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IN SEARCH OF GOOD MOTHERHOOD
HOW PRENATAL SCREENING SHAPES WOMEN’S VIEWS ON THEIR MORAL DUTIES TO THEIR FAMILY

ELISA GARCIA GONZALEZ
In search of good motherhood
How prenatal screening shapes women’s views
on their moral duties to their family
The study presented in this thesis has been performed at the Institute for Research in Extramural Medicine, Department of Public and Occupational Health, VU University Medical Centre, Amsterdam and the Section of Ethics, Philosophy and the History of Medicine, of the Scientific Institute for Quality of Healthcare, Radboud University Nijmegen Medical Centre, Nijmegen (IQ healthcare). IQ healthcare is part of the Nijmegen Centre for Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Nijmegen and the Netherlands School of Primary Care Research (CaRe), acknowledged by the Royal Dutch Academy of Science (KNAW).

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Nijmegen, 2011

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In search of good motherhood
How prenatal screening shapes women’s views on their moral duties to their family

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

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ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
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in het openbaar te verdedigen op donderdag 23 februari 2012
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prof. dr. J. van Vugt
prof. dr. T. Swierstra (Universiteit Maastricht)
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INTRODUCTION
One of the main concerns of pregnant women is the wellbeing of the foetus. Until relatively recently pregnancies took their natural course. Women could do little or nothing to assure a health child beyond a healthy lifestyle and diet. Reassurance about the health of the foetus or confrontation with a disabled child came only with birth. Scientific and technological developments in the area of prenatal testing have open up new novel opportunities for choice and control in human reproduction. Nowadays women have the possibility to obtain potentially significant information about the health status of their foetus during pregnancy and to choice in some extent the desirable characteristic of their offspring.¹

Prenatal testing includes both diagnostic and risk assessment procedures. The diagnostic tests provide certainty about whether or not the foetus has a disability. Current available diagnostic tests are chorionic villus sampling (CVS) and amniocentesis (AMN). CVS is performed between the 10th and 14th week of gestation through either transcervical or transabdominal removal of a sample of the placental tissue (chorionic villi). AMN is usually performed in the second trimester of pregnancy (between 15th and 18th week of gestation) through a transabdominal aspiration of a small amount of amniotic fluid. Because of the invasive character of AMN and CVS, they are associated with a risk of miscarriage of 0,3 % -0,8.² Other risks of these tests include bacterial infection and foetal injury.²⁻⁵ Hence, it is customary to reserve the invasive diagnostic procedures for pregnancies deemed to be a high risk for certain foetal genetic conditions. These risks include being of advanced maternal age (from 36 years and more), having had a previous child with a congenital anomaly and having a family history of congenital defects.⁵

Conventionally, the assessment of the risk of the foetus being affected by a certain disease or condition is determined through prenatal screening. During the period in which this study was carried out, the most commonly used prenatal screening tests included the Nuchal Translucency Measurement (NTM) and the Maternal Serum screening test (alpha-feto protein, human chorionic gonadotropin, and unconjugated estriol; MST). These screening tests provide information about the risk of the foetus having Down syndrome and other trisomies.³⁻¹⁴ NTM is performed in the first trimester of pregnancy (at 10th and 14th week of gestation). It involves the determination of gestational age and measurement of the thickness of the nuchal translucency zone. The deviation of the nuchal translucency from what is normal at the gestational age together with
the woman’s age-related risk produces an individualised risk estimation of the foetus having Down’s syndrome. The sensitivity of the NTM is about 70 to 75% with a specificity of 95%. MST is a blood test that is performed in the second trimester of pregnancy between the 6th and 18th week of gestation. An unusual high level of these three serum markers in the mother’s bloodstream combined with the maternal age and the woman’s age-related risk indicates the individualised risk of having a foetus with Down syndrome or neural tube defects. The sensitivity of MST is about 60 to 70% with a specificity of 95%.

An advantage of prenatal screening is that it does not involve any physical risks for the mother or the unborn child. A “normal” result from prenatal screening means that fewer women undergo further invasive testing reducing the number of miscarriages caused by invasive diagnostic.

Concerns in relation to prenatal screening involve the difficulty to interpret the odds of the screening tests. The possibility of false positives and negatives makes the assessment of the screening results more difficult. Since screening only estimates a woman’s risks for having an affected pregnancy, further diagnostic is needed to confirm the presence or absence of the screened condition. Once a woman has this information she must decide whether she wants to take the risks of invasive diagnostic and what is the right option according to her moral beliefs and values in case of a confirmed disability. The point should also be made that many of these decisions are bound by time constraints.

These facts have led disability group advocates and liberal feminists to claim that prenatal screening is actually not providing women greater autonomy in their reproductive decision making, but rather is placing pressure on women to assure the birth of a healthy child.

Prenatal screening in the Netherlands

While prenatal screening for Down syndrome and neural tube defects became accepted as part of standard prenatal care in most western countries a decade ago, health policy in the Netherlands has been reluctant to make screening available to all pregnant women. At the time the data for this study were collected (2002-2004), prenatal screening (NTM and MST) was not offered as part of prenatal care. The Population Screening Act (Gezondheidsraad: Commissie WBO, 1996) was enforced to protect people from screening for
serious conditions for which no cure or prevention exists. As termination of pregnancy is not regarded as neither treatment nor prevention population based prenatal screening by risk assessment tests was not allowed by law. Consequently, a specific license for prenatal screening was required. Only women with a higher risk for having a child with a congenital anomaly were offered invasive diagnostic tests. Women under the age of 36 or without specific risks could have a screening test if they asked for it and if they paid for the test themselves.25-28

This approach in which pregnant women outside the risk groups could have a test only at their own initiative presented two mayor disadvantages: 1) the age limit for the provision of prenatal screening deprived young women from knowledge that would help them to make better informed decisions regarding invasive diagnostic and 2) it could lead to inequality between those women who are well-informed and often better educated and those women who are not well-informed.27,28

From January 2007 onward, however, the policy has changed. Nowadays Dutch caregivers are legally obliged to inform each pregnant woman, regardless of her age, about the options for prenatal screening. Women who express interest in prenatal screening should be provided with both verbal and written further information about methods for foetal screening and diagnostic with the emphasis on voluntary participation. Women in the risk group may directly choose for CVS or AMN. Women under the 36 year and with not known risks are only eligible for risk assessment tests. Cost of these test are still reimbursed only for women in the risks groups. The costs of diagnostic tests are reimbursed for women younger than 36 of the screening result indicates an increased risk.29

The decision of the Dutch parliament of expanding information about prenatal screening to young women has been debated for over two decades.25-27,30,31 Crucial to this debate were the ethical, social and cultural aspects associated with an unsolicited test offer.

While prenatal screening is commonly presented as offering new reproductive choices for women (and their partners)17,32-35, one of the main concerns of the Dutch parliament regarding the introduction of nationwide prenatal screening program was the negative impact that an unsolicited test offer could have on women’s reproductive autonomy and ethical decision making. Despite the fast technological development of means for detecting affected foetuses, the possibilities for antenatally curing congenital diseases of
foetuses are still very limited. The only options which are generally available to a woman following detection of an affected foetus are either termination of pregnancy or preparing for the birth of a disabled child.\textsuperscript{36,37} Consequently, an active offer of prenatal screening might force women to make value-laden decisions about the life of the foetus, bringing them into complex ethical dilemmas.\textsuperscript{20-23}

Contributing to the discussion about the coercive character of the choice was the idea that incorporation of screening into routine prenatal care leads to medicalisation of pregnancy transforming it from a normal and joyful period to a risk-dominated and technology guided event.\textsuperscript{38} This is a development that is contrary to the traditional support given in the Netherlands to a ‘natural approach’ to pregnancy and delivery.\textsuperscript{39,40}

**Autonomy of the choice**

At the basis of the debate about the desirability of expanding prenatal screening to all pregnant women is the assumption that women have an indisputable right to autonomous reproductive choices. Two different views about the effect of an active offer of prenatal screening on the women’s reproductive autonomy and ethical decision making can be distinguished.

Defenders of a standard offer of prenatal screening are of the opinion that more knowledge about the health of the foetus gives pregnant women the opportunity to enhance their reproductive autonomy.\textsuperscript{32} This assumption is based on the rule that for rational individuals more choices are always preferred to less choices or no choices at all. According to this line of thinking, women should be informed of all the tests available in order to enable them to make informed, objective decisions about their need for prenatal testing.\textsuperscript{12,41 47} Depriving women of the possibility of performing prenatal screening, would thus restrict their autonomy by impeding their access to the detection of serious malformations and therefore to abortion and other options.\textsuperscript{48}

For their part, opponents of the standard offer of screening to all pregnant women claim that an unsolicited offer does not provide women with greater autonomy but rather restricts their scope for deciding themselves whether they want to know all possible deficiencies in their child. Women to whom screening is offered cannot avoid making a decision about whether or not to use to test.\textsuperscript{25-27} The obligatory character of the choice, might place pressure on women to make use of the available means to ensure the birth of a healthy child.\textsuperscript{41,44-48}
forcing them to make decisions that meet society's norms and values.\textsuperscript{4,20,49-60} Therefore, they argue that autonomy would be respected only when women ask for screening themselves. Only in this case, the request would reflect their personal values without pressures due to the expectations of family, practitioners, friends and society at large.\textsuperscript{61}

**New choices and new dilemmas**

One of the arguments of the Dutch Government against a nationwide prenatal screening programme was that an unsolicited test offer might bring women into a moral dilemma when considering having the test performed or not. This dilemma was sketched as follows: since there is no therapy available for most of the screened disabilities, women receiving abnormal results are forced to make a choice between two equally binding and mutually exclusive ethical principles, namely the moral duties of "respecting the life of the unborn" and "avoidance of suffering". These two principles support two incompatible options: 1) bringing the pregnancy to term, implying direct responsibility for the suffering of a disabled child; or 2) opting for abortion and therefore violating the right to life of the foetus.\textsuperscript{25-27,29} The impossibility to foresee either the degree of suffering or the consequences of a disability makes it more difficult to determine what is the right choice from a moral perspective.

**Added responsibility**

Debates about the women's right to make their own reproductive decisions highlight the double-edged nature of this desire for reproductive autonomy.\textsuperscript{62,63} More knowledge entails more choices: a choice whether or not to take the test and subsequently a choice on whether or not to abort a disabled child. Whereas in earlier times the birth of a disabled child was just bad luck, the development of prenatal screening has turned disability into something that could have been prevented making parents morally responsible for the burdens of a disability on the child itself, their family and society at large.\textsuperscript{1,64}

While the prevention of disabled children do not form the main objective of prenatal screening, the decision of the Dutch parliament to offer information about the test to all pregnant women makes the prevention of children with the screened disabilities the express responsibility of individual pregnant women. According to Tijmstra, women would become more and more dependent on medical technology and related expertise, feeling more and more weighed
down with the responsibility for the full term of the pregnancy and the outcome.\textsuperscript{38}

**Need for empirical moral evidence**

The growing consensus is that women will only benefit from the test offer when they are able to make an autonomous decision in accordance to their ethical values and beliefs.\textsuperscript{33,34} However, little attention has been paid to the impact of women’s ethical beliefs on decision making. Most of the studies on women’s motives for accepting or declining prenatal screening tests, principally focus on the psychological and emotional aspects of decision making.\textsuperscript{17,65-75} Other studies focus on the influence of culture and religion. These studies are limited to groups with strong religious convictions.\textsuperscript{76-79} Consequently, although it is assumed that the ethical values of parents also play an important role in decision making,\textsuperscript{51,80,81} their precise significance is not sufficiently clear. The concrete impact of women’s ethical beliefs in decisions regarding prenatal testing needs to be addressed in order to determine under which conditions the offer of prenatal screening can be justified from an ethical viewpoint.

**Objective of this thesis**

The aim of the study presented in this thesis is twofold. First it aims to highlight the impact of a test offer on the women’s reproductive autonomy. In accordance with the ethical principle of autonomy, decisions regarding screening should be guided by the woman’s own ethical beliefs and values without any external influence coming from the views and interests of other persons. Therefore, it is important to determine the ethical considerations behind decisions regarding the use of prenatal screening and whether women to whom prenatal screening has been offered decide according to their own ethical values and beliefs.

A second aim of this study is to assess the effect of an unsolicited test offer on the women’s views on their moral duties toward their offspring.

In order to explore the conceptual framework of this thesis we addressed four central research questions that come to the fore in the Dutch debate:

1. What are the women’s ethical views regarding prenatal testing and control of the offspring characteristics? What is the concrete impact of these ethical beliefs on decision making regarding participation in prenatal screening? (chapter 2 and 3)
2. Does an unsolicited offer of a prenatal screening test impede women to decide according to their ethical beliefs and preferences? Can we say that the test offer is a threat for the autonomy of the woman? (chapter 4)

3. Does the test offer compel women to choose between two or more equally demanded (ethical) norms and values that require different and exclusive choices, bringing them into an ethical dilemma? (chapter 5)

4. Which is the impact of the availability of prenatal screening on the woman’s views regarding their moral duties towards their offspring? (chapter 6).

Answer to these questions will provide an original contribution to existing studies on women’s reasons and motivations for using prenatal screening and to existing debates about the desirability of expanding an active test offer to all pregnant women.

Methods

The study presented in this thesis is a qualitative study that forms part of a larger research project, which was a randomized controlled trial (RCT) carried out at the VU Medical Centre between May 2001 and April 2004. The RCT aimed to investigate risk perception, decision making and the psychological wellbeing of pregnant women who are offered prenatal screening.

Participants were enrolled from 44 midwifery and gynaecology practices all over the Netherlands, between May 2001 and April 2004. Exclusion criteria of the RCT were: a gestational age of more than 16 weeks and command of the Dutch language. Women who gave informed consent were randomized into two intervention groups and a control group. Women in the first intervention group were offered a defects a NTM for Down syndrome; women in the second intervention group were offered a MST for Down syndrome and neural tube defects; women in the control group received normal care at that moment in the Netherlands (no offer). The test offer consisted of an information booklet sent to the participants at home and an oral explanation by the midwife or gynaecologist. The booklet contained information about the particular screening test, the disorder(s) screened for, the possible test outcomes and the options available in case of an increased risk.

Data collection took place through postal questionnaires at different points in time during and after pregnancy: before any information about screening was given (T1); after a prenatal screening test was offered but before it was performed (T2); after the test result was know or at a comparable time for
women in the intervention group who declined the screening test and for those in the control group (T3); at the last trimester of pregnancy (28th week) (T4); and within two months after delivery (T5). During the inclusion period, 4077 pregnant women were asked to participate in the study. A total of 2986 women (73%) gave informed consent. To protect anonymity, each woman was allocated a numerical code.

A subgroup of participants of the RCT was randomly selected for participating in the qualitative study (n=140). These women received an extra questionnaire with open ended questions at T1, T4 and T5. The questionnaires included questions about the women’s ethical views regarding the selection of the offspring’s characteristics and abortion. In questionnaire T4 we included additional questions about their feelings regarding the test offer and the decision they made. An additional question concerning their view about the right decision in case of a foetus with Down syndrome was included. In questionnaire T5 we asked participants whether they would make the same decision in a next pregnancy and the reasons for their decision. This questionnaire was directed to assess whether the availability of prenatal screening leads women to believe that they have a moral duty to accept testing. A total of 130 women returned questionnaire T1 (63 from the MST group and 67 from the NTM group). A total of 117 women returned questionnaire T4 (60 from the MST group and 57 from the NTM group). A total of 111 women (44 from the MST-group and 67 from the NTM-group) returned the T5 questionnaire.

Some participants who were in the process of deciding about testing (T2) were also randomly approached for participating in a face to face semi-structured interview (n=81). The aim of the interview was to obtain deeper insight into the consideration that women make when deciding about the acceptance of a prenatal screening. Participants were asked by phone to make an appointment within a week after the test offer was received and before the test would eventually be performed. In total 59 women (26 from the MST group and 33 from the NTM group) agreed to be interviewed.

As this thesis was aimed at exploring the ethical aspects of decision making of women to whom a prenatal screening test was offered, and the participants in the control group were not offered prenatal screening, only data of pregnant women in the intervention group were used.

An overview of the different times of data collection and number of participants is given in table 1.
Outline of this thesis

Chapter 2 explores the role of the women’s individual ethical beliefs and moral norms in decision making regarding the use of prenatal screening and their impact on the final decision. Under the notion of ethical beliefs we understand personal values, moral standards, intuitions, sentiments and views about what is right and wrong in topics related to reproductive issues. Our leading question was: “which, if any, is the impact of the women’s personal ethical beliefs and moral norms in decision making?” For this analysis we used data from the semi-structured interviews performed with participants who were in the process of deciding about the acceptance of screening (T2).

The analysis of the semi structured interviews showed that considerations about the legitimacy of intervening in the course of nature were taken into consideration when deciding about the acceptance of the test offer. In chapter 3 we analyses what women exactly mean when they appeal to nature and the impact of those meanings on decision making. Data for this analyse were collected from the semi-structured interviews performed at T2.

Chapter 4 focuses on the effect of an active offer of prenatal screening on women’s autonomy. The question we aimed to analyse in this chapter was: does the offer of prenatal screening impede women in making autonomous choices? To answer this question we explored whether women to whom a test was offered, decided freely according to their personal values and beliefs or were on the contrary compelled to make a certain kind of choice by both external - i.e. the opinion of important ones, social or cultural expectations- and internal pressures- i.e. emotions, doubts and wishes - raised by the test offer. Data for this chapter were collected from the above mentioned semi-structured interviews. (T2)

Chapter 5 explores the possible conflicting aspects in the choice regarding the acceptance of prenatal screening. The main aim of this chapter was to analyse whether women confronted with a test offer face a (genuine) moral dilemma. Like the previous chapters semi-structured interviews provided the data for this chapter. In order to detect possible (moral) conflict we analysed the interviews for expressions of doubt and worry, conflicting duties, needs and wishes.

Chapter 6 looks at the impact of an unsolicited prenatal screening test on women’s believes about their parental duties. The central question in this chapter was whether the availability of prenatal screening leads women to
believe that they have a moral duty to test. Data for this chapter were collected from the open ended questionnaire sent at T5.

Chapter 7 includes a case study that show a change in ethical views and attitude to prenatal screening by a woman who declined the offer of the screening test during our study and delivered a child with Down syndrome. In Chapter 8 the implication of the findings of this study for ethical theory and clinical practice are discussed.
Table 1: Schema of data collection.

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<th>Data collection</th>
<th>Time</th>
<th>Approach</th>
<th>Participants</th>
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<tr>
<td><strong>T1</strong></td>
<td>Before prenatal screening has been offered</td>
<td>Open ended questionnaire with items about participants’ ethical views regarding the selection of the offspring’s characteristics and abortion.</td>
<td>N = 130 (63 from the MST group and 67 from the NTM group)</td>
</tr>
<tr>
<td><strong>T2</strong></td>
<td>During decision making about the acceptance of the screening offer</td>
<td>Semi-structured interview with items about: - Participants’ reasons for their decision. - Participants’ ethical views regarding the selection of the characteristics of the offspring and abortion.</td>
<td>N = 59 (26 from the MST group and 33 from the NTM group)</td>
</tr>
<tr>
<td><strong>T4</strong></td>
<td>In the last trimester of pregnancy</td>
<td>Open ended questionnaire with questions about: - Participants’ ethical views regarding the selection of the offspring’s characteristics and abortion in case of a foetus with Down syndrome. - Participants’ ethical views regarding the offer of prenatal screening and regarding the decision they made.</td>
<td>N = 117 (60 from the MST-group and 57 from the NTM-group)</td>
</tr>
<tr>
<td><strong>T5</strong></td>
<td>Within two months after delivery</td>
<td>Open ended questionnaire about: - Participants’ opinion on the test offer - Participants´ decision in a next pregnancy - Participants’ ethical views on the significance of testing within their parental duties and rights</td>
<td>N = 111 (44 from the MST-group and 67 from the NTM-group)</td>
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THE IMPACT
OF ETHICAL BELIEFS
ON DECISIONS ABOUT
PRENATAL SCREENING TESTS:
SEARCHING FOR JUSTIFICATION.

ELISA GARCIA / DANIELLE R. M. TIMMERMANS / EVERT VAN LEEUWEN
SOCIAL SCIENCE & MEDICINE 2008, 66 753 764
Abstract

Prenatal screening for Down syndrome and other chromosomal anomalies has become common obstetrical practice. The purpose of this intervention is to provide women with the information needed to make informed reproductive choices. It is assumed that the ethical beliefs of the women play an important role in decision making about whether to undergo testing or not, but little is known about their precise significance. More insight into how women conceptualise their choice of using prenatal screening tests may clarify the impact of personal ethical beliefs. With this aim, we conducted qualitative research consisting of semi-structured interviews with 59 women in the Netherlands who were offered a prenatal screening test.

Analysis of the interviews revealed that the ethical views between acceptors and decliners showed similar diversity. In contrast with the currently accepted view, we conclude that ethical beliefs are one of the factors implicated in the decision. Women decide about prenatal screening by balancing the information provided by the test against the risks of further investigation, the emotional burden of a disabled child on their wellbeing and life perspective, as well as on those of family members. Normative moral principles are introduced once the choice is made, namely as factors in justifying and supporting the decision.
Introduction

Prenatal screening for Down syndrome and neural tube defects has become common obstetrical practice in many countries.\(^1,2\) The purpose of this intervention is to provide women with information in order to enhance their reproductive choice.\(^3\) An important ethical condition for the introduction of prenatal screening is that women decide according to their own values and are able to come to terms with their decision.\(^4\)

Since no treatment is available for the defects detected by the test, women receiving a prenatal screening offer are thought to be confronted with ethical questions about the value of a disabled life and their parental responsibilities regarding an affected foetus. Therefore, the women’s ethical beliefs assumingly play a leading role in the decision on prenatal testing.\(^5-7\) The aim of the present study is to explore the impact of the woman’s personal ethical beliefs on decision making regarding prenatal testing. Under the notion of ethical beliefs, we understand the total set of personal values, moral standards, intuitions, sentiments and views about what is right and wrong.

Many studies have been performed on women’s motives for accepting or declining prenatal screening tests. Some of these studies principally focus on the social, psychological and emotional aspects of decision making.\(^8-16\) Other studies focus on the influence of culture and religion. These studies are limited to groups with strong religious convictions.\(^17-20\) Little attention has been paid to the impact of ethical beliefs on decision making in Western secular societies. In many countries prenatal screening has become normal antenatal care. This may impede women to contemplate the ethical norms related to reproduction and to decide in consequence. Consequently, the concrete role of women’s ethical beliefs in decisions regarding prenatal testing is not sufficiently clear.

In contrast to other countries, prenatal testing was still not part of normal antenatal care in the Netherlands at the time our study was performed. According to the Population Screening Act (PSA; 1996), the Dutch population needs to be protected against screening programs that could be a threat to psychological or physical health. Prenatal screening for serious and untreatable disorders was supposed to be such a threat and is therefore not allowed by law. Only women with an increased risk of giving birth to a disabled child due to advanced maternal age or a medical indication were allowed to be offered prenatal testing. Although it was forbidden to offer testing to women without an increased risk, tests were allowed if women requested the test themselves.
Since January 2007, this policy has changed in so far that women with normal risks can be informed about available tests, but the tests are not reimbursed.

The prohibition on the explicit offering of prenatal tests made it possible to study the effects of such offering in a randomised controlled trial. The RCT enrolled 1968 pregnant women from 44 midwifery and gynaecology practices all over the Netherlands. The study was carried out at the EMGO Institute of the VU University Medical Centre (VUMC). Exclusion criteria were: a gestational age of more than 16 weeks, and no command of the Dutch language. Participants were randomised in two intervention groups and one control group. One intervention group was offered a Nuchal Translucency Measurement (NTM) for Down syndrome (n=729). The other intervention group received a Maternal Serum Screening Test (MST) for Down syndrome and NTD (n=670). The control group (n=569) received normal antenatal care without any test offer. The purpose of the RCT was to assess the decision making of women when confronted with a prenatal test offer, the psychological effects of the decision and its consequences. Data collection took place through questionnaires about the personal reasons for accepting or declining the test. A special permit for explicitly offering of prenatal screening was granted by the Minister of Health, under the PSA. The study was also approved by the Medical Ethics Committee of the VUMC.

A qualitative study was developed in conjunction with the RCT in order to get more insight into the impact of ethical beliefs on decision making.

Methods

In the qualitative study, we focused on the ethical topics that women take into consideration when deciding about prenatal screening.

Participants of the RCT, who were in the process of deciding whether to accept the offer, were asked by phone to participate in an interview. Participants were randomly selected and asked to make an appointment within a week after the test offer was received and before the test would eventually be performed. We approached 81 women from the intervention groups. Since our purpose was to study the impact of ethical beliefs on decision making after being confronted with a test offer, we did not include participants of the control group because a test was not offered to its members.

In total 59 (of 81) women (26 from the MST group and 33 from the NTM group) agreed to be interviewed. The reasons for declining the interview were
lack of time (n=16) and the impossibility of making an appointment before performing the test (n=4). Two women (n=2) refused because of the nature of the subject.

The demographic characteristics of the interviewees, compared to the group of participants in the RCT, are summarised in Table 1. The interviewed group resembles a representative sample of all the women participating in the quantitative research project, when compared to social status, level of education, age and religious conviction.

Table 1. Demographic characteristics of women participating in the present study and of the total participants’ group.

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<td>NTM=729 MST=670</td>
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<table>
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<th>Age</th>
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<tr>
<td>&lt;35</td>
<td>45</td>
<td>1,227</td>
</tr>
<tr>
<td>&gt;35</td>
<td>14</td>
<td>123</td>
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<table>
<thead>
<tr>
<th>Educational level</th>
<th>Interview sample</th>
<th>Total participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>25</td>
<td>579</td>
</tr>
<tr>
<td>Middle</td>
<td>23</td>
<td>616</td>
</tr>
<tr>
<td>Low</td>
<td>9</td>
<td>165</td>
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</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Interview sample</th>
<th>Total participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>39</td>
<td>925</td>
</tr>
<tr>
<td>Cohabitating</td>
<td>19</td>
<td>448</td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
<td>24</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Interview sample</th>
<th>Total participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>29</td>
<td>602</td>
</tr>
<tr>
<td>1</td>
<td>20</td>
<td>574</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>163</td>
</tr>
<tr>
<td>&gt;3</td>
<td>3</td>
<td>60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>Interview sample</th>
<th>Total participants</th>
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</thead>
<tbody>
<tr>
<td>Active</td>
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<td>58</td>
</tr>
<tr>
<td>Somewhat active</td>
<td>10</td>
<td>255</td>
</tr>
<tr>
<td>Inactive</td>
<td>18</td>
<td>412</td>
</tr>
<tr>
<td>Without religion</td>
<td>29</td>
<td>668</td>
</tr>
</tbody>
</table>

NTM: Nuchal Translucency Measurement; MST: Maternal Serum screening test. For the interview sample, the totals of degree of religiosity and educational level do not add up to 59 because of missing values on these questions. For the total sample, the totals of age, marital status, degree of religiosity, and educational level do not add up to 1399 because of missing values on these questions.
Interviews

Interviews were carried out at the participant’s home. We decided to interview only women because we assumed that this might facilitate a more open discussion. Furthermore, some of the women included in the study were single. We included a question in the interview regarding the opinion of the partner and its effect on the woman’s final decision. The interviews were conducted by E. Garcia and two professional interviewers ascribed to the VUMC. Interviews were recorded and transcribed with permission. To protect anonymity, each woman was allocated a numerical code.

All interviews followed the same semi-structured plan, with two distinguished parts. Firstly, we started with open-ended questions about the women’s reasons to accept or decline the screening test. Special attention was paid to other topics emerging in responses and identified as important by the participants. We studied the contribution of others on the decision making, by explicitly asking the women which persons they had approached and the influence of their opinion upon their final decision. Secondly, we extended the dialogue to ethical topics considered to be of importance in making a choice about prenatal testing in general (not only on prenatal screening) such as, “worth of a life with a disability”, “parental rights and responsibilities”, “moral status of the foetus” and “abortion”.

The interview questions were assessed for their intelligibility after performing the five first interviews. No adaptation was needed.

Data analyses

Interviews were qualitatively analysed using a two-steps inductive approach. In a first analysis, we looked for the reasons women reported for accepting or declining the test offer. The second part of the interview was coded according to the themes discussed. The themes were then sorted into sub themes according to the different views that emerged from the responses, using the assistance of computer software N-Vivo (Nudist-Vivo, 2.0, QSR software, Durham, UK).

After some adaptations, the different ethical items were finally organised into nine main categories. The resulting categories were then discussed by other researchers participating in the RCT-study. To test the reliability, the first three interviews were analysed by other researchers. Differences were found in fragments admitting a double coding among “being against abortion”, “parental
responsibility to respect the life of the unborn”, “accepting the child unconditionally” and “accepting their own destiny”.
After some discussion, these differences in interpretation were resolved.

Results
Before we present the ethical reasons that are involved in the decision making process, we give a summary of the test uptake and the reasons given for accepting and declining the test offer based on the RCT study. Then we will proceed with the results of the qualitative study.

Test uptake among participants
Table 2 gives the distribution of acceptors and decliners. The overall acceptance was 46% among the RCT participants and 35% among the participants of the qualitative study. No reason was found for this difference and it may be attributed to coincidence. The NTM test acceptance (36%) among interviewers was significantly lower than in the RCT (53%). More concordance was found in the MST update with 34% of the women interviewed accepting the test offer, comparing with 38% test uptake of the total participants.
From the RCT study it becomes clear that no differences were found between the two intervention groups with respect to the diversity of reasons in the acceptance or denial of the test offer.21,22

Table 2. Test uptake of the interview sample in comparison with the total participants group.

<table>
<thead>
<tr>
<th>Prenatal test offer</th>
<th>Accepting screening</th>
<th></th>
<th>Declining screening</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total participants</td>
<td>Interview sample</td>
<td>Total participants</td>
</tr>
<tr>
<td>NTM&lt;sup&gt;a&lt;/sup&gt;</td>
<td>387 (53%)</td>
<td>12 (36%) &lt;sup&gt;c&lt;/sup&gt;</td>
<td>342 (47%)</td>
</tr>
<tr>
<td>MST&lt;sup&gt;b&lt;/sup&gt;</td>
<td>254 (38%)</td>
<td>9 (34%)</td>
<td>416 (62%)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Nuchal Translucency Measurement.
<sup>b</sup> Maternal Serum screening test.
<sup>c</sup> One of the participants has not performed the test because there was no place in the hospital.
<sup>d</sup> Two participants declined the screening test because they wanted to perform amniocentesis.
<sup>e</sup> One participant preferred to perform an NTM offered by the gynaecologist.
**Reasons for declining**
The reasons for declining the screening offer are given in Table 3. These reasons coincided with those given by the interviewees who declined the offer.

There was one difference between the data from the RCT and the qualitative data. Opposing abortion was a reason against screening for only 15% of the participants of the RCT. Nevertheless, analysis of the qualitative data showed that all interviewees (100%) mentioned unwillingness to decide about termination of pregnancy in the case of Down syndrome as an important factor. Down syndrome was described as being not serious enough for justifying termination. The impossibility of controlling everything and concerns about the acceptability of intervening in the natural outcome of pregnancy were mentioned in the interviews as additional reasons for declining.

Practical reasons, such as the difficulty in making an appointment at the hospital and the lack of time, were also reported as extra reasons by a minority of the decliners (2/39). Two participants declined the screening test because they opted for amniocentesis.

**Table 3. Overview of the reasons for declining screening.**

<table>
<thead>
<tr>
<th>Reasons for declining screening</th>
<th>One of the reasons (n=758)</th>
<th>Decisive reason (n=500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inaccuracy of the test</td>
<td>42</td>
<td>22</td>
</tr>
<tr>
<td>Anxiety</td>
<td>36</td>
<td>13</td>
</tr>
<tr>
<td>Adverse characteristics of diagnostic test</td>
<td>32</td>
<td>11</td>
</tr>
<tr>
<td>No wanting to perform abortion</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td>Acceptance destiny</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>Non necessary</td>
<td>35</td>
<td>12</td>
</tr>
<tr>
<td>Practical reasons</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>

**Reasons for acceptance**
Reasons for accepting the test offer are given in Table 4. In the qualitative study, acceptors gave fewer reasons to accept the test compared to the decliners. This finding was not confirmed by the RCT analysis.

None of the acceptors mentioned the finding of Down syndrome or abnormal conditions as reason for using the screening. The qualitative study showed that desiring more knowledge about the health of the foetus is related to the desire to obtain reassurance and to exclude worries during pregnancy. This differs
from the quantitative results where the desire to obtain reassurance was reported only by 8% of the women as a reason for testing.

Table 4. Overview of the reasons for accepting screening.

<table>
<thead>
<tr>
<th>Reasons for accepting screening</th>
<th>One of the reasons (n=641)</th>
<th>Decisive reason (n=353)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Favourable characteristics of the screening test</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>Gaining knowledge</td>
<td>50</td>
<td>29</td>
</tr>
<tr>
<td>Basis for deciding about diagnostic test</td>
<td>36</td>
<td>21</td>
</tr>
<tr>
<td>Personal risks</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Wanting a healthy child</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Reassurance</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>

Results from the qualitative study

The ethical beliefs were divided into nine categories on the basis of the topics discussed in the second part of the interviews. The results are given by referring to acceptors and decliners and to all participants where the whole study group is meant. As a key to the presentation of interview data in the following sections, K indicates a participant recruited from private midwife practice and O indicates a participant recruited from a hospital-based midwife practice; these letters are followed by the number assigned to the practice, then the number assigned to the interviewee and finally information on whether the interviewee had accepted or declined the MST or NTM.

Parental responsibilities

All participants described their parental responsibilities in terms of protection, care and guaranteeing their children and themselves an adequate quality of life. Prenatal screening was described as a free personal option. Women felt compelled to avoid situations and habits during pregnancy that might endanger the health of their offspring, such as smoking and drinking. The main reason for not considering screening as a parental obligation was that the test does not give sufficient information for further decisions.

"It seems to me to be far too complicated to make a choice or take a decision. Suppose they say it is not good. Well, to what degree then? And it seems to me to be far too difficult to say I will not do it, or I am going to have it tested, or I will have taken it away. I don't know." (K194-150; NTM-acceptor)
Both women accepting and declining the test described their parental responsibilities as being context dependent. All of them admitted that their choice could be different in different circumstances.

**Control of offspring's qualities**

A perfect child was described as an unachievable ideal. Still, participants were of the opinion that parents have a right to decide whether the child's characteristics fit their life, according to their personal situation and based upon what they consider good. This includes selection of those children they think they are able to care for.

"In principle I agree that parents have the right to make that choice, because while the government might indicate that you cannot have an abortion in case of a child with Down syndrome and in fact, the parents are convinced that they cannot deal with having a child with Down syndrome, what kind of a life would such a child have? No life either, even if it has but a small disability. So I do think that in principle it is something for the parents to decide." (K037-101; MST-decliner)

All participants agreed that unconditional acceptance of children is the most praiseworthy approach.

"I admire that. I have incidentally read about two women, one was about thirty-eight or something and the other was forty-two and both were having a baby without considering taking a test. And I do think that is admirable. I am not sure what I would do myself. It is really difficult to say. But indeed, I admire them for taking things the way they are." (0609-079; NTM-decliner)

All participants worried about the obsession with physical perfection in society. They feared that prenatal testing would be used as a eugenic means, leading to the commodification of children.

"I think that these things are part of life, so I would dislike it if people were to say on a given moment that if the child has a risk of being deaf, we do not want him anymore, or if the child has freckles I do not want him." (K188-189; MSTM-acceptor)
There was one difference between acceptors and decliners. It had to do with the significance attached to the avoidance of Down syndrome, while knowing that other anomalies can also be present.

**Interest of the child**

The interest of the child was formulated in terms of happiness, quality of life and being loved. All participants connected the child’s happiness with the possibility of developing a satisfactory and autonomous life, according to accepted social standards.

“The most important thing for me, thinking about my child, is that he can be independent and make his own choices and that he can be happy in life, and I find that very difficult in the case of a child with Down syndrome.” (K034-074; NTM-acceptor)

Closely related with this view, participants also agreed that not-to-be-born could be the most acceptable option; when a reasonable normal life cannot be reached because of the severity of the disability. In case of less severe disabilities, the future happiness of the child was described as depending on the degree of acceptance by the parents and of their capacity to love such a child.

“Yes, it is only fair to such a child, because if the parents really are convinced that they cannot raise such a child yet they would have it, then a child like that can never be happy. Nor the parents, in fact. But the child would not. Then I am afraid such a child will end up being the victim of the situation within the family, or very soon outside the family. So then I think that the child itself is not better off to be born with parents who do not want him.” (K037-101; MST-decliner)

The difference between acceptors and decliners had to do with their assessment of the information provided by the test, in relation to the best interest of the child. Acceptors considered it as a means to ensure a good life for their child. Decliners considered avoiding unnecessary risks for the foetus as the most rational action in the best interest of the child.

**Status and foetus’ right to life**

All participants defended the right to life of all foetuses, even those who did not consider the foetus as a real child. However, the right to life of the foetus was not reported as absolute and to be protected in all cases. Participants
supported the right to life of the unborn child as being subordinated to the quality of life of the child itself and to the wellbeing of their family members.

"In principle I think that they have the right to exist, but I do think that as a parent you should have the choice to decide yourself what you want and in how far you want to go." (K372-051; MST-acceptor)

Participants differed in their opinions about when the foetus has to be considered a human being. The opinions fluctuated between the moment of conception and the moment on which they could feel the foetus. Paradoxically, all participants defined abortion or miscarriage in the first months of pregnancy as the loss of a real child.

**The value of a life with disability**

During the conversation about screening tests, none of the participants mentioned experience with neural tube defects. Discussion about the disabilities detected by prenatal screening was limited to a possible child with Down syndrome.

Children with Down syndrome were described as mostly happy and with a reasonable quality of life, even if they might suffer from other physical disabilities, such as heart and breathing problems.

"Children with Down syndrome always smile and are cheerful. Of course, they are moody now and again but then again So I am. But in general they are very happy people." (K303-119; MST-acceptor)

All participants agreed that a disabled child might help family members to cope with adversity and to appreciate the worth of little and irrelevant things.

"But even then, I think, you can learn a great deal from these situations. That in life sometimes things happen through which you become more aware that little things mean a lot. And I find that very essential." (K188-189; MST-acceptor)

In spite of this opinion, participants shared a concern about the burdens that they and other family members could face when a disabled child is born, due to the special attention the child requires, such as more worries, lack of attention for other children, more financial costs and loss of time for other activities.
"But suppose it is severely disabled or multiple disabled. Firstly you cannot do that to your other children, because all the attention will go to this child and you will hardly be able to handle this child yourself. Meanwhile, what is the quality of life of such a baby? It is undoubtedly very important, to what extent they are able to say something regarding that for themselves." (K194-144; NTM-acceptor)

A negative factor has to do with the social discrimination they might face. Women complained about the fact that everybody would look at them, even when they expected they could cope with the emotional and physical burdens of a child with Down syndrome.

"Yeah, I think so and this is not so much determined by yourself, but mostly by your environment. Your child is not normal, but it is still your child. And you may be happy with it, but everybody says oh god, I am so sorry for you, whereas you may be perfectly happy with it. And even when it grows up, it will still remain that girl or boy with Down syndrome, instead of the child next door." (K185-148; MST-decliner)

An important difference between acceptors and decliners was the emotional impact they expected from a disabled child. Women who accepted the test considered the care for a disabled child as an unbearable emotional and physical burden to them and their family. Women declining the test trusted that they could emotionally cope with an affected child and take care of it.

**Views on abortion**

All participants shared similar ideas about the ethical acceptability of abortion. Nobody evaluated it as something absolutely wrong. All of them considered that it might be ethically justified in extreme cases. For instance, in case of a severely disabled with a short life expectancy.

"Well, you should not cross a certain line. There ought not to be a choice between having a boy or a girl. I think that is just not acceptable. But in case of something like, let's say, very severe diseases, or so, then I think it is just right that abortion is possible." (K236-147; NTM-decliner)

Termination in the case of Down syndrome was reported to be a little egoistic. Nevertheless, participants reported it as ethically permissible when parents
cannot take care of a disabled child, or when they cannot cope with the burdens that such a child can have on their personal and family life.

“Well, I would personally consider myself egotistic. And why? Yes, the child itself has no say in anything. You have not even seen it, you do not know anything yet and still you would terminate the pregnancy. Well, you choose for yourself and not for the child, at that time. The child may have a nice fine life, but I do think that it would be a big burden. But you can have the same with other children. A child does not necessarily have to have Down syndrome, for that matter. So I do consider it somewhat egotistic.” (K236-167; MST-acceptor)

The difference between acceptors and decliners had to do with their perception of the relation between abortion and prenatal screening. For decliners, prenatal screening goes hand in hand with abortion. Therefore, women who showed reluctance to consider termination, did not consider prenatal screening as an acceptable option for themselves. According to their opinion, testing is only useful for women who plan to terminate pregnancy.

“If you take a test you make beforehand the decision to terminate pregnancy if you hear that you’ll get a child with Down syndrome. I think that you take a test with the purpose to terminate your pregnancy. And for me it doesn’t matter if it is a Down syndrome child.” (K037-079; NTM-decliner)

Although acceptors did not exclude termination of their pregnancy in the case of a confirmed diagnosis, they did not directly associate testing with the possibility of abortion. Most of them opted for waiting for further diagnostic tests before making a decision. Acceptors who reported that they did not want to terminate pregnancy, described the test as useful information for making a better choice concerning invasive diagnostics and for preparing themselves for the birth of a child with Down syndrome. Those acceptors who indicated they would opt for termination gave as reason their commitments to other children and their own life perspective. Still, they reported abortion as an experience they personally preferred to avoid.
"I trust that it is normal, I mean that my chance is normal for my age. If the screening results give a higher risk, well I’ll think what to do at that moment. I do not really know. I don’t think I’ll say I do not want the child anymore. But, I don’t know. I’ll decide at that moment." (K383-176; NTM-acceptor)

Moral authority of nature
All participants shared as a common belief the conviction that everything that happens has a meaning and that we cannot always overcome destiny. Furthermore, participants believed that “defective” foetuses would be eliminated through spontaneous abortion by natural selection.

“You should sometimes accept that certain things are meant to be, and which you should deal with, perhaps. It sounds quite philosophical, but I think you just cannot avoid all difficulties. That it will backfire at you somehow. I strongly believe that you have a certain fate and certain things happen because of that and you should learn from them.” (K037-095; NTM-acceptor)

The difference found between acceptors and decliners has to do with their willingness to interfere in the course of pregnancy. Women declining are of the opinion that nature has to take its course and described the healthy status of the foetus as destiny.

“I am convinced that nature has to take its course. You should not mess with faith by performing so many tests beforehand, when there is no reason to do so.” (K236-142; NTM-decliner)

For their part, acceptors defined the test offer as a possibility to control nature and to interfere in the outcomes of pregnancy in order to guarantee a good life for themselves and their children.

“I think that when you talk about these cases, of having no life expectancy, for example, then I think that if nature does not do its job, you should decide for yourself.” (K037-096; NTM-acceptor)

Parenthood and the meaning of children in their life
Having children is described as a personal project that must fit with one’s personal life’s project.

Participants described having children in terms of enrichment. They considered children as a projection of the parents themselves and a source of
joy in spite of the expected difficulties and responsibilities in parenthood. Even though children were reported as important, participants added that they were not absolutely necessary for their own happiness.

“I have a partner, but one remains an individual. I know a lot of people think I should stop exaggerating, but I believe that the moment you have a baby, you have duplicated yourself, more or less. You produce a little human being. I think that is just so beautiful, so exceptional even. For no one else could have made my daughter, or my son. I am the only one, together with him.” (K372-061; NTM-decliner)

Having healthy children who can enjoy a happy and good life was reported as the underlying aim of reproduction. Both acceptors and decliners agreed that an affected child would be an impediment for completely realising the values of parenthood.

Participants claimed the personal right to have children even by recurring to technological methods when reproduction is not possible in the normal way. This right was considered to disappear when parents are not able to care for and raise the child.

The difference between acceptors and decliners had to do with their perception of the personal recourse to technological control to fulfil their reproductive desires. Women who considered children as gifts from God or nature were more reluctant to make use of prenatal testing. Participants who saw children as a personal right, considered the use of technical methods for control of the characteristics of their offspring as ethically acceptable.

**Standard access to prenatal testing**

Participants showed positive attitudes towards the offer of prenatal screening, independently of whether they wanted to make use of it or not. Testing was considered as ethically acceptable as long as it does not introduce health risks for the foetus and the mother.

Although most participants were in favour of the offer of screening, they did not consider standard testing as self-evident. They defended the right of the parents to take their own private decisions about the use of new technological methods, according to their preferences and beliefs. Furthermore, they expressed their worry that testing becomes a commonplace when offered in a standard manner to all pregnant women.
"I do not think it is obvious. I believe you should only test on indication. Every test has its downside. Tests that make you unnecessarily afraid, like the risk of a premature birth and so on. I do not think one should willingly and knowingly take these risks upon oneself." (K236-136; MST-decliner)

Participants tended to limit the test offer to groups at risk. Their reasons were the possible increment of spontaneous abortions caused by invasive diagnostic procedures and the uncertainty and additional stress that testing can introduce in pregnancy.

Participants also expressed their concern that parents would have a test without making a carefully well-considered decision about the consequences. Even though women felt free to undergo screening, they worried that it might become more and more difficult to opt for a pregnancy without testing.

"I think you have to consider what you want to know and what do the test results mean. You can know whether it has Down syndrome, but what is the extra worth of this information? And I think that few people consider all these things. People test without thinking about the consequences of the test." (K038-095; NTM-acceptor)

No differences between acceptors and decliners were found regarding their views about standard access to prenatal screening.

Discussion
Given the Dutch policy up to 2007 regarding the offer of prenatal tests, we had a unique opportunity to gain insight into the impact of ethical views on the decision making process regarding prenatal screening. A strength of this study is the use of qualitative data to clarify the results from a concomitant RCT.

According to other studies\textsuperscript{17,23} none of the acceptors mentioned the finding of Down syndrome or abnormal conditions as reason for using the screening. Most of the women who opted for prenatal screening aimed to know whether the foetus was healthy. From our qualitative analyses it became clear that such knowledge is associated with the desire to eliminate uncertainty about the health status of the foetus. Acceptors did not consider abortion as the most obvious follow-up in case of a confirmed disability. Women who opt for testing without the intention of terminating pregnancy consider the screening as a way to prepare themselves for the birth of an affected child. Acceptors who would
opt for abortion defined the test as a means for controlling the outcomes of pregnancy in order to guarantee a good life for themselves and their family.

For their part, decliners reported as their main reason for not using the test the uncertainty and stress that testing might cause them. Results from the interviews showed that this uncertainty was related to their unwillingness to consider abortion in the case of Down syndrome and to interfere in the natural course of pregnancy. For decliners testing was closely linked to the decision of aborting an affected foetus. Therefore, they did not view the test as a personal option.

In spite of their different personal attitudes towards testing and termination of pregnancy in the case of Down syndrome, acceptors and decliners appear to be more alike than different in their ethical views. All participants were quite open to technical control of pregnancy outcomes. They also agreed in considering termination of pregnancy as ethically acceptable when it is performed in the best interest of the child. At the same time they manifested their concern about the acceptability of intervening in the natural outcome of pregnancy and feared that testing would become a routine procedure aimed to select healthy children.

These findings show that ethical views about testing are not directly related to personal decision-making regarding the acceptance of prenatal screening. Diversity of views was a characteristic of both acceptors and decliners. All participants reported that their choice was context related and that they would decide another way in different circumstances. This result is contrary to studies supporting the view that different ethical views and religious beliefs would lead to different choices regarding prenatal testing. An explanation for this diversity of views between acceptors and decliners might be due to the low proportion (ca. 23%) of active religious women in the qualitative study (11/47) and in the quantitative study (313/1399). The agreement on the acceptability of abortion might be due to the fact that abortion is legally permitted in the Netherlands.

In order to understand the impact of personal ethical views on the decision making process, we made a distinction between “personal ethical considerations” and “universal moral principles”. We interpreted as personal ethical considerations expressions in terms of desires or wishes such as “I don’t want to abort a pregnancy” or “I worry that testing becomes a means of selecting perfect children”, and universal moral principles were interpreted in
normative expressions such as “abortion is morally good when performed in the interest of the child”, or “parents have the right of access to prenatal testing for selecting their children”. According to this interpretation, the ethical reasons given by our participants for accepting or declining prenatal screening could be characterised as personal ethical considerations, since women referred to their personal feelings as the explanation of their choice. They also admitted that the opposite choice would be ethically justified in different circumstances. These feelings would reflect the participant’s views about the value of a disabled child according to their capacity to take care of it and to provide it with a reasonable level of wellbeing.

When discussing the ethical acceptability of prenatal testing and abortion, participants referred to universal moral principles to support their decision regarding the test. This fact may indicate that concordance with a moral norm is an important factor for women in order to justify their choice. Decliners mentioned “the unacceptability of interfering in the course of nature and in their own destiny”, as well as “the wrongness of taking unnecessary risks for the child” as arguments against prenatal screening. Acceptors reported “the parental duty of protecting the child from extreme suffering” and “the right of everyone to have a good and happy life” as justification for their decision to test the foetus. Both acceptors and decliners appealed to “the duty of the parents to decide in the best interests of the child” and “the right of the parents to decide according to their personal circumstances”.

Based on these findings, we distinguish two levels in the decisional process regarding the decision about prenatal screening: on the first level, women decide what they want to do by looking at their existing personal and familiar circumstances. Women make a decision mainly by balancing the psychological and emotional effects of the test’s information against the emotional and other burdens they expect a disabled child would have on their commitments to other children and themselves. In fact, all participants considered further testing as a logical step after a positive screening result. Therefore, the emotional risk associated with invasive diagnostic procedures would be a central factor in decision making. Societal expectations might have more impact on the emotional attitude towards a disabled child than the financial and physical burdens that such a child entails. The service provision for disabled people is relatively well organised in the Netherlands, where many organisations promote the participation and integration in society of individuals with a disability.
On a second level, normative moral principles are introduced as additional arguments, backing and supporting the decision made on the first level. On this level, ethical norms appear to perform an instrumental role as normative reasons, being brought into play in order to give a moral justification to the reproductive preferences of the women regarding the place of a disabled child in their lives. We conclude this from the fact that although participants reported mainly emotional or psychological arguments as the most decisive reason for their decision, they appealed to universal moral principles to explain their decision in the course of the interview.

The right of parents to select the children they think they can care for and those with the highest chance of having a good life, was quoted as essential in justifying their choice, both by women declining and accepting the screening test. Participants claimed the right of the parents to make their own decision about the use of prenatal testing and to determine which child fits their lives. It should be noted that this right can be only effective when the technical means are available that allow parents to know the characteristics of their offspring early enough.

The finding that both women accepting and declining refer to the same moral principles in order to support their choice, might be an indication that decisions regarding prenatal testing have not yet been integrated into the ethical beliefs of the parents. This can be due to the difficulty of identifying the limits between what can be considered acceptable parental interests and what kinds of suffering and burdens are sufficient enough to justify termination. An additional interpretation of these findings would be that women are reluctant to consider the moral implications and the added responsibilities raised by the increase in available information about the health status of the foetus, as Gregg and Lippman suggest.\textsuperscript{25,26}

In view of these considerations, we argue for the existence of a tension between the moral theories that suggest that decisions about prenatal testing are mainly guided by women’s moral beliefs and the way in which women decide in practice. The moral theories are founded on a deontological view based on a link between the concepts of right action, moral rule and rationality. Contrary to the assertion of these theories, our analysis shows that the choices about prenatal testing are not primarily driven by the ethical convictions of women, even though these are considered when making the decision. The decision appears to derive less from the moral duty to protect the
child against the consequences of a disability, than from the burden that they expect a disabled child would have on their lifestyle and that of those close to them. Personal beliefs about testing, abortion and the value of a disabled life are brought in among other personal and practical reasons with regard to their wellbeing and life perspective, as well as those of family members. Together they shape the final decision. Reproductive decisions about prenatal testing appear to get their moral significance within a system of cultural and social ideals, in which individuals claim the right to determine what they consider good or bad, according to their individual view of a worthy life and based upon what they judge good for them in accordance with the actual context of their lives. Based on these considerations, we presume that decisions regarding prenatal testing take place according to a pragmatic ethics, in which each decision is ethically valuated according to individual circumstances by weighing up the consequences of one's action for oneself and others.

Given the impact of the expected burdens of a child with Down syndrome on women's family and personal lives, we suggest that health professionals must provide clear information about the disabilities for which prenatal testing is offered to help couples to make informed reproductive choices. This information should include the clarification that testing is not directly related to abortion, as Ahmed argues.\textsuperscript{17,23} In addition, parents must be allowed to make their decision about what to do with the test results. The need of balanced information is more urgent in countries where prenatal testing is routinely offered. It remains important to examine the implications that a broad offer of prenatal screening and the pressure of dominant opinions in society regarding disability might have on women's views about their parental responsibilities.
References


WOMEN’S VIEWS
ON THE MORAL STATUS
OF NATURE IN THE CONTEXT
OF PRENATAL SCREENING DECISIONS.

ELISA GARCÍA / DANIELLE R.M. TIMMERMANS / EVERT VAN LEEUWEN
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Abstract

Appeals to the moral authority of nature play an important role in ethical discussions about the acceptability of prenatal testing. While opponents consider testing a dangerous violation of the moral inviolable course of nature, defenders see testing as a new step in improving dominion over nature. In this study we explored the meaning of appeals to nature among pregnant women to whom a prenatal screening test was offered and the impact of these appeals on their choices regarding the acceptance of screening. Contrary to theoretical debates we found that appeals to the moral authority of nature do not prevent women from welcoming the possibilities of controlling the outcomes of pregnancy, neither do they provide prima facie justification for (not) intervening in the natural course of events. Both acceptors and decliners believed in an inherent morality in nature that must be respected. They welcome the possibility of knowing more about the health of the foetus and to make their own reproductive decisions. Concerns for the quality of their child’s life and for their capacity to assure a good life for their family and disabled child appear to play a central role in the decision regarding the use of screening. Appeals to nature can be interpreted as an attempt to justify beliefs regarding suffering that must be avoided and the impact that family interests may have on the decision. These findings have significant implications for ethical guidance in debates about the acceptability and boundaries of control of offspring characteristics by prenatal testing.
Introduction

Most parents long for children that are healthy and will enjoy a good life. For many decades parental influence on their offspring began after birth. Before the introduction of prenatal testing there was no way for parents to prevent a congenital disability except by not having children. The genetic constitution and health status of the foetus were left to the regulation of nature, deity, destiny or blind chance. With the development of prenatal testing for congenital disorders this situation has profoundly changed. Parents can now get extra information about the health of the foetus on the basis of which they can make reproductive decisions regarding the birth of a disabled child that was previously left to the influence of nature.1-3

While the expanded scope of parental choice is perceived by some as a positive effect of technological developments in reproductive medicine, not everyone welcomes prenatal testing.4 Debates on the acceptability of prenatal testing often include appeals to the moral legitimacy of human interference with the natural course of pregnancy. Contemporary thinking includes two main opposing and extreme viewpoints about the moral status of nature:

The first view recognises an inherent morality in nature as the source of objective moral values that must be used as a reference point for normative restrictions regarding human interference. The underlying assumption in this view is that we are beholden to a morally inviolable natural order of things with a specific purpose for mankind that must always be respected. An important implication of this view is that humans should have no say in the outcome or make-up of a child. They must simply accept the 'gift' that is provided and make no attempt to change, direct, control, design or exclude it. This view condemns most attempts to control or select the characteristics of offspring because they would make children the products of choice, determined strictly according to our plans and serving only our desires. This control conflicts with the idea that children are unconditional gifts undermining the unconditional acceptance of children that is central to parenthood. In this view disability is not an impediment for a full human life.5-7

The second view considers nature as simply a (biological) matter of neutral worth, which proceeds without purpose or any guidance in matters of good and bad. Defenders of this view ascribe nature only a relative value that is derived from its relationship to human functioning and flourishing. Furthermore, it is important to indicate that recognition of the features that are necessary for
human functioning and flourishing might be associated with particular views about human nature. Human beings are encouraged to dominate nature by striving to improve it. The only limits to human freedom in this respect are provided by human reason. Disability is portrayed as an undesirable condition where suffering and limited capacities override the possibility of developing a fully human existence. Prenatal testing is seen as a chance to exert rational control over the undesirable characteristics of human offspring and consequently it is seen as inherently beneficial and even necessary, while choosing to remain ignorant and to accept or allow disability would be morally wrong.9-13

Quantitative and qualitative data produced in a randomised controlled trial (RCT) designed to analyse the factors that play a role in choices regarding the use of prenatal screening have shown that considerations about the moral duty to follow nature appear to play a role in decision-making on the acceptance of a test offer.14,15 Those considerations were mentioned both by women who accepted screening and by those who declined it. In this paper, we aim to explore what participants meant when they appealed to nature and the impact of their considerations on decision-making.

**Methods**

This paper results from a qualitative sub study examining the impact of ethical beliefs on decisions regarding prenatal screening that was embedded in a RCT. The intervention group of the RCT was offered a Nuchal Translucency Measurement (NTM) or a Maternal Serum screening test (MST). The control group received no offer of a test.14,15 Participants in the RCT who were in the process of deciding whether to accept the offer were randomly selected and asked by phone to participate in an interview within a week after the test offer was received and before the test would eventually performed. In total 59 women (26 from the MST group and 33 from the NTM group) agreed to be interviewed. With permission, all interviews were recorded and later transcribed. To protect anonymity, each woman was allocated a numerical code.14

The demographic characteristics of the participants in this qualitative study were compared with the total of participants in the RCT. The subgroup resembles a representative sample of the RCT participants regarding social status, level of education, age and religious convictions.
Data analyses
Qualitative analysis was performed through a two-step inductive approach using the assistance of computer software N-Vivo (Nudist-Vivo, 2.0; QSR software, Durham, UK). In a first analysis, we looked for the reasons women reported for their decision. In a second analysis reasons were divided into meaning units corresponding to the issues discussed in the interview. The meaning units were subsequently condensed and shortened into nine categories that corresponded with ethical considerations that emerged from the responses. One of the categories had to do with the moral status attributed to nature.\(^{14}\) Within this category new codes were made based on differences and similarities and sorted into six subcategories that correspond with two main underlying views regarding the relationship between nature and prenatal testing: 1) nature ought not to be changed nor totally controlled; and 2) helping nature to do its work well.

Results
The findings from the MST group and the NTM group are presented together, as previous studies showed no differences in ethical views between the two intervention groups.\(^{14,15}\) Differences between acceptors and decliners are identified when present.

1. Nature ought not to be changed nor totally controlled
1.1. Health status of the foetus as a matter of fate or destiny
Participants reported the health status of the foetus as something that is determined beforehand by nature or God. They believed that the characteristics of their offspring are part of their own fate and that parents get the children they deserve. According to this view, both acceptors and decliners believed that respecting the natural course of pregnancy, without trying to control everything, was the most acceptable ethical option.

"I know people who say that they do not want to test because they accept their child how it is. I really believe that is the best way to act. Nobody wants a disabled child. This is a fact. But what is tricky is that we all accused Hitler because he didn’t want disabled people and we are doing the same with so many tests. Taking things the way they are is indeed the best option." (K027-134; MST-acceptor)
Nevertheless, they argued that parents are free to control and decide about the birth of a severely disabled child.

"Some people think that they have to accept the child and to enjoy him because that is the goal of their life. I don't agree with this! I think that nature sometimes makes mistakes that even God should disapprove. Parents do not need to accept it." (K037-101; MST-decliner)

1.2. Nature knows better

Participants opined that there is a meaning in everything that happens. Both acceptors and decliners reported that everyone ought to allot his own fate a place in his life and ought to learn from it.

“You should sometimes accept that certain things are meant to be and you should deal with them. It sounds quite philosophical, but I think you just cannot avoid all difficulties. I strongly believe that you have a certain destiny and things happen with a purpose and you should learn from them.” (K037-095; NTM-acceptor)

Participants reported that nature itself will determine which disabilities are compatible with a fair quality of life and which are not. They trusted that severely disabled foetuses would be eliminated by nature through spontaneous abortion. Nevertheless, participants believed that parents have the responsibility to decide what the best option is when a severe disabled foetus is not naturally eliminated.

“I think that what nature finds wrong is wrong. If this child is not good, nature should eliminate him. But I think that in cases of no life expectancy if nature does not do its job, you should decide for yourself.” (K188-198; MST-acceptor)

A difference found between acceptors and decliners signified to what extent they judged they may intervene in pregnancy. Acceptors welcomed the possibility of making their own decision that comes with testing.

“I have always known that I would want to know whether there was something wrong with the child beforehand. Plainly because I don’t like the idea of having a child that is severely disabled or has Down syndrome. If you cannot do anything it is all right. But if I there is a chance of making my own choice I want to do so.” (K236-167; MST-acceptor)
Decliners preferred to avoid difficult decisions about the desirable characteristics of their child. They feared that attempts to control everything might result in unforeseen consequences.

"I am convinced that nature has to take its course. You should not mess with faith by performing so many tests beforehand when there is no reason to do so. I want a perfect child. But some things happen irremediably and you cannot control them. You have to accept them as they come." (K236-142; NTM-decliner)

1.3. Disability belongs to life

Participants saw disability as something that belongs to human life and is not always an impediment for a good life. A society with only perfect people was reported as something we must not strive for. Furthermore, participants believed that disability is not without value because it helps people to value the positive things of life.

"There are so many reasons why children are not 100% healthy. That's part of life! Thank goodness! Imagine a world where everybody is perfect! I believe that some things go wrong so that we realise how happy we must be with things that go well." (K188-188; MST-acceptor)

A difference between acceptors and decliners was found in their expectations about parenting a disabled child. Decliners trusted that they could care for child with Down syndrome, while acceptors considered the care for a disabled child as an unbearable burden.

2. Helping nature to do its work well

2.1. Improving health

Participants believed that they have a duty to employ all available means to improve the health of the foetus and to avoid substances that can create substantial risks. Still, this improvement was reported to be limited by the congenital status of the foetus.

"You can take folic acid before you get pregnant and avoid salt, alcohol, red meat and that kind of things but that’s all you can do. You cannot change that the child has Down syndrome; it is determined by nature." (K383-164; NTM-decliner)
Both acceptors and decliners reported that women have a duty to seek available prenatal care. They did not link this responsibility with the use of testing because it does not contribute to the health of the foetus.

2.2. Testing the foetus

All participants were aware that testing could not guarantee a completely healthy child. They also questioned the adequacy of the information given by prenatal screening. Therefore, screening was not considered necessary in pregnancy.

Nevertheless, participants mentioned that testing becomes necessary when women have sufficient reason to fear severe disabilities of the child, for instance because of advanced age or because of medical reasons.

"I think that you must look at the age of the women. It is less worthwhile to offer a test to a young woman. But it is normal that women older than 36 get a test because they have a higher risk of getting a disabled child. If you have the feeling that there is something wrong with the baby you can always ask for a test." (K027-133; MST-acceptor)

A difference found between acceptors and decliners had to do with their assessment of the utility of screening for controlling the health of the foetus. Acceptors reported the test as an extra chance to exert some control and in case of a confirmed disability to make their own decision about the birth of the child.

"I want to make use of every extra chance of knowing whether the child is healthy or not. A child with some disabilities would have a very big impact on our lives. I want to think very hard about whether I want to accept it." (K380-192; NTM-acceptor)

For their part, decliners did not believe that screening offers real control, since it only indicates the possibility that the foetus has a disability. They did not want to take the risks of an invasive diagnostic test. Therefore, they opted to wait until delivery.

"The test does not give any assurance! It gives only a chance and the smallest chance is already a chance that there is something wrong. Actually you don’t know anything. You can know it better after delivery." (K185-148; MST-decliner)
Whatever their decision, decliners reported that they would have a detailed ultrasound scan to determine the duration of pregnancy and to visualise their foetus.

2.3. **Deciding about the characteristics of the offspring**

Participants were concerned about the difficulty of determining the boundary between ‘desirable’ and ‘undesirable’ characteristics. The decision was reported to be even more difficult in case of Down syndrome because participants believed that this condition might be compatible with a good quality of life.

> "It is impossible to judge the quality of life of the child. A disabled child can have a good life. We find it burdened, but nobody knows whether the child is happy. Down syndrome has many gradations. This makes it more difficult to know what is acceptable and unacceptable." (K188-189; MST-acceptor)

Participants did not see disability as something that must be avoided at all costs. Nevertheless, they reported abortion as morally acceptable in case of severe disabilities with a very low quality of life or when parents cannot provide the child the necessary care. In these cases, termination was described as doing something in the best interest of the child.

In spite of this view, participants opting for testing mentioned that parents might actively help nature in interrupting pregnancy when foetuses with a severe disability are not naturally eliminated.

> "For me this is a very difficult issue. I’ve once been in an institution for disabled children. There were children who were lying down all the day; they couldn’t walk or sit. They couldn’t even talk. If you could know that beforehand! This is the point. Such a child has no life. I think you must make a choice thinking of the child. Well, it is not good if parents can choose between a boy and a girl. This would be not normal. But it is good that it is possible to find out about very severe disabilities in the best interests of the child”. (K236-147; NTM-decliner)

A difference between acceptors and decliners was found in their views on the acceptability of abortion in their own personal situation. Acceptors were open to possibility of abortion in case of Down syndrome.
"If I get a high risk I will find out about what it implies to have such a child and about the burdens of caring for him. I think about how difficult it will be for me if I decide to terminate pregnancy." (K185-150; NTM-acceptor)

For decliners abortion was not acceptable in their individual circumstances because of their ability to care for a disabled child.

"For me Down syndrome is not a reason for abortion. I find it hypocritical to do a test if you don’t do anything with the result. If the child is disabled, it should be very sad, but that is how it is." (K236-171; NTM-decliner):

Discussion

Prenatal testing is offered as a tool to support parents to make conscious decisions about their offspring. In discussions about the admissibility of prenatal testing the ethical argument about the acceptability of intervening in nature is frequently brought up. For some, testing is a way of putting autonomy above nature by deciding on the desirable characteristics of the foetus. For others, the genetic constitution of our children is a matter of fate or God’s will that is beyond our choice and control. Therefore, these people consider testing with the aim of selecting the traits of the offspring as necessarily in conflict with the idea of children as ‘unconditional gift’. Moreover testing promotes the idea that children are a made or chosen ‘product’.

Since Greek antiquity nature has been a source of arguments in ethics and (natural) law. Some ethical traditions consider nature as synonymous with good. Others reject nature as arbitrary and meaningless. Arguments derived from these basic valuations refer to nature as a secure guide or source of moral precepts or reject and distrust nature in favour of human endeavour. Those references need to be clarified in ethical debate and decision-making.

Contrary to the arguments derived in the above sketched ethical traditions, we found that both acceptors and decliners believed in the existence of rationality and purpose in the natural course of events that must be respected. Therefore they believed that parents ought not to make any attempt to change or to control the characteristics of their children. However, they also confirmed that parents can and sometimes ought to intervene in the natural course of
pregnancy to guarantee the health of their offspring and to avoid disability, including the abortion of a disabled foetus.

From these results it seems that appeals to the moral authority of nature do not provide sufficient guidance in decision making. As we see the same views about the significance of nature lead to different choices. However, the fact that participants spontaneously referred to the acceptability of intervening in nature, indicates that views about the moral status of nature are important for them. At this point it is interesting to consider what participants exactly meant when they appealed to the moral authority of nature.

Our results show that participants recognise some value in nature. That value is often identified with personal fate, destiny, or the meaning of their own life within a rational natural order. Every intention to control or manipulate the course of pregnancy has then moral significance. Therefore, it is not surprising that participants mentioned those considerations when deciding about screening. At the same time, participants also value the possibility to gain knowledge about the health of the foetus and to make their own decisions. This possibility comes together with new expressions of responsibility that are considered to be exclusively the concern of the women tested and not of nature anymore. That responsibility has no restrictions and includes the life of the future child. The offer of prenatal testing faces women with the choice of the kinds of disability that can be avoided and the reasons which justify that decision. As Dworkin argues, by providing this choice, prenatal testing undermines the assumptions that the health of the foetus lies beyond the control of the parents because it is fixed by nature and therefore escapes their moral responsibility.21

From our results it is clear that the expected suffering caused by disability plays a central role in decision making. Although participants accepted that nature determines the child's constitution, they were concerned with the quality of their child's life. Additionally, they had concerns about their family's strength and capacity to satisfactorily deal with the care for a disabled child. Women decide by balancing the moral risk to interfere in nature against the moral risk of carrying the responsibility for the suffering of their future child and family. As we found before, women are faced with a conflict of interests.22 In line with this thinking, the decision both for and against testing might be interpreted as an attempt to control in some way the health of the foetus and to escape from undesirable pregnancy outcomes. As our findings illustrate,
acceptors see screening as a way to assure that everything is going well. Although they hoped not to make further decisions about the life of the foetus, they did not totally exclude abortion in case of a confirmed disability. For their part, decliners opted for avoiding the risks that are bounded with testing as a way to assure the health of the foetus.

Based on these findings we suggest two possible explanations for the significance of participants' appeals to nature when deciding about testing:

First, appeals to nature can be interpreted as an expression of the difficulties women face when deciding on the suffering that should or should not be avoided given the weight that the well being of other family members might have. According to this interpretation “nature” refers to the women’s beliefs regarding the disabilities that ought to be accepted”.

Secondly, appeals to nature might be associated with the women’s assessment of the utility of prenatal screening for holding some control over the natural outcomes of pregnancy. In this sense “nature” signifies “that what is beyond our choice and control”. Acceptors might welcome the test as a means to make a decision on their own and ruling out at least Down syndrome and some forms of disability. For decliners appeals to nature can be interpreted as their lack of confidence in a test that only gives a chance approximation and therefore does not give certain information about the health of the foetus.

Our results indicate the complexity of decisions regarding the control of offspring characteristics. Some authors fear that a standard offer of screening will result in women using arbitrarily the test without making a well considered decision.\textsuperscript{23-25} Contrary to this view our results show that this will not be the case. Women feel responsible for the well being of their child and family. Their decision grounds in their perception of the capacity to assure a good life both for their child and their family.

The above results show that direct application of moral theories of nature within the framework of prenatal testing is flawed. The distinction between nature or fate and choice, that comes up in theoretical debates is far from the practical considerations women make when deciding about testing. As our results highlight, appeals to the moral authority of nature do not function as normative moral prescriptions. Consequently, they do not impede women to welcome the possibilities of controlling nature neither does it provide prima facie justification for (not) engaging the natural course of events.
Based on our results we suggest that debates about the acceptability of prenatal testing should not be centred on the moral authority of nature. As we have showed it does not bring much clarity in the morality of control and selection of the offspring's characteristics. Nature is a questionable and dim concept, which includes a wide variety of conceptions between matters that are beyond our control and those that we ought not to manipulate. We think that debates should be centred on the impact of prenatal testing on women's views about the characteristics that are necessary and those that are an impediment for a good life. Reference to nature always needs explanation from those perspectives.

Future research should investigate the impact of these views on the way women shape their moral beliefs about the actions that belong to responsible parenthood in the framework of reproduction.
References


RETHINKING AUTONOMY IN THE CONTEXT OF PRENATAL SCREENING DECISION-MAKING.
Abstract

Objective: Answering the question: Does the offer of prenatal screening impede women in making autonomous choices?

Methods: Semi-structured interviews with 59 women to whom a prenatal screening test was offered and who were in the process of taking a decision.

Results: Women described the offer as confronting but expressed a positive attitude towards screening and considered the offer as an opportunity for making up their minds about testing. Participants stated that they took decisions freely following their individual perspectives. Nevertheless, they preferred to share the responsibility of the decision and its consequences for other family members with their partner and closely related persons.

Conclusions: The active offer of an unsolicited prenatal test need not be considered as an impediment for making an autonomous choice. The moral significance of prenatal testing is inseparably bound with the social context in which it is practiced. Influence from other persons and emotional reactions due to the test offer can be interpreted as supportive for making a choice. In clinical practice, testing should be timely offered in order to give women the opportunity of discussing their views with significant others. Caregivers should care for the emotions experienced by women so as to help them decide according to their values.
Introduction

Ethical discussions about the desirability of offering prenatal (screening) testing focus mainly on the autonomy of the women involved. The growing consensus is that women will only benefit from the test offer when they are able to make an autonomous decision.¹

Authors who underline the importance of a broad offer of prenatal screening, establish their arguments on the assumption that more choices will enhance reproductive autonomy.² According to this line of thinking, women must be informed about all the tests available in order to make a well-considered decision.³⁵ Still, several studies have shown that a prenatal screening test offer may negatively influence women’s autonomy. In countries where prenatal screening is routinely offered, women use testing without considering its consequences.⁶¹⁰ Furthermore, an unsolicited test offer may limit the women’s freedom by forcing them to make a choice.¹¹⁻¹³ Therefore, opponents of a standard offer of prenatal screening uphold that an autonomous choice is only guaranteed when women themselves request for the test.¹⁴ Because of this controversy, it is important to examine the implications that the offer of prenatal screening might have for the women’s autonomy.¹⁵

Autonomy belongs to the dominant ethical principles of western healthcare and bioethics. Central to autonomy is the thought that persons are able to make informed decisions, in light of the available information. Elements considered to be a necessary condition for autonomous decision making are: the presence of valuable options; clear information about the alternatives; and the absence of actual constrains.¹⁶⁻¹⁹ This consideration entails that external constraints should be absent, so also internal constraints, such as emotions, doubts or scruples that may limit the capacity for reflecting critically upon the available options.²⁰,²¹

Applying this reasoning to prenatal screening, the question arises as to whether a test offer compels women to decide according to what others expect them to do.²² Emotional reactions due to the offer may also impede to act in accordance with their underlying values and preferences.²²,²³

When this study was performed (2002-2004), offering prenatal screening to pregnant women, who are not at increased risk of giving birth to a child with congenital defects, was prohibited in The Netherlands.²⁴ Women with low risk were allowed to use testing only on request. Because of this situation, we were able to conduct a randomised controlled trial (RCT) to study the effects of a
explicit test offer on decision making.\textsuperscript{25,26} Since testing was not routinely offered, women confronted with a test offer were likely to make a well-considered decision. Since January 2007, this policy has changed so much that women with low risk may be informed about available tests but then have to pay for it themselves.

A qualitative study was developed on top of the RCT in order to get more insight into the impact of ethical beliefs on decision making. This article reflects the results of the qualitative study. We explored the impact of the test’s offer on the decisional process. The central question is: Are women to whom prenatal screening is offered able to autonomously decide according to their personal values and beliefs? In answering this, we analyse the existence of possible external pressures and internal constraints as consequence of the test offer.

A special permit, for explicitly offering of prenatal screening, was granted by the Minister of Health, and the Institutional Review Board of the VU University Medical Centre.

**Methods**

Women participating in the RCT to whom a prenatal screening test was offered and who were in the process of deciding were asked through phone calls to participate in an interview. Participants were randomly selected and asked to contact within a week after the offer was received and before the test would eventually be performed. We approached 81 women and 59 agreed to be interviewed. The demographic characteristics of the interviewees are summarised in Table 1.

Of the 59 interviewees (26 from the MST group and 33 from the NTM group), 21 accepted the screening offer (11 from the NTM group and 10 from the MST group) and 38 declined it (22 from the NTM group and 16 form the MST group). Two women who refused screening, wanted to undergo another type of prenatal test (see Table 2 in chapter 2 at pag. 31).

Since we aimed to study the effect of the active test offer on the decision making process, we did not include the control group in the qualitative study. Participants of the control group should have to be fully informed about the possibility of having the test, thereby breaking up the methodology of the RCT.
Table 1. Demographic characteristics of women participating in the study.

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<td>Inactive</td>
<td>18</td>
</tr>
<tr>
<td>Without religion</td>
<td>29</td>
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The totals of age, degree of religiosity, and educational level do not add up to 59 because of missing values on these questions.

**Interviews**

Interviews were carried out in the participants’ homes. The interviews were conducted by E. Garcia and two professional interviewers. To protect their anonymity, each woman was allocated a numerical code.

All the interviews followed the same semi-structured plan. We started with open-ended questions about the reasons for accepting or declining. In looking for external pressures, we asked which persons had to be approached during the decision making. To explore internal constraints, we incorporated questions about the women’s personal experience regarding the offer and the feelings they experienced in making their decisions. The discussion was extended to themes identified as important by the participants. The interview questions were discussed for their comprehensibility after performing the first five interviews.
Interviews were recorded and transcribed with prior consent of the participants. The analysis was done by using N-Vivo (Nudist-Vivo, 2.0, QSR software, Durham, UK). Each interview was coded according to the themes discussed. In a first analysis, we looked for external and internal constraints to autonomy. In a second analysis, external constraints were divided into subcategories based on the relationship with the persons approached. Internal constraints were subdivided into three categories according to reported feelings regarding the women’s emotional reaction to the test offer; the women’s worries about the foetus’ health and the women’s feelings toward a disabled child.

To test reliability the first three interviews were analysed by other researchers. Differences were found in fragments admitting a double coding. After some discussion, these differences were resolved.

Results

1. External constraints: influence of other persons
Participants emphasised that they made their own choice without being overtly pressed by others. Nevertheless, they reported supportive influences of these others during the decision making process.

1.1. The partner
Most of the male partners ceded to the decision of their spouses and supported their final choice. However, they did have an important impact on the women’s decision making, especially in the acceptance of the test. Participants stated that the decision regarding testing should be made in partnership and agreement, and sought input from their partners. They reported some uneasiness when their partners differed from their views. In case of disagreement, women finally went along with their partners’ opinions. Still, they maintained that they were at liberty to decide by themselves whether to follow their partners’ views, without being pressured. One of the reasons for going along with their partners’ opinions was to avoid tension and conflict in the family.
“My husband was very much in favour of it. I admit that I don’t know the consequences for me. And I think that if the results become abnormal, that he would be more outspoken than I would. He finds it very difficult to get a disabled child. He doesn’t admit it, but he acts in his own interest. Well, I expect that I’ll get a good result to go further without problems.” (0609-068; MST-acceptor)

1.2. Other closely related persons
Once the choice was made, participants approached those closed to them with the aim of informing them, to seek their reinforcement and to share their decision. Participants who discussed their decisions with others, reported that these people supported their final decision.

Although participants mentioned that the influence of relatives was minimal, they also reported some pressure to use testing because of the attitude of their relatives towards Down syndrome.

“I do feel some pressure. Suppose I get a high risk from the test, than my parents would undoubtedly press me. They would try to force me to terminate pregnancy. But it is comprehensible because we had a neighbour girl who had a very severe form of Down.” (K188-189; MST-acceptor)

1.3. Midwife and obstetrician
Participants defined the advice of caregivers as welcome, but were unwilling to involve them in decision making. The assistance expected was limited to the provision of information about risks and the impact of a disability on the child and on the family.

“The final decision is to the parents. The doctor has absolutely a very important role in pointing out how and what it is. He has the medical knowledge about the severity of the disability. I think that he also knows very well the consequences of terminating or not terminating pregnancy, because of his expertise.” (K027-104; MST-decliner)

Those women who were not completely certain about their choice appreciated professional support and recognised that they would change their mind in relation to their midwives’ advice.
"I completely trust my midwife. If I was to go to my midwife next week, no matter how scared I am for having a serum screening test, and she tells me that it might be wise to do it, I would indeed do it." (K236-136; MST-decliner)

1.4. Society
Participants endorsed women’s right to freely decide about screening. Despite this argument, both acceptors and decliners expressed their concern regarding social reactions of intolerance. For instance, decliners feared that they would be held accountable for the negative consequences of their decision, even when they felt confident that they could deal with an affected child.

“The ones surrounding, they press you. Your child is disabled but it still is your child. And everyone says, oh my God, I am so sorry for you, whereas you may be very happy with it. And even when it grows older, it still will be that girl or boy next door having Down syndrome, instead of just Cathy for instance.” (K185-148; MST-decliner)

Acceptors mentioned the social assumption that the abortion of a disabled child can be the best option, as a pressure that influenced their final decision. On their part, decliners gave a reason against testing, the fact that everybody knew about their pregnancy, and they would have to justify their decision for abortion.

“You do talk about it with your partner beforehand, and you don’t go around telling everybody that you’re pregnant. In that case you are pregnant, but still you do not know whether it will continue. Then you also have to let everybody know you ended the pregnancy, or you have to make up some excuse, having had a miscarriage or something.” (K027-136; NTM-decliner)

Participants also showed minimal confidence in the medical and financial support that they might get from Health Insurance if they decline the test.

“Your insurance company can oblige you to take a test if you are older than 36. And if you decide to keep your child, perhaps you would not have any right more. I do not know, but why they should make it obligatory then? I do not think they can oblige you to undergo testing, but this is another issue.” (K236-168; NTM-acceptor)
2. Internal constraints

2.1. Emotional reactions to the test offer

Participants were positive about the screening offer and mentioned being satisfied with their decisions. Nevertheless, some ambivalent feelings were reported.

Acceptors were reluctant to decide about the birth of the child, in case of a confirmed disability. They reported uncertainty about what they should do with the results of the test.

“I want to use it, but I have mixed feelings. I must admit that I would have preferred not to have the choice. But because I had it, I must think about it. The most difficult thing for me was what to do with the test result. For it does not give you 100% certainty. The age related risks is also a kind of chance approximation. It is almost the same. Your individual chance can only result lower or higher and then you have to take one more test.” (K027-133; MST-acceptor)

The miscarriage risk connected with diagnostic testing aggravated the problematic situation of having to decide about further steps. Acceptors reported that they would feel guilty if they were responsible for the loss of a healthy child.

“I have never had a miscarriage. It may be awful. A child is not miscarried without a reason. There must be something wrong. This is what they always say. But in this case, it is not the nature that has caused it, but it has been a needle. This feels awful, because I have given it a hand. I had given my approval. If something goes wrong, I will ask myself: Oh my God What I’ve done?” (K303-119; MST-acceptor)

Decliners doubted whether they had to use testing in the best interest of the child and themselves. They wondered whether being ignorant and letting things happen would be considered irrational.

“The most important reason for not using the screening is that I will not terminate pregnancy and if I do not want to terminate, then I do not want to know beforehand. I will love it anyway. But sometimes rational thoughts overwhelmed me: “it can be very hard: I is not wanting to know not stupid and naïve?” (K078-142; MST-decliner)
2.2. Worries about the foetus’ health
Participants made decisions regarding testing with the intention of reducing their anxiety about the health status of the foetus and to enjoy their pregnancy.

Acceptors decided to test with the intention of confirming the health of their foetus. All of them reported that they believed in obtaining a good test result. Therefore, they postponed further decisions until the screening results were known.

“It is quite difficult. What do you do with the consequences? For me it is unclear. I try not to think about it. And if it isn’t good, well, I’ll see. I think that I should try to deal with it, but I can’t know whether I’ll think the same at that moment. Actually, I do the test with the hope that it is good.” (0609-068; MST-acceptor)

Decliners followed the same pattern of reasoning in wanting to avoid anxieties. A decisive reason for not testing was that they did not want to worry about the health of the foetus. They trusted that everything was going well and opted for dealing with an unexpected disability at the time of birth. As a result, they reported being uncomfortable with the screening test as they felt it was not needed for them.

“I think that when you are having the test done, you will have reasonable doubts. I would wonder: is it affected or is it no? And if I would have a screening test done, I would feel very insecure during my entire pregnancy.” (K383-164; NTM-decliner)

2.3. Feelings towards a disabled child
A central element in the participants’ decision was the emotional impact a disabled child would have on their lives. Acceptors considered the care for a disabled child as an unbearable emotional burden on them and their families.

“I’m very happy with my life. I have a one-year-old daughter. And I think that you get extra worries if you get a child with Down syndrome and I should find it very difficult, because you have to take care of it for all your life. Your responsibility never ends” (K034-074; NTM-acceptor)

For their part, decliners believed that they could emotionally cope with an affected child and take care of it.
“In The Netherlands we have enough organisations that help you to care for such a child. I think we should be able to take care of it, also when I realise that it would require extra efforts.” (K188-167; NTM- decliner)

Discussion

Prenatal screening aims to help pregnant women to make well considered reproductive choices. The ethical principle of autonomy states that women should make their choice without being influenced by the opinion of other persons.\(^{27,28}\) Our finding that women wanted to share their decision with others, even if they were not directly involved in the process of decision making, is therefore noteworthy. Participants approached other persons for obtaining approval and support. This suggests that relationships do play an important role in decision making regarding prenatal testing. As autonomous decision making takes into consideration the advice of others, the input from third persons should not be evaluated so much as a social pressure.

Participants tended to follow the opinions of their partners in case of disagreement. In opposition to studies that claim that complying with the partner impedes women in making their own decisions\(^ {29-32}\), participants stated that they freely made their own decisions in choosing to follow their partners’ views. This finding may indicate that women do not want to shoulder all the responsibility for their decisions. Taking decisions in partnership would help women feel more comfortable with their final choice. The partner may also be considered as an intrinsic element in the decision making, since he is part of the pregnant couple.

Participants reported assistance from caregivers as important for interpreting the screening results and for making a well considered decision. However, participants used the provided information without involvement of the caregivers. This finding contradicts studies that claim that trust in the medical authority constraints autonomous choice by compelling women to decide according to the medical value system.\(^ {10,13,30,33-35}\) Participants who were ambivalent about their choice, were indeed more likely to follow the advice of their caregivers. However, this should not necessarily be interpreted as a constraint to autonomy since women did not report any form of involuntariness when they indicated that they would follow the advice of their midwives. Data
from the RCT confirm that participants embraced their decision and did not feel manipulated by their caregivers.\textsuperscript{26,36}

Researchers see the availability of testing as an external factor that constrains women to adapt their individual values and desires to the most accepted social opinion.\textsuperscript{37-39,12} In agreement with this claim, participants reported concern about social reactions and intolerance regarding the birth of a disabled child. Social and cultural views about the worth of human life with a handicap undoubtedly influence the choice taken regarding testing.\textsuperscript{40} Nevertheless, the finding that participants emphasised that they were not overtly pressed by others in their decision may suggest that this influence would not always be considered a social pressure that compromises autonomy.

Another requisite for autonomous choice is that women are not emotionally impeded to act upon what they rationally know is the best. Studies suggest that the availability of testing may impede women to decide autonomously by generating worries that might conflict with their values and beliefs.\textsuperscript{41-45} In agreement with these studies, participants reported conflicting feelings regarding their desire to obtain more knowledge about the health status of the foetus and the fear to hear that something was wrong with the foetus. Both acceptors and decliners shared a reluctance to make further decisions regarding their child’s future. In spite of this reluctance, participants were positive about the screening offer and embraced their final choice, even if they recognise that they would have preferred not to have to make a decision.

The conflicting feelings that women reported might be considered as a normal process in making up their mind about the place of testing within their parental responsibilities. The availability of prenatal screening requires women to adapt their values and beliefs to the new circumstances created by the technical developments. In case of indeterminacy, these feelings may have an important role as tie-breakers in helping to choose between options that are rationally considered to be equivalent.\textsuperscript{46} Therefore, these feelings do not have to be considered as constraints for making a well considered autonomous choice. This assumption is confirmed by the results of the RCT where most of the women (82\%) were found to make value-consistent decisions.\textsuperscript{36}

Our results are based on a qualitative study in a small group; so it is not possible to draw any definite conclusions. However, the views expressed by our participants suggest that from the autonomy perspective there is no reason to reduce access to prenatal screening. The fact that women cannot evade a
choice, even in cases where they prefer not to make one, might be an opportunity to shape their personal ethical views.

Our findings also raise questions about the adequacy of the current concept of autonomy within the context of prenatal screening. According to Faden and Beauchamp, autonomy is related to a person's capacity to pursue his/her own goals and choose according to his/her own values, beliefs and preferences.\textsuperscript{47} Only from such a position, it seems clear that influences from other persons as well as social values and expectations and internal emotions would constrain women's autonomy. However, autonomy should not be limited to a right to be free from the intrusion from others. As Nedelsky argues\textsuperscript{48}, autonomy cannot be considered independent of the relational network of the moral agents. Moreover, autonomy comes into existence and is maintained by the responsibilities that spring from relationships with others. Hence, respect for autonomous decision making need not be incompatible with recognising that an individual's social context inevitably informs and influences his or her choices.\textsuperscript{49}

We suggest that an ethical analysis of autonomy in prenatal testing should reflect upon women's responsibilities and their ties with others. Assuming that woman's decision on prenatal testing is only autonomous if it is unmediated by external influences, may fail to capture the relationship in which decisions are made. Women make their choices in a context where personal and social factors need to be integrated along with emotions, personal values and judgments on the views of other people.\textsuperscript{50} As our results show, women prefer to discuss options with their partners, family and friends.

Translated into clinical ethical reasoning our findings suggest that every offer should be timely done in order to give women the opportunity to discuss testing with significant others. On return, the clinic should check whether the influence of others has been impeding or enhancing their free choice. Caregivers should also care for the women's emotions when confronted with a screening offer. The advice of caregivers may be helpful as clinical recommendations for providing guidance in decision making. They should inform them beforehand about the difficult decisions that a high-risk result can lead to, as well to the different options to follow. One condition would be that the degree of "directiveness" should be negotiated.
References


RECONSIDERING PRENATAL SCREENING: AN EMPIRICAL-ETHICAL APPROACH TO UNDERSTAND MORAL DILEMMAS AS A QUESTION OF PERSONAL PREFERENCES.

ELISA GARCIA / DANIELLE R.M. TIMMERMANS / EVERT VAN LEEUWEN

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Abstract

In contrast to most Western countries, routine offer of prenatal screening is considered problematic in the Netherlands. The main argument against offering it to every pregnant woman is that women would be brought into a moral dilemma when deciding whether to use screening or not. This paper explores whether the active offer of a prenatal screening test indeed confronts women with a moral dilemma. A qualitative study was developed, based on a randomised controlled trial that aimed to assess the decision making process of women when confronted with a test offer. A sample of 59 women was interviewed about the different factors balanced in decision making. Participants felt themselves caught between a need for knowledge and their unwillingness to take on responsibility. Conflict was reported between wishes, preferences and ethical views regarding parenthood; however, women did not seem to be caught in a choice between two or more ethical principles.

Participants balanced the interests of the family against that of the foetus in line with their values and their personal circumstances. Therefore, we conclude that they are not so much faced with an ethical dilemma as conflicting interests. We propose that caregivers should provide the opportunity for the woman to discuss her wishes and doubts to facilitate her decision. This approach would help women to assess the meaning of testing within their parental duties towards their unborn child and their currently offspring.
Introduction

Although prenatal screening for Down syndrome and neural-tube defects has become routine prenatal care in most western countries, health policy in the Netherlands has been reluctant to offer screening to all pregnant women. At the time this study was performed (2002-2004) only women of advanced maternal age (from 36 years old) or with medical indications were offered invasive testing. Active offering of screening tests to women with a low risk was forbidden; the test could be performed only on request.¹

One of the main reasons for the Dutch government to limit prenatal screening to women in the risk group was that an unsolicited offer would bring women into a moral dilemma when considering whether or not to have the test performed. This dilemma can be sketched as follows: because there is no therapy available, women receiving abnormal results would be forced to make a choice between two equally binding and mutually exclusive ethical principles, namely the moral duties of “respecting the life of the unborn” and “avoidance of suffering”. These two principles support two incompatible options: bringing the pregnancy to term (implying direct responsibility for the suffering of a disabled child), or opting for termination and therefore violating the right to life of the foetus. The impossibility of foreseeing either the degree of suffering or the consequences of a particular disability makes it difficult to determine the best choice from a moral perspective.³⁻⁶

For their part, proponents of routine offering of prenatal screening claimed the right of the parents to be informed about all existing test to make autonomous and well-considered decisions.⁷

This discussion in the Netherlands indicates a need for more research about the issues involved in routine offering of prenatal screening. Many studies have been performed on the decision making involved in prenatal testing.⁸⁻¹⁶ From these studies, it seems that women experience difficulty in determining what is the best choice.¹⁷⁻²⁰ In this paper we analyse whether this difficulty should be considered as an ethical dilemma. Although the Dutch policy changed in January 2007, so that women with low risk have to be informed about the possibility of screening, the study we performed was carried out in 2002-2004, and thus we made use of an unique opportunity to study the effect of an active test offer on women’s decision making in a context where prenatal screening was not routine, but rather part of a randomised controlled trial (RCT). The RCT consisted of three different groups: (1) one receiving the offer of a Nuchal Translucency
Measurement (NTM), (2) one receiving the offering of a Maternal Serum test (MST), and (3) a control group.¹²,²¹

A qualitative study was developed on the basis of the RCT to obtain more insight into the effect of ethical beliefs on decision making. This paper reflects the results of the qualitative study. We explored the effect of a test offer on the decisional process and the various factors women balanced when deciding whether or not to accept the offer.²²,²³

Methods
A special permit for explicitly offering prenatal screening was granted by the Minister of Health and by the Medical Ethics Committee of the VU University Medical Centre.

Participants
Participants of the RCT who were in the process of deciding about the test were randomly selected and asked by phone to participate in an interview. Interviews were performed within a week after the test was offered and before the test would eventually be performed. In total 59 women agreed to be interviewed (26 from the MST group and 33 from the NTM group). As we were investigating here only the effect of the test offer, we did not include participants from the control group. Participants of the control group would have needed to be fully informed about the possibility of testing, thereby breaking the protocol of the RCT.

Interviews
Semi-structured interviews were chosen to make it possible for the participants to explain their own experience about the test offer and to allow a deeper insight into the women's motivations for their choice. The interviews lasted approximately 1 hour and were conducted at the participant's home (by EG and other professional interviewers with the VUMC). With the participant's permission, all interviews were recorded and transcribed. To guarantee anonymity, each woman was allocated a number code.

Interviews started with open-ended questions about the woman's reasons for accepting or declining the test. To explore the various factors involved in the decision we included questions about the goals that participants aimed in accepting or declining the test; their needs, wishes and preferences regarding
testing; the ethical principles they considered when making their decision; and their feelings regarding their choice. Subsequently, we extended the discussion to the participants’ ethical views about issues relating to prenatal testing, i.e. parental duties toward the unborn and current offspring; the worth of a disabled life; the acceptability of controlling the offspring’s characteristics; the status of the foetus; and the permissibility of abortion in general and for Down syndrome in particular. 

The interview questions were assessed for their intelligibility after performing the five first interviews, and it was considered that no adaptation was needed.

**Data analysis**

Participants’ views regarding testing and their reasons for their decision were analysed with Nudist-Vivo (N-Vivo), software V.2.0 (QSR Software, Durham, UK). Segments of the interview were coded, and codes were then grouped together into key themes. Analysis delivered nine categories according systematic ordering of the themes (different views) that emerged from the responses. Within these categories conflicting views were found. For the purposes of this paper further analyses were aimed at identifying the themes related to the conflicts mentioned by participants. Based on these analyses three topics were identified: (1) parental duties, (2) the woman’s needs and wishes and (3) the woman’s ethical principles.

**Results**

The results identify the conflicting aspects reported. ‘Participants’ indicates the whole study group. Where statements are quoted, the woman’s code number, group, and whether she had decided to accept (acceptor) or decline (decliner) the test are given. The findings from the two intervention groups are presented together. From the RCT no differences were detected in views between participants in the NTM and MST groups.

1. **Parental duties**

1.1. Towards the unborn

Participants agreed that parents have a duty to look for the health and well being of their unborn child. This duty was not linked to the use of prenatal screening, neither to the prevention of disability. Participants limited their responsibility to the avoidance of actions that might have a negative influence
on the health of the foetus, such as smoking or drinking alcohol. Reasons for not including testing as a parental obligation included that the screening does not give sufficient information for further decisions and the awareness that testing does not guarantee a completely healthy life for the child.

"Actually, everybody wants a healthy child. But there are so many things that can go wrong! You never have a guarantee that everything is good also when you do all those tests." (0609-079; NTM-decliner)

Acceptors and decliners differed in their view about the significance of testing within their duties towards their unborn child. Although none of the acceptors aimed to avoid a child with Down syndrome, they used the screening with the aim to obtain assurance about the health of the foetus. At the same time, acceptors reported their unwillingness to take further decisions because of the difficulty in assessing which level of suffering should be prevented in the interest of the child.

"How can you find out what is good for the child? To what degree does such a child realise that he has a disability? I find this quite difficult. My brother is deaf. For others it is awful, but he does not know it can be different, he has always been deaf. He has done very well in his life; he has a family, two healthy children. You could have decided that he should not be born, while he is very happy." (0609-068; MST-acceptor)

Decliners considered avoiding unnecessary risks as the best action in the interest of the child. Important reasons given were the ambiguity of the screening results and the risks of invasive testing. At the same time, decliners questioned whether they had to accept the screening offer in the interest of their future child.

"I think that disabled children have many qualities that can be stimulated. On the other hand, which future does such a child have? Well, this is quite problematic. The child may suffer, so are you not selfish if you allow him to be born? That is a very difficult issue." (K078-122; MST-decliner)

1.2. Towards other children

Participants reported the expected negative impact of a disabled child on their family as important in their decision about screening. Both acceptors and
decliners indicated that they would make another choice if their personal and familiar circumstances were different.

In the case of a disability that might be compatible with a reasonably good life, participants questioned to what extent family interests should weigh against the life of the unborn. Disability was not always entirely considered without value. Participants mentioned that a disabled child might have a positive effect on the family. In spite of this opinion, they concerned about the burdens that their family could face when a disabled child is born.

"I think you can learn a great deal from these situations. That in life sometimes things happen through which you become more aware that little things mean a lot. But I feel some pressure, because of the impact on my family. This is quite difficult." (K188-189; MST-acceptor)

A difference between acceptors and decliners was found in the extent to which they thought that raising a disabled child would impede them in fulfilling their parental responsibilities towards their other children. Acceptors feared that they would be unable to give enough attention to their family because of the extra care a disabled child would require.

"You never know how your life will be. But this is one of the things you can know beforehand. I am very happy with my life; I have a daughter who is 1 year old. It is very important for me that my children are happy and this would be very difficult with a child with Down syndrome because it will need extra care." (K034-07; NTM-acceptor)

For decliners, a reason against testing was their perceived capacity to deal with a disabled child and the care for other children. At the same time, they were aware of the extra care that a child with Down syndrome needs and questioned whether declining the test would not be against their responsibilities towards their family.

"For me this child is number two. A child with Down syndrome should require extra care. Perhaps that will be a reason for me to terminate my pregnancy because my child would get less attention. A child with Down syndrome would be prejudicial for my family." (K078-152; NTM-decliner)
2. Women’s needs and wishes

Participants made their decision in order to reduce anxiety during pregnancy. All of them said they were satisfied with their final choice, even when they reported that it was not an easy one.

Acceptors chose testing moved by a wish for more knowledge that would help them to avoid the anxiety of wondering if their baby was healthy and to confirm that everything was good. On the other hand, they reported reluctance to make further decisions. They postponed thinking about further options until the screening results were known.

“It’s sure that I want to take the test. What will I do with the result? Well I will see. That’s the problem. I do not want to think. I feel that I want to keep the baby but I also think that I will terminate. I have doubts about what is the best choice.” (K383-176; NTM-acceptor)

Decliners chose to avoid the uncertainty and anxiety that might come with the screening. The fear for a miscarriage due to invasive procedures was reported as not weighing against their desire for reassurance about the health of the foetus. At the same time, decliners welcomed information. They admitted they would consider testing if the screening gave a sure diagnostic.

“It is a chance approximation and this implies you have actually to perform an extra test. And that test is risk. I think that if I did not need to do that extra test I would take the screening.” (0754-09; NTM-decliner)

3. Women’s ethical principles

Participants shared the view that parents ought to accept their children unconditionally. An exception to this rule was when the child would be so severe disabled that a life full suffering and without expectative would be expected. In this case, participants agreed that parents have a duty to decide about the birth of the child based upon the child’s best interests. Even so, termination was reported to be morally problematic because it clashes with the right to life of the child. Participants expressed doubt about the reasons that would make termination of pregnancy morally acceptable. They voiced worries that only perfect children may be born in the future.
"I find abortion acceptable when you honestly do it in the interest of the child because you cannot care for it and then it would be unhappy. But there are so many reasons that I find egoistic. I wonder whether we are like sitting on the chair of God, in case He exists, that we want to decide about those things. I think that we are going too far in this feasible world, that we want everything to be perfect." (K188-167; NTM-decliner)

Termination of pregnancy in case of disabilities that may be compatible with a good life was reported as egoistic. Down syndrome was not assumed to be the kind of suffering that parents ought to prevent. Nevertheless, participants approved termination when parents cannot cope with such a child, for the child would not have the care and love that is needed for a good life.

“If the parents are convinced they cannot care for the child and they allow it to be born, that child would not be happy. Neither would the parents. I fear that the child would be neglected. Certainly, I disapprove of the parents, but on the other hand I also think that it is not good for the child to be born with parents who do not want it.” (K037-101; MST-decliner)

One of the main reasons decliners gave for not testing was that termination would be morally wrong in their personal circumstances. At the same time, they reported their difficulty to know in what cases termination would be a good option looking to the interest of the child.

“Actually, you think in terms of quality of life. Is it severely disabled or is it a child who should have a good life, also if it has limitations? I find it very difficult to know what the best decision is. Neither do I know what the boundaries are.” (K188-77; MST-decliner)

Discussion

In this paper we explored the effect of an active offer of a prenatal screening test in a context where testing is not normal part of prenatal care. In contrast to studies that maintain that information facilitates women in making well considered decisions, participants described the choice as difficult to make because of the implications of the test results not only for the future child, but also for their family and ultimately for themselves. Although they were positive about their choice, participants mentioned they found themselves caught
between a desire for information and reassurance about the health of the foetus and their fear of making difficult decisions about their unborn child. They were concerned as to what degree family and personal well being may be weighed against the right to life of the foetus. The main question at this point is whether this difficulty can be defined as a genuine ethical dilemma.

A moral dilemma occurs when an agent has valid moral reasons to support two or more exclusive actions, at least one of which he is required to do. These reasons involve moral principles that are equally strong and values that are equally central to the life of the agent. Participants in our study claimed their right to freely decide whether they want to use testing according to their assessment of the usefulness of the screening test in their individual and family circumstances. Closely related to this was the physical and emotional burden they expected from a disabled child on their family life. Down syndrome in itself was reported as a morally insufficient reason for termination. Nevertheless, participants judged termination as morally acceptable when parents cannot cope with the burdens that such a child would bring on their personal and family life. At the same time, participants voiced ethical concerns about selection of “perfect” children and questioned what would constitute a sufficiently serious disability to justify termination. All of them were reluctant to consider having a termination themselves. These results suggest that women’s preferences about testing often deviate from their ethical values.

Based on these results, we believe that women to whom a prenatal test is offered are confronted with a decision about what interests, preferences or needs would be given priority and not about two or more ethical principles they are compelled to follow. Therefore, we cannot define it as a genuine moral dilemma. Our results indicate that the possibility of testing generates a wish for extra information. At the same time, women fear the consequences of testing. The conflict that participants reported could be interpreted as the difficulty of assessing the usefulness of the screening to their personal situation. As Anderson argues the choice regarding the use of prenatal testing, could in reality be defined as a moral choice in which women have to decide which interests, needs and desires must be given priority in order to find which is the best option from a moral point of view. For our results it becomes evident that participants decided by balancing the interest of the foetus against their individual wishes and the family needs to find the option that was most in line
Dilemma’s by prenatal screening

with their values. Although participants embraced their decision, they also reported that they would decide differently in other circumstances.

Our findings also indicate the existence of a gap between ethical decisions in practice and those based on ethical theory regarding the possibility of moral dilemmas. Anderson claims that moral dilemmas are only possible within Kantian approach of ethics in which personal and moral matters are separated and in which moral principles are universal expressions of moral duties. This approach reduces the decision about what is right and what is wrong to the rational application of ethical principles and norms. According to this approach, conflicts between principles must be rationally resolved by consulting a higher-level principle. When different ethical principles are both equally relevant to apply, an agent is caught in a situation in which there is no way to determine which choice is morally right for the particular situation. In this way, ethical decisions are reduced to technical decisions undermining the importance of the individual desires, preferences, circumstances and the possible consequences, in the decision making. However, as our results show, a rational and purely abstract analysis of the factors involved without taking into consideration the concrete persons who are embodied or implicated in the decision regarding testing is unlikely to capture the emotional and circumstantial concerns in which decisions are made. Furthermore, rational analyses of normative decisions often fail to take into consideration agent’s values and desires, which are difficult to quantify.

These considerations suggest a clear need for a new ethical framework of thinking in reproductive decisions. A virtue ethical approach might be a promising alternative for identifying the nature of the conflicts that women reported when deciding about testing. This framework of ethical thinking assumes that the morality of an action varies with the circumstances of each particular occasion. Within this approach, an action is morally right only if it is what a virtuous person would do in the same circumstances. The central question when deciding about testing is not “is the action against any ethical principle?” or “does it harm anyone?” but “what would a good parent do in these circumstances?” Two fundamental characteristics of good parenthood are accepting children as they are and safeguarding the children’s well being and happiness. Parenthood is at the same time a self-directed project. In deciding about testing, women are compelled to determine the effect of knowledge about the foetus in their acceptance and pursuit of the well being of their
children and in their own interest. The individual concept of a good life and the consequences of their choice in the short and long term play a central role in defining their decision.

This study was developed in a context where there was no routine screening on offer. Despite this, our findings may also have implications for countries where testing is a standard procedure. As Suter suggests, the offer of testing might be regarded as self-evident and women would be likely to participate automatically without considering its ethical implications. Moreover, women might believe that they are morally compelled to use testing in the interest of their child and family.

In the light of these results, we believe that the nature of the conflict women experience when deciding about testing needs to be carefully analysed before new screening tests are offered to a general, low-risk population. We propose that routine offering of prenatal screening and testing is ethically justified when the offer is accompanied by broad-based counselling. As counselling aims to assist women to choose the course of action most appropriate to them in view of their goals and according to the ethical values they hold, identifying this conflict should help caregivers to discern whether women make their decisions under pressure from needs, wishes and additional duties that might be triggered by the test offer and therefore not in the line with their ethical values. To help women to assess the meaning of testing within their parental duties, counselling should include discussion of the effect of the woman's wishes and preferences regarding testing, her familiar context-bounded needs and her ethical values. Caregivers should ensure that women understand the advantages and disadvantages of testing and the scenarios they might face in case of a bad test result. Furthermore, all options, including that of not testing should be presented. Some practical points that may be discussed are: the women's thoughts about life with a child with Down syndrome; what they want to do with the information once they have it (that is whether they want to take further tests and whether termination would be an option); and whether they would prefer to be confronted with a disabled child at the time of birth or to prepare themselves and their family beforehand.
References

PARENTAL DUTIES
AND PRENATAL SCREENING:
DOES AN OFFER OF PRENATAL SCREENING
LEAD WOMEN TO BELIEVE THAT THEY ARE
MORALLY COMPELLED TO TEST?
Abstract

Background: In debates around prenatal screening it is frequently argued that responsible parenthood implies the acquisition of all available medical information about the health of a foetus, and the use of this information to benefit the future child.

Objective: To analyse whether an active offer of a prenatal test leads women to believe that they are morally obliged to control the health of their foetus.

Design: A substudy within a randomised controlled trial (RCT) aimed to assess the decision-making process of women when confronted with an offer of a prenatal screening test.

Participants: 111 women participating in an RCT were retrospectively asked their views on the meaning of testing within their parental duties.

Findings: Testing was described as a personal option that goes beyond the normal parental responsibilities. Participants did not believe that they ought to control the health of the foetus or to avoid disability. A duty to test was only reported when the birth of a disabled child would have a negative impact on family life.

Conclusion: Women's accounts suggest that two main factors are involved in making testing morally obligatory: 1) the woman's views on her moral duties to her family; and 2) the expected burden of a disabled child on the well being of the family. A family-centred approach would be more suitable to assess the moral imperative character of testing.

Implications: A test offer should not be limited to communication of the technical characteristics of the test and the test results. In helping women to assess the meaning of testing within their parental duties, counselling should include the family situation in which women have to decide, the women's expectations about living with a child with Down syndrome or any other disability, and the women's views on their commitments towards their family.
Introduction

Prenatal screening by means of Nuchal Translucency Measurement (NTM) and the Maternal Serum screening test (MST) provides pregnant women with information about the risk of the foetus having Down syndrome and other trisomies. In addition, the MST gives information about the risk of neural tube defects. The aim of prenatal screening is to provide women the information they need to make their own reproductive decisions.\(^1\)\(^-\)\(^3\) These tests give an estimation of the chance that a foetus has a particular abnormality. Although the consensus on free parental decision making with regard to testing still prevails, the tendency to appeal to responsible parenthood is growing, with the claim that all relevant information concerning the health of the foetus should be obtained and used to benefit the prospective child.\(^4\)\(^-\)\(^7\) It has been argued that women who decide not to undergo testing are morally responsible for intentionally bringing a disabled child into the world, for whom future suffering could have been avoided.\(^8\)\(^-\)\(^10\) Consequently, women who are offered a prenatal test may believe they have a moral duty to be tested in order to ensure the health of their future child.\(^4\)\(^,\)\(^11\)\(^-\)\(^15\)

Duty is a central issue in ethics. Having the moral duty to perform an action means that one ‘ought to’ perform that action. In other words, not fulfilling one's duties is considered to be morally wrong.\(^16\) Moral duties arise from undertaking particular commitments. Within the field of reproduction the intention to have children simultaneously entails obligations relating to that intention.\(^17\) Parents have the duty to look out for the well being and happiness of their children. This duty entails making use of all available means to provide their children with a satisfactory life.\(^18\)

The use of prenatal testing is often justified by the parental moral duty of ‘preventing avoidable suffering’ and ‘seeking the best health of the offspring’.\(^2\)\(^,\)\(^4\)\(^,\)\(^13\) In practice, it is not easy for parents to foresee the impact of disability for their child. In case of prenatal screening the decisions would be more complex since a increased risk result does not necessarily mean that the foetus is affected. Invasive diagnostic with a risk of foetal loss is necessary to confirm or to exclude the presence of a disability. Furthermore, diagnostic tests do not give any information about the consequences of the disability for the child. Therefore, it may not be easy for parents to determine whether testing is a parental duty. In the case of a higher risk of minor disabilities that may be compatible with a fair quality of life, such as
Down syndrome, the decision would be even more difficult than in the case of severe disabilities with intolerable suffering. Due to these difficulties, it is important to examine the effect of the availability of prenatal (screening) tests on women's ethical views and beliefs regarding their moral duties towards their offspring.

Some studies on the factors that influence decision making regarding prenatal screening include moral values and beliefs. Most of them describe situations in which prenatal screening is already part of customary antenatal care. Consequently, women may deal with screening in a routine manner without explicit consideration of its moral significance. Studies have shown that the routine offer of screening places a moral responsibility on women to comply with screening, making women believe that the prevention of disability is a matter of responsible parenthood. In contrast to other Western countries, health policy in the Netherlands has been more reluctant to make screening available to all pregnant women. At the time when this study was performed (2001-2004), prenatal screening (NTM and MST) was not offered in the Netherlands as part of prenatal care. The active offer of prenatal testing to pregnant women was forbidden by law. Only women of advanced maternal age (aged ≥ 36 years) or women at increased risk of having a disabled child because of medical indications were offered invasive tests. Women with a low or normal risk had to request the test themselves. Health-care workers have only been allowed to inform all pregnant women about the options for prenatal screening at the booking visit since January 2007.

The Dutch situation before 2007 created a unique opportunity to study the different motives involved in decision making. A randomised controlled trial (RCT) was designed to assess the decision-making process when women were confronted with the offer of a prenatal screening test. The RCT was developed with an intervention group (women offered an NTM or an MST) and a control group (women who were not offered a prenatal screening test). Data were collected using open-ended questionnaires at five different times during pregnancy: before any information about screening was given, and a decision about whether or not to have screening was not actual (T1); after women had decided for or against prenatal screening (T2), but (if applicable) before they had received the screening result; after the screening result was known or at a comparable point in time when screening was denied (T3); at
28 weeks of pregnancy (T4); and within two months after delivery (T5). Questionnaires included open-ended questions about background variables such as age, education, parity and religion (T1); participants' reasons for accepting or declining the prenatal screening test (T2); and participants' view on and satisfaction with the decision they made (T3, T4 and T5). 27

In addition to the RCT, a qualitative study into the impact of the participants' ethical beliefs on decision making was undertaken. This qualitative study consisted of interviews on T2. These interviews revealed that the offer of prenatal screening compelled participants to reflect on the value of information about the health of the foetus in their individual family and personal situation, and ultimately about the meaning of testing within their parental and reproductive duties. 28, 29

Methods

In order to gain a better understanding of the concrete impact of the availability of prenatal screening on the way in which women shape their moral duties to their prospective child, a second substudy was developed at the end of the RCT. All women who were still participating in the RCT were approached to answer an additional open-ended questionnaire. The questionnaire was designed to assess whether the availability of prenatal screening leads women to believe that they have a moral duty to accept testing.

The questionnaire

The questionnaire consisted of two parts. The first part focused on the views of participants on prenatal screening. Participants were asked to give their opinion on the screening offer, and to indicate which decision they would make in a subsequent pregnancy and their reasons. The latter question aimed to assess the relationship between the theoretical view of participants regarding screening and actual decisions.

The second part of the questionnaire consisted of eight ethical axioms about reproductive and parental duties and rights in relation to prenatal testing. The participants were asked to indicate whether or not they agreed with each statement, and to explain their reasons. The topics assessed by the axioms were drawn from analysis of the participants' interviews at T2. The selected topics were confronted with themes that were mentioned in the
literature.\textsuperscript{24,30} To test the comprehensibility of the axioms, eight pilot questionnaires were performed with colleagues and students who were not involved in the research. Axioms that were difficult to interpret were adapted. The questionnaire is given in Table 1.

This substudy was approved by the Minister of Health and the Medical Ethics Committee of the VU University Medical Centre.

Table 1. Questionnaire.

<table>
<thead>
<tr>
<th>First part: View on prenatal screening and the decision regarding the acceptance of the screening offer in the past pregnancy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- You were offered a prenatal screening test during your pregnancy. What, at this moment, is your opinion regarding this offer? Could you please indicate the reason(s) why you find it good or not?</td>
</tr>
<tr>
<td>2- Did you perform a prenatal (screening) test?</td>
</tr>
<tr>
<td>If you did, which test did you perform?</td>
</tr>
<tr>
<td>Will you make the same choice regarding testing in a subsequent pregnancy?</td>
</tr>
<tr>
<td>Could you specify the reasons for your decision looking to the interests of your child, your partner and yourself?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second part: Moral views about the meaning of prenatal testing and abortion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below there are some statements related to prenatal testing and termination of pregnancy. Could you indicate whether you agree and give the reason(s) why? Please use the subsequent form in your answer: I agree/ do not agree with this statement because...]</td>
</tr>
<tr>
<td>3.&quot;An unborn child has an absolute right to life even if it is (severely) disabled</td>
</tr>
<tr>
<td>4.&quot;If prenatal screening/ testing is offered as normal pregnancy care parents would believe that it is good to test the foetus&quot;</td>
</tr>
<tr>
<td>.Parents have the moral duty to use prenatal screening/testing in order to get more knowledge about the health of their child&quot;</td>
</tr>
<tr>
<td>4.&quot;Parents who do not want to use testing are accountable for the personal and social consequences of a disabled child&quot;</td>
</tr>
<tr>
<td>5.&quot;Parents have the duty to take all the available measures to assure a health child”</td>
</tr>
<tr>
<td>6.“Parents have the duty to protect the life of their unborn child “</td>
</tr>
<tr>
<td>7.&quot;Parents have the right to freely decide about the birth of a disabled child”</td>
</tr>
<tr>
<td>8. “Termination of pregnancy is morally good when performed in the best interests of the child”</td>
</tr>
</tbody>
</table>

Participants

The questionnaire was sent to 136 women who were still participating in the RCT. In total, 111 women (44 from the MST group and 67 from the NTM group) returned a completed questionnaire. Of these women, 109 delivered
Healthy children and two delivered a disabled child (Down syndrome and anal atresia). The latter two women did not make use of prenatal screening.

The demographic characteristics of the participants in this substudy were compared with the participants in the RCT. The subgroup was found to be a representative sample of the RCT participants in terms of social status, level of education, age and religious convictions. The demographic characteristics of the participants are given in Table 2.

**Table 2. Demographic characteristics of participants.**

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;26</td>
<td>9</td>
<td>8.1%</td>
</tr>
<tr>
<td>26-30</td>
<td>45</td>
<td>40.5%</td>
</tr>
<tr>
<td>31-35</td>
<td>46</td>
<td>41.4%</td>
</tr>
<tr>
<td>&gt;35</td>
<td>11</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational level</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>9</td>
<td>8.1%</td>
</tr>
<tr>
<td>Middle</td>
<td>48</td>
<td>43.2%</td>
</tr>
<tr>
<td>High</td>
<td>51</td>
<td>45.9%</td>
</tr>
<tr>
<td>unknown</td>
<td>3</td>
<td>2.7%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>2</td>
<td>1.8%</td>
</tr>
<tr>
<td>Married</td>
<td>78</td>
<td>70.3%</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>31</td>
<td>27.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>56</td>
<td>50.4%</td>
</tr>
<tr>
<td>1</td>
<td>40</td>
<td>36.0%</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>10.8%</td>
</tr>
<tr>
<td>≥ 3</td>
<td>3</td>
<td>2.7%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Professional work</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>96</td>
<td>86.5%</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>13.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without religion</td>
<td>45</td>
<td>42.3%</td>
</tr>
<tr>
<td>Christian</td>
<td>58</td>
<td>52.2%</td>
</tr>
<tr>
<td>Muslim</td>
<td>3</td>
<td>2.7%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>2.7%</td>
</tr>
</tbody>
</table>
Analysis of the data
The first part of the questionnaire was analysed both quantitatively (SPSS 11.0) and qualitatively (Nudist-Vivo, 2.0, QSR software, Durham, UK). Answers were coded according to the different reasons that women gave when describing their view on the screening offer, whether or not they had decided to have a prenatal screening test, and the decision they would make in a subsequent pregnancy.

The comments to the ethical axioms of the second part of the questionnaire were analysed qualitatively (Nudist-Vivo, 2.0, QSR software, Durham, UK). Responses were divided into meaning units that corresponded to the issues discussed in the questions. The meaning units were subsequently condensed and shortened into codes. The codes were compared based on differences and similarities, and sorted into four categories that correspond with two main underlining themes: “making one’s own reproductive decisions regarding the offspring’s characteristics” and ‘duty to assure the well being of the offspring”.

All the questionnaires were analysed separately by two researchers (EG and trainee), and codes fragment were compared. Differences were found in fragments with a double coding (i.e. ‘the duty to terminate an affected pregnancy’ versus ‘the duty to guarantee a good life for the future child’). After discussion, these discrepancies were resolved. The final version of the coded document was revised by EvL and DT.

Findings
Participants’ views on the screening offer and the decision they made during pregnancy and their views about their parental rights and duties are presented below. Citations are quoted with the code assigned to each participant. The data in parentheses indicate: the screening test that was offered to the participant; whether or not the participant decided to have a screening test (acceptors are women who accepted the offer of a screening test; decliners are those who decided not to have a screening test); and the decision the participant would make in a subsequent pregnancy.

1. Women’s view on the screening offer
The majority of participants (91/111) had a positive view of prenatal screening and opined that screening should be offered to all pregnant
women. Both the women who accepted a screening test and those who declined it described the offer of the screening test during our study as an opportunity to shape their views about testing. However, they recognised that the decision was not easy to make:

"I appreciate the possibility to think about these issues. And the choice was on me. I didn’t accept the screening because I decided that my child was welcome, it didn’t matter anyhow. But it was a difficult choice." (K236-180; MST-decliner, would not test)

Participants who described the offer of prenatal screening as negative (11/111) reported that they were compelled to think about everything that could go wrong with the foetus. The fact that screening only gives a risk estimation was seen as an additional source of worry.

"I was forced to think about things I didn’t want to think about. The test does not give any assurance. Nothing is completely sure. I would become insecure as the screening gave a bad result." (K027-133; MST-acceptor, would test)

An overview of participants' views on the offer of prenatal screening is given in Table 3.

Table 3. View of participants of the offer of prenatal screening.

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Negative</th>
<th>Positive and negative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (%)</td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>Prenatal screening performed</td>
<td>39 (92.9%)</td>
<td>3 (7.1%)</td>
<td>-</td>
</tr>
<tr>
<td>Prenatal screening not performed</td>
<td>52 (75.4%)</td>
<td>8 (11.6%)</td>
<td>9 (13%)</td>
</tr>
<tr>
<td>Total</td>
<td>91 (81.9%)</td>
<td>11 (9.9%)</td>
<td>9 (8.1%)</td>
</tr>
</tbody>
</table>

2. Women's decision in a subsequent pregnancy

Most participants who made use of prenatal screening (39/42) embraced their decision and would make the same decision again in a subsequent pregnancy. The main reasons given for opting again for screening were: to get assurance about the health of the foetus; to avoid the burdens of a disability for the child itself and for their family; to obtain useful information for further
decisions; because of a higher personal risk due to a more advanced age in a next pregnancy; and to prepare emotionally for the birth of a disabled child.

"I would use screening again because it gives me and my partner the possibility of the presence of a disability in the child. You get clear information. So we can prepare us for the birth of a disabled child." (K372-052; MST-acceptor, would test)

Few acceptors (3/42) reported that they would not have a screening test in a subsequent pregnancy. The reasons they gave were: the lack of personal risk; the impossibility of excluding all disabilities; their unwillingness to make further decisions about invasive testing and abortion; and the fact that screening only gives a risk approximation.

"Actually you don’t know anything and you have to make very difficult decisions based on a risk approximation." (K027-134; MST-acceptor, would not test)

Most decliners (67/69) were happy with the decision they made. Many of them (54/67) considered screening to be unnecessary because they thought that a child with Down syndrome can have a good life. The reasons they gave for not making use of screening were: the belief that parents ought to accept every child regardless of its health status; the unwillingness to decide about termination of pregnancy; and the lack of a personal risk.

"A disabled child can be happy. Children with Down syndrome are often happy. I don’t want to have to decide about termination. It is not good that parents choose which kind of children they want and which they do not." (K078-157; NTM decliner, would not test)

Decliners also mentioned the ambiguity of a risks assessment test as an additional reason for their decision against screening.

"You can use screening, but what for? The screening does not give any clear result. It only gives a likelihood of your child having a disability or not. You cannot do anything with that information." (K380-195; MST-decliner, would not test)

Some decliners (13/69) would make use of prenatal screening in a subsequent pregnancy. The main reason they gave was the impact of a disabled child on their family life. Most of these women (11/13) reported that even if they believed that a disabled child has a right to live, they would choose to have a
screening test due to the impact of a disabled child on the well being of their family.

"I think that a disabled child also has right to live. But looking to my partner and family, I would use testing in a next pregnancy because a disabled child would have an enormous negative impact on my family." (K027-136; NSM decliner, would test)

A second reason given by decliners for using screening in a subsequent pregnancy was the increased personal risk of a disabled child because of more advanced age (6/13). Additional reasons were: to prepare for the birth of a disabled child; and to reassure that everything is going well.

Information about the view of participants on their decisions and the decision that they would make in a subsequent pregnancy are given in Table 4.

Table 4. View of participants on their own decision regarding the acceptance/non-acceptance of prenatal screening and the decision that they would make in a subsequent pregnancy.

<table>
<thead>
<tr>
<th>View on own decision</th>
<th>Decision in a subsequent pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Number (%)</td>
<td>Would test Number (%)</td>
</tr>
<tr>
<td>Negative Number (%)</td>
<td></td>
</tr>
</tbody>
</table>

| Prenatal screening performed | 39 (92.9%) | 3 (7.1%) | 39 (92.9%) | 3 (7.1%) | - |
| Prenatal screening not performed | 67 (97.1%) | 2 (2.9%) | 13 (18.8%) | 54 (78.2%) | 2 (2.9%) |

| Total | 106 (95.5%) | 5 (4.5%) | 52 (46.8%) | 57 (50.4%) | 2 (1.8%) |

3.-Women’s views on the meaning of prenatal screening within their parental duties and rights

Two main categories came to the fore from the analysis of the open-ended answers to the ethical axioms: 1) the right of the parents to make their own decisions regarding the characteristics of their child; and 2) the parental duty to assure the well being of the offspring. A summary of the themes and subthemes is given in Table 5.
Table 5. Summary of the themes and subthemes that emerged from the analysis of the questionnaires.

<table>
<thead>
<tr>
<th>Women’s views on the meaning of prenatal screening within their parental duties and rights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making their own reproductive decisions regarding the offspring’s characteristics</td>
</tr>
<tr>
<td>Duty to assuring the well being of the offspring</td>
</tr>
</tbody>
</table>

3.1. Making their own reproductive decisions regarding the characteristics of the child.

- **Following the own needs and preferences.**

Participants claimed that parents have a right to freely decide whether they want to use screening according to their individual and family needs. In line with this view, they stated that caregivers must give women the chance to follow their own priorities without being pressured to conform to medical and social norms.

“*Parents have to freely decide what the best for their child is. They are the ones who have to care for it!*” (K383-158; NTM acceptor, would not test)

Many of the participants reported the concern that autonomous decision making would be compromised if screening becomes standard prenatal care. They feared that women would see screening as part of normal care, having the test without making well considered decisions.

- **Carrying the responsibility for one’s offspring.**

All participants reported that parents always have responsibility for their children. This responsibility was limited to ensure that children have a good and happy life. However, participants did not think that this responsibility includes the duty to control the health of the foetus through prenatal testing. On the contrary, they believed that parents can make responsible choices by ignoring information if they think that extra knowledge would not contribute to better decision in the interest of the child.
“Parents have the only duty to create an optimal environment where their children can grow up and develop. This does not mean that they have a duty to seek information about the health of their unborn child.” (K194-158; NTM decliner, would not test)

3.2. Duty to assure the well being of the offspring

- Assuring a healthy child.
Participants recognised the wish to have healthy children as a legitimate parental concern. They reported that women have an absolute duty to use all available means to assure and improve the health of their offspring. Most of them associated this duty with the avoidance of those substances that could harm the foetus. Causing impairment to the foetus due to negligence was reported as irresponsible and unethical behaviour.

“The unborn depends completely on the mother. When you decide to bring a child into the world, you have to give some things up and try to live healthily. You must avoid everything that can negatively affect the foetus.” (K188-189; NMT acceptor, would test)

Prenatal screening was not reported as part of the parental duty of seeking the best health for the foetus. The main reason given for not considering screening as morally mandatory was the uncertainty about the best course of action in the case of an unfavourable screening result.

“What do you with the information if the screening is positive? There are not concrete indications about which is the best option by each test’s result.” (K187-189; NTM acceptor, would test)

The right of parents to avoid difficult decisions regarding termination was also reported as an argument against a parental duty to use screening.

Contrary to the above, participants reported that screening should be advised for women who already know they are at a higher risk for a disabled child because of their personal or family history.

- Avoiding disability.
Participants believed that parents are not morally bounded to avoid those disabilities that are no consequence of voluntary undertaking. The parental decision to allow a disabled child to be born was considered to be a
responsible line of conduct when parents think that they can guarantee a good life for the child. In the case of a child with Down syndrome, this view was supported by the fact that participants believed that such children are generally happy.

Participants manifested their concerns about the changes in societal attitudes to disabled children, and feared that parents would be compelled to only have perfect children.

“If a disabled child has a happy life, then that life is a worthy life. We cannot make a society where everybody has the choice to have only perfect children.” (K037-089; MST acceptor, would test)

Both participants who welcomed screening and those who opposed it believed that parents ought to accept their children and to care for them regardless of their health status. They reported termination as morally acceptable only in the case of severe disabilities when a life full of suffering could be expected.

“It is up to the parents to decide about the life of the child. They are the only ones who know whether they are able to care for him. But I think it is better for a severely disabled child not to be born. Parents can avoid such a child coming into the world if they know this on time. But this only when the child would be severely disabled.” (K236-130; NTM acceptor, would test)

Discussion

This study explores whether the offer of a prenatal screening test leads women to believe that they are morally obliged to control the health of their foetus. In ethical literature, it has been argued that the availability of prenatal testing results in a morally binding perspective for pregnant women.\textsuperscript{5,12,15,18,26,30,31} The results of this study contradict this argument. Both the participants who were personally in favour of screening and those who were against it considered that testing goes beyond the normal parental duties towards a prospective child. Although most of the participants had a positive view about the offer of screening tests and agreed that screening should be offered to everyone, they defended the autonomy of women to freely decide whether or not to undergo a test and whether or not to continue with the pregnancy in the case of a confirmed disability.
Participants opined that mothers have the responsibility to seek the best health for their child. This responsibility was limited to those measures that contribute to a healthy pregnancy. Testing was not reported as part of this responsibility. The only case in which participants reported a moral duty for screening was in the case of a pregnant woman who is high risk for a foetus with disabilities due to personal or family history. In this case, testing was described as prudent for assurance of the health of the foetus. Still, participants claimed that further decisions about the birth of a disabled child always belong to the parents.

In contrast to the participants’ standpoint that testing should be in the best interests of the child, the main reason they gave for the use of prenatal screening in a subsequent pregnancy was the negative impact of a disabled child on their commitments to their existing children. Most participants believed that a child with Down syndrome could have a good and happy life. Nevertheless, they feared that the care for such a child would result in loss of time and attention for the other children in the family. Even if participants believed that good mothers should care for a disabled child and protect its life, they argued that the cost to families of raising a disabled child might justify the abortion of a foetus with Down syndrome.

Women’s accounts suggest that two main factors underline the decision regarding testing: 1) the women’s views on their moral duties to their offspring; and 2) the expected burden of a disabled child on the well being of their partner and other existing children. Women confronted with a prenatal screening test are compelled to balance their moral duties towards their future child and their family. The parental duty to ensure that children have a good and happy life may lead women to believe that they ought to undergo prenatal testing if they believe that the extra care needed for a disabled child would impede them from giving their existing children the necessary time and attention.

The findings of this study highlight the importance of the social context in decision making regarding the use of prenatal testing. What is considered to be a minimum condition for a good life is, to a large extent, socially determined. The general social views about the quality of life of a disabled child and the alleged burdens that such a child may inflict on the family may place a moral responsibility on women to comply with screening, making
them believe that the prevention of disability is a matter of responsible parenthood.

Conclusions and implications
The strength of this study lies in the fact that the offer of screening during the RCT gave participants the opportunity to make up their minds about the place of testing within their parental responsibilities. The retrospective approach allows women to (objectively) manifest their views regarding testing without being influenced by the pressure of making a decision. Furthermore, it allows women to incorporate their experience with screening not only during pregnancy - and therefore in relation to a prospective child - but also in relation to the concrete child they decided to test or not to test.

Some limitations of this study must be mentioned. Firstly, the finding that participants did not consider screening to be morally obligatory may be related to the fact that the offer of screening in the Netherlands emphasises the free character of the choice. At the same time, this fact does confirm the impact of the societal and cultural context on women's decisions. Studies in countries where prenatal screening is performed as routine prenatal care show that it is generally expected that women participate in testing. A comparative study on the offer of prenatal screening showed that choice was mentioned only briefly or not at all in most of the leaflets.

In these countries, the rates of termination of pregnancy for foetal anomaly following prenatal testing are high. The concrete impact of the cultural and social framework on the ethical deliberation of pregnant women on accepting or declining a prenatal screening test is the subject of further research.

Another limitation of this study is that most participants were not confronted with undesirable pregnancy outcomes. This fact may mean that the decliners did not consider screening to be necessary. Also, for most acceptors, the screening test was a confirmation of the health of their foetus, and therefore they would repeat this positive experience in a next pregnancy.

The percentage of well-educated women in the study was higher than the percentage in the total population. This difference may have affected the pattern of acceptance and decline of screening tests. However, results from the RCT and the qualitative study did not show any significant difference in the acceptance of testing or ethical beliefs between women with low and
high levels of education. This conclusion can only be confirmed by future research including a representative percentage of low-educated women.

Translated to medical practice, these results indicate that in order to help women to assess the meaning of testing within their parental duties, the personal and family situation in which women have to decide should be discussed when screening tests are offered. Counselling should also include discussion about the women’s expectations about living with a child with Down syndrome or other disability, and the women’s views on their commitments towards her family.

The results of this study do not only have clinical relevance but are also relevant for ethical theory. Debates about the ethical convenience of offering prenatal screening tests to all pregnant women are focused on the duties of pregnant women towards their unborn child, and on the rights of the foetus to (a good) life.\textsuperscript{38,39} The study findings indicate that practical decisions are driven by perceptions of the burden of a disabled child on a woman’s commitments to her family. This reveals the importance of the interplay between the decision regarding the acceptance of prenatal testing and the family context in which the decision is made. This interplay is often omitted in discussions about testing.\textsuperscript{40} A family-centred approach may be more suitable to assess when and how prenatal testing involves a parental duty than ethical discussion about the rights of the foetus and the woman’s duties towards her unborn child.
References


CASE STUDY:
HOW THE AVAILABILITY OF PRENATAL SCREENING
SHAPES WOMEN’S ETHICAL VIEWS REGARDING THEIR
PARENTAL DUTIES.
Introduction

Precedent chapters in this thesis have shown the central role of the context in which choices are made in case of prenatal screening and testing. The women's duty to provide the best possible life for their family can morally compel women to make use of screening when they expect that they will not be able to give a disabled child and their family the care and attention they need. The choice regarding prenatal testing appears to be determined by: 1) the women's physical, emotional and financial capacity to guarantee a good life for a (disabled) child and their family; 2) the care they owe to their family and 3) the women's willingness to take responsibility through choice.

To illuminate these findings, we offer in this chapter a reflexive analysis of the experience of one participant in our qualitative study who declined the offer of a Maternal Serum screening test (MST) and delivered a child with Down syndrome. She was married and younger than 35 year. This child was her second child. Her first child (a girl) was born healthy. She declined the MST because she did not want to be confronted with further decisions about invasive diagnosis and abortion. Furthermore, she did not consider Down syndrome as severe enough to justify termination of pregnancy. Therefore, she preferred to be confronted with a disability at the moment of the birth. Also if her ethical views regarding testing and abortion did not change after the birth of her disabled child, she reported that she would use prenatal testing in a next pregnancy in order to avoid the birth of a (second) disabled child.

Data collection

Data collection took place at four different times: before the screening was offered (T1); within a week after the test offer was received and before the test would eventually be performed (T2); in the last trimester of pregnancy (T4); within two months after delivery (T5).

T1, T4 and T5 took place through open ended questionnaires. All questionnaires included items about the woman's ethical views regarding the selection of the offspring's characteristics and abortion. In questionnaire T4 we included additional questions about her feelings regarding the test offer and the decision she made. An additional question concerning her view about the right decision in case of a foetus with Down syndrome was included. In questionnaire T5 we asked her whether she would make the same decision in a next pregnancy and the reasons for her decision. In this questionnaire some items on
the meaning of prenatal screening within the parental reproductive duties and rights were included.

Data collection at T2 took place through a semi structured interview. We opted for an interview to facilitate participant in the manifestation of her motivations for her decision.

Results

1. View on the offer of prenatal testing

Participant described the offer of prenatal screening as confronting because it made her aware of the possibility that her unborn child could be disabled. She also feared that the midwife would compel her to accept the test.

"I became scared. I felt uncertain and confused. I worried that I would be pressured to test. I called the midwife and I thought that she would tell me that I have to accept it." (From T2)

She was also concerned about medical dominance over pregnancy. Therefore, she did not think that testing should be offered to all pregnant women.

"Everything is becoming so medical! You can no longer enjoy your pregnancy. You worry all the time about your baby. You are supposed to enjoy a little bit. It seems that pregnancy is a medical condition, but it is something natural. I do not think it is good that testing become something normal." (From T2)

At the same time, she believed that parents always have a right to decide about the birth of a disabled child. Therefore, she considered that testing should be offered to all pregnant women even if she considered screening as ethically unacceptable for her.

"I think it is good that people get the chance to have a test performed. Everybody must get the opportunity to decide whether they want such a child." (From T4)

2. Reasons for declining the test

The main reason she reported for declining MST was that she did not want to have an abortion. She justified abortion only in case of a severely disabled child when a life full of suffering could be expected. She did not see Down syndrome as severe enough to justify termination. She believed that such a child can be happy and have a good life. The only reason she saw for accepting screening was to prepare herself for the birth of a disabled child.
"Down syndrome is not a reason for abortion. If I were to know that my child would have a worthless life, then I think I would opt for abortion. It is irrational to continue pregnancy when a life full of pain and suffering could be expected. But this is not the case for a child with Down syndrome. I think that children with Down syndrome can have a happy life. You have of course severe forms of Down syndrome but in general they are happy children. Well, it is a very ethical issue.” (From T2)

Her personal experience with a disabled sister made her positive about the potential of living a full life with a disability.

“I will only think about abortion if my baby is severely disabled. But a minor disability, say blindness, would not be a reason for me for termination. Such a child can have a fairly normal life. I think it is ethically acceptable to terminate the pregnancy. But only in case of severe disabilities.” (From T1)

Participant was of the opinion that good parents and especially mothers ought to accept their children as they are unconditionally. She described striving for perfect children as being against good motherhood.

“You bring a baby into the world and you hope that everything is good. If it has a disability, you must love him as much as other children. It is not the fault of the child! Sometimes you hear about mothers who abandon their child immediately after birth because it has Down syndrome! I think: what kind of mother are you? You are still its mother! It is so odd that she doesn’t have any feeling for the child. It is a baby!” (From T2)

Participant reported that mothers bear the responsibility for the well being of their children. She extended her responsibilities toward her unborn child to live healthy during pregnancy.

“Mothers ought to seek for the health of their baby. They have a duty to avoid risk for the health of their future child such as using alcohol and drugs. They have to try to eat healthy and to avoid places where people smoke. If you want children you have to try to live as healthy as possible.” (From T1)

Additional reasons she gave for declining the screening offer were the lack of personal risk since her health was good and her first pregnancy was without
problems. Therefore, she believed that there was no need for her to have a screening test.

"I didn’t have any problem in my first pregnancy. And I don’t think that I have a high risk to get a child with Down syndrome. We both have healthy families. No I don’t think I have a high risk.” (From T2)

During the interview at T2 it became clear that the most important reason for declining screening was her fear of an unfavourable screening result. She acknowledged that she did not want to take the responsibility of further decisions about invasive diagnosis with a risk for the foetus and eventual abortion in case of a confirmed disability. Therefore, she preferred to be confronted with a possibly disabled child at birth.

“When I got the booklet with information about the Maternal Screening test I got upset. I read it and I saw that you should consider an amniocentesis if the screening result is too high. I don’t want a needle in my belly. My first reaction was to throw the booklet away. But later I picked it up and I thought, well I must have a blood test because I’m Rhesus negative. They can test the baby at the same time. Perhaps it is good that I got this chance and I should take it. But the fear won! For suppose they find something wrong. Suppose that it is not good! I know what the consequences are and that scares me. You have to wait, I don’t know how many weeks, and I don’t think I could sleep till I knew the results. I’m so afraid for the results.” (From T2)

Although she believed she had no reasons to fear that something was wrong with the baby, she expressed her need to have assurance that everything was going well. One of her reasons for declining the screening offer was the uncertainty of the screening results. Despite her desire for reassurance from the test, she weighed this up against the anxiety related to a high risk. She expected that the 20th week ultrasound would confirm that the baby was healthy.

“If the test would give 100% certainty about the presence of a disability I might accept it. Well I hope that they can say anything in the 20th week standard ultrasound. It is a pity that I’ve not received the other screening test, I mean the Nuchal Translucency Measurement, because I think that I might have accepted it, just to see my baby and know that everything is going well.” (From T2)
3. Input of other persons in her decision

Participant shared her decision to decline the screening with her partner. Although, he liked her to accept the MST he could understand her motives and agreed that the screening test would make her uncertain and more worried.

"We (she and her husband) have talked about and discussed these issues. He gave me his opinion. He said: “you have the opportunity to do it, why don’t you take it?” But he could also understand me, and he agreed with me- He agreed that it was better for me not to take the test. Because he knows how I am. He said I know you and I understand that you do not want to do it.” (From T2)

The positive attitude of her partner about screening made her doubt about her decision to decline the test. After discussion with her partner about their capacity to care for a child with Down syndrome, she was confirmed in her decision. The fact that her partner also believed that a child with Down syndrome has a right to live made her more confident.

“When he said that he would prefer to have the screening, I began to doubt about it. We talked again about it. He said: “you must decide, you are the one who is pregnant, you’re the one who will be with child most of the time and if you say that you can cope with it …” And he believes that I can. I carry the baby! I’ll care for the child. He wouldn’t. He is at his work most of the time. Of course, he is at home in the evening, and he helps me. Therefore, I think that we can manage it. And he also believes that a child with Down syndrome or with a minor disability has a right to live.” (From T2)

Participant approached one of her sisters who had used testing during pregnancy because of medical reasons. Her sister confirmed her in her decision that it was not necessary for her because she did not have any reason to fear that the child would be disabled. Like her husband she could understand her fear for the MST.

“My sister used testing. But she told me that she had to do it because she had cancer when she was young and got chemotherapy. She did not have another option. But that is not my case! And she said to me: We all know you. You are always so scared. “Miep panic.” That is my nickname!” (From T2)
4. View on her decision of not using screening

The offer of prenatal screening during our study confronted her with the possibility that her child will be disabled. During the interview she reported ambivalent feelings about her decision not to use screening. She wondered whether she had to accept the test in order to confirm that her child did not have Down syndrome.

"I already knew that there is always a chance that something goes wrong with your baby, but the offer made me more aware. I think that 1/900 is a very high risk. I hadn’t realized this before. I’m now aware that I can be just that one among the 900. (..) What if I get a child with Down syndrome? Sometimes I think that I would have to accept the test." (From T2)

She demonstrated her feelings of uncertainty through searching for information about Down syndrome. She also talked with a work colleague who was mother of a child with Down syndrome. Her colleague made her aware of the burdens of raising a child with Down syndrome.

"I’ve looked for information before I finally made my decision. I think it is very important to be informed before you decide what to do. I also talked with a colleague who has a child with Down syndrome. She said that they couldn’t detect it by her. And she told me that such a child is an economic burden because they (the government people) do not give her much money and she has more children!" (From T2)

She continued to manifest ambivalent feelings during the course of pregnancy. At one side she reported her doubts about whether she had to assure that her child was not severely disabled. On the other side she believed that she had made the right decision. She considered screening not acceptable for her because she did not want to decide about abortion. Furthermore, she reported that screening can never guarantee that the child would not be disabled.

"Suppose that it is severely disabled. Then I would doubt all my life whether I’ve made the right choice for the child. But I think that screening is not acceptable for me. I do not know whether I could live with the idea that I did not allow my child to be born. And it is not sure that you get a healthy child also when you get a good screening result." (From T4)
After the birth of her child with Down syndrome she reported that she was happy with the decision not to accept the screening test. Otherwise, she would not have enjoyed her pregnancy knowing that her child was disabled given that she had not chosen for abortion.

“I can only speak for myself. I’m very happy I didn’t take the screening! My baby has Down syndrome! I would not have enjoyed my pregnancy if I knew this before.” (From T5)

Some days after she returned the last questionnaire (T5) she spontaneously sent us an e-mail where she manifested her concerns about the pro-abortion mentality that she thought was bound to prenatal testing. She asked us to give positive information about Down syndrome.

“I am now the mother of a child with Down syndrome. I’ve experienced the test as anti-Down. Testing pressures you to abort if it shows that the child is disabled. I’ve not read anywhere about the happiness such a child gives you. Please give the right information about Down syndrome. It is not so awful!”

5. Decision in a next pregnancy

Regardless of her ethical views about the acceptability of abortion for Down syndrome she reported that she would use screening in a next pregnancy to avoid the burden of a disabled child on her family. She feared that she would not be able to assure a good live for her daughter and two disabled children.

“In a next pregnancy I would accept screening in the interest of my family and partner. It should be an extreme burden to have two disabled children. I don’t know whether we would be able to cope with this.” (From T5)

Still, she considered abortion only acceptable for severe disabilities and remained concerned that only perfect children would be born.

“I think that abortion is acceptable in case of severe disabilities. But not for minor disabilities. I fear that only perfect people will be born in the future. Many parents will not choose for a child with Down syndrome. We cannot create a world where only perfect children are welcome.” (From T5)
Discussion

This case illustrates the different considerations that shape women’s choices regarding the acceptance of prenatal screening. It also reveals the importance of the interplay between the decisions regarding prenatal testing and the context in which choices are made. This interplay confirms the adequateness of a relational concept of autonomy for ethical deliberation regarding prenatal testing.

For this participant, screening was closely linked to the decision of aborting an affected foetus. Therefore, she did not see the test as a personal option. Although, she believed that parents have a right to decide whether they can cope with the care of a disabled child, she judged Down syndrome as not severe enough to justify termination of pregnancy.

The screening offer during our study caused a conflict between her wish for reassurance about the health of the foetus and her unwillingness to make further decisions about her unborn child. Despite her desire for reassurance from the test, she decided to avoid the difficult decisions that might come with knowledge about the health status of the foetus.

She also reported a conflict between her duty to avoid suffering due to (severe) disability and the duty to accept children unconditionally. This conflict was expressed in feelings of guilt and moral concerns about whether she had to accept the screening offer in order to exclude a severe disabled child. She reported these feelings both during decision making and in the course of pregnancy. Her way to escape from this conflict was to avoid the responsibility of further decisions that might come with knowledge about the health of the foetus and to leave the pregnancy to follow its natural course. Regardless of her doubts and ambivalent feelings about her decision, her moral beliefs about the right of life of the foetus and the parental duty to unconditionally accept every child gave her enough reasons to believe that their decision to declining the screening was right.

After the birth of a disabled child, however, she reported that she should test in a next pregnancy, in order to avoid the burden of a disabled child on her family. Although, she still did not agree with abortion for Down syndrome the responsibility for the care of a disabled child produced a change towards acceptance of prenatal screening and abortion in a next pregnancy. In contrast to early attitudes toward testing and termination she puts the well being of her
family in the first place and concludes that her initial moral standpoints would not justify another disabled child.

The apparent inconsistence between the participant’s ethical beliefs and her decision in a next pregnancy can be seen as part of moral development. Although she was aware during her pregnancy that there can be always something wrong with the health of the foetus, she hadn’t any reason to fear that she belonged to a high risks group. Therefore, she did not believe that she had a moral duty to accept the screening. However, the birth of her child with Down syndrome made her aware of her real possibility of getting a disabled child. Knowing about this risk, should make the birth of a subsequent child with a disability not more the result of “misfortune” of the work of nature but matter of personal responsibility. This shift in moral responsibility led participant to see testing as morally imperative in order to ensure her family the care and attention she considered necessary for its well being.

The central role of the wellbeing of the family on decisions regarding the acceptance of testing highlights the nature of the conflicts women face when confronted with a prenatal test offer. Women are compelled to review their moral beliefs about their responsibilities toward the foetus and their other existing children and partner and sometimes modify them.

Results also confirm the relational aspect of decision making regarding testing. Participant freely sought to share the decision with their partner and with other closed persons (her sister and a colleague with a disabled child) to confirm she had made the right decisions. The support and understanding of these persons helped her to embrace her decision. In ethical literature it is argued that autonomous decision can only be guaranteed when women decide on their own without any interference of other persons. Our findings contradict this individualistic concept of autonomy. Terms and concepts such as individual choice, autonomy, and non interference, do not capture all the emotional and circumstantial concerns in which decisions are made. As we have indicated above, support and approbation of closed ones might be seen as an important factor that help women to make well considered choices.
GENERAL DISCUSSION
Introduction

The purpose of this study was to explore the impact of ethical beliefs on decision making regarding the use of prenatal screening. A second purpose was to assess the effect of an unsolicited offer on the way women shape their parental moral duties: whether the test offer leads women to believe that they ought to use testing in order to avoid inflicting harm and to assure the well being of their future child. Two additional questions are closely bounded with these main topics we addressed in this thesis: 1) whether an active offer of an unsolicited prenatal test hinders women to make decisions that meet their norms and values\(^1,2\) and as consequence of this, 2) whether the test offer brings them into an ethical dilemma.

In this chapter the answers to these questions are discussed. We first summarize the main findings. Subsequently the relevance of our findings for ethical theory and the practice on prenatal screening (testing) is discussed. The chapter finally presents some ideas for future research.

Main findings of this thesis

Secondary role of ethical beliefs in decision making as ethical justification post hoc of the women's reproductive preferences

Contrary to studies that assert that different ethical views lead to different choices regarding prenatal testing\(^3\)\textsuperscript{,}\textsuperscript{9} we found that choices about prenatal screening were not primarily driven by the women's ethical views. We conclude this from the following findings:

1) Acceptors and decliners appeared to be more alike than different in their ethical views about the control and selection of offspring characteristics: they believed that parents can and sometimes ought to intervene in the natural course of pregnancy to avoid the suffering caused by a severe disability, including the abortion of a disabled foetus. At the same time, they stated that perfection should not be strived for, neither perfect children nor a perfect society. The only difference between acceptors and decliners was their personal attitude toward abortion in case of Down syndrome. This difference was mainly based on their capacity to assure the child and their family a good life. Decliners did not consider abortion as an option for themselves while acceptors were open for abortion, although they hoped not to be confronted with the decision (chapter 2).
2) The main reasons that participants gave for their decisions were mainly related to the following factors: the reassurance provided by the screening; the emotional consequences of further decisions regarding the use of invasive diagnostic and abortion; and their view about parenting a child with Down syndrome. Acceptors opted for screening as attempt to assure the health of the foetus and to escape from unwilling effects of nature by ruling out at least Down syndrome and some forms of disability. Decliners reported the uncertainty that may come with the test results as the main reason for not using screening. They tried to assure the birth of a healthy child by avoiding the risks of a wrong decision regarding invasive testing (chapters 3 and 5).

3) Both women accepting and declining afterwards appealed to normative ethical principles to justify and support the decision they had already made regarding the acceptance of screening (chapter 2).

Based on these findings, we distinguish two levels in decision making: on the first level, women balance the psychological and emotional effects of the information acquired by the test, against the expected burdens of a disabled child on their family and their own life perspective. On a second level, normative moral principles are introduced as additional arguments, backing and supporting the decision made on the first level. On this level, ethical norms appear to perform an instrumental role as normative reasons, being brought into play in order to give a moral justification to the women’s reproductive preferences regarding the place of a disabled child in their lives.

These findings must be interpreted with caution. Previous research showed that cultural and religious convictions and experience with disabled children have impact on ethical beliefs and decision making. Our finding that the decision is not lead by the woman’s ethical beliefs might be due to the low proportion of active religious women in this study (ca 23%). The acceptability of abortion between participants may be also due to the fact that abortion is legally permitted in The Netherlands.

**Impact of an unsolicited test offer on the women’s autonomy**

Prenatal screening aims to enhance women’s reproductive autonomy by offering them the information needed to make an informed decision. In accordance with the ethical principle of autonomy, decisions regarding the use of prenatal screening should be guided by the women’s own ethical views. Some authors
however question whether reproductive choice is actually enhanced. They fear that external pressures coming from close related persons and caregivers could compel women to make a concrete choice, and consequently dismiss them in their autonomy. The social views of disability as a tragedy together with the presumption that preventing disability is a desirable goal and a worthy pursuit would also lead women to believe that they ought to accept testing in order to avoid the birth of a disabled child. Social attitudes to women who declined testing or decide to give birth to a disabled limit the women’s autonomy rather than the enhancement of their reproductive choice.

Women’s relationship with their surroundings plays an important role in decision making. Participants freely decided to share the decision with their partner, other important persons and their midwife or gynaecologist. Analysis of the interviews we performed during the process of decision making showed that participants tended to comply with the opinion of their partner especially in the acceptance of the screening offer, also if they would decide differently on their own. Family and friends were approached in order to seek their approval and support for their decision. They were not directly implicated in the process of decision making. Although participants reported being influenced by their family’s feeling about having a child with Down syndrome they stated that they were not constrained to follow the advice of these persons. Participants also appreciated the support of caregivers in the form of information and medical advice. In spite of these external influences participants stated to have freely made their own choice without pressure from other persons. Societal influence was expressed in the form of concerns about reactions and intolerance of colleges and neighbours regarding their decision about testing and the birth of a disabled child. These concerns did not appear to impact the final choice (chapter 4).

Opponents of standard practice of prenatal screening argue that an unsolicited test offer may impede women to make an autonomous choice by generating an internal desire to have a healthy child that might conflict with the women’s values and beliefs. In accordance with this claim, both acceptors and decliners reported conflicting feelings regarding their wish to reassurance about the health of the foetus and their unwillingness to make difficult decisions about their unborn child. Regardless of these conflicting feelings, participants showed a positive attitude towards prenatal screening offer and argued that the test should be offered to all pregnant women. They managed to
embrace their choice, even if they recognise that they would have preferred not to have to make the decision (chapters 4 and 6). The conflicting feelings reported by participants should not be seen as an impediment to rational choice. Experiencing uncertainty during decision making belong to choices in which it is difficult to foresee the consequences of the different options. This uncertainty can be interpreted as a normal process in forming their personal view about the place of testing within their parental responsibilities.

These results indicate that an unsolicited offer of a prenatal screening test does not necessarily impede women to make an autonomous free choice. Participants expressed a clear awareness of the optional character of screening. Therefore, from an autonomy point of view, there is no reason to reduce access to prenatal screening. On the contrary, the offer of prenatal screening might help women to shape their own view about the ethical significance of control of the offspring characteristics. Women in our study carefully balanced the different goods and interests that should be affected by a disability. They also foresaw the risk of diagnostic testing in case of a high screening result and the consequence of a confirmed diagnostic.

Dilemmas due to the offer of screening as expression of conflicting interests; Central role of the parental duties

The conflicting feelings reported by participants might be interpreted as an expression of the difficulties women face when deciding about the ethical acceptability of testing.

Most participants stated spontaneously that decision making was a difficult ethical issue. They reported unease to decide when a termination of pregnancy is justifiable. They worried about the selection of the offspring's characteristics and questioned the limits we need to set. Disability was described as something that belongs to human life and is not without a meaning. Participants also saw getting a disabled child as the manifestation of their own destiny against which they cannot do anything (chapter 3). Decisions were felt to be particularly hard in case of anomalies as Down syndrome which may be compatible with a good life or when diagnosis and prognosis are uncertain. They pointed out that during pregnancy no one can foresee what a child's life will be (chapter 5).

A second issue raised by participants concerned the level of family suffering that justifies abortion of a foetus with Down syndrome. Participants worried about the negative impact of a disabled child on their commitments to their
Discussion

existing children and partner. Regardless of their doubts about the appropriateness of testing and, both acceptors and decliners reported that women ought to use testing accept testing when the care required for such a child would be an impediment to give other children the attention they considered necessary.

The views above highlight the nature of the quandary women experience when they have to decide about prenatal testing. As we pointed out above, prenatal screening compels women to reconsider their personal beliefs about respect for (unborn) human life or unconditional acceptance of children against the aims that may be attained by testing. Participants balanced the interests of the family against that of the foetus in order to find what is in line with their values and their personal circumstances. Therefore, we conclude that they are not so much faced with an ethical dilemma as well as a conflict of interest.

Discussion of our results

Our results suggest a gap between ethical theory about and the practice of decision making in prenatal screening.

Theoretical discussions on prenatal testing claim the right of the pregnant women to autonomous decision making without any interference from other persons that might constrain them to decide according to their ethical views and preferences. This interpretation of the concept of autonomy is unlikely to capture the emotional and circumstantial concerns in which decisions are made.

The instrumental role that individual ethical beliefs play in decision making together with the central role of the family interest and the women's need for social support suggest a clear need for a new ethical framework of thinking in reproductive decisions. Ethical deliberation on prenatal testing is still mainly based on deontological or consequentialistic theories. Within these theories ethical deliberation limits itself to a pure rational application of some universal principles (deontological) or to an evaluation of the consequences of each available option (consequentialistic) without taking into consideration the concrete persons and each particular situation. Our results demonstrate that a context-bounded ethics in which the moral responsibilities and duties that spring from relationships within the women's relational network are central would be more adequate to understand the decisions women make in the practice. This ethical approach might also offer a promising alternative for
identifying the nature of the conflicts that women reported when deciding about testing.

**A new approach of reproductive autonomy**

Traditionally decision making in the area of prenatal testing is discussed within an ethical framework of supporting individual choice free from external pressure. According to this concept autonomous decision making can only be guaranteed when women are free to decide based upon their personal values and beliefs without any influence coming from the views and interests of other persons.\(^4\) \(^{23-25}\) In contraposition to these studies, our results show that the impact of other persons does not impede women to decide according to their own views and preferences. These results raise questions about the typical concept of autonomy and its use within the context of reproduction technologies.

Participants freely sought to share the decision with their partner and other closely related persons even if this involvement limits them in their choice. It can be argued that influence of the partner may be considered as being against the women’s autonomy, since some women accepted screening only to comply with the partner’s opinion. On the other hand, active participation of their partner in decision making might help to avoid that women shoulder all the blame for making a wrong decision (chapter 4). On the same way, family and friends appear to have a role in reassuring women that they made the right decision, since they are approached with the aim of obtaining approval and support. From this perspective the input of third persons should not be evaluated so much as undesired influence but as a way to help women to embrace the decision they made and therefore to increase their feeling of autonomy. This conclusion is confirmed by our finding that participants were satisfied with their choice and stated that they decided without being forced to follow the views of other persons. Quantitative analyses within the RCT also confirmed that women decide autonomously without being pressured by others.\(^26\) The advice of sharing the decision with others, especially with those who are the most closed to the women help women better assess the appropriateness of their desires, motives, preferences and aims in order to shape their mind about the significance of testing within their personal moral framework and to feel secure in their choice.\(^27\)
Our results suggest that the moral significance of prenatal testing is inseparably bound with the (social) context in which it is practiced. This context serves as an interpretative framework for the ethical assessment of prenatal testing. Hence, respect for autonomous decision making needs not to be incompatible with the recognition that an individual’s social context inevitably informs and influences his or her choices. As our results show, autonomy and relationallity need not to be positioned as mutually exclusive concepts, but rather as mutually informing and reinforcing aspects. Women do not make their decisions in a vacuum but within an *a priori* family, social and cultural context that both shape and is affected by their choices. Pretending that women decide without involvement of valued relationships is confusing autonomy with independence and individualism. This account of autonomy fails to recognize the women’s need for support and advice from important ones.

If prenatal screening is intended to stimulate and guarantee responsible reproductive decisions, then a broader conception of autonomy that recognizes the role of the partner in decision making and the influence of women’s family and social contexts in which decisions are made is required. We propound a concept of relational autonomy that takes into consideration the framework in which decisions take place, and the limitations that relations within that context impose on the self determination of the individuals. Understanding the relational, social and cultural factors behind the decision may illuminate women’s practical responses to prenatal screening and testing. This understanding may help clinical practice to support women to act according to their moral framework when confronted with the moral choices inherent within the offer of prenatal screening.

**Pragmatic character of the decision**

The instrumental role of moral principles and beliefs in decision making and the guiding role of the family needs might be interpreted as an expression of a pragmatic ethics in which women determine what they ought to do according to their view of a worthy life and based upon what they judge good for them in accordance with the actual context of their lives by weighting up the consequences of his action for himself and others. Within this ethical framework the family and women well being and the women’s strength to guarantee the child a good life becomes central.
This ethical pragmatism can be interpreted as a consequence of the moral relativism in the Netherlands where there are no absolute values that function as moral guiding rules for everybody. However, the finding that women appeal to moral principles as post hoc justification of their choice indicates that women struggle with moral questions -often without defining or recognising their moral character- and try to find the most acceptable ethical option.

Reproductive decisions take place in a relational context where competing goods and desires must be carefully negotiated, balanced and fused. Prenatal decisions have consequences not only for the future child but also for the women and for their family and other loved persons. The relational constructed deliberation informs decision making and thus may explain that women do not focus on discerning the good decision that is in accordance with ethical principles but try to find the option that can be integrated with the good, desires and expectations of the persons whose lives will be significantly affected their decision.

The uncertain character of the information provided by prenatal screening might make it difficult to interpret the practical significance of odds for the application of moral principles that are central in ethical theory over prenatal testing i.e. “avoiding suffering”, “worth of human (disabled) life”, “moral status of the foetus” and “abortion”. Quantitative results of the RCT also show that women find it difficult to interpret the results of prenatal screening and to make further decisions that imply risks for the foetus. The difficulty to interpret the information given by prenatal screening might explain the guiding role of the women’s views about the impact of a disabled child on the conditions the consider necessary for a good life and the individual and family circumstances in decision making. Our finding that ethical principles do play a guiding role when there is a known, clear and direct relation between action and the foetus health support this conclusion. Participants (acceptors and decliners) believed that women that have sufficient reasons to fear disability ought to test. All of them found abortion acceptable in case of severe disabilities.

Change in ethical beliefs: Transition phase
Prenatal testing gives women the possibility to prevent the suffering that accompanies disability and to fulfil their desire to have a healthy child. This
possibility has changed the traditional paradigm according to which disability is considered to be beyond our control because is fixed by nature.

While this possibility may give women the possibility to exert rational control over the outcomes of pregnancy it also confronts women with new moral responsibilities. Before the introduction of testing there was no way for parents to prevent a congenital disability except by not having children. With the introduction of prenatal testing, women come to face a choice about the characteristics that are acceptable in their children and which disabilities justify—and for some demand—the abortion of an affected foetus. As Dworkin argues, by providing this choice, prenatal testing has challenged the assumption that disability lies beyond the control of the parents because it is fixed by nature and therefore escapes their moral responsibility. This shift in moral responsibility undermines our most basic assumptions about the boundary between what we are morally responsible for in choosing and what lies beyond our control. As such it destabilizes much of our conventional morality. Consequently, it is argued, that the possibility to know in advance about the health status of the foetus leads to a shift in the ethical beliefs regarding our reproductive responsibilities and the ethical significance of testing within good parenthood. Long lasting values within the field of reproduction and parenting such as the unconditional acceptance of children; the worth of every child as a gift becomes substituted by moral values and being the author of your own life.

This shift in ethical beliefs regarding reproductive responsibilities and good parenthood came to the fore in the narratives of our participants. Participants reported conflicting feelings regarding their wish to avoid the negative impact of a disabled child on the care they owed to their other children and partner and their reluctance to take responsibility through choice. They were concerned about the acceptability to intervene in the natural course of pregnancy. As we pointed out above, decliners tried to escape the difficulty of decision making by delegating the choice to nature, fate or God. Acceptors, on the contrary, performed testing as an attempt to confirm that the foetus is healthy in order to avoid further decisions. These feelings and concerns suggest that women's preferences about testing often deviate from their hold ethical values. This conflict may also be seen as an indication that the values embodied by prenatal testing were not yet incorporated in the women's ethical beliefs. Women deciding about prenatal screening are faced with the difficult task of specifying
and interpreting their hold moral principles and beliefs and adjusting them to
the new ethical values embodied by testing with which they have not yet
identified totally.

**Implications for ethical theory; Need of a new situation related ethical
approach**

Up to now we have shown that decisions regarding prenatal testing acquire their
ethical significance within a relational and social context that shape women's
beliefs, values, desires and aspirations. This conclusion draws us to question the
necessity of an ethical theory that incorporates the contextual frame work in
which decisions take place and the emotional and relational aspect of decision
making. Ethical theory regarding prenatal testing has long been dominated by
deontological and consequentialism ethical theories. Results of this thesis
indicate that these theories do not catch the complexity of the reality in which
decision are made.

The flaw of both deontological and consequentialist theories is that they rely
on one rule or principle that is expected to apply to any moral situation and
decision (e.g. Mill's Greatest Happiness Principle and Kant's Categorical
Imperative). The personal, family and social circumstances in which decision
making takes place vary from one woman to another. We should not expect that
simple rules that do not admit exception provide a standard solution regarding
the permissibility or impermissibility of testing. Furthermore, moral principles
do not offer clear direction to resolve the (moral) dilemmas and conflicts that
women face when confronted with a test offer. The same moral principles may
pull women in different directions. This is evident from the fact that both
acceptors and decliners mentioned the same moral principles as justification for
their decision.

The same can be said about a consequential approach. Certainly women
consider the advantages and disadvantages of testing for themselves, the foetus
and those affected by its birth. However, the consequences are difficult to
predict since testing does not give accurate information about the prognoses
nor about how life will be with such a child. The interest of those involved: the
future child, the woman, parents, other children and closely related persons
often conflict and lead women to different options in practice.

Based on the results of this thesis we propose that a context-bounded ethics
in which the moral responsibilities and duties that spring from relationships
within the women's relational network play a central role would be more adequate to understand the decisions women make in the practice. The birth of a (disabled) child has not only impact on the life of the child itself but also on other family members and on the women's social network. Therefore, decisions about testing cannot be considered apart from the values and goods that women aim for their family and closely related persons.

A virtue ethics approach

Within a relational concept of autonomy we propose a virtue approach of ethical theory as a more promising alternative for (enhancing) the moral discourse on prenatal testing. Virtue ethics maintains that the right action is that which a virtuous agent in said circumstances, would choose. Unlike deontological and consequentialist theories, virtue ethics entails that ethical deliberation does not limit itself to a pure rational application of universal principles neither to an evaluation of the consequences of each available option. Virtue ethics is concerned with the good life and what kinds of persons we should be. According to this ethical approach the central ethical question is not “is the action against any ethical principle?” or “does it harm anyone?” but “what would a good (virtuous) person do in these circumstances?”49 Virtue related ethical concepts and ethical questions could be identified in the narratives of participants:

- Women decide motivated by their responsibility to look for the well being of their family. Their choice can be interpreted as an expression of their wish to be a “good mother”. Acceptors opted for screening as a way to guarantee a good life for their existing children and partner (chapters 5 and 6). The main reason for the acceptance of prenatal screening was the belief that a disabled child would be an obstacle to fulfil their responsibilities to their family. Participants who chose not to have screening reported that the information gleaned about the risk of a disability was irrelevant to them since they could care for both their child and their family.

- A key component of virtue ethics is the virtue of prudence that is associated with wisdom, insight and knowledge. Prudence consists in the ability to accurately perceive, and to rationally interpret and evaluate the relevant aspects within a given situation. As consequence a prudent person is able to act
always in a fitting manner. An aspect of prudence is seeking for information and for the advice of reliable persons. Someone who wants to make responsible decisions seeks to be influenced by all the relevant facts and points of view; in short, such a person wants to be able to decide on the basis of all the good reasons available.⁵⁰-⁵²

Participants in our study did not decide motivated by irrational or emotional considerations. As our results show women make their decisions by rationally deliberating about i.e. the significance of the screening odds for further decisions regarding further testing; the risks factors related to invasive tests and the consequences of their decisions for the future child and the lives of those affected by the birth of a disabled child. They also reflect about the meaning and appropriateness of their feelings and try to incorporate them to rational decision.

Participants also seek the advice and support of closely related persons when deciding about prenatal testing. Advice of others gives women additional arguments to consider during decision making. As we have mentioned above the advice of important ones might also enhance the women’s autonomy by helping them to assess the moral value of the different options and the appropriateness of their desires, and aims.

- Another distinctive feature of virtue ethics is the central role that the circumstances in which the choice is made play in determining the ethical right decision. Virtue ethics entails the application of the principles of morality to the concrete events and circumstances of each particular occasion. It is the virtuous application of rules to the concrete circumstances which makes those action and rules morally valid.²²

The dependence of the circumstances was evident from our results. Women’s choices are based upon an evaluation of their capacity of care for a disabled child and their family within their family and personal circumstances. Although, participants did not believe in a moral duty to avoid disability neither to guarantee health, they believed that testing becomes imperative when the extra care that a disabled child demands would prevent them to give other members of their family the time and attention they owed to them. They also reported that women who have a higher risk of having a disabled child should use testing. When values, beliefs, goods, interests and emotions conflict -as it appears from our results-, there are rarely answers that are clearly “right”.
best, there is an answer that is most acceptable for women within their concrete family and individual circumstances at that particular time in their lives. In fact, most women who declined the screening offer indicated that their decision was not necessarily the result of strong opposition to the test itself. Even those who declined the test offer reported that they could see themselves accepting it in different circumstances.

- According to virtue ethic the aim of the moral decision is to reach the good life which is based on the Aristotelian idea of eudemonia of happiness, which means living well.\textsuperscript{53} This eudemonia is achieved when the moral choice is in line with the (moral) values of the agent, and the moral good that she wants to achieve. The virtue of prudence is just aimed at making the right choice for action concerning what is good and useful for a successful life.

From our results it became evident that the moral motive behind the decision is the well being and happiness women want for their family, the child and themselves. The main motivation for accepting screening was assuring their future child and their family a good and well life by protecting them of the burdens of disability. A main motive for declining the screening was the possibility to give a disabled child and the family the care and attention that they need to have a good and happy life. Motives of personal wellbeing as psychical and emotional health and a good relationship with the partner were also indicated as important in the decision. Women decide by balancing the personal psychological and emotional effects of the test’s information, against the burdens they expect a disabled child would have on the well being of their family.

- The Aristotelian doctrine of the mean is perhaps the most important, and distinctive, aspect of virtue ethics that can be applied in interesting ways to the issue of prenatal testing. Virtue “lies in a mean” between two (vicious) extremes because the right response to each situation is neither too much nor too little. Within reproductive decisions virtuous mothers seek the mean between the vices of over-caring and neglecting parents.

Participants struggle with the meaning of testing within their moral duties to the unborn and their family. They questioned the limits of their desire to know and to control the offspring characteristics and their moral duty to employ all the available means to ensure the well being of their children. They seek to find
a compromise (a mean) between their moral duties for the unborn and the other children and partner.

- Contrary to deontological moral theories, virtue ethics is based on a model of moral choice that does not see emotions as contrary to rational decision making. Virtues are considered to be the right expression or moderation of the passions and emotions ‘in the right place and at the right time’.\textsuperscript{53-56} Within virtue ethics the distinctive of right moral choice is the satisfaction with the decision made that is expressed in sentiments of gladness and peace of mind. These sentiments are important in theories of decision making as indicators of agent’s autonomy.\textsuperscript{57}

From the narratives of our participants it came to the fore that emotions help women as tiebreakers, to decide in a conflict situation in which it is difficult to determine the practical fulfilling of ethical principles and which interest must be given preference. Feelings of satisfaction with the decisions were reported by participants as indication that they had made the right decision in line with their values and preferences.

**Practical implications**

What are the implications of our findings for health care provision? From our results it follows that the decisions regarding prenatal screening are not easy for many women. Its purposes, benefits, and limitations are difficult to comprehend. Even though most women in this study felt that prenatal screening gave them the opportunity to make informed reproductive decisions, they also reported that they found it difficult to assess the significance of testing within their parental duties and to find which option is the most acceptable form an ethical viewpoint.

The above indicates that although the decision is not guided by ethical beliefs, women struggle with moral issues, often without explicitly defining or recognizing their moral character. Therefore, we propose that the moral aspects of the choices deserve more emphasis. At present, the moral character is not denied, but neither receives it much active attention. The medical model of counselling which is still influential in the context of prenatal testing deals mainly with psychosocial and medical aspects of the test. Such features only present a partial picture of all aspects implicated in the decision. Emphasis on the moral character would be more in touch with the reality of decision-making.
process and render women more prepared for assuming the consequences of their decision. Decisions regarding prenatal testing affect the women’s view about what sort of mother they should be, their reproductive responsibilities and their relationships with their partner. It also confronts women with the responsibility of the impact of their decision on their family. Counselling should discuss the impact of the availability of prenatal testing on the women’s views about these issues. Caregivers should also take into consideration that the women’s personal views about their responsibilities toward their existing children are of primary importance in the decision being made. Furthermore, caregivers should assure that women understand that a positive result does not mean that they are in the clear. Giving this information would enable women to make up their mind about the place of prenatal testing within their parental duties.

The moral dimension of decision making becomes more relevant with the possibility to isolate and analyse free foetal DNA and RNA (ffDNA cf fDNA/RNA) or whole foetal cells in maternal blood. This development holds the promise of non invasive prenatal diagnostic early in pregnancy and without the risk of foetal loss that the current invasive procedures of Chorionic Villus Sampling and Amniocentesis carry. The feasibility of NIPD for trisomy 21, 13 and 18 has already been shown. Since the most important reason for declining screening are absent, the women’s views about their duty to avoid preventable suffering and the acceptability of abortion might become central in the decision.

Given the impact of the expected burdens of a child with Down syndrome on the women commitments to other family members counselling should find out what women know about the condition, the accuracy of their knowledge and their beliefs about raising children with disabilities. Care givers should discuss the women’s view on the life with a child with Down syndrome and the implications that living with such a child for the women and their family. In order to help women to assess the role of testing within their parental duties, additional information should be given about the (symptoms of the) disabilities they are testing for and the available treatments. Such information should include, at a minimum, a detailed description of the biological, cognitive, or psychological impairments associated with specific disabilities, and what those impairments imply for day-to-day functioning. The costs of available treatments and the existing forms of societal support should be also discussed.
The actual offer of prenatal screening presupposes that pregnant women decide on their own regardless of the social and cultural context in which decisions take place. Therefore, it emphasises the personal character of the decision, ignoring the necessity of women on support and advices of closely related persons and care providers. Our results indicate that women are more concerned about how to ensure that they made the correct decision, than about the possibility to make an autonomous choice. They need and value the support of partner and other persons. They also welcome objective medical information and the advice of the caregivers. These findings suggest that every offer should be timely done in order to give women the opportunity to discuss testing with significant others. Furthermore, if others’ views are highly valued, caregivers should encourage discussion with significant others. On return, the clinic should check whether the influence of others impedes or enhances free choice. Caregivers should avoid that women are forced to accept or decline prenatal testing by medical, social or cultural pressures.

In sum, some practical points that should be discussed are: the understanding of the pros and cons of testing and the scenarios they might face in case of a high test result; what they want to do with the information once they got it i.e. whether they want to take further tests and whether abortion would be an option; the women’s feelings about a positive result and how they will cope in response to this; the women’s values and beliefs regarding their reproductive rights and duties, abortion, worth of disabilities; the view of their partner and his input in the decision; the implications that living with a child with Down syndrome would be for the woman and her family. To facilitate reproductive autonomy, counselling should provide all relevant information about the characteristics of the test and of the disabilities tested. Accurate information about the testing procedure, the possible risks, and the possibility of ambiguous results should also be provided. Women should also be informed beforehand about the difficult decisions that a high screening result can lead to, as well to the different options to follow.

It would be useful to develop an aid for decision making that incorporates all the above mentioned practical issues. This aid or guide could be offered to women together with the offer of prenatal screening. It should encourage women to consider the ethical aspects related to prenatal screening, the motives for their decision and the consequences of the different options. It
should also encourage women to discuss the decision with their partner and the importance that they attach to the view and support of their family and friends.

**Future research**

The present study pleads for a virtue ethics approach for ethical reasoning regarding the decision about prenatal screening and testing. Future research should establish the relevance of virtue ethics in decisions regarding the control and interference in the characteristics of the offspring. Research should analyse the virtues that are relevant to these decisions. This research should also elucidate the relation between the fulfilment of the women's commitments toward the unborn, their partner and other children and their moral satisfaction. Additionally, research should analyse the relationship between the control (and selection) of the offspring characteristics and the women's moral beliefs about the aim of procreation, good motherhood, good life and happiness. Results of this research might contribute to deeply understand the ethical aspects of decisions not only about prenatal screening and testing but also in the framework of the embryo selection through prenatal genetic diagnostic and (newborn) genetic testing of children.

The view of the partner regarding testing was assessed on basis of the narratives of participants. As the partners were not directly approached the concrete impact of their views in decision making could not be deduced. Furthermore, the view of the women regarding the opinion of their partner might reflect their own impression without being objective. Future research should incorporate the view, beliefs, values and attitudes of partners in order to determine their role in decision making and their impact on the autonomy of the women.

In contradiction to other studies we found that social views and expectations do not impede women to decide according to their values and beliefs. This might be due to the fact that prenatal screening was not part of normal prenatal care in the Netherlands at the time of our study. Therefore, women in our study might consider testing as not necessary for health pregnancy outcomes. Furthermore, since prenatal screening was not standardly performed, society might be seen as more tolerant towards women who did not want prenatal testing. Studies in other countries show that the way in which parental duties are conceived might then change over time when prenatal testing has become a routine practice. Additional research is needed to determine the concrete impact of social norm in the actual Dutch situation in
which all pregnant women receive information about the possibility of performing a prenatal test. Research should explore the real impact of the social values, ideals, welfare standards and views on disability on the women’s view about the meaning of prenatal testing within their parental duties to their prospective child and family.

The possibility of the application of reliable non-invasive prenatal diagnosis without prejudicing the safety of the mother or her unborn is an important and exciting development that will introduce new ethical, social and economic issues. The fact that screening only gives a chance approximation about the presence of disability makes it difficult to make well considered decisions in the interest of the child. Further invasive testing is necessary to confirm the presence of a disability. For many women the risk of pregnancy loss of invasive diagnostic outweighs the possible (ethical) benefits of testing. If a barrier to testing is removed, will women feel less justified in declining or be more open to persuasion? Research should also contemplate the concrete impact of the parental duties to the unborn and other family members as well as the impact of the interest of women and family on the application of the ethical principles on decision making. Managing the introduction of this new technology will require attention to the understanding and views of women and couples regarding the avoidance of diagnostic disabilities. Non invasive prenatal diagnostic also forces us to revisit existing debate and dilemmas in prenatal diagnosis in order to determine how they might change and what safeguards might be required.

An additional focus of future research should be on determining the ethical aspects of unexpected findings i.e. whether and how unexpected findings should be passed on to women; Whether women should be beforehand informed about all the conditions that can be seen or only about the conditions that are standard tested before testing takes place; Whether a difference should be made between treatable and not treatable and between genetic and not genetic conditions.
References


The impetus for this study came from the ethical debate associated with the expanding of the offer of prenatal screening for Down syndrome (DS) and Neural Tube Defects (NTD) to pregnant women in low risk groups. Contrary to other Western countries, health policy in the Netherlands has been reluctant to making screening available to all pregnant women. Till 2007 prenatal screening was not offered as part of antenatal care. Only women with an increased risk of giving birth to a disabled child due to advanced maternal age (from 36 years old), or to a medical indication were routinely offered a diagnostic test (chorionic villus sampling or amniocentesis). It was forbidden by law to offer tests or to give general information on these tests to women outside these high risk groups. From January 2007 onward, however, the policy has changed. Nowadays Dutch caregivers are requested to ask all pregnant women whether they want to receive information about prenatal screening as part of prenatal care. When women want caregivers have to provide both verbal and written information about methods for foetal screening and diagnostic with the emphasis on voluntary participation. Cost of these test are reimbursed only for women in the risks groups.

One of the main arguments of the Dutch parliament against the introduction of nationwide prenatal screening program was the negative impact that an unsolicited test offer could have on women’s reproductive autonomy and ethical decision making. Central in the Dutch debate was whether an unsolicited offer of prenatal testing allows women to make autonomous choices based upon their personal values and beliefs or on the contrary pressures them to make decisions that meet society’s norms bringing them into complex ethical dilemmas. At issue was whether women to whom a test is offered can successfully determine the significance of prenatal screening within their moral duties toward their offspring. An additional question was the impact of the availability of testing on the women’s views about the conditions needed for a good life. The main objective of this thesis was to answer and discuss these questions. Most of the studies on women’s motives for accepting or declining prenatal screening tests mainly focus on the impact of psychological, social and emotional factors of decision-making. Consequently, little is known about the concrete role of women’s ethical values and beliefs on decision making regarding prenatal screening.

Which moral norms do women take into consideration when deciding on the use of prenatal screening? which -if any- is the concrete role of the women’s
ethical values and beliefs in decision making? And what is the effect of an unsolicited test offer on the women’s views on their moral duties toward their offspring. These factors need to be analysed before the impact of an unsolicited prenatal screening offer on women’s reproductive autonomy can be assessed.

In order to gain more insight in the impact of the women’s ethical principles and beliefs on decision making we developed a qualitative study within a randomised controlled trial (RCT) that aimed to assess the decision making process of women when confronted with a prenatal screening test offer. The RCT was carried out at the VU Medical Centre between May 2001 and April 2004. It consisted in two research groups, being offered a Nuchal Translucency Measurement (NTM) for DS or a Maternal Serum Screening Test (MST) for DS and NTD and one control group that received normal care at that moment in the Netherlands (no offer).

Data collection took place at five different times: before a screening test was offered (T1); during decision making (T2); after the screening result was known or at a comparable point in time when screening was denied (T3); in the last trimester of pregnancy (T4) and within two months after delivery (T5). A subgroup of participants of the RCT randomly was selected for participating in the qualitative study. These participants received an extra open-ended questionnaire at T1, T4 en T5. Some participants were approached for participating in a face to face semi-structured interview during the process of decision making (T2).

All questionnaires included questions about the women’s ethical view on the control of the offspring’s characteristics and abortion. In questionnaire T4 we included additional questions about their feelings regarding the test offer and the decision they made. In questionnaire T5 we asked which decision they would make in a next pregnancy and the reasons for their decision. In this questionnaire some items on the meaning of prenatal screening within the parental reproductive duties and rights were included.

As this thesis was aimed at exploring the ethical aspects of decision making of women to whom a prenatal screening test was offered, only data from women in the intervention group were used.

Chapter 1 (introduction) provides an overview of the factors that come to the fore in debates about the desirability of expanding the offer of prenatal screening to all pregnant women independent of their age and their family and
personal medical history. The methodology and outline of the thesis are described.

**Chapter 2** explores the impact of the women's ethical views and beliefs on decision making. Contrary to the most accepted view, we found that choices about prenatal screening were not primarily driven by the women's ethical views. Participants' choices where mainly related to: the reassurance provided by the screening; the emotional consequences of further decisions regarding invasive diagnostic and abortion; and their view of a life with DS together with personal considerations about the acceptability of abortion in case of DS together with the expected burdens of a disabled child on their family and their own life perspective. All these considerations shape together the final decision. Participants mentioned ethical principles as support for their decision. Remarkably acceptors and decliners reported the same moral principles. These findings suggest that ethical beliefs might perform an instrumental role as normative reasons, being brought into play in order to give a moral justification to the women's reproductive preferences regarding the place of a disabled child in their lives.

One of the ethical considerations that were mentioned both by acceptors and decliners was the moral duty to respect nature without controlling the outcomes of pregnancy. In **chapter 3** we explored what women exactly mean when they appeal to nature and the impact of those considerations on decision making. Contrary to theoretical debates we found that appeals to the moral authority of nature do not provide *prima facie* justification for (not) controlling or intervening in the outcomes of pregnancy. Both acceptors and decliners believed in an inherent morality in nature that must be respected. They welcome the possibility of knowing more about the health of the foetus and to make their own reproductive decisions. They also believed that parents ought to take an active part in the course of pregnancy by employing all the available means that can assure a healthy foetus. Concerns for the quality of their child's life and for their capacity to assure a good life for their family and disabled child appear to play a central role in the decision regarding the use of screening.

Participants' appeals to nature might be interpreted as an expression of the difficulties women face when deciding about the acceptability and necessity of
testing. According to this interpretation “nature” refers to the women’s views about the disabilities that ought to be accepted”. Appeals to nature might also be associated with the women’s assessment of the utility of prenatal screening for holding some control over the health of the foetus. In this sense “nature” refers to “that what is beyond our choice and control”.

The impact that an active and unsolicited offer of prenatal screening may have for women’s autonomy is explored in chapter 4. The central question that is assessed in this chapter is: does an unsolicited prenatal screening offer impede women to make an autonomous decision in line with their ethical values and beliefs? In order to analyse this question we searched for the existence of both external pressures coming from family and social context and internal constrains such as feelings and expectations caused by the test offer, that may hinder rational decision making. From our results it became clear that support and approbation of close related persons might be seen as an important factor that help women to make well considered choices. Participants did not want to bear the responsibility of the consequences of their choice on their own. Therefore, they freely chose to involve their partner, family and friends in decision making. They also searched for the advice of their midwifery of gynaecologist. All participants reported that they freely made their own decision. These results indicate that the influence of other persons cannot be seen as an impediment for making an autonomous choice. On the contrary sharing their decision with other persons might enhance women’s autonomy by helping them to assess the different options and to shape their ethical views regarding prenatal testing. Sharing the decision with important ones might also help participants to assess the conflicting feelings that they experienced during decision making. At one side they wanted to obtain assurance about the health of the foetus. At the other side they were unwilling to decide about its life. These conflicting feelings could be interpreted as a normal process in forming the women’s personal view about the place of testing within their parental responsibilities. They may have an important role as tie-breakers helping to choose between options which rationally are considered to be equivalent. From the autonomy perspective, there is no reason to reduce the offer of prenatal screening.

Based on the above results we propound a concept of autonomy that takes into consideration the relational aspects of the human existence and the impact of the social framework in which decisions take place. As our results show, the
involvement and consultation with relatives are important conditions for autonomous choices.

**Chapter 5** explores the conflicting feelings that participants experienced could be considered as the manifestation of a moral dilemma. The main question in this chapter is whether the offer of a prenatal screening test brings women in the difficult position to choose between two exclusive actions that they are morally required to do. Although, both acceptors and decliners described the choice as hard to make they were satisfied with their final choice and believed that their choice was the right one in their concrete circumstances. They did not report feelings of guilt and uncertainty that are characteristic of moral dilemmas. The conflict that participants experienced could be interpreted as the difficulty of assessing the significance of the testing within their personal and family circumstances. They found it hard to find the option that met either their moral views and the family and individual interests. Therefore, we conclude that women are not so much faced with an ethical dilemma as a conflict of interest.

The above results indicate that the availability of prenatal screening compels women to review their moral beliefs about their responsibilities toward their offspring and to adapt them to the new technical possibilities. The concrete impact of the availability of testing on the women’s views about their moral duties to the unborn and their family is explored in **chapter 6**. At issue is whether the availability of prenatal screening leads women to believe that they have a moral duty to accept testing. Results show that although participants felt responsible for the health of their child, they did not believe in an absolute moral duty to guarantee health, neither to avoid disability. A duty to test was formulated only when women had a high risk to get a disabled child. In this case, testing was described as a prudential measure to assure the health of the foetus. Still, participants claimed that further decisions always belong to the competency of the parents. The capacity for guaranteeing a good life both for their future child and their family appears to be a crucial factor in determining whether testing becomes morally obligatory. Participants who accepted screening and those who opposed to it agreed in the view that testing becomes necessary when the birth of a disabled child would stand in the way of the well being of their family. Participants’ accounts suggest that the women’s wish of providing the best possible life for their family might morally compel women to
make use of screening. When they expect that they will not be able to give a disabled child and their family the care and attention they need, then alone screening becomes imperative.

Our finding that participants did not judge screening as moral obligatory might be related to the fact that prenatal screening was not part of normal prenatal care in the Netherlands during our study. The way in which parental duties are conceived might change over time if prenatal screening becomes a routine practice. In countries where prenatal screening is standard part of prenatal care, women's participation in testing is not always preceded by a conscious well considered decision. The impact of the medical and social framework on the ethical deliberation of pregnant women on accepting or declining a test offer is subject of further research.

Chapter 7 illustrates at the hand of a case study the impact of the availability of prenatal screening on the way women shape their ethical views. This case illustrates the different considerations that shape women's choices regarding the acceptance of prenatal screening. It also reveals the importance of the interplay between the decisions regarding prenatal testing and the context in which choices are made. This interplay confirms the adequateness of a relational concept of autonomy for ethical deliberation regarding prenatal testing.

Findings of this thesis suggest a clear need for a new ethical framework of thinking in reproductive decisions. Our results demonstrate that a context-bounded ethics in which the moral responsibilities and duties that spring from the women's views about what constitutes a good life, would be more adequate to understand the decisions that women make in the practice. We propose a virtue centred model of ethical thinking for the decisions regarding prenatal testing. This model does not only include the women's moral views and values about the acceptability of quality control of the foetus. It also allows room for the attitudes and emotions of the women triggered by a test offer as well as for contextual influences from the medical practice and closed persons. The central question when deciding about testing is not “is testing against any ethical principle?” or “does testing harm anyone?” but “which decision would a good mother make in these circumstances?”
Translated to clinical practice, findings of this thesis suggest that every offer of prenatal screening testing should be timely done in order to give women the opportunity to discuss the offer with significant others (i.e. partner, friends and relatives). Caregivers should also care for the women’s emotions when confronted with a test offer. Women should also be informed beforehand about the difficult decisions that a high screening result can lead to, as well about the different options to follow. For helping women to assess the meaning of testing within their parental duties, a test offer should not be limited to the communication of the technical characteristics of the screening and of the test results. Counselling should include discussion about the women’s wishes, preferences and expectations regarding testing, their family situation, the women’s thoughts about the life with a child with DS and their view on their commitments to their family.
Samenvatting

De drijfveer achter deze studie is het ethische debat rond de uitbreiding van het aanbod van prenatale screening op het syndroom van Down (DS) en het neurale buisdefect (NBD) aan zwangere vrouwen die niet tot de risicogroepen behoren.

In tegenstelling tot andere westerse landen was Nederland terughoudend ten aanzien van het beschikbaar stellen van de prenatale screening aan alle zwangere vrouwen. Screening maakte tot 2007 geen onderdeel uit van de prenatale zorg. Diagnostische tests, zoals de vlokkentest of de vruchtwaterpunctie, werden slechts aangeboden aan vrouwen met een verhoogde kans op de geboorte van een gehandicapt kind, door hogere leeftijd (36 jaar of ouder) of op basis van erfelijke belasting. Het was wettelijk niet toegestaan om risico schattingstests of algemene informatie over deze tests te verstrekken aan vrouwen buiten deze risicogroepen. Sinds januari 2007 is dit beleid veranderd.

Als onderdeel van de zwangerschapszorg worden thans zorgverleners geacht alle zwangere vrouwen te vragen of zij informatie wensen over de prenatale screening. Vrouwen die dit wensen krijgen zowel schriftelijke als mondelinge informatie over de beschikbare screening en diagnostische tests, waarbij de vrijwillige deelname aan deze tests wordt benadrukt. De kosten van deze tests worden echter alleen vergoed voor vrouwen die tot een risicogroep behoren.

Eén van de voornaamste bezwaren van de Nederlandse overheid tegen het invoeren van een landelijk programma voor prenatale screening op aangeboren afwijkingen was de negatieve impact die het testaanbod zou hebben op enerzijds de reproductieve autonomie van zwangeren en anderzijds op hun ethische besluitvorming.

Centraal in het Nederlandse debat stond de vraag of vrouwen die geconfronteerd worden met een ongevraagd testaanbod in staat zouden zijn een vrije keuze te maken in overeenstemming met hun persoonlijke morele waarden en opvattingen, of dat zij daarentegen onder druk worden gezet om een bepaalde keuze te maken, waardoor zij in een ethisch dilemma terecht komen. Het debat draait dus om de vraag of vrouwen aan wie de test wordt aangeboden erin slagen de betekenis van prenatale testen binnen hun morele opvattingen over hun plichten ten opzichte van hun kinderen te plaatsen. Tevens is het van belang te bezien of zij de testen binnen hun concept van wat goed leven is weten te interpreteren.
In dit proefschrift wordt een antwoord gezocht op bovenstaande vragen en deze worden nader besproken. De meerderheid van de studies naar de redenen van vrouwen voor het wel of niet laten verrichten van een prenatale test richt zich op de invloed die psychische, sociale en emotionele factoren op de besluitvorming hebben. Over de rol die morele opvattingen spelen in het beslissingsproces van vrouwen is weinig bekend. Welke morele normen worden in beschouwing genomen bij de besluitvorming over de prenatale screening? Wat is de concrete rol van de ethische waarden en opvattingen die de vrouw heeft, gesteld dat deze een rol spelen? Wat is de impact van een ongevraagd testaanbod op de visie van vrouwen op hun morele plichten ten opzichte van hun kinderen? Deze vragen moeten worden beantwoord alvorens het concrete effect van de prenatale screening op de autonomie van de vrouwen kan worden bepaald.

Teneinde meer inzicht te krijgen in de rol van de morele waarden en opvattingen van vrouwen in de besluitvorming omtrent het gebruik van prenatale screening, ontwikkelden wij een kwalitatieve studie binnen een groter onderzoeksproject. In het grote project werd gewerkt met een gerandomiseerde gecontroleerde trial (RCT). De RCT richtte zich op onderzoeksvragen betreffende de risicoperceptie, de besluitvorming, en het psychische welbevinden van zwangere vrouwen die wel of geen prenatale screening kregen aangeboden. De RCT werd uitgevoerd bij het VU Medisch Centrum in de periode van mei 2001 tot april 2004. Hij bestond uit twee interventiegroepen die een vorm van prenatale screening kregen aangeboden: een Nekplooimeting (NTD) of een Maternale serumtest (MST). Daarnaast was er nog een derde groep die bij wijze van controle de gebruikelijke zorg op dat moment in Nederland kreeg (dus geen testaanbod). Dataverzameling vond plaats middels vragenlijsten die de deelnemers op vijf tijdstippen tijdens de zwangerschap ontvingen: voordat prenatale screening werd aangeboden (T1); gedurende de besluitvorming (T2); nadat de uitslag van de test bekend was of op een vergelijkbaar tijdstip voor vrouwen die niet op aanbod ingingen (T3); tijdens het laatste trimester van de zwangerschap (T4); en twee maanden na de bevalling (T5). Voor de kwalitatieve studie selecteerden wij via randomisatie een subgroep van de deelnemers van de RCT. Deelnemers aan deze studie ontvingen een extra vragenlijst op T1, T4 en T5. Sommige deelnemers werden willekeurig benaderd voor een semi-gestructureerd interview gedurende de besluitvorming (T2).
Alle vragenlijsten bestonden uit open vragen over de morele opvattingen van de vrouwen over de controle van de eigenschappen van hun nageslacht en over abortus. Vragenlijst T4 bevatte extra vragen over de visie en gevoelens van de vrouwen naar aanleiding van het testaanbod en hun eigen beslissing. In vragenlijst T5 vroegen wij naar de beslissing die deelnemers zouden maken in een eventuele volgende zwangerschap en naar de redenen voor hun beslissing. In deze vragenlijst werden ook stellingen over de betekenis van prenatale screening voor de reproductieve plichten en rechten toegevoegd.

Dit proefschrift heeft tot doel het onderzoeken van de ethische aspecten van besluitvorming over prenatale screening. Daarom werden alleen data van vrouwen uit de interventiegroepen gebruikt.

Hoofdstuk 1 (Inleiding) geeft een overzicht van de factoren die op de voorgrond treden in de debatten over de wenselijkheid van de uitbreiding van het aanbod van prenatale screening aan alle zwangere vrouwen, ongeacht hun leeftijd en hun familiare, persoonlijke en medische geschiedenis. De methodologie en de hoofdlijnen van het proefschrift worden beschreven.

Hoofdstuk 2 onderzoekt de invloed van de morele opvattingen van de vrouwen op de besluitvorming. In tegenstelling tot de meest gebruikelijke zienswijze wijzen de resultaten van ons onderzoek erop dat vrouwen niet met ethische overwegingen worstelen bij de besluitvorming over prenatale screening. De keuze van deelnemers was gerelateerd aan de volgende factoren: het verschaffen van geruststelling door prenatale screening; de emotionele last die gepaard gaat met verdere beslissingen over invasieve tests of abortus; de persoonlijke visie op wat het leven met een kind met DS inhoudt; de persoonlijke overwegingen over de aanvaardbaarheid van abortus in geval van DS; en de verwachte (over)belasting die een gehandicapt kind het gezin en hun eigen levensperspectieven zou geven. Deze genoemde factoren geven vorm aan de definitieve beslissing. Zowel de vrouwen die ingingen op het screeningsaanbod als degenen die het afwezen, rechtvaardigden hun keuze met dezelfde morele principes. Op basis van deze bevindingen concluderen wij dat morele principes een instrumentele rol spelen door als normatieve redenen op te treden. Deze redenen worden namelijk ingezet als een morele rechtvaardiging achteraf van de reproductieve voorkeuren van de ouders met betrekking tot de plaats van een gehandicapt kind in hun leven.
Een van de overwegingen die werd genoemd door zowel vrouwen die op het screeningsaanbod ingingen als door vrouwen die het screeningsaanbod afwezen, was de morele plicht om de natuur te volgen zonder de uitkomsten van de zwangerschap te controleren. In hoofdstuk 3 onderzoeken wij nader wat vrouwen precies bedoelen als ze zich beroepen op de natuur en welke invloed deze overweging heeft op de besluitvorming. Wij vonden, in tegenstelling tot de visie die naar voren komt in ethische debatten, dat de erkenning van een moreel gezag in de natuur geen prima facie argument is om het natuurlijk beloop van de zwangerschap te controleren en/of hier in te grijpen. Zowel vrouwen die ingingen op het screeningsaanbod en vrouwen die dit afwezen geloofden in een normatief karakter dat in de natuur besloten ligt en dus gerespecteerd dient te worden. Anderzijds waren ze van mening dat ouders een actieve rol kunnen en dienen te spelen in het beloop van de zwangerschap teneinde een gezonde foetus te waarborgen. De verwijzing van deelnemers naar het morele en normatieve gezag van de natuur kan worden gezien als een uiting van de moeilijkheden die vrouwen ervaren bij de beslissing over leed dat moet worden voorkomen. Volgens deze uitleg kan “natuur” geïnterpreteerd worden als de handicaps die volgens de opvatting van de vrouwen moeten worden geaccepteerd. Het doen van een beroep op het morele gezag van de natuur kan echter ook worden gekoppeld aan de waarde die de vrouw gaf aan het nut van prenatale screening om enige controle te kunnen uitoefenen over de natuurlijke uitkomsten van de zwangerschap. In deze context is ‘natuur’ dat wat buiten onze controle en keuze ligt.

In hoofdstuk 4 behandelen wij de impact van een ongevraagd aanbod van prenatale screening op de autonomie van de vrouwen. De centrale vraag die in dit hoofdstuk wordt onderzocht is of een screeningsaanbod zwangeren belemmert een autonome beslissing te nemen die in overeenstemming is met hun eigen morele waarden en opvattingen. Om deze vraag te beantwoorden keken wij naar de aanwezigheid van druk vanuit de omgeving en de gevoelens of twijfels die door het screeningsaanbod worden veroorzaakt en die de mogelijkheid van een autonome besluitvorming in de weg staan of kunnen beperken. Uit de resultaten werd duidelijk dat naasten een ondersteunende rol spelen in de besluitvorming over het verrichten van een prenatale screening. Deelnemers wilden de verantwoordelijkheid van de gevolgen van hun beslissing niet alleen dragen. Daarom kozen ze ervoor om samen met hun partner te
beslissen en hun keuze te delen met hun geliefden, ook als die niet rechtstreeks betrokken waren bij het besluitvormingsproces. Ze zochten ook de steun van familie en vrienden en het advies van hun verloskundige of gynaecoloog. Deelnemers rapporteerden dat zij vrij hadden besloten. Op basis hiervan kan de invloed van derden niet worden gezien als een belemmering voor het maken van een autonome keuze. Integendeel, het delen van de beslissing met anderen kan de autonomie van de vrouwen vergroten door hen te helpen de verschillende opties te beoordelen en vorm te geven aan hun visie over prenatale tests. De steun en advies van derden kan helpen vrouwen om een plek te geven aan de tegenstrijdige gevoelens die zij ervoer tijdens het besluitproces. Aan de ene kant verlangden zij meer te weten over de gezondheid van de foetus. Aan de andere kant wilden zij liever geen beslissing nemen over het leven van hun foetus. Deze tegenstrijdige gevoelens kunnen worden gezien als een normaal proces in de vorming van hun persoonlijk standpunt over de plaats van prenatale tests binnen hun ouderlijke verantwoordelijkheden. In het geval van onzekerheid en twijfel kunnen deze gevoelens beslissend zijn bij de keuze tussen opties die rationeel als gelijkwaardig worden beschouwd. Vanuit het perspectief van de autonomie is er dus geen reden, om het aanbod van prenatale screening te beperken.

Op basis van de bovenstaande resultaten stellen wij een concept van autonomie voor dat meer recht doet aan de interdependentie en de relationele aspecten van het menselijke bestaan, waarmee wordt erkend, zoals onze resultaten aanduiden, dat betrokkenheid en overleg met naasten belangrijke voorwaarden zijn voor autonome beslissingen.

Hoofdstuk 5 onderzoekt de mogelijke tegenstrijdige aspecten bij de besluitvorming met het doel te analyseren of vrouwen aan wie een test wordt aangeboden in een ethisch dilemma terechtkomen. Hoewel beide groepen (degenen die wel en degenen die geen test kiezen) de keuze als moeilijk beschreven, waren beiden positief over hun beslissing. Zij waren ook van mening dat zij de juiste beslissing hadden genomen binnen hun concrete omstandigheden. Zij vermeldden geen schuldgevoelens of onzekerheid; kenmerkende gevoelens voor ethische dilemma’s. Het conflict dat deelnemers ondervonden kan worden geïnterpreteerd als de moeilijkheid om de betekenis van testen binnen hun persoonlijke en gezinsomstandigheden te bepalen. Het is namelijk moeilijk te bepalen wat het meest in overeenstemming is met zowel
Samenvatting

De eigen morele waarden en opvattingen als met het eigenbelang en het belang van hun gezin. Daarom concluderen wij dat de vrouwen niet zozeer terecht komen in een ethisch dilemma maar in een belangenconflict. De bovenstaande resultaten suggereren dat de mogelijkheid om een prenatale screening te doen, vrouwen ertoe aanzet hun morele opvattingen over hun verantwoordelijkheden ten opzichte van hun nageslacht te herzien en deze aan te passen aan de nieuwe technische mogelijkheden.

De concrete invloed van prenatale screening op de manier hoe vrouwen hun morele verantwoordelijkheden ten opzichte van hun kinderen invullen, wordt onderzocht in hoofdstuk 6. De centrale vraag is of de beschikbaarheid van prenataal onderzoek vrouwen doet geloven dat ze een morele plicht hebben om op het testaanbod in te gaan. Vrouwen voelen zich verantwoordelijk voor de gezondheid van hun kind. Zij geloven echter niet dat zij een absolute morele plicht hebben om de gezondheid van hun kind te verzekeren, noch om beperkingen te voorkomen. Het testen werd alleen als een plicht ervaren in geval van een verhoogd risico op de geboorte van een gehandicapt kind. In dat geval werd het testen beschreven als een zorgvuldigheidsmaatregel om de gezondheid van de foetus te bevestigen. Toch stelden de deelnemers dat verdere beslissingen in deze altijd tot de bevoegdheid van de ouders behoort. Het vermogen van vrouwen om een goed leven te garanderen, zowel aan hun gezin als aan hun toekomstige kind, lijkt een beslissende factor te zijn bij de bepaling of vrouwen zich moreel verplicht voelen zich te laten testen. Zowel deelnemers die een screeningstest hadden gedaan als degenen die het screeningsaanbod hadden afgewezen, waren het met elkaar eens dat testen noodzakelijk wordt zodra de geboorte van een gehandicapt kind een belemmering zou betekenen voor het welzijn van hun gezin. De wens om het best mogelijke leven aan hun gezin te geven kan wel een morele druk op vrouwen uitoefenen om toch de screening te gebruiken. Wanneer zij denken dat ze hun gezin geen goed leven kunnen waarborgen vanwege de extra zorg en aandacht die een gehandicapt kind vereist, dan en alleen dan, wordt het gebruik van een prenatale test als een morele plicht gezien.

Onze bevinding dat vrouwen zich niet moreel verplicht voelden op het test aanbod in te gaan kan samenhangen met het feit dat prenatale screening geen normale procedure was in de prenatale zorg in Nederland tijdens onze studie. De wijze waarop ouderlijke plichten worden gezien kan veranderen zodra
prenatale tests een routine praktijk worden. In landen waar prenatale screening al lang onderdeel is van de standaard prenatale zorg wordt het laten doen van een prenatale test niet meer voorafgegaan door een bewuste weloverwogen keuze. Het testen is meer iets dat erbij hoort. De concrete impact van de medische en sociale context op de ethische besluitvorming van zwangeren bij het accepteren of weigeren van een testaanbod is onderwerp van nader onderzoek.

Aan de hand van een case study illustreert hoofdstuk 7 het effect van het beschikbaar stellen van prenatale screening op de morele opvattingen van vrouwen. Deze case study laat de overwegingen die vorm geven aan de beslissing over het gebruik van prenatale screening duidelijk zien. Dit hoofdstuk laat de samenhang zien die er bestaat tussen de beslissingen over prenatale tests en de context waarin deze beslissingen worden genomen.

Bevindingen uit dit proefschrift suggereren een duidelijke noodzaak van een hernieuwde ethische benadering voor beslissingen binnen de voortplanting. Onze resultaten tonen aan dat een contextgebonden ethiek waarbinnen de morele plichten en verantwoordelijkheden die voortvloeien uit de visie van vrouwen over wat het goede leven inhoudt geschikter zou zijn om de besluitvorming over prenatale screening beter te begrijpen. Wij pleiten voor een deugd gecentreerd model voor de ethische analyse van de besluitvorming omtrent prenatale tests. Dit model omvat namelijk niet alleen de morele opvattingen en waarden van de vrouwen over de aanvaardbaarheid van de controle van de kwaliteit van de foetus. Het deugd gecentreerde model biedt bovendien ruimte aan zowel de emoties die door een testaanbod worden veroorzaakt als de invloed vanuit de medische praktijk en de dichtstbijzijnde personen. De centrale vraag bij een afweging over de verschillende alternatieven bij prenatale screening is dan niet “gaat het gebruik van een test in tegen een ethische norm of principe?” of “schaadt de test iemand? maar “welke beslissing zou een goede moeder nemen in deze concrete omstandigheden?”

Uit de bevindingen van dit proefschrift volgt dat ieder aanbod van prenatale screening voortijdig moet worden gedaan om vrouwen de gelegenheid te geven met belangrijke personen in hun sociale context te kunnen overleggen (partner, vriend(inn)en en familiekring). Zorgverleners zouden aandacht moeten geven
aan de emoties van de vrouwen wanneer zij met een testaanbod worden geconfronteerd. Het is ook van belang vrouwen vooraf te informeren over de moeilijke beslissingen die een verhoogd risico met zich meebrengt, evenals over de verschillende opties waartussen zij kunnen kiezen. Indien vrouwen geholpen moeten worden om de betekenis van prenatale tests voor hun ouderlijke verantwoordelijkheden te bepalen, dient een testaanbod meer gericht te zijn op de morele afweging van de vrouwen en niet slechts op de technische en medische details van de test en de testuitslagen. Counseling dient gericht te zijn op de volgende aspecten: de wensen, voorkeuren en verwachtingen van vrouwen met betrekking tot het testen; hun gezinssituatie; hun gedachten over het leven met een kind met DS; hun visie op hun verplichtingen ten aanzien van het ongeboren kind en haar bestaande kinderen; en hun visie over hun verantwoordelijkheden ten opzichte van het voorkomen van handicaps.
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Lieve papa en mama, jullie liefde en vertrouwen in mij hebben de basis gelegd voor alles wat ik doe. Ik had meer tijd aan jullie willen besteden en jullie bijstaan in minder leuke perioden. Ook als ik fysiek niet altijd aanwezig kan zijn, ben ik heel dichtbij jullie.
Curriculum Vitae

Elisa Garcia Gonzalez is in Cartagena (Spanje) geboren. Na het behalen van haar doctoraal in de Biologie aan de Universiteit van Valencia (Spanje) is zij naar Nederland gekomen voor haar Phd in de Moleculaire Biologie. Na haar promotie heeft zij een aantal jaar als onderzoeker en docent Moleculaire Biologie gewerkt. Teneinde een gedegen ondergrond voor haar interesse in de Ethiek te leggen, besloot zij in 1998 Filosofie te gaan studeren. Na het behalen van haar doctoraal begon zij aan haar promotie onderzoek binnen de Medische Ethiek waarvan dit boek het resultaat is.

Gedurende deze jaren was zij eveneens werkzaam voor het Lindeboom Instituut waar zij betrokken was bij een project over de ethisch aspecten van het patenteren van embryonale stamcellen. Samen met Evert van Leeuwen heeft zij in opdracht van het Ministerie van VWS aan een rapport over de ethische en juridische aspecten van het vermengen van menselijk en dierlijk materiaal voor het verkrijgen van stamcellen gewerkt.

Daarnaast werkte zij als universitair docent “filosofie en medische ethiek” bij de faculteit Geneeskunde van het Vrije Universiteit Medisch Centrum te Amsterdam en als gastdocent “klinische ethiek” aan de Amstel Academie en de Hogeschool in Holland.

Sinds januari 2012 is zij werkzaam als postdoc onderzoeker bij de afdeling IQ healthcare, sectie Ethiek, Filosofie en Geschiedenis van de Geneeskunde, van het UMC St Radboud Nijmegen.