.

> For us, this was just straightforward. We did not talk about it, it just was there, it was something we were going to do. Because we have this opinion you see, to get information of possible inherited diseases, which you can diagnose early in pregnancy, then it is just fine to do it. Then you have a choice. (Prospective father 2, Interview 1)

In the first interview, most men said that they were reconciled that the woman had made the decision, but in the second interview, reflecting on the process, some of them felt that they had missed the opportunity to have a more thorough discussion and gain information about the screening. Taking part in the study had encouraged some couples to talk about the screening, which was experienced in a positive way and seen as an opportunity to share views. However, previous experience of having children since introduction of the screening reflected that the couples had a strong perception of screening as a routine procedure which there was no need to discuss.

> We did not need to discuss whether we wanted or needed to have the screening, as it was something I was supposed to do (referring to two previous pregnancies). But we made this decision to have the screening, just as we have always done it, as we would like to know if everything is all right. (Prospective mother 1, Interview 1)

Although this woman, who had NT screening in two previous pregnancies, described the screening as part of routine care, she still felt that she was making a choice.

Discussion

This study aimed to gain understanding of what factors influence prospective parents' decisions and experience of screening, and to inform policy and practice. The intention was to approach prospective parents before they had any communication with a health professional apart from a telephone call to arrange their booking interview. However, as described above, all the women had been to see a physician, most often an obstetrician at a private clinic, before they were approached about the study. This shows the predominant position of obstetricians in the private sector in Iceland, and gives rise to new speculations about pathways for care and the responsibility of providing information in early pregnancy. The draft antenatal guidelines published recently by the Directorate of Health (2006) indicate that decisions should be based on an informed choice, and the responsibility of professionals is emphasised.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

However, in the Icelandic system, it is not necessarily assumed that care in the first trimester is provided within the traditional public health system.

This study explored which factors influence prospective parents' decisions about accepting NT screening in very early pregnancy, and the different experiences of screening for prospective mothers and fathers. It must be emphasised that the findings are limited to a small number of parents and are therefore tentative. It also needs to be highlighted that this study was conducted within a social context where 90% of women accept screening. Many of the women in this study had already decided to accept screening before they had any contact with a health professional, which is in accordance with findings of previous studies, although little explored (Pilnik et al., 2004). One could speculate that the fact that many participants showed lack of understanding about what screening could and could not do, could affect uptake in the setting and reinforce screening as a component of routine care. Another possible source of influence on decision-making could be the presentation of screening in the Icelandic context, as an analysis of the discourse on screening in the Icelandic media shows that the emphasis on choice is highlighted at the cost of important information about the implications of screening (Gottfredsdóttir and Björnsdóttir, 2007, submitted for publication). Furthermore, in some interviews, especially with the women, it was noted that they felt obliged to follow the advice of accepting screening. For many of them, it seemed to be an obvious option, supported by the attitude of their obstetrician. Recent studies have highlighted that offering screening to every pregnant woman can result in a moral responsibility to accept screening (Williams et al., 2005). Similarly, Marteau and Drake (1995) suggested that both lay groups and health professionals make judgements about women's responsibilities in the birth of children with disabilities. The explanations of how medical technology has changed women's knowledge base regarding the confirmation of pregnancy from feelings and touch to visualisation can probably be applied to screening in very early pregnancy. As compliance has been described as one of the main components in coping with the decision to undergo ultrasound in early pregnancy, it is tempting to apply that to NT screening in the Icelandic context with high uptake (Nicol, 2007).

The discourse around antenatal screening in Iceland has highlighted the importance of choice, but the findings from this study raise concerns about what influences parents' decisions in early pregnancy. Expectations of both parents are the main impetus for accepting screening, which is in accordance with the writings of Brown and Webster (2004) on the role of expectations in decision-making. Most of the study participants had high expectations of technology, as shown by the numerous comments about confirmation of a healthy baby. Communication with professionals, described in some of the interviews, shows reluctance to explain the parents' risk status after screening. The authors followed the participants through the process, and found that if prospective parents had not been given explanations about their risk status, high expectations remained or they were left with unanswered questions and anxiety.

The importance of control, emphasised by men, is in line with findings from studies on men's educational needs and experiences during pregnancy. One study showed that men, like women, value being in control, but pregnancy is a time, maybe the first time in their lives, when they feel the opposite (Gottfredsdóttir, 2005). Accepting screening can be a way to fulfil this need and thereby decrease uncertainty.

To the authors' knowledge, the difference in perceptions of disability in the context of screening between men and women has not been raised previously. That, however, must be of importance, since the aim of screening in the first place is to detect anomalies and provide prospective parents with a more accurate evaluation of their risk status. The study findings revealed that men were far more direct in their description of disability, and more outspoken in their discussion of disabled people in society. Their view that disabled children are a financial burden on the family is related to findings of studies on fathers who have a child with Down's syndrome, which showed that their greatest concern was the long-term provision for their children (Hornby, 1995; Trute, 1995). Although it is impossible to predict how the different perceptions of disability and expectations between men and women adds to the decision-making process, this study draws attention to these issues. Furthermore, it should be of interest in the context of reproduction in Iceland whether those views encourage high screening uptake and a high termination rate.

This analysis indicates that the decision to accept screening lies with the women in the majority of cases, although all the women in the study described it as a joint decision. However, the majority of their partners claimed that it was for the woman to decide and they respected that decision. Their knowledge concerning screening

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

was usually dependent on information that the woman had provided; a finding which is in accordance with studies exploring educational needs of prospective fathers in a broader spectrum (Donovan, 1995; Zechmeister, 2001; Gottfredsdóttir, 2005). It seems likely, as with contraception and family planning, that the health-care system does not particularly exert itself in approaching and informing men when it comes to decisions regarding fetal screening.

Conclusions and implications

The strength of this study lies in the fact that, unlike previous studies, prospective parents were approached in very early pregnancy, before entry into the public health system. Similarly, interviews were conducted separately with men and women on two occasions during pregnancy to gain a better understanding of the decision-making process. The limitations of this study were that most women had seen a private obstetrician prior to joining the study, most of whom were described as having a positive attitude to screening. It is possible that descriptions of which factors influence decision-making would have differed if the women had been approached before their appointment with an obstetrician. However, this study highlights the importance of organising antenatal care to ensure that health-care workers have a good knowledge of all the technology being used and its impact on prospective parents. For the parents in this study, expectations were the key element in decisions about screening, resulting in unquestioning acceptance among most of the participants. Most of the women felt that the screening was optional, despite the way that they expressed their communication with their physician, which supports the view that screening has been 'routinised' to such an extent that there is perhaps no decision to be made. The prospective fathers in this study did not feel well informed, although they were content with accepting the screening. When approached later in pregnancy, they said that, in retrospect, they would have liked to be more involved from the beginning. The study findings stress the importance of exploring further the interplay between men and women at the beginning of pregnancy, and gender differences in views on fundamental issues such as disability.

The implications of this study for the clinical context, therefore, rest on the need for a clear definition of how both prospective parents should be provided with information in early pregnancy, and how this information should be handled and discussed before pregnancy. To reach that goal, future effort should be invested in exploring the accessibility and availability of information in the public domain, and the potential value of computerised decision aids for prospective parents before they book an antenatal care visit. Studies in other areas of maternity care on the use of decision aid tools indicate increased knowledge and more effective decision-making among its users (Montgomery et al., 2007). Further research is needed on the acceptability and effectiveness of such an aid in the Icelandic health-care system.

Acknowledgements

The authors wish to thank the prospective parents who participated in this study and the midwives who helped with recruitment of participants. This study was funded by the Icelandic Science Foundation and the Association of Midwives in Iceland, and supported by a Visiting Research Fellowship in the Florence Nightingale School of Nursing and Midwifery, Kings College.

References

Beardshaw, T., 2001. Supporting the role of fathers around the time of birth. MIDIRS Midwifery Digest 11, 474–477.

Becker, S., 1996. Couples and reproductive health: a review of couple studies. Studies in Family Planning 27, 291–306.

Bjarnadóttir, R.I., 2003. Burdarmálsdaudi á Íslandi: Getum vid enn lækkad tidnina? [Perinatal mortality in Iceland. How low can we go?]. Laeknabladid 10, 745–746.

Brown, N., Webster, A., 2004. New Medical Technologies and Society: Reordering Life. Polity, Cambridge.

Browner, C.H., Preloran, H.M., 1999. Male partners' role in Latinas' amniocentesis decisions. Journal of Genetic Counselling 8, 85–108.

Davis-Floyd, R.E., 1994. The technocratic body: American childbirth as cultural expression. Social Science & Medicine 38, 1125–1140.

Di Gregorio, S., 2003. Teaching grounded theory with QSR NVivo. Qualitative Research Journal 3, 79–95.

Directorate of Health, 2006. Medgönguvernd Heilbrigdra Kvenna í Edlilegri Medgöngu (Antenatal Care in Normal Pregnancy). 〈http://landlaeknir.is/Uploads/FileGallery/Kliniskar%20leidbeiningar/Medgonguvernd_KL_nov.2006.pdf〉.

Donovan, J., 1995. The process of analysis during a grounded theory study of men during their partners' pregnancies. Journal of Advanced Nursing 21, 708–715.

Dormandy, E., Michie, S., Hooper, R., et al., 2006. Informed choice in antenatal Down syndrome screening: a cluster-randomised trial of combined versus separate visit testing. Patient Education and Counseling 61, 51–64.

Ekelin, M., Crang-Svalenius, E., Dykes, A., 2004. A qualitative study of mothers' and fathers' experience of routine ultrasound examination in Sweden. Midwifery 20, 335–344.

Esposito, N., 2001. From meaning to meaning: the influence of translation techniques on non-English focus group research. Qualitative Health Research 11, 568–579.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

Gottfredsdóttir, H., 2005. Prospective first-time fathers and their views on fatherhood in the context of new policy on parental leave in Iceland. Birth Issues 14, 128–134.

Green, J., Thorogood, N., 2004. Qualitative Methods for Health Research. Sage Publications, London.

Heyman, B., Hundt, G., Sandall, J., et al., 2006. On being at higher risk: a qualitative study of prenatal screening for chromosomal anomalies. Social Science & Medicine 62, 2360–2372.

Hornby, G., 1995. Fathers' views of the effects on their families of children with Down syndrome. Journal of Child and Family Studies 4, 103–117.

Jacques, A., Bell, R., Watson, L., et al., 2004. People who influence women's decision and preferred sources of information about prenatal testing for birth defects. Australian and New Zealand Journal of Obstetrics and Gynaecology 44, 233–238.

Knudsen, L.B., Gissler, M., Bender, S., et al., 2003. Induced abortion in the Nordic countries: special emphasis on young women. Acta Obstetricia et Gynecologica Scandinavica 82, 257–268.

Kolker, A., Burke, B.M., 1994. Prenatal Testing: a Sociological Perspective. Greenwood Publishing Group, Westport, CT.

Kvale, S., 1996. Interviews: an Introduction to Qualitative Research Interviewing. Sage Publications, London.

Lalor, J.G., Devane, D., 2007. Information, knowledge and expectations of the routine ultrasound scan. Midwifery 23, 13–22.

Locock, L., Alexander, J., 2005. 'Just a bystander'? Men's place in the process of fetal screening and diagnosis. Social Science & Medicine 62, 1349–1359.

Marteau, T., Drake, H., 1995. Attributions for disability: the influence of genetic screening. Social Science & Medicine 40, 1127–1132.

Michie, S., Dormandy, E., Marteau, T., 2003. Informed choice: understanding knowledge in the context of screening uptake. Patient Education and Counseling 50, 24–53.

Montgomery, A.A., Emmett, C.L., Fahey, T., et al., 2007. Two decision aids for mode of delivery among women with previous caesarean section: randomised controlled trial. British Medical Journal 334, 1305.

Nicholaides, K., 2004. Nuchal translucency and other first-trimester sonographic markers of chromosomal abnormalities. American Journal of Obstetrics and Gynecology 191, 45–67.

Nicholaides, K., Health, V., Liao, A., 2000. The 11–14 week scan. Baillière's Best Practice & Research Clinical Obstetrics & Gynaecology 14, 581–594.

Nicol, M., 2007. Vulnerability of first-time expectant mothers during ultrasound scans: an evaluation of the external pressures that influence the process of informed choice. Health Care for Women International 28, 525–533.

Nordic Committee on Bioethics, 2005. Assisted Reproduction in the Nordic Countries. A Comparative Study of Policies and Regulation. Copenhagen. 〈http://www.ncbio.org/NcBioBurrell.pdf〉.

Ólafsson, Ó., 1998. Health in Iceland. Directorate of Health, Reykjavík.

Pilnik, A., Fraser, D.M., James, D.K., 2004. Presenting and discussing nuchal translucency screening for fetal abnormality in the UK. Midwifery 20, 82–93.

Porter, M., Macintyre, S., 1984. What is must be best: a research note on conservative or deferential responses to antenatal care provision. Social Science & Medicine 19, 1197–1200.

Press, N., Browner, C., 1997. Why women say yes to prenatal diagnosis. Social Science & Medicine 45, 979–989.

Regulation on Health Care Centres, 2007. Reglugerd nr. 787/2007 Fyrir Heilsugaeslustödvar (Reykjavík). Ministry of Health and Social Security.

Ritchie, J., Lewis, J., 2003. Qualitative Research Practice: a Guide for Social Science Students and Researchers. Sage Publications, London.

Santalahti, P., Hemminki, E., Latikka, A.M., et al., 1998. Women's decision making in prenatal screening. Social Science & Medicine 46, 1067–1076.

Schott, J., 2002. Parent education: meeting the needs of fathers. Practicing Midwife 5, 36–38.

Skirton, H., Murakami, K., Ito, M., et al., 2007. A report of two linked studies of knowledge and attitude to prenatal screening and testing in adults of reproductive age in Japan and the UK. Midwifery, in press, doi:10.1016/j.midw.2006.10.009.

Sorenson, J.R., Wertz, D.C., 1986. Couple agreement before and after genetic counselling. American Journal of Medical Genetics 25, 549–555.

Sullivan, A., 2002. Gender differences in coping strategies of parents of children with Down syndrome. Down Syndrome Research and Practice 8, 67–73.

Trute, B., 1995. Gender differences in the psychological adjustment of parents of young, developmentally disabled children. Journal of Child Psychology & Psychiatry 36, 1225–1242.

Twinn, S., 1997. An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. Journal of Advanced Nursing 26, 418–423.

van Teijlingen, E.R., Hundley, V., Rennie, A.M., et al., 2003. Maternity satisfaction studies and their limitations: 'what is, must still be best'. Birth 30, 75–82.

Williams, C., Sandall, J., Lewando-Hundt, G., et al., 2005. Women as moral pioneers? Experiences of first trimester antenatal screening. Social Science & Medicine 61, 1983–1992.

Zechmeister, I., 2001. Foetal images: the power of visual technology in antenatal care and the implications for women's reproductive freedom. Health Care Analysis 9, 387–400.

Please cite this article as: Gottfredsdóttir, H., et al., 'This is just what you do when you are pregnant': a qualitative study of prospective parents in Iceland who accept nuchal translucency screening. Midwifery (2008), doi:10.1016/j.midw.2007.12.004

Paper III.

Social Science & Medicine 69 (2009) 274–277

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Short report

How do prospective parents who decline prenatal screening account for their decision? A qualitative study☆

Helga Gottfreðsdóttir [a,*], Kristín Björnsdóttir [b], Jane Sandall [c]

[a] Department of Midwifery, Faculty of Nursing, University of Iceland, Reykjavik, Iceland
[b] Department of Nursing, Faculty of Nursing, University of Iceland, Reykjavik, Iceland
[c] Health and Social Care Division, King's College, London, UK

ARTICLE INFO

Article history:
Available online 28 May 2009

Keywords:
Nuchal translucency screening
Iceland
Decision making
Pregnancy
Prospective parents
Downs syndrome

ABSTRACT

Despite the aim of nuchal translucency screening to enhance reproductive choices among prospective parents, research on the experience of those who choose to decline this screening has been fairly limited. The objective of this study is to gain an understanding of how parents who decline screening account for their decision in a setting where screening for Down's syndrome in early pregnancy is the norm. The majority of research on prenatal screening choices has been conducted retrospectively; there has been very little research that has explored decision making on a prospective basis and that has included both parents.

In order to study this question, a purposive sample of ten couples who had decided to decline screening was recruited from four health care centres in Iceland. Data were gathered in semi-structured interviews conducted with each participant twice during the pregnancy (at 7–12 weeks pregnant and at 12–24 weeks pregnant), for a total of 40 interviews. We find that the decision to decline screening is largely determined by what prospective parents bring with them to the pregnancy, i.e., their personal philosophy of Down's syndrome and the high value they place on maintaining the complexity of life. The test is also considered unreliable by some of the participants. These findings have implications for those who are involved in formulating and providing antenatal screening policies and practices.

In most countries where nuchal translucency screening (NT) has been introduced, the uptake has been widespread. NT screening is a probability test, performed between the 11th and 14th weeks of pregnancy (Kagan, Avgidou, Molina, Gajewska, & Nicholaides, 2006). The results of the test are used to evaluate risk for giving birth to a child with a chromosomal anomaly, especially Down's syndrome. Its use is based on the argument that it enhances the reproductive choices of prospective parents (NICE, 2008) and that it reduces the risk of unintended abortion associated with the use of invasive diagnostic tests such as amniocentesis and chorionic villus sampling (CVS). The wide uptake of prenatal screening is partly driven by high expectations of what screening may do in terms of reassurance and confirmation of a healthy baby (Gottfredsdóttir, Sandall, & Björnsdóttir, in press; Santalahti, Hemminki, Latikka, & Ryynänen, 1998). There is evidence that the uptake of NT screening increases the identification of anomalies and the use of selective abortions, which leads to fewer children born with Down's syndrome (Kjaergaard et al., 2007). Although the use of screening has been widely accepted as an improvement in prenatal care, scholars and activists within disability studies have raised the concern that prenatal screening has a potent message that reinforces negative attitudes about people with disabilities among the general public (Saxton, 2000; Shakespeare, 1998).

Research on NT from a social science perspective at the micro level has focused on the impact of routinisation on perceptions of personal responsibility (Williams et al., 2005), the role of screening in the social construction of risk (Heyman et al., 2006, Pilnick, 2008), and an exploration of factors influencing the decision making process (Garcia, Timmermans, & van Leuwen, 2008). At the macro level, social science research has focused on the potential societal implications of the introduction of prenatal screening for Down's syndrome and the potential eugenic outcomes of such policies (Shakespeare, 1998). However, data has been collected retrospectively, which carries the risk that post-hoc rationales are used to explain decision making (Garcia et al., 2008). There has been very little research that has been able to explore such issues

☆ The authors wish to thank the prospective parents who participated in this study and the midwives who helped with collection of participants. This study was funded by the Icelandic Science Foundation and the Association of Midwives in Iceland, and supported by a Visiting Research Fellowship in the Florence Nightingale School of Nursing and Midwifery, Kings College.

* Corresponding author. Tel.: +354 525 4989.
E-mail address: helgagot@hi.is (H. Gottfreðsdóttir).

0277-9536/$ – see front matter © 2009 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2009.05.004

on a prospective basis, accessing both parents early in pregnancy before the screening process is undertaken. Current knowledge is largely based on studies conducted in the last decades of the twentieth century, when invasive diagnostic tests such as amniocentesis, offered to women over 35, played the major role in the detection of Down syndrome. Those studies showed a weak association between religiosity and screening refusal, and attitudes towards abortion and screening use seemed to be complex, affected by ethnicity or religion and the woman's personal experience of abortion (Markens, Browner, & Press, 1999; Rapp, 2000). Few studies controlled for a wide range of factors simultaneously. Several studies have found that a personal knowledge of Down's syndrome is correlated with a more positive perception of screening, which supports the theory that attitude based on experience has a strong impact on views towards screening (Bryant, Green, & Hewison, 2006; Bryant, Hewison, & Green, 2005). Our search revealed no published studies exploring prospective mothers' and fathers' views on this issue in particular in early pregnancy and how those views develop as the pregnancy progresses.

The study upon which this paper is based was conducted in the capital area of Iceland, Reykjavik, where the use of screening among prospective parents has become widespread. NT screening was first introduced in Iceland in 1999 when it was initially offered to all women over 35 years of age as a method to decrease the use of amniocentesis. Within a few years, it became a routine part of antenatal care offered to all pregnant women, so that by 2006, NT screening use was around 90% in the capital area, where the access to screening clinics is good (Geirsson, Gardarsdóttir, Palsson, Bjarnadóttir, & Hardardóttir, 2006). In a setting that is heavily oriented towards routine screening, it is important to understand how people who decline screening experience their choice and how they account for their decision. Those parents are the focus of this paper.

Method

This paper is based on data from an extensive qualitative study, where the overall aim was to explore the experience of decision making to undergo nuchal translucency screening among both couples who accept and couples who decline screening (Gottfredsdóttir et al., in press). To explore how decisions around screening were formulated and reflected upon, the data collection was designed to gain access to the prospective parents as early in the pregnancy as was possible. Twenty couples were interviewed, ten underwent screening and ten declined. This paper will focus on the parents who declined the screening. The study took place at four primary care centres in Reykjavik. Permission to conduct the study was given by the Head of Nursing and Midwifery and Medical Director at each centre. Ethical approval for the study was obtained from the National Bioethical Committee in Iceland (05-125-S1).

Recruitment and sample

The couples were recruited when they contacted midwives at each of the primary health centres to make an appointment for antenatal care. Based on the inclusion criteria of cohabitation, ability to express oneself in Icelandic and no previous history of genetic anomaly (as the focus of the study was to gain understanding of how parents without pre-defined risk experience the decision of NT screening), women who declined screening were asked if they and their partners would be willing to participate in the study. All the women and their partners we approached agreed to participate. All informants were Icelandic. Informant education levels ranged from secondary school to a university degree, and thirteen had university educations. Although issues related to religion were only discussed when raised by participants, it should be noted that about 90% of the nation belongs to the Lutheran state church. One of the participants had undergone NT screening in an earlier pregnancy, and seven of the ten women in this sample had children. Compared to the participants who accepted screening, the women who declined were more likely to have previous pregnancies and births, and had a slightly higher mean age. No other differences in socio-demographic background could be found between those who accepted screening and those who declined.

Data collection and analysis

In order to explore how decisions around screening develop as the pregnancy progresses, two interviews were conducted with each participant, the first when the women were between 7 and 12 weeks pregnant and the second between 21 and 24 weeks, for a total of 40 interviews. The interviews were conducted from April to August 2006, and took place at the couples' homes by their own choice. The interviews varied in length from 45 to 95 min with no gender difference in the length of interviews. Interview topics are listed in Table 1.

The interviews were tape-recorded and later analysed using thematic framework analysis. In thematic framework analysis, emphasis is placed on two major stages: the management of data and making sense of the evidence through descriptive or explanatory accounts (Ritchie, Spencer, & O'Connor, 2003). The transcripts were structured and organized using the NVivo software (Di Gregorio, 2003).

Results

All the participants spoke openly about the topics raised in both interviews and did not decline to answer any of the questions. Therefore, despite the relatively small sample size, the data collected were rich in content and the findings raise issues that have gained limited attention in previous studies. In the second interview, the decision remained strong and almost all participants emphasized that this was a decision that they would opt for again. Half of the couples said that the pregnancy was planned. Most respondents also said that they had a mutual understanding of the screening and emphasized a joint decision made in early pregnancy. Although all the participants had decided against screening, six couples had planned to have a 12-week dating scan, which is offered to parents who do not wish to have NT screening.

The identification of recurrent themes was compared between participants, and these themes were used to create the categories of data seen in this paper. The following section includes quotations that best represent the categories generated by the data.

Personal philosophy of Down's syndrome

One of the first observations made in the data analysis was that many participants were familiar with disability. Of the twenty men

Table 1
Interview topics in the first interview.

The pregnancy so far – is it a planned pregnancy?
Previous experience of pregnancy and birth, if any.
Pregnancy related concerns.
Experience of disability.
Public media discourse on foetal screening.
Offer of NT screening on a national basis.
The meaning of NT screening.
Attitude towards abortion.
Was this a joint decision?

and women, eleven had previous experience with disabled people through their work or personal acquaintanceship. Therefore, some of them were quite familiar with Down's syndrome and the services that are provided to those individuals by the community. The Icelandic law on disability reflects a commitment to providing comprehensive services that will allow the disabled to live independently. These include precedence in day care, support in regular schools, special schools when needed, support for families, respite care for parents, rehabilitative services and other health care and social services for the disabled living in their own homes (*Law on the disabled, 1992*, Chap. III).

Although all but one of the participants supported the availability of abortion and favoured the option of screening, most of the participants decided against screening because, for them, Down's syndrome was not severe enough to terminate pregnancy. From their perspective, screening should be aimed at the most serious anomalies, such as severe heart and brain malformations and conditions where the prognosis is poor. At the same time, they acknowledged that it is not self-evident that everyone is in a position to raise a child with Down's syndrome. In their view, the decisions for or against the birth of a child with Down's syndrome should be guided by a consideration of the quality of life the prospective child will enjoy. All of the interviewees agreed with their partners about the decision. One father, who had worked for many years with disabled children, especially children with severe autism, described his view thus:

> I would say that Down's syndrome is a difficult condition. It is difficult for the parents, but at the same time enjoyable. They seem to be happy, most of them, but they sometimes have difficult temper just like small children, can be very angry one minute, but extremely happy the next. They also have lower life expectancy than other people, but I don't think that is the worst thing … (man no 2: 17: 1).

Another participant pointed out that one has to be realistic about the condition of these children and their life should not be glorified.

> It is demanding for parents to raise a child with Down's syndrome. I know quite a few teenagers; their development stops and they will perhaps always be like twelve year old children (woman no 2: 10: 1).

Tolerance for diversity

Although the participants in general had a positive attitude towards Down's syndrome, eight participants, three men and five women, strongly emphasized that all parents want a healthy child and should not be ashamed to admit that. At the same time, they felt that variability and complexity in ability and health should be maintained in society. They talked about feelings of responsibility as they described their thoughts of the unborn child. Three of the men and four of the women argued that when making decisions about unborn children, the emphasis should be on care and respect. In their view, the birth of children with anomalies is an experience that can make people stronger as individuals.

The following quotation is from an interview with a man expecting his second child. He is aware that a small percentage of pregnancies are affected by foetal anomalies, but he explains that he is willing to raise a child even if it has some anomalies:

> For me it is not necessary to know … You could just as well say that you had hoped for a boy, but then you find out that it is a girl. What I mean is that if something is wrong then we will deal with that. People have been born with various kinds of anomalies but lived a happy life (man no 2: 4: 1).

Four of the women felt that they had to justify their decision to decline screening, both within their context of family and friends and with health professionals providing antenatal care. Respondents experienced a lack of flexibility and understanding from others, as described by one man who explained how he and his partner had been offered NT screening while they were having the 12-week dating scan:

> Well, she [the midwife performing the ultrasound] just said it in the middle of the examination: 'Do you want a Nuchal Translucency screening?' It just came in the middle of the conversation we had as she was measuring the femur length and then the circumference of the head and explaining that to us and then just: 'Do you want a Nuchal Translucency screening?' We both said no … (man no 2: 4: 2).

Many participants felt a need to explain their philosophy of life, and some related their former experience as the underlying reason for their choice. One of the participants, who had worked with disabled people for many years, said:

> I know disability as I have worked with disabled individuals for many years. People tend to say to me: 'Then you know what it is worth to have a healthy child'. But when you have experience with disabled children and adults you also know what it is worth to have them. I mean you could turn it around (man no 2: 12: 1).

An unreliable test

One topic that was raised with the participants was their perception of NT screening as unreliable. Many of them expressed the view that prenatal screening could never provide certainty, a view that was more likely to be expressed by those who had less experience with disabled people. One woman explained in her second interview how she felt that professionals who provide care during pregnancy need to explain what the screening entails, rather than just saying, "this is on offer." She said:

> This feeling of uncertainty after the NT screening, you know nothing. Something could be wrong and if you want to know more you will need an amniocentesis or something. It is not possible to provide any accurate answers after the NT screening. I would not like to proceed with this screening and end up with that possibility and have to live with that uncertainty throughout pregnancy (woman no 2: 10: 1).

Five women referred to cases they knew of where either healthy foetuses were lost following amniocentesis or children with Down's syndrome were born after a negative screening result.

> I have thought about this very much since I knew it was possible to have the screening and I do not want to go. As I say, what I have heard is that the answer you will get is 'It is possible' that something might be wrong. And if you want to know something further you need to have an amniocentesis and that involves high risk. I know of two healthy foetuses that were lost after such procedure as they thought that they had chromosomal anomalies (woman no 2: 10: 1).

Many participants indicated that their decision to decline screening was influenced by the fact that NT screening was a probability test and went on to explain that the information provided by the health care centre was insufficient for them and did not give them accurate answers. Their refusal was as such motivated by their distrust of scientific probability and their view that

screening should be aimed at detecting the most serious anomalies such as severe heart and brain malformations and conditions where the prognosis is poor:

> If you could know for sure that your baby would experience suffering and be born with severe malformations and limited life expectancy … if the test would provide you with such information then the decision would be different (woman no 2: 19: 1).

Discussion

This study explores how people who decline screening experience their choice and how they account for their decision using a prospective design. We find that each individual refusal of screening exhibits a complex interplay between personal views, values and the social context. Thus, the findings reflect the relationship between the participants' experiences of disability, knowledge and understanding of risk involved in undergoing screening and the context of antenatal care.

Although the participants supported the availability of screening, many had decided against screening on the grounds that they did not view Down's syndrome as a severe enough condition to justify termination of pregnancy. This view was based on their direct knowledge of the cognitive and physical abilities of people with Down's syndrome and the support provided to this group within their community. That view remained strong in later pregnancy. The participants emphasized that life is a complex phenomenon where diversity must be accepted. Although they expected that all parents want a healthy child, for them, health is a complex concept, allowing for numerous deviances. In their view, screening should be reserved for the most serious conditions.

These findings coincide with other studies where acquaintance with a disabled person had an influence on attitudes towards screening, as personal experience of the condition was linked to more positive attitude about the quality of life of the individual with Down's syndrome (Bryant et al., 2006; Santalahti, Hemminki, Aro, Helenius, & Ryynänen, 1999). Additionally, personal experience with a family member with Down's syndrome can override socio-economic variables influencing attitudes towards prenatal diagnosis and termination (Bryant et al., 2005).

The overriding majority of parents in our study supported the availability of abortion, unlike studies conducted in the US in the late 1990s (Markens et al., 1999; Rapp, 2000). The view towards screening was not necessarily related to a broader objection to technology. Most of the women wanted to have an ultrasound to confirm the length of pregnancy, but some parents saw the screening as potentially inaccurate and based their decision to decline on that view. In general, we are able to say that some participants had good knowledge and understanding of disability and of the screening test, while other participants would have preferred more information from professionals, either in the private or the public system.

This study is the first to interview couples in early pregnancy on how decisions to decline screening emerge. Our findings suggest that some parents experience their choice as free and uncoerced, while others felt that they had to justify their decision in their interactions with professionals. Their considerations include factors rooted in their values and beliefs, as well as their knowledge of disability and the predictive accuracy of NT screening. As such, parents who decline articulate a number of issues that relate to their personal experience and the contexts to which they belong. These considerations are somewhat different from those of participants who accept screening and were interviewed in another part of this study. In this regard our findings are in line with studies on women who refuse amniocentesis and form their own "embodied knowledge" (Browner & Press, 1996; Lippman, 1999), meaning that they weave together various threads of understanding, experience and feelings.

Conclusions

The importance of this study lies in the issues raised by participants, and as such, it increases our knowledge on the views and experience of parents who decline screening. Realistic expectations and adequate knowledge of NT screening is fundamental for the individual parent who is confronted with the offer of screening, but if that parent's values, beliefs and experiences are unknown to professionals, they cannot fulfill their role as providers of informed antenatal care. If screening is to be implemented effectively and equitably, this knowledge should be part of the introduction of screening procedures in early pregnancy.

References

Browner, C. H., & Press, N. (1996). The production of authoritative knowledge in American prenatal care. *Medical Anthropology Quarterly, 10*, 141–156.

Bryant, L. D., Green, J. M., & Hewison, J. (2006). Understanding of Down's syndrome: a Q methodological investigation. *Social Science & Medicine, 63*, 1188–1200.

Bryant, L., Hewison, J. D., & Green, J. (2005). Attitudes towards prenatal diagnosis and termination in women who have a sibling with Down's syndrome. *Journal of Reproductive and Infant Psychology, 23*, 181–198.

Di Gregorio, S. (2003). Teaching grounded theory with QSR NVivo. *Qualitative Research Journal, 3*, 79–95, [Special issue].

Garcia, E., Timmermans, D. R., & van Leuwen, E. (2008). The impact of ethical beliefs on decisions about prenatal screening tests: searching for justification. *Social Science & Medicine, 66*(3), 753–764.

Geirsson, R. T., Gardarsdóttir, G., Palsson, G., Bjarnadóttir, R. I, & Hardardóttir, H. (2006). *Skýrsla frá faedingaskráningunni fyrir árid 2005*. [*Registration of births in Iceland in 2006*]. Reykjavik: Landspitali-Haskolasjukrahus [Landspitali University Hospital].

Gottfredsdóttir, H., Sandall, J., & Björnsdóttir, K. This is what you do when you are pregnant: a qualitative study on prospective parents who accept nuchal translucency screening. Midwifery. Available online 04.03.08. in press.

Heyman, B., Lewando-Hundt, G., Sandall, J., Spencer, K., Williams, C., Grellier, R., et al. (2006). On being at higher risk: a qualitative study of prenatal screening for chromosomal anomalies. *Social Science & Medicine, 62*(10), 2360–2372.

Kagan, O. K., Avgidou, K., Molina, F., Gajewska, K., & Nicolaides, K. H. (2006). Relation between increased fetal nuchal translucency thickness and chromosomal defects. *Obstetrics & Gynecology, 107*, 6–10.

Kjaergaard, S., Hahnemann, J. M., Skibsted, L., Neerup, L., Sperling, H., Zingenberg, A., et al. (2007). Prenatal diagnosis in Denmark after the introduction of nuchal translucency screening. *European Journal of Human Genetics, 15*(Suppl. 1).

Law on the disabled, no. 59, 1992, § 7.

Lippman, A. (1999). Embodied knowledge and making sense of prenatal diagnosis. *Journal of Genetic Counseling, 8*, 255–274.

Markens, S., Browner, C. H., & Press, N. (1999). Because of the risks: how US pregnant women account for refusing prenatal screening. *Social Science & Medicine, 49*, 359–369.

National Institute for Health and Clinical Excellence [NICE]. (2008). *NICE clinical guideline 62. Antenatal care: Routine care for the healthy pregnant woman*. London: Author. Retrieved April 10th 2008 from. http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf.

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 Health and Illnesses, 30*(4), 511–530.

Rapp, R. (2000). *Testing the women, testing the fetus*. NY: Routledge.

Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out qualitative analysis. In J. Ritchie, & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 219–262). London: Sage Publications.

Santalahti, P., Hemminki, E., Aro, A., Helenius, H., & Ryynänen, M. (1999). Participation in prenatal selective termination in Finnish maternity care. *Fetal Diagnosis and Therapy, 14*(2), 71–79.

Santalahti, P., Hemminki, E., Latikka, A. M., & Ryynänen, M. (1998). Women's decision making in prenatal screening. *Social Science & Medicine, 46*, 1067–1076.

Saxton, M. (2000). Why members of the disability community oppose prenatal diagnosis and selective abortion. In E. Parens, & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 147–164). Washington, DC: Georgetown University Press.

Shakespeare, T. (1998). Choices and rights: eugenics genetics and disability equality. *Disability & Society, 13*, 665–681.

Williams, C., Sandall, J., Lewando Hundt, G., Grellier, R., Heyman, B., & Spencer, K. (2005). 'Women as 'moral pioneers'?: experiences of first trimester nuchal translucency screening. *Social Science & Medicine, 61*(9), 1983–1992.

Paper IV.

The meaning of ethical concepts and their reflection in the context of fetal screening.

Helga Gottfredsdóttir[1] and Vilhjálmur Árnason[2],

[1] Department of Midwifery, Faculty of Nursing, University of Iceland, [2] Department of Philosophy & Centre for Ethics, University of Iceland,

Address all correspondence to:

Helga Gottfredsdóttir, Assistant professor of Midwifery,

University of Iceland, Faculty of Nursing, Department of Midwifery,

Eiríksgata 34, IS-101 Reykjavík, Iceland.

Fax #: 354-525 4963,

helgagot@hi.is

Abstract

In accordance with guidelines on fetal screening the main role of health professionals is to inform prospective parents in a way that encourages their autonomy and informed decision making. In this paper we analyse the meaning of autonomy and informed decision making from the theoretical perspective and attempt to show how those concepts are described among prospective parents in early pregnancy and in the public media in a society where NT screening is almost a norm. Our data consisted of interviews with Icelandic prospective parents in early pregnancy (N=40) and material covering the discourse in the media over five years period (from 2000 to 2005). Analysis of our data indicates that there is an important difference in the interpretation of those concepts between the theoretical perspective on the one side and the public media and prospective parents on the other. This has been neglected in the implementation of screening. The context in which these decisions are taken does not encourage moral reflection and when making decisions about screening a lack of dialogue is described among prospective parents.

Keywords:

Fetal screening, autonomy, informed decision, prospective parents, ethics, experience.

Introduction

The discussion around fetal screening has been characterized by emphasis on informed decision making of parents and respect for their autonomous choice. This has been widely highlighted in recommendations and guidelines on screening, where it is considered the role of health professionals to provide prospective parents with information on various screening procedures (Directorate of Health, 2006; NICE, 2008). Although prenatal screening is routinely used in some countries to enhance reproductive choices of parents, routinization can be seen to reduce, rather than expand, choice. Incorporating screening in a traditional antenatal care impoverishes the informed consent process and the more routine a test becomes the less prospective parents and providers focus on ethical dimensions of the screening (Suter, 2002). Hence, construction of ethical concepts in the context of fetal screening will affect the ongoing development and practice of screening.

In the past two decades, there has been a growing literature on fetal screening, mostly emerging from the medical context about the efficacy and possibilities of the new technology (Kagan et al., 2006; Nicholaides, 2004). Within other disciplines the focus has been on the decision making from the psychological, social and emotional aspect of screening. These studies have increased understanding of the difficulties that arise in relation to offering screening within the traditional antenatal care (Pilnik, 2008; Rapp, 2000). Furthermore, studies report on women's high satisfaction with the care they receive during pregnancy, intrapartum and postpartum, which actually supports the status quo of current service and explains why women are not likely to express a preference of something else (Teijlingen, Hundley, Rennie, Graham & Fitzmaurice, 2003).

Women have high expectations of what the screening can do and believe that what is offered is the right thing to choose (Gottfredsdóttir, Sandall & Björnsdóttir, 2008). Consequently, the role of responsibility in the decision making process has been highlighted and described as creating a tension when women are confronted with the choice of accepting or declining screening (Williams et al., 2005; Chadwick, 1999). Although slightly explored, it is argued that many women think carefully about their decision but are left alone in considering the moral implications of the screening (Williams et al., 2005). As such, there is limited knowledge of the impact of women's ethical beliefs on decision making, particularly in early pregnancy. However, both supporters and critics of screening justify their decision by the same moral principles as they highlight the right of the parents to decide for themselves. This concordance in views can indicate that prenatal testing has not yet been integrated into the ethical beliefs of the parents and, as such, is reflected differently in practice than in moral theories (Garcia, Timmerman and van Leeuwen, 2008). Berkel and Weele (1999) show that almost all women in their study expressed roughly the same set of considerations despite different choices made in the end. Interestingly, one norm was emphasised by all the participants, namely that everybody should decide for themselves. Further analysis revealed few very general norms or understanding how to reach a decision. Speculations of tension between uneasiness to decide and autonomy are considered to relate to fear of compromising autonomy. Hence, this leaves the decision making process as a neglected area.

In the light of rapid uptake of prenatal screening there is a growing urgency to explore the underlying ethical reasoning involved when complex decisions have to be made. To our knowledge, however, studies on how bioethical concepts, in particular, are reflected in real circumstances and whether they have the same significance for prospective parents who accept

and decline screening are scarce. The framework of culture, values and beliefs shapes the views and action prospective parents take in their decisions as well as the diversities between defining the pregnancy as a normal or risky time fundamental in practice around screening (Williams, Alderson & Farsides, 2002). It is also likely that the media in modern societies has an impact on public policy and public opinion, as has been highlighted in reports on technical improvements in health care, such as in genetics diagnosis (Peterson & Bunton, 2002, Kitzinger & Williams, 2005). In an Icelandic study on media discourse around the intended establishment of a Health Sector Database in the country, it was especially highlighted notified that there was a lack of true dialogue of the matter (Pálsson & Harðardóttir, 2002). Another Icelandic study exploring in particular the presentation of the development of genetic technologies in the country, reported that the media did not serve as a source of critical debate, but encouraged the optimistic vision of the innovation both in the market and the medical context (Hjörleifsson, Árnason & Schei, 2008).

This paper aims to respond to the need for multidisciplinary work on how traditional ethical concepts are reflected in the clinical and social context. The following section of the paper presents a short overview of the clinical background of NT screening as well as our study material and the background. We then present the theoretical perspective of autonomy, choice and informed decision. From there we go on to explore how the participating prospective parents frame their decisions to accept or decline screening and evaluate how those concepts are enacted or exercised through discussion. Finally, we analyze how the context, in which those decisions are taken, introduces and supports, informed decision making where we use the media discourse to exemplify the social discourse. In conclusion, we discuss the political and moral space where this development has taken place.

Clinical background

NT screening was introduced in the UK following expansion of the ultrasound technique and the introduction of first trimester biochemical markers in the 1990s. Combined with maternal age and length of pregnancy, the risk score for every woman for giving birth of a child with chromosomal anomaly, especially Down's syndrome, is evaluated (Nicholaides, 2004). As such, there is an important distinction between the technique of fetal diagnostic tests and fetal screening which is a probabilistic test, used to provide an indication for further diagnostic tests (Skirton, & Patch, 2002). NT screening was introduced in Iceland in the late 1990's and the uptake of the screening rapidly became high. We have reported elsewhere (Gottfredsdóttir & Björnsdóttir, 2009, *accepted for publication*) that at that time, there were no national guidelines for that particular screening in use in the country. In 2006, around 87% of women in the capital area where there is easy access accepted the screening.

In general, there seems to be a tacit assumption within the medical domain that fetal screening is a desirable progress which will enhance reproductive choices of prospective parents (Chervenak, McCullough & Chasen, 2005). However, in this situation the option is either to continue the pregnancy or to have a selective abortion. In the light of this development, questions have been generated regarding choice, informed decision making and autonomy of prospective parents in the context of screening. These concepts have been the subject of debate and the expansion of fetal screening has created new speculations of their characteristics. For example, with increasing detection of fetal condition for which treatment is available after birth, a shift in the status of the fetus to that of a patient is possible. Those speculations highlight another dimension of choice which women are confronted with (Williams, 2005).

Study background and methods

This paper reports on one aspect of a project which focuses on the decision making process around NT screening in early pregnancy. Here we examine the significance of ethical concepts in the context of fetal screening. We present an analysis of bioethical concepts in the literature where the focus is in particular on autonomy and informed decision making. This is discussed in the light of a brief overview of three models of professional-patient relationship which place different emphasis upon the key ethical elements of decision making. In order to set the study within a wider context it draws on two sets of data. The first are interviews with prospective parents in pregnancy where participants were recruited from health care centres in Reykjavík, the capital of Iceland, following ethics committee approval (05-125-S1). The participants included twenty couples, equally parents who had decided to accept and decline NT screening. Two interviews were conducted with each individual, in the 7th–11th week of pregnancy and after the ultrasound at twenty weeks, a total of 80 interviews, The interviews were conducted as guided conversations using informal interview schedule and explored the following themes: previous pregnancy and birth experience, knowledge of NT screening, communication with health professionals during this pregnancy, views on abortion, experience of disability. The second set of data includes examination of the public media material that the general public was exposed to and referred to screening. Television programmes, newspaper and magazine articles and booklets written for prospective parents, from the beginning of 2000 until the end of 2005 were explored. The full results of these studies, discussing women's and men's considerations in depth and the analysis of the media discourse is published elsewhere (Gottfredsdóttir & Björnsdóttir, 2009; Gottfredsdóttir, Sandall & Björnsdóttir, 2008). In this paper, we are concerned with straightforward understanding of how individual prospective parents interpret choices they

are offered in the social context in addition to the media presentation of the offer of NT screening. By using extracts which reflect descriptions of choice and decision making we highlight how particular ethical concepts are topicalized. The data were initially indexed on a case by case basis, which allowed patterns and relationship between the codes to emerge within the data set. Here, analysis was performed by detecting and classifying the various occurrences of what was said about choice and decision making. (Ritchie & Lewis, 2003; Foucault, 1980)

Autonomy and decision making: traditional definition and adoption in practice.

The concept of autonomy is defined in a number of ways, but in the context of decision making in health care it is most often analyzed in terms of the right to make informed decisions. (Beauchamp & Childress, 2001). The main preconditions for such a decision are (i) that patients are informed about medical treatment or study and the options relating to it; (ii) that they understand the information; (iii) that there are no controlling influences that determine their actions. Each of these conditions is context dependent and a matter of degree. Various standards have been put forth regarding appropriate disclosure of information, ranging from objective criteria of what is reasonable for professionals to provide and for patients to know about a certain treatment, to meeting the subjective needs of the individual person making the decision.

In the context of our discussion, it would seem that a mixture of objective and subjective standards is needed. Prospective parents need to be informed both about the general aspects of fetal screening and about the particularities relating to their own treatment. The aim is not, however, that parents-to-be are fully informed, but sufficiently informed to be able to make an informed decision. Such understanding always takes place against a web

of background beliefs or knowledge of the individual (Kristinsson & Árnason, 2007) which can both facilitate and distort understanding. In the past years, a number of studies have highlighted that although the emphasis is to preserve autonomy and support informed decision making of patients, the manner in which health care is delivered can serve to undermine the role of the patient as an active partner in his health care (Hasman, Coulter & Askham, 2006).

In fetal screening, where information about risk is provided in terms of statistical probabilities and possible outcomes, understanding can be particularly difficult for someone who is not versed in such a discourse. This has been reported in recent studies where most women favour the option of screening but, at the same time, have limited knowledge of the procedure and its implications (Williams et al., 2005; Gourounti & Sandall, 2008).

The third criterion of autonomous decision making is that it is free from controlling influences. Obviously, the absence of controlling influences will never be absolute; this condition can only be met to a greater or lesser extent. In the real world people always act under various influences; therefore, it is important to consider the particular context of decision making and ask how the influences embedded in the situation may affect the self-determination of the agent. As pointed out by Marteau and Dormandy, an informed choice has two core characteristics: the decision is based on relevant good information and it reflects the decision-maker's values. The latter is insufficiently explored (Marteau & Dormandy, 2001) and can be very difficult to evaluate. People acquire values and norms in a process of socialization, and autonomy implies that people are able to reflect critically on their values (Dworkin, 1988).

In the context of fetal screening, many features need to be taken into account, such as the strong emotional aspect of the decision, the professional tendency to routinize the procedures, the medicalization of pregnancy and

the strange mixture of needing to make a most personal and 'domestic' decision in an 'Unheimlich' hospital setting. However, the rhetoric of autonomy is such that it is difficult to argue against it without falling into the trap of giving the impression of arguing against individual rights (Kerr, 2004). Therefore, it is important to gain insight into the context in which choices are made. This study takes place in a setting where, in 2006, around 87% of women underwent NT screening. These features will play a role in our subsequent analysis.

The conditions for autonomous decision making tend to be shaped by the models of patient-professional relationship that are predominant in the practice of health care (Smith, 1981; Veatch, 1981; Árnason, 1994, 2000). In the first model mentioned, which has strong paternalistic features, the main emphasis is on the expert medical knowledge of the health care professional whose primary responsibility is to help the person in medical need. This implies that the disclosure of information is guided by commitment to the patient's welfare as judged by the professional; he will rely on the good judgment of the experienced practitioner. Consequently, this model of the patient-professional interaction pays little attention to the requirement of patients' decision making, and the question of controlling influences does not arise.

In any event, it seems clear that the paternalistic model is flawed insofar as it identifies knowledge of the patient's medical condition with his best interests. This is particularly questionable in the decision making context of fetal screening where personal values, subjective beliefs and moral reasons play a significant role in weighing the risks and evaluating other information provided to the parents-to-be. These are nonmedical decisions and need to be freed from "the entrenched values and goals of medical professionals" (Beauchamp & Childress, 2001, p. 82). Although this model can be expected to belong to the past, recent studies of professional-patient relationship have

shown a gap between patients' desire for involvement and their experience (Coulter, 2006).

The second prevailing model of the patient-professional interaction, the patient autonomy model, takes this personal aspect of decision making strongly into account and places the main emphasis on the right of the patients to make decisions based on their own values. The main role of the professional is to provide medical information, preferably in a non-directive or even neutral way in order to free the patient from the values and goals of the medical professionals. In line with this, the patient should make up her own mind, free from the controlling influences of the professional who should limit his role to the medical and technical aspects of the situation. This is reflected in the attempt to develop clinical guidelines and regulations about screening where autonomy of the patient is often emphasized but suggestions regarding communication of information tend to be lacking.

One main feature of the patient autonomy model is that patients are to be 'left alone' in their deliberations, which can cause a feeling of abandonment, anxiety and a loss of trust which may undermine his decision making abilities. Despite their differences, the paternalistic and the patient autonomy model share in effect a major characteristic which has questionable consequences for patient autonomy. Neither model facilitates conversations or dialogue between patients and professionals. Each in its own way, these models are monological in the sense that they emphasize either the professional communication of medical information or the patient's communication of his personal values and preferences. They do not foster dialogical deliberation as a vehicle of informed and reflective decision making.

It is our contention that a communicative model which sees informed decision making as a cooperative task meets the conditions discussed above better than the other two models. Firstly, the best way to find an adequate

disclosure of information for a particular patient is to have a dialogical exchange of questions and answers. Only in this way can professionals know what information patients care and need to have and what they do not. Secondly, a conversation between patient and professional will show better than other available means whether the patient has understood the information or not. Thirdly, good communication has two main objectives which relate to freedom from restricting factors: information or freedom from ignorance and emotional support or freedom from fear and anxiety. Both cognitive and emotional factors can disrupt autonomous decision making and a dialogue where people meet in a joint task can serve as a midwife of good decision making. Such a dialogue, if authentically conducted and aimed at mutual understanding, also breaks up the institutional routine because it takes time and is not subject to the demands of efficiency and control. It is also the best way to build up trust which too many patients is more important than the exercise of self-determination.

It could be argued that a dialogical model of this sort is bound to strengthen the professional power in the relationship at the cost of patient autonomy. This is because the dialogue is inevitably asymmetrical as the patient has a weaker standing, both as a person in need of help and as depending on the professional for information and understanding. In the case of ultrasound and fetal screening this is particularly true (Nicol, 2007), but these facts also provide support for the need for a communicative approach to decision making: the professionals know more about the treatment or study, the patients know more about themselves (Katz, 1984), e.g. their own values and history. Both types of knowledge are needed to exercise shared decision-making or partnership approach to decision making (Coulter & Ellins, 2007). We see our analysis of the prospective parents' decision making experience in antenatal care as one test of this.

There is an important difference here between the information aspect and the value aspect of the situation. The information relevant for making an informed decision needs to be conveyed and understood; the values of the person making the decision need to be clarified and critically reflected upon, eath with a different amin; on the one hand that the person can make a decision that is informed and on the other hand that the person makes a decision that she can live with. A major complication in counselling is to provide an opportunity for reflection on values without directly affecting the decision. This is one reason why the autonomy model seems to be appealing: the person is given information but she should make up her mind without the influence of the professional. This model, however, is unlikely to ignite critical reflection about values and preferences which is part of the idea of autonomy (Dworkin, 1988).

The interpretation of bioethical concepts in the context of fetal screening

In this section we explore how prospective parents frame and explain the decision they are confronted with in early pregnancy, and relate our discussion with the Icelandic health care system. We also present how the media contributes to ethics in the context of fetal screening and how, in particular, it interprets certain ethical concepts such as choice, autonomy and informed decision making.

The significance of informed decision making among parents who accept and decline screening?

In Iceland, all women seek care within the primary health care system, except if the pregnancy is seen as high risk, then the care is provided within a special clinics (Regulation Health Care Centres, 2007). In this study it is important to be aware of the nature of the communication women have with

professionals in early pregnancy. In low risk pregnancies midwives attend all pregnant women throughout pregnancy, in cooperation with GPs and obstetricians if necessary. However, before signing up for antenatal care many women have had their pregnancy confirmed by their obstetrician who, in most cases, runs a private clinic. Of the twenty women who participated in this study, the majority had been to see an obstetrician before signing up for their first antental visit and six had their pregnancy confirmed with a GP. Two women had already met their midwife. Our data reveal a wide range of descriptions of how women are provided with information and other resources required to exercise their choices. During this first contact professionals are in a unique position to act in a way that facilitates the woman's understanding and promotes her autonomous decision making capacity if they frame their work within the communication model. It is of importance that expectant parents truly make decisions that are harmonious with their personal values and preferences; hence the informed decision making process must prepare them for the possible psychological and social ramifications of deciding to undergo screening, including the anxieties that might arise and the range of difficult decisions parents may face. This will not be achieved unless a dialogical exchange has taken place between the professional and the parents-to-be. Many examples in the interviews demonstrated that parents experienced that it was for them to decide on screening, but often expressed, at the same time, a lack of discussion on issues related to technical knowledge of screening, and not least on implications of the screening in the wider context. This was more apparent among parents who accepted the offer of screening. The following examples demonstrate how they describe the choices they are offered in relation to NT screening in early pregnancy:

We went to the doctor, the GP, as soon as we found out [about the pregnancy] and he told us not to worry about anything being wrong. [We should] just base our expectations on the fact that we were young, at the optimal age, both studying, and outdoor persons and so on. He said the GPs were not involved in this [the antenatal care] ... and I should just book a first antinatal visit with the midwife and they would take care of this…. He did not mention the NT screening at all. I only know about it from a book I bought in the beginning [of the pregnancy], where it was briefly mentioned.. (Woman no. 15).

I went to the general practitioner at the health care centre in our neighborhood. She [the GP] was entirely impartial. She said that some people accepted the screening and some did not. She neither spoke for it nor against and left it entirely to me to decide and told me I could go home and contact her again if I decided to go for it. I did not have to make up my mind there and then. – And next week I can get a referral from the midwife. But she did not tell me a whole lot, she (the GP) just referred to the LUH website and I have now read the information that is available there... I think it is a good idea to offer it [the test]. And I have also decided to do it because it is not obligatory. You choose whether to have it (done) or not (Woman no. 9).

Woman no. 11: She (the obstetrician) just handed the referral to me before I left and did not explain it further

Researcher: Had you already decided to have NT screening before you went to see your obstetrician?

Woman no. 11: No, I thought I would get information and advice regarding what to do.

As far as these women are concerned, their experience of choice differs. In the first example there is a young couple expecting their first child. They both went to the GP who only confirms the pregnancy. The GP in the second quotation does not see it as as his responsibility to explain the offer of screening but invites the woman to contact her again if she decides to proceed with the test. Hence, the woman is left with having to make the decision without any information at this stage. In the third example the lack of assuming responsibility for explaining the screening is also reflected in the comments of the obstetrician. All three quotations show in a different way an avoidance of participation in the discussion around screening and although most of the women who accept screening said it was a choice they made they argued that their decisions were based on the routinization of the screening.

Among the parents who declined, choice was experienced more as an evaluation of options. This was, however, rarely because of a different experience of disclosure with professionals as the following comments reflect:

I got information on the Internet. I read that there were mainly two chromosomal defects you screen for, apart from Down's syndrome. There you are looking at some probabilities and if the nuchal fold is increased then the risk for Down's syndrome is increased. (Woman no. 12)

This woman was expecting her second child and she had not been to see any health professional in the beginning of her pregnancy. Her choice not to

have the screening was based on her values and experience, as well as on the information she had found on the Internet.

Another woman in her third pregnancy described her experience in the following way:

> *I decided to phone my gynaecologist because I know him quite well... He said that we should just wait, which turned out to be the right thing to do. I had a very good discussion with him and he emphasized that this was a probability test, there were healthy fetuses lost in the process... he didn´t say what to do but we discussed also what it is to be healthy... what kind of a child do you want to have. (Woman no. 20)*

This woman was content with the discussion with the gynaecologist which helped her to make sense of all the information she had got from the Internet and from discussion with her family and friends.

The ethics of generating and disclosing information on NT screening in the media.

The implementation and development of fetal screening can be seen through the lens of the media discourse, where the media acts as a representative for the system which introduces the screening in each society. Analysis of the media coverage of fetal screening highlighted striking patterns. In an earlier paper the analytic themes were described which dominated the discourse in the Icelandic media around NT screening. Most references to fetal screening referred to professionals' perception of the screening as a progressive technique (optimism). This perspective was particularly dominating in the discussion during the first years, when, when the technique was being introduced. It was reflected in emphasis on the

effectiveness of the screening and its superiority over amniocentesis which had been offered to women thirty-five years of age or older (*Morgunbladid,* August 29, 2000). As time passed, other issues became more apparent in the debate. The issue of choice was prominent and targeted towards parents-to-be from the beginning. In an interview in the Icelandic newspaper *Morgunbladid* in 2002 with Chervenak, an influential physician and ethicist, he explains choice in the following way:

> *I think it is important and I emphasize that doctors give expecting mothers the best information available. The women themselves have to be in a position to make an informed choice/decision about their pregnancy (Morgunbladid*, June 30, 2002).

Chervenak does not question the implementation of NT screening which he defines as "a medically reasonable component of the management of pregnancy" in an article (Chervenak et al., 2005, p. 278), but he highlights that doctors must respect women´s autonomy to decide for themselves.

More examples are in line with this perspective. In an article with an obstetrician in *Morgunbladid*, choice is discussed in particular from the perspective of free, uncoerced choice and autonomy:

> *In my opinion it is the absolute right that parents have to accept or reject screening as it is they who will raise the child. Parents' circumstances are different and there is a variation in how well they are prepared to handle difficulties which accompany illness or disability of their children.*" *(Morgunbladid,* January_11,2004).

In our analysis of the press we found only few references to health benefits of fetal screening in the wider context. One example is an editorial (*Morgunbladid*, September 24, 2003), where it was claimed that the decrease

in stillbirths was the result of increased use of first trimester screening. Throughout the small number of TV news bulletins that could be found on the subject, differences in the discussion from the articles in the newspapers is clearly noticeable. This is probably because more than one speaker takes part in the discussion each time which calls for argumentation from different perspectives. In one instance (*Kastljós*, August 11, 2005), where there were three speakers, one ethicist/doctor, a mother of a Down's child and a consultant, the concepts of choice and informed decision were prominent. The mother said that the information people are provided with is based on the assumption that the life of children with Down's and their families is bound to be difficult. She further refers to the information people are offered, where the three trisomies are equally placed in the discussion, which is misleading and undermines the capacity of parents to make an informed choice. By contrast, the consultant claims that people today are well equipped to make decisions "We should rely on people's judgement, people are better informed today to make their own decisions." By framing the comment in this way the consultant shows an avoidance of the matter and he places the whole responsibility on the parents by highlighting their ability and autonomy.

Discussion

The answer to the question how ethical concepts are reflected in the clinical context is not clear cut. This study reveals, however, that both prospective parents and the public media include ethical terms in their rhetoric around fetal screening although those concepts differ in their expression. Hence, many of the prospective parents are explicit about the choice they made, which must be considered a positive finding. There were, however, interesting differences between the two groups of prospective parents in how choice was explained. The members of the former group,

those who accept screening, were less clear about their moral values and beliefs, which indicates that their attitude of screening was more characterized by compliance. Thus, one could argue that their values were more in line with the norms that prevail within the society in general. As such, their autonomy to make an informed choice can not be seen as coerced but affected by a number of factors. The value component was less visible in the interviews with participants in this group and as such it was difficult for them to recognize that there were other choices to be considered in the situation. Among individuals in the latter group moral values and beliefs were more visible. This is understandable because their decision is in conflict with the prevailing social norm and thus they become more aware of the values upon which it is based. This does not necessarily mean that a decision to decline is more autonomous than a decision to accept, but it can be regarded as requiring more independent judgement (Dworkin, 1988).

Marteau and Dormandy claim that in the context of screening the notion of informed choice has to refer to knowledge as well as values and beliefs of prospective parents (Marteau & Dormandy, 2001). However, it was hardly ever described in the interviews that the participants were confronted with a discussion of informed choice of this kind by professionals. It is recognized that professionals in the context of screening find it difficult to construct the discussion of informed choice and, although they recognise the centrality of the concept in fetal screening, they have many doubts whether it could be achieved (Williamset al., 2002; Alderson, Farsides & Williams, 2002). Also, the prominent view within the health service identifies numerous problems associated with Down's syndrome leaving out the more positive aspects which should be brought forward in the discussion. This can result in that information around screening is not questioned by professionals and the discussion is one sided (Alderson, 2001). In our data, only in a small number of interviews was it actually possible to describe the discussion as

cooperative or shared decision in the context of professional–parent relationship. One has to bear in mind, however, that those interviews are only with twenty couples and reflect on their experience of the situation.

Generally speaking, we found the presentation of screening in the media to be positive. This was reflected in two main issues: scientific achievement and the expansion of choice for prospective parents. Much of the items, however, frame choice and decision making in an idealistic way. They are sometimes superficial and lack connection with real situations, which corresponds to the autonomy model where the right to make an autonomous choice is highly emphasized and the responsibility rests with the parents first and foremost. This may affect other important aspects of patient-professional relationship (Williams et al., 2005). Furthermore, arguments are not given equal weight in the discourse nor do they act in the same manner on an audience. As others have noted, it is difficult to make generalizations about the impact of the media on public opinion and public policy. However, the correlation between the views expressed in the media and in the interviews suggests that the understanding of bioethical concepts is socially constructed. In such situations the meaning of bioethical concepts finds its own way through a mainstream discourse which has limited connections to the theoretical definitions. It is difficult to speculate if this actually promotes autonomy or facilitates informed choice in the context of screening in general, but it indicates that there is a considerable gap in the interpretation of those ethical concepts in the interviews and the media on the one hand and in theory on the other. These are complex effects of screening implementation which need to be incorporated in the discussions with prospective parents.

Conclusion

There seems to be a consensus in Iceland that fetal screening such as NT should be the choice of prospective parents. However, the discussion in the media hardly reaches the level of a moral debate where the actual meaning of ethical concepts is taken into account. Despite the fact that some professionals were eager to highlight parents' autonomy, the discussion was hardly ever accompanied by deliberation to reach informed choice. It has been pointed out that perhaps the routinization of screening limits moral reflection based on fundamental ethical concepts in the context and we believe that this present study supports that explanation. The Icelandic media mostly served as an amplifier for technological advance of NT screening and discussion of complex moral issues was scarce.

It is our hope that this study will be significant in the continued development of antenatal screening practice in Iceland.

References:

Alderson, P., Farsides, B., & Williams, C. (2002). Examining ethics in practice: Health service professionals' evaluation of in-hospital ethics seminars. *Nursing Ethics, 9*(5), 508–521.

Alderson, P. (2001). Prenatal screening, ethics and Down´s syndrome: A literature review. *Nursing Ethics*, *8*(4), 360–374.

Árnason, V. (1994). Towards authentic conversations. Authenticity in the patient-professional relationship. *Theoretical Medicine*, *15*, 227–242.

Árnason, V. (2000). Gadamerian dialogue in the patient-professional interaction". *Medicine, Health Care and Philosophy, 3*, 17–23.

Beauchamp, T.L., & Childress, J.F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press..

Berkel, D., & Weele, C. (1999). Norms and prenorms on prentatal diagnosis: New ways to deal with morality in counseling. *Patient Education and Counseling*, *37*, 153–163.

Chadwick, R. (1999). Genetics, choice and responsibility. *Health, Risk & Society, 1*, 293–299

Chervenak, F.A., McCullough, L., & Chasen, S. (2005). Clinical implications of the ethics of informed consent for first-trimester risk assessment for trisomy 21. *Seminars in Perinatology, 29*(4), 277–279

Coulter, A. (2006). *Trends in patients experience of the NHS*. Oxford: Picker Institute Europe.

Coulter, A. & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, *335*(7609), 24–27.

Directorate of Health (2006). *Medgönguvernd heilbrigdra kvenna í edlilegri medgöngu. Klíniskar leiðbeiningar* [Antenatal care in normal pregnancy. Clinical guidelines]. Retrieved 11, January. http://landlae knir. is / Uploads/FileGallery/Klininskar%20leidbeiningar/ Medgonguvernd_KL_-nov.2006.pdf.

Dworkin, G. (1988). *The theory and practice of autonomy*. Cambridge: Cambridge University Press.

Foucault, M. (1980). *Power /Knowledge: Selected interviews and other writings 1972–1977*. New York: Pantheon Books.

Garcia, Timmermann & van Leeuwen (2008). The impact of ethical beliefs on decisions about prenatal screening tests: Searching for justification. *Social Science and Medicine*, *66* (3), 753-764.

Gottfredsdóttir. H. & Björnsdóttir, K. (2009). 'Have you had the test?' A discourse analysis of media presentation of prenatal screening in Iceland. *Scandinavian Journal of Caring Sciences.* (in press)

Gottfredsdóttir, H., Sandall, J., & Björnsdóttir, K. (2008). "This is just what you do when you are pregnant": A qualitative study of prospective parents in Iceland who accept nuchal translucency screening, *Midwifery* (doi:10.1016/j.midw.2007.12.004).

Gourounti, K., & Sandall, J. (2008). Do pregnant women in Greece make informed choices about antenatal screening for Down's syndrome? A questionnaire survey. *Midwifery*, *24,*153–162.

Hasman, A., Coulter, A., & Askham, J. (2006). *Education for partnership: developments in medical education*. Oxford: Picker Institute Europe. Also available from http://www.pickereurope.org/ Filestore/PIE_reports/project_reports/E4P_report_19-5-06-_with_cover.pdf.pdf

Hjörleifsson, S., Árnason, V., & Schei, E. (2008). Decoding the genetics debate: Hype and hope in Icelandic news media 2000 and 2004. *New Genetics and Society*, *27*(4), 377–394.

Kagan, O.K., Avgidou, K., Molina, F., Gajewska, K., & Nicolaides, K.H. (2006). Relation between increased fetal nuchal translucency thickness and chromosomal defects. *Obstetrics & Gynecology*, *107*, 6–10.

Kitzinger J, & Williams, C. (2005). Forecasting science futures: Legitimising hope and calming fears in the embryo stem cell debate. *Social Science & Medicine*, *61*, 731–740.

Katz, J. (1984). *The silent world of doctor and patient*. New York: The Free Press.

Kerr, A. (2004). *Genetics and society: A sociology of disease*. London: Routledge.

Kristinsson, S. & Árnason, V. (2007). Informed consent and human genetic database research. In M. Häyry, R. Chadwick, V. Árnason, & G. Árnason *(Eds.)*, *The ethics and governance of human genetic databases. European perspectives* (pp. 199–216). Cambridge, New York: Cambridge University Press.

Marteau, T., & Dormandy, E. (2001). Facilitating informed choice in prenatal testing: How well are we doing? *American Journal of Medical Genetics, 106*, 185–190.

National Institute for Health and Clinical Excellence [NICE] (2008). *NICE clinical guideline 62. Antenatal care: Routine care for the healthy*

pregnant woman. London: Author. Retrieved April 10th 2008 from http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf

Nicol, M. (2007). Vulnerability of first-time expectant mothers during ultrasound scans: An evaluation of the external pressures that influence the process of informed choice. *Health Care for Women International*, *28*, 525–533.

Nicholaides, K. (2004). Nuchal translucency and other first trimester sonographic markers of chromosomal abnormalities. *American Journal of Obstetrics and Gynecology, 191*, 45–67.

Pálsson, G & Hardardóttir, K. E. (2002). For whom the cell tolls: Debates about biomedicine. *Currents anthropology, 43(2),* 271-287.

Petersen A., & Bunton, R. (2002). *The new genetics and the public's health*. London: Routledge.

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), 511–530.

Rapp, R. (2000). *Testing the women, testing the fetus*. New York: Routledge.

Regulation on Health Care Centres no. 787/2007. [Reglugerð um heilsugæslustöðvar nr. 787/ 2007].

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. London: Sage Publications.

Skirton, H., & Patch, C. (2002). *Genetics for healthcare professionals: A lifestage approach*. Oxford: BIOS Scientific Publishers Limited.

Smith, S. (1981). Three models of the nurse-patient relationship. In T.A. Mappes & J.S. Zembaty (Eds.), *Biomedical ethics* (pp. 120–126). New York: McGraw-Hill.

Suter, S. M. (2002). The routinization of prentatal testing. *American Journal of Law and Medicine*, *28*, 233–270.

Van Teijlingen, E.R., Hundley, v., Rennie, A.M et al (2003). Maternity satisfaction studies and their limitations: ´what is must still be best.´*Birth, 30,* 75-82.

Veatch, R.M. (1981). Models for ethical medicine in a revolutionary age, In T.A. Mappes & J.S. Zembaty (Eds.), *Biomedical ethics* (pp. 56–59). New York: McGraw-Hill.

Williams, C. (2005). Framing the fetus in medical work: rituals and practices. *Social Science and Medicine, 60*(9), 2085-2095

Williams, C., Sandall, J., Lewando-Hundt, G., Grellier, R., Heyman, B., & Spencer, K. (2005). Women as 'moral pioneers'?: Experiences of first trimester nuchal translucency screening. *Social Science & Medicine*, *61*(9), 1983–1992.

Williams, C., Alderson, P., & Farsides, B. (2002). Is nondirectiveness possible within the context of antenatal screening and testing? *Social Science & Medicine, 54*, 17–25.