

Couples' experiences of an information model about prenatal screening

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**Couples' experiences of an information
model about prenatal screening
Decision-making and satisfaction**

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Abstract

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The overall aim of this thesis was to describe pregnant women's and partners' views and experiences on early prenatal screening with the combined test, with special focus on the two-step information model.

Interviews were performed with 15 couples who had taken part in the extended information visit about prenatal screening, describing their perceptions of the information model (I) and ten couples or women of those, for a follow-up interview exploring their decision-making process (II). Seven couples, who had not taken part in the extended information visit, were interviewed describing their views and experiences about prenatal screening (III). A questionnaire was answered by 295 women and by 223 partners about their satisfaction about the decision whether or not to participate in the combined test, and their assessment of whether or not this choice had been difficult (IV).

The results showed that different opinions were expressed about the offer of the extended information visit. The separate visit was welcomed by most couples (I). The decision-making process regarding whether to take part in the test or not was described by most couples as a fairly straightforward decision, while for others it was a more complex process that required a great deal of consideration (II). An apprehension of the test, by some of those who had refrained the extended information visit, was that it was an expression of society's involvement in decisions that belong to the expectant parents (III). Ninety-three percent of both women and partners considered the decision about participating in the combined tests as uncomplicated, and well over 90%, of both women and partners were satisfied with their decision (IV).

The conclusions in this thesis, are that the decision whether or not to participate in the combined test is multidimensional and influenced by different views. The two-step information model helped the pregnant woman and the partner to make a decision in a fairly straightforward process or a more complex process with mixed feelings.

Keywords: decision-making, patient education, patient satisfaction, prenatal screening

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ORIGINAL PAPERS

This thesis is based upon the following studies, referred to in the text by their Roman numerals:

- I. Wätterbjörk I, Blomberg K, Nilsson K, Sahlberg-Blom E. Pregnant women's and their partners' perception of an information model on prenatal screening. *Prenatal Diagnosis*, 2012;32,461-66.
- II. Wätterbjörk I, Blomberg K, Nilsson K, Sahlberg-Blom E. Prenatal screening – the decision-making process described by pregnant women and their partners. *Health Expectations*, published online 1 OCT 2013, DOI: 10.1111/hex.12147.
- III. Wätterbjörk I, Sahlberg-Blom E, Nilsson K, Blomberg K. Views on prenatal screening among pregnant women and partners declining an extended information. Submitted.
- IV. Wätterbjörk I, Sahlberg-Blom E, Blomberg K, Nilsson K. Decision-making about prenatal screening – are pregnant women and partners satisfied with their decision? Submitted.

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FOREWORD

In 2006 the Swedish Council on Technology Assessment in Health Care published a systematic review “Methods of Early Prenatal Diagnosis”¹. One of the conclusions was that the Combined Ultrasound and Biochemical test (combined test) is the clinically evaluated method of assessing the probability of Down syndrome in the foetus that gives the best balance between the percentage of detected cases and false positive results. Another conclusion of the report was that the information about prenatal screening for the pregnant woman and the partner must be increased but there was a lack of evidence as to how it should be achieved¹. The Swedish National Council on Medical Ethics opinion about the combined test, emphasized the importance of information given to the pregnant woman and the partner prior to the decision whether or not to take part in the test².

When Örebro County Council introduced the combined test as a method of prenatal screening in November 2008, a model for providing information in two steps was also implemented. The information model was developed according to the conclusions from the Swedish Council on Technology Assessment in Health Care’s systematic review¹ and the opinion of the Swedish National Council on Medical Ethics². This information model was further elaborated by the Maternal Health Care Programme in Örebro County Council with help from enthusiastic and committed midwives. I had worked as a midwife in antenatal care for 20 years and my special interest was in discussing with my “patients” to help and guide them in pregnancy, parenthood and reproductive health. So I was delighted when I was asked to work with the group of colleagues developing the information model. For a short period I also took part in the extended information visits and met pregnant women and partners for consultation. The Örebro County Council had decided, when introducing the combined test, that the information model should be scientifically evaluated, and a research group was formed for that purpose. I then had the opportunity to become a PhD student with Kerstin Nilsson, the chairperson of the working committee of the systematic review of the Swedish Council on Technology Assessment in Health Care, as my supervisor. The information model is described in the Background section in this thesis.

BACKGROUND

Transition to parenthood

Becoming pregnant and childbearing is a major life event that brings about many new challenges. At such a major life event, previous experiences and learned responses are not enough to understand the new situation which is ushering in a new stage of life³. According to Melies' theory of transition⁴, change is an event or situation, and transition is one's experience of the event or situation and how one responds to it. Change may happen at a point in time, but transition is a long process, and could start a long time before the actual change. In that sense parenthood is a transition starting in early pregnancy or even before, when planning the pregnancy⁴.

Pregnant women have described a feeling of loss of control over their lives even in the early stages of pregnancy. The shift in focus from oneself to the needs of the foetus indicates that the transition may begin in very early pregnancy^{5, 6}. In a Swedish study by Olsson⁵ the women described the meaning of pregnancy in terms of mixed feelings as: undergoing an arbitrary physical process, partly understanding what is happening, being troubled by the failing body and the growing baby, adjusting to a new lifestyle, being a burden on the environment, being confident in the pregnancy, and being unconcerned for the pregnancy. The Swedish male partners described the meaning of a pregnancy as: seeking to understand what is changing, supporting the pregnant woman and family life, and worrying about the child's and the pregnant woman's health⁵.

The Swedish Maternal Health Care Programme

The Swedish antenatal care service has a role in women's and families' health situation through guidance within sexual and reproductive health. More than 95% of the pregnant women in Sweden are enrolled and following the national programme. The Maternal Health Care Programme has a mission to prevent and identify health risks for women and children during pregnancy and the midwife is the hub of the Maternal Health Care Programme⁷. The World Health Organization (WHO)⁸ has been calling for the partner of the pregnant women to become more engaged in health care since there is evidence that this can positively influence the health outcomes for the whole family. Despite this, the needs of the partner for information as a parent, is often excluded in the Maternal Health Care Programme, where the service is focused more on the health of the mother and child⁸.

A caring perspective by the midwife is essential in all activities. A primary task for the midwife is to support the woman and the partner in the development of parenting and to liberate and strengthen the resources of both the individual and the couple^{9, 10}.

Screening

In the 1940s the benefits of screening for disease prevention were first demonstrated by the use of radiography for the identification of individuals with tuberculosis. The first comprehensive reviews of the principles of screening were published in 1961¹¹, and in 1968, when Wilson and Jungner produced their *Principles and Practice of Screening for Disease*¹², which was published as a WHO monograph.

The definition of screening evolved over the years but the current definition could be summarized in four criteria: condition, diagnosis, treatment, and balance in risk/benefit. This means that, the condition sought should be an important health problem and, should have a recognizable latent or early symptomatic stage and a safe and acceptable screening test. Procedures to establish the final diagnosis should be available, and early treatment should alter the prognosis from that of cases diagnosed after the onset of symptoms or signs. The costs should be economically balance¹¹.

Prenatal genetic testing

Prenatal genetic screening usually tests for three chromosomal aberrations, all of which are characterized by mental retardation. Trisomy 21, or Down syndrome is the most common chromosomal aberration. Down syndrome is associated with a variety of congenital malformations and medical conditions, for example, cardiac defects, eye disease, and hearing loss¹³. In 2011, 134 children with Down syndrome were born in Sweden¹⁴. The second most common autosomal trisomy syndrome is Trisomy 18, or Edwards syndrome. The main clinical features are characteristic craniofacial features; distinctive hand posture with overriding fingers, and major malformations including of the heart. The live birth prevalence of trisomy 18 ranges from 1/3600 to 1/10.000, but it is well known that trisomy 18 pregnancies have a high risk of foetal loss and stillbirth¹⁵. Trisomy 13, or Patau syndrome, is the third most common chromosomal trisomy and is clinically associated with various anomalies of the cardiac and central nervous systems and with high neonatal and infant mortality¹⁶. The prevalence has been reported as 1/5000 to 1/29.000 in live born^{17, 18}. The prognosis is lethal; 50% of infants with trisomy 13 will not live longer than a week, and only 5%–10% of infants will live past 1 year^{19, 20}.

For genetic screening the present main purpose is to prevent rather than treat disease, and in this it differs from many other current screening practices¹¹. The WHO states that the goal for prenatal genetic testing offered by the member states, should be that it has to be available, in order to reduce suffering for the unborn child and the parents²¹. Prenatal genetic testing includes both screening methods and diagnostic techniques. Screening examinations address the entire pregnant population without known increased risk for chromosomal aberrations or foetal malformations. Targeted screening can also be done in groups that for, some reason, such as age or history, have an increased likelihood of chromosomal aberrations or foetal malformation. Prenatal diagnosis means investigation undertaken to establish or refute a suspected diagnosis because of a circumstance in the particular case or because of the outcome of a previous screening procedure. Screening methods could be ultrasound scans with, for example, measurement of the nasal bone or soft markers that could indicate a chromosomal aberration. Serum screening with maternal blood sample is another method that has been used for many years. During the last decade the combined test has been available as a prenatal screening method. Culture of foetal cells for chromosomal analysis after amniocentesis or chorionic villus sampling is a technique used for diagnosing a chromosomal aberrations and has been used for several decades¹.

According to the WHO²², of all pregnancies, about 5% result in the birth of a child with a significant genetic disorder, congenital malformation, or disability. Families remain profoundly affected by genetic conditions, even though many affected individuals live full and happy lives. In many developed nations, people with severe mental retardation and developmental disabilities now live a nearly normal lifespan, but responsibility for most of their care falls on their families. There is lost economic output from family members who care for persons with genetic disorders as well as a substantial cost to society for non-institutional, outpatient, educational, medical, and social services. Because of the importance to individual families as well as the community the WHO advocates for continued efforts to develop effective treatments, and make them available worldwide²².

The Swedish Council on Technology Assessment in Health Care concluded in the systematic review in 2006, that the combined test was the most favourable method of screening for trisomy 21 in early pregnancy¹. The combined test gives a likelihood of trisomy of 13, 18 and 21 in the individual case, which is judged as better than the earlier routine of using the woman's age as a risk factor. The combined test is an algorithm that

consists of an ultrasound scan with a nuchal translucency measurement, a blood sample, and the age of the woman. Maternal serum free h-hCG and pregnancy associated plasma protein-A are analysed in the blood sample²³. The nuchal translucency is a fluid-filled space at the back of the foetal neck. This space only exists in early pregnancy and is measured in millimetres²⁴. The test is performed in early pregnancy, and the individual risk for carrying a foetus with these chromosomal aberrations is calculated with a cut-off from 1/200 to 1/300. About 5% have a high-risk result, in which case the pregnant woman is offered invasive testing amniocentesis or chorionic villus sample, for diagnosis^{23, 25, 26}. The invasive tests have a procedure-related risk for miscarriage of up to 1%^{27, 28}.

In Sweden all pregnant women should be offered general information about prenatal genetic testing and the decision whether or not to participate belongs to the woman, according to Swedish law²⁹. Swedish health care is decentralized and therefore, offers of care vary between different county councils and regions. Prenatal screening is an area where the offers differ regarding the kinds of methods provided. Sixteen of 21 county councils and regions offered the combined test in 2012, six of them to all pregnant women, and the others to women over the age of 35 years. Although a few counties have other criteria that also include some younger women, considerably more women age 35 and older take the test³⁰. The risk of chromosomal aberrations increases with maternal age, and if the foetus has a chromosomal aberration the risk of miscarriage or stillbirth is increased³¹.

The National Board of Health and Welfare in Sweden reports that, although the average age of women giving birth has risen sharply, from age 26.0 in 1973 to age 30.8 in 2012, the number of children born with trisomy 21 has been relatively constant over time since 1978, (1 per 700 - 800 births)³⁰. Between 1999 and 2012 there was a significant increase of abortions due to chromosomal aberrations. In 1999 about 53% of the pregnancies with a chromosomal aberration were aborted, and in 2012 about 69% of these pregnancies resulted in an abortion. A National Board of Health and Welfare in Sweden report³⁰ showed no significant difference in the incidence of trisomies among children born in Swedish county councils that offered the combined test, compared with babies born in County Councils that did not offer the test in 2008 - 2012. There was, however, a significantly increased incidence of abortions due to chromosomal aberration in county councils where the combined test was offered. It is well known that a pregnancy where the foetus has a chromosomal aberration often leads to early spontaneous abortion, but at an early mis-

carriage no chromosome analysis is performed. Foetuses with chromosomal aberrations will therefore largely be identified by the combined test, but not otherwise. This can result in a false increase in the observed presence of trisomy 21 in the county councils where the combined test is offered. The report showed clearly that early rendering of detected chromosomal aberrations results in more abortions, but maybe should some of these abortions of pregnancies have ended in miscarriage anyway further on in the pregnancy³⁰.

There are no consistent statistics in Sweden for how the combined test is used, because between the county councils differ as to whether the screening is offered or not. In Stockholm, 34% of pregnant women in 2009 participated in the combined test when 70 - 85% of all pregnant women in the area were offered the test³². About 60% participate in Örebro County Council where all pregnant women are invited. In comparison with other countries, where all pregnant women are offered the combined test, in Denmark 95% of the women participate^{33, 34}, while in the Netherlands only 35% accept the test³⁵.

All pregnant women in Sweden are offered a mid-pregnancy ultrasound scan in pregnancy week 16 - 20³⁶. All ultrasound scans are voluntary, but this scan is seen more or less as routine, and about 97% of all pregnant women attend. The aim of this scan is to examine viability, to screen for multiple pregnancies, to estimate gestational age, to localize the placenta and to estimate amount of amniotic fluid. Structural malformations are also detected, by using a standardized check-list³⁶.

Attitudes towards and experiences of prenatal screening

For pregnant women with a positive attitude towards prenatal screening, the reasons for participating have been cited as a desire for confirmation of the pregnancy or for reassurance about the health of the foetus³⁷⁻⁴². Among those who decline, a main reason given is that an abortion in case of a chromosomal aberration is not considered an option for the woman^{40, 43}. Other reasons for women to decline have included a perception of the test as having unfavourable characteristics, for example, that it is just a calculation and, that the test gives no certainty and is not reliable^{41, 44}.

Studies have shown that negative attitudes towards Down syndrome are significantly associated with higher screening uptake and testing^{45, 46}, but not all women considered their personal attitudes towards Down syndrome to be relevant to their screening decisions⁴⁵.

Religion, health care systems, traditions, and cultural background seem not to affect utilization of prenatal screening⁴⁷⁻⁴⁹. An Italian study showed

that religious conviction had a stronger impact on the attitude toward termination of pregnancy than on the attitude toward prenatal genetic testing⁵⁰ and Moroccan women with a child with Down syndrome had a positive attitude to prenatal screening in future pregnancy⁵¹.

Ekelin³⁷ has shown that in the transition to parenthood in modern societies the mid-pregnancy ultrasound scan in pregnancy week 16 - 20 has become an important event. The pregnant woman and the partner reported that the visual confirmation of the baby made the pregnancy more real, and they were looking forward to the ultrasound scan³⁷.

The effect of maternal-foetal attachment after ultrasound scan included in prenatal screening in early pregnancy, has been investigated by Kleinveld⁵² and Georgsson Öhman⁵³. The studies measured whether the combined test compared with the mid-pregnancy ultrasound scan, affected the maternal-foetal attachment in mid-pregnancy. The studies showed small⁵² or modest⁵³ increased maternal-foetal attachment after the combined test, but the effect was temporary⁵². Also women's anxiety about the health of the baby, general anxiety, and depressive symptoms, in mid-pregnancy and two months after delivery, were not affected by the combined test compared with the mid-pregnancy ultrasound scan⁵⁴.

Autonomy related to prenatal genetic testing

The concept of personal autonomy is considered as a key-stone for offering prenatal genetic testing. Dworkin⁵⁵ described the concept of autonomy as the capacity to reflect upon one's motivational structure and to make changes in that structure. Autonomy is an ability to alter one's preferences and to make them effective in action, partly because one has reflected upon them⁵⁵. Juth and Munthe⁵⁶ pointed out another aspect of autonomy in prenatal screening by: "if individuals possess the knowledge that they or their offspring have an increased risk of contracting some disease, they are in better position to plan their lives in accordance with their own conception of a good life, to live in accordance with their own values or basic wishes or to realize their own important project. To live such a life is roughly what it means to live an autonomous life or being an autonomous person, according to traditional general accounts of autonomy"⁵⁶(p.22).

Juth and Munthe⁵⁶ commented further that in the field of ethics, traditionally autonomy has not been considered as a value to be promoted. Autonomy has been discussed as something that should be protected from being violated by other people; there is a moral obligation to respect autonomy, but not necessarily to promote it. Juth and Munthe⁵⁶ advocated that a screening programme could encourage a person to make an auton-

omous decision. But a side effect of screening could be that the more benefits the screening offers, the more pressure there is to participate. The more pressure there is to participate, the more problematic from the point of view of autonomy⁵⁶. This situation was found in an Icelandic study where the offer of screening had become a routine and time for an autonomous decision was not available⁵⁷. Seavilleklein⁵⁸, reached a conclusion opposite to that of Juth and Munthe⁵⁶, that women's autonomy is not being protected or promoted in screening, and therefore, that prenatal screening should not be offered to all women. Seavilleklein⁵⁸ argue that women do not have enough knowledge to make an informed choice⁵⁸.

The concept of informed choice in prenatal screening has been developed over the years. All definitions have two elements in common; an informed choice is based on sufficient knowledge about the relevant aspects of the available alternatives and is consistent with the decision-maker's values. Some of the definitions include a third element; an evaluation of the alternatives, for example, a process of deliberation about the alternatives and weighing up their pros and cons⁵⁹.

Garcia et. al.⁶⁰, described the external and internal constraints on autonomous decision-making in prenatal screening. Emotional reactions towards the offer could impede the women from acting according to their underlying values and preferences. This means that internal constraints such as emotions, doubts, and scruples may limit the capacity for reflecting critically and making an autonomous decision. Nevertheless, the women in this study decided to follow their individual perspectives⁶⁰. This is in line with McLeod⁶¹ who brought up the idea of self-trust as a major factor in the woman's ability to make an autonomous decision. Women's reproductive freedom could be inhibited by new medical technologies and cultural authorities, if the women's self-trust is not respected. McLeod argues for understanding of the importance of self-trust for autonomy⁶¹.

A study from the Netherlands showed that the ethical views of acceptors and decliners of prenatal screening showed similar diversity. The researchers' conclusion was that ethical beliefs are one of the factors implicated in the decision⁶².

However, the concept of informed choice in prenatal genetic testing is not universally valued, as indicated by a population-based survey in different countries in Europe and Asia⁶³. The respondents from northern Europe believed that undergoing prenatal genetic testing should be an informed choice, but respondents from southern Europe and Asia perceived that significant others' views were of great importance when making the decision⁶³. Therefore, it is suggested that guidelines cannot be applied to all

members of multicultural societies; instead a more individualistic approach needs to be taken⁶⁴.

Information and counselling in prenatal genetic testing

What to include in the information about prenatal genetic testing provided to the pregnant woman and the partner is not defined in a general way. There is a professional consensus from guidelines in the USA and the UK about what women need when offered prenatal genetic testing, and this includes 1) information on the condition for which testing is being offered, 2) the characteristics of the test, and 3) the implications of possible test results⁶⁵. In Sweden the 2012 guideline from the National Board of Health and Welfare in Sweden reflects similar content⁸¹, except that that the recipient of the information is described as woman or couple.

The individual risk for carrying a foetus with chromosomal aberrations is calculated with a cut-off at 1/200 or 1/300 in the combined test²³. People generally prefer to receive risk information in numbers, but it could be difficult to understand these risks and use them to make decisions. An important aspect of decisions is the individual's perceptions of risk. To make risks personally meaningful, the individual sometimes focuses on the outcome of a risk. A numeric risk is then often translated into two broad categories: either the event will happen or it will not happen, and the outcome will evoke emotions. The decision about prenatal screening also involves emotions, and this sometimes makes it difficult to clearly communicate risks⁶⁶⁻⁶⁹.

Decision aids are used to improve decision-making about health care matters and as a supplement to health care professionals' counselling about options⁷⁰. Different tools have been used in informing pregnant women and partners about prenatal screening, for example, information films^{71, 72}, information booklets^{73, 74} and information given verbally to groups or individuals^{75, 76}. The result of a Cochrane review⁷⁰ from 2009 showed that decision aids increased knowledge of the options, created accurate risk perceptions of their benefits and harms, reduced difficulty with decision-making, and increased participation in the process. Nevertheless, decision aids did not seem to have an effect on satisfaction with decision-making or on anxiety⁷⁰. However, according to another systematic review⁷⁷, decision aids increase knowledge, decrease decisional conflict and decrease anxiety. A Swedish study showed that an information film tended to increase the number of women who made an informed choice about screening⁷¹. The film did not increase anxiety and worries, but may have caused worry at the time of viewing⁷⁸. In a randomized controlled trial from the USA interactive information aids were shown to enhance

knowledge, regardless of health literacy, electronic health literacy, or educational level. Women in the intervention group had better post-test knowledge than women receiving standard care counselling⁷⁹.

The information model of Örebro County Council

The Örebro County Council, Sweden⁸⁰, introduced the combined test in November 2008, and was the first county council in Sweden offering this screening to all pregnant women without an age limit. The test is a service free of charge. The information model is divided into two steps and starts with brief information about prenatal screening delivered by the midwife at the pregnant woman's first visit to the Maternal Health Care Programme. Those women or couples who want extended information about prenatal screening prior to making the decision, are offered a separate visit with a specially trained midwives⁸⁰ (Figure 1).

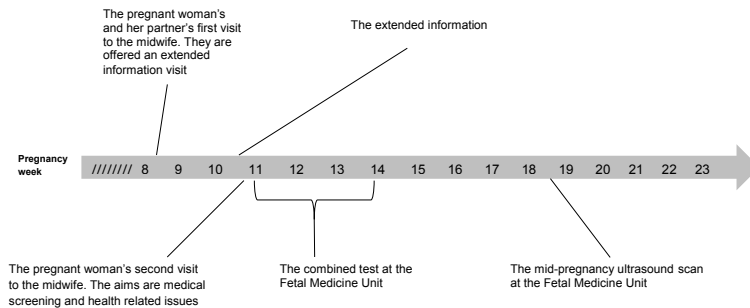


Figure 1. Schedule of the Maternal Health Care Programme, Örebro County Council, Sweden, in early to mid-pregnancy, with extended information visit and the combined test as additional visits

The aim of the extended information visit is to inform the pregnant woman and partner about available methods of prenatal genetic testing and what can be obtained from these methods, and what kind of further decisions they may face. How to take part in the screening is also discussed. Since the introduction of the combined test, about 50% of all pregnant women enrolled in the Maternal Health Care Programme in Örebro County Council have participated in the extended information visit at the Maternal Health Care Programme in Örebro County Council. This model is also in accordance with the 2012 guidelines issued by the National Board of Health and Welfare in Sweden, which advocate for information to be offered in a two-step information model⁸¹.

RATIONALE OF THE THESIS

Prenatal screening is offered in early pregnancy and the pregnant woman and the partner are faced with the decision whether to accept or decline this offer. There is a professional consensus that it is an obligation for the health care to provide adequate information on prenatal screening for enabling women and partners to make this decision. However, there is insufficient evidence about how this is best achieved. Furthermore, we have little information on how pregnant women and partners come to a decision on prenatal screening and their perceptions about this afterwards.

A two-step model for information about prenatal screening has been advocated and is now implemented as a routine procedure in Örebro County Council. How this model is experienced by the recipients is however mostly unknown. When introducing new concepts in health care, such as prenatal screening, including new information models, it is important to understand how this is perceived and if the needs of the target population are met. This is especially important in issues that may be experienced as ethically sensitive

AIMS

The overall aim of this thesis was to describe pregnant women's and partners' views and experiences on early prenatal screening with the combined test, with special focus on the two-step information model.

To achieve the objectives, the research studies were designed to:

- describe the pregnant women's and her partners' perceptions of a specific information model on prenatal screening.
- explore couples' decision-making, that is, how the pregnant woman and her partner, who had taken part in a population-based information programme, described the process of their decision-making about prenatal screening and diagnosis.
- describe views and experiences about prenatal screening and on information on this subject, among couples who had not taken part in an extended information visit.
- describe pregnant women's and partners' satisfaction about the decision whether or not to participate in the combined test, and their assessment of whether or not this choice had been difficult.

MATERIALS AND METHODS

Design

Four separate data-gathering procedures were used in this doctoral thesis (Table 1).

Studies I and III have a descriptive qualitative design, and this was the choice to gain understanding of pregnant women's and partners' perceptions of a specific information model for prenatal screening (I), and views and experiences about prenatal screening and on information on this subject, among couples who had not taken part in an extended information visit (III)^{82, 83}. Study II has an exploratory qualitative design to explore in depth, and gain new understanding of couples' decision-making, that is, how the pregnant woman and her partner, who had taken part in a population-based information programme, described the process of their decision-making about prenatal screening and diagnosis^{83, 84}. Qualitative design is rooted in humanistic thinking⁸³. The ontological reality in qualitative studies means an understanding of the individual as a whole, and the knowledge derives from the participants', pregnant women and partners, experiences. The findings are a construction of the interactive process⁸³. Study IV has a quantitative, cross-sectional design⁸³ to obtain information from a sample of pregnant women and partners about their satisfaction with the decision whether or not to participate in the combined test and their assessment of how difficult this choice was. The multiple methods design approach⁸⁵ provided a possibility of perceiving a wider understanding of the experiences of the pregnant women and partners about an information model used in a prenatal screening programme.

Table 1. Overview of design, material and analysis of the studies

Study	Design	Participants	Data collection	Analysis
I	Descriptive qualitative	15 couples (who had participated in the extended information visit)	Semi-structured interviews: 10 separately with the woman 6 separately with the partner 10 with the couple together	Content analysis
II	Explorative qualitative	15 couples (the same couples as in study I)	Semi-structured interviews: 15 separately with the woman 6 separately with the partner 16 with the couple together	Interpretive Description
III	Descriptive qualitative	7 couples (who had not participated in the extended information visit)	Semi-structured interviews: 7 with the couple together	Interpretive Description
IV	Cross-sectional survey	295 women + 223 partners	Questionnaire (Decision Regret Scale with additional questions)	Descriptive statistics

Participants

The pregnant women and partners were recruited in Örebro County Council, Sweden at different appointments in the Maternal Health Care Programme during early and mid-pregnancy (Figure 2).

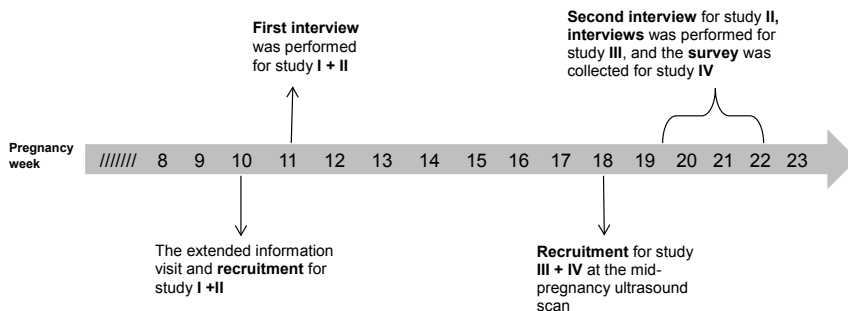


Figure 2. A schedule of recruitments for the studies in early to mid-pregnancy

The recruitment for studies I–III was stratified to meet a maximum variation sampling⁸³. Women were divided into three age groups, ≤ 25 , 26–34, and ≥ 35 years, and into different groups for nullipara and multipara. The county was divided into four parts.

Women and their partners who attended the extended information visit were invited by the midwife to take part in study I. All ten midwives at the four information centres were asked to recruit at least two couples each, from different age and parity groups. After the information session, the midwife provided verbal and written information about the study, and couples agreeing to this were then contacted by the researcher. There were preparations made to use an interpreter, if needed, but at the time for the interviews in 2009, it was not common that pregnant women and/or partners who needed an interpreter accepted the extended information visit. Twenty-three couples were invited, 19 couples accepted to be contacted, and 15 finally agreed to participate. The reason for declining participation was lack of time, in all four cases.

After the interview for study I, the couples were asked by the interviewer if they would agree to be contacted after the mid-pregnancy ultrasound scan for a follow-up interview for study II. Twelve couples consented, while two couples declined referring to lack of time. One of the couples who had consented declined just before the interview without giving a reason, which left eleven couples. The plan was for the interview for study

II to be conducted with the couple together, but this was not possible in five cases because of shortage of time on the part of the partner.

The midwives at two hospitals with a Fetal Medicine Unit in Örebro County Council, Sweden recruited couples after the mid-pregnancy ultrasound scan to take part in study III and study IV. For study III, the midwife, immediately after performing the mid-pregnancy ultrasound scan, gave verbal and written information about the study. In the case of an abnormal finding at the ultrasound scan, the present study was not discussed. The smaller hospital (650 births per year) was asked to recruit at least two couples, and the university hospital (2800 births per year) to recruit six couples. Altogether ten couples were invited and ten couples accepted to be contacted by the researcher. Of those, eight finally agreed to participate. The reason for declining was lack of time. In one case the partner could not participate in the interview due to work, and the interview with the woman was excluded, leaving seven interviews for analysis.

For study IV the inclusion criteria were age 18 years or older, able to understand oral and written Swedish and a normal mid-pregnancy ultrasound scan. The midwife presented oral and written information about the study to the pregnant woman and the partner after the mid-pregnancy ultrasound scan, performed at the two Fetal Medicine Units described above. The pregnant women and partners who agreed to take part in study signed an agreement and chose whether they wanted to receive the questionnaire in digital or paper form. The recruitment lasted from December 2013 to February 2014. Since no Swedish data was available, the sample size was estimated from a Danish study³³, where 340 women were included. During the recruitment time 488 pregnant were available for recruitment, out of those 104 women were not eligible and finally the questionnaire was answered by 295 women and by 223 partners.

Data collection

In the qualitative studies I - III all the interviews were conducted by the author. Care was taken to create a calm and friendly atmosphere that enabled the participants to speak freely⁸⁶. Therefore, the participants chose the location for the interviews, and most of the interviews took place at the participants' homes. For studies I and II just a few participants choose to be interviewed at the research centre.

Studies I and II

Creating an interview guide⁸⁶ was the first stage in planning the studies, and it was discussed within the research group what kinds of question

areas should be addressed, either individually or with the couple together. The opening question for study I in the individual interview was, “What do you know about prenatal screening and diagnosis?”. This was followed up with, “What information have you received?” The question areas for the interview with the couple were about the extended information visit and their perception of voluntariness.

For study II the supplementary questions during the first couple interview were, “Have you decided about the combined test?” and “How were you able to decide, or how are you going to make a decision?” The couples who had participated in the combined test were also asked, “What is your experience of the combined test?”

The intention was to carry out individual interviews with the woman and partner separately and a joint interview with the couple together. That was possible in five cases, but was not fulfilled in the other cases due to time constraints of the couple. Ten interviews were performed with the couple together, and these were the richest interviews regarding content and length. The couples reminded each other about thoughts and reasoning from their joint discussions. Although the interviews were planned so that the couple could be interviewed at the same time, in the end four interviews were only with the woman. This was due to the partner not being able to get away from work at the scheduled time. The partners were offered another appointment for interview, but all declined due to lack of time. The interviews with each couple or woman lasted 40 - 60 minutes (mean 44 minutes).

The follow-up interviews in study II were ten interviews with six couples and four women. The reason that all were not couple interviews as planned, was the same reason as described for study I. The interviews for study II lasted 30 - 60 minutes (mean 52 minutes). See Table 2 for characteristics of women and partners participating in the interviews for studies I and II.

Table 2. Number of interviews and characteristics of women and partners participating in the interviews for studies I and II

Couple number	The first interview	The second interview	Number of children, woman/partner	Age (yrs), woman/partner	Educational level, woman/partner
1	Woman/Partner/Couple	Couple	2/2	26/30	Secondary school/Secondary school
2	Woman/Partner/Couple	Couple	2/2	29/34	University/Secondary school
3	Couple	Woman	0/0	28/35	University/Secondary school
4	Couple	Couple	4/4	35/45	Secondary school/Secondary school
5	Couple	Woman	2/2	32/33	Secondary school/Secondary school
6	Woman		1	29	University
7	Woman	Woman	0	30	University
8	Woman		0	28	University
9	Woman/Partner/Couple	Couple	0/0	29/29	University/University
10	Woman/Partner	Woman	0/0	20/22	Secondary school/Secondary school
11	Woman/Partner/Couple	Woman	0/0	32/36	University/University
12	Woman/Partner/Couple	Couple	0/0	21/24	Secondary school/Secondary school
13	Couple		0/0	27/27	University/University
14	Couple	Couple	0/0	36/29	University/University
15	Woman		1	38	University

Study III

For study III in focus for the interview were the couples' reasoning and experiences of the invitation to the extended information and of prenatal screening. The opening question was, "What are your experiences of prenatal screening and the invitation to the extended information visit?" The answers were follow-up by "Why?", "What?" and "How?", to evoke more in-depth accounts. The interviews involved the couples for a joint discussion, and lasted 31 - 55 minutes (mean 42 minutes). See Table 3 for characteristics of women and partners participating in the interviews for study III.

Table 3. Characteristics of women and partners participating in the interviews for study III

Interview	Number of children, woman/partner	Age (yrs), woman/partner	Educational level, woman/partner
Couple	1/1	28/30	University/Secondary school
Couple	1/1	35/37	University/University
Couple	0/0	28/30	University/University
Couple	0/0	18/20	Secondary school student/Secondary school
Couple	3/3	34/36	University/University
Couple	1/1	24/25	Secondary school/Secondary school
Couple	1/1	33/31	University/University

Study IV

The questionnaire (Appendix 1) consisted of the instrument, the Decision Regret Scale (DRS)⁸⁷ (Appendix 2) and additional questions. The definition of decision regret in DRS is remorse or distress over a decision and the instrument is a five-item scale measuring distress or remorse after health care decisions. The DRS has been validated and psychometrically tested on both women and men^{88, 89}. It was also used in a study on decision-making regarding prenatal screening in Denmark³³, and therefore was a natural choice for the present study. The additional questions were: "Have you been to a visit with extended information on prenatal screening?" (Yes or No), "Has early prenatal screening with the combined test been performed?" (Yes or No), "Who made the decision whether or not to participate in the combined test?" (Myself, My partner or Us together), and "How easy or difficult did you think it was to make the decision whether or not to participate in the combined test?" The women and partners were asked to choose the options that best fit their experiences on a five-point response scale from 1 = very easy to 5 = very difficult. Back-

ground data such as year of birth, country of birth, zip code, highest completed education, and number of children were also collected.

The questionnaire was translated from English to Swedish and tested on five researchers who validated the translation by translating the questionnaire back to English. The questionnaire was further validated by having six pregnant women fill out the questionnaire before it was used in our study. They were interviewed about the meaning and their understanding of the questions concerning decision regret, and no changes were needed. These steps to ensure validity were deemed appropriate for these general questions⁸³.

During the recruitment time, for study IV, 488 pregnant women came to the Fetal Medicine Units for a mid-pregnancy ultrasound scan, and were available for consideration for recruitment. Out of those 104 women did not fulfil the inclusion criteria, or were not invited for other reasons. Altogether 359 women and 315 partners agreed to participate. The questionnaire was answered by 295 women and by 223 partners. Three questionnaires were excluded, because “woman” or “partner” was a missing answer. The final response rate was 77%. See Table 4 for demographic data for women and partners participating in study IV.

Table 4. Demographic data for women and partners participating in study IV

	Women		Partners	
	n = 295	(%)	n = 223	(%)
Age				
mean years	30.7		33.15	
range	20 - 42		22 - 52	
Parity				
	n = 294		n = 220	
0	124	(42)	103	(46.2)
1 - 4	170	(57.6)	117	(52.4)
Education*				
	n = 292		n = 221	
Low	4	(1.45)	6	(2.7)
Medium	138	(46.8)	121	(54.3)
High	150	(50.8)	94	(42.2)
Country of birth				
	n = 294		n = 223	
Sweden	273	92.5	211	94.6
Other Nordic countries	1	0.3		
Rest of Europe	12	4.1	5	2.2
Outside Europe	8	2.7	7	3.1

*Education: low = up to 10 years, medium = more than 10 years and less than 13 years, and high = at university level

Data analysis

Qualitative analyses were used in studies I - III to identify patterns and variations in the interview data in order to provide new insights, knowledge, and understanding⁸².

Study I

Qualitative content analysis⁹⁰ was used in study I with an inductive approach to the data. Content analysis was used as the purpose was to capture the participants' own descriptions of the subject and to identify patterns and variations in experiences⁸².

First the interviews were transcribed and then read through several times to gain a sense of the whole. Data relevant to the aim were analyzed using qualitative content analysis⁹⁰. Manifest data were considered, and the unit of analysis; an entire phrase, a specific statement of it, or just words related to the aim was marked out. Further on, were headings written down that described all aspects of the content. Related events and incidents were grouped together into subcategories. Next, by combining subcategories with similar contents, categories and finally main categories were formulated. See Table 5 for the analysis process.

Table 5. Three examples from Study I, showing the analysis process, from unit of analysis to main category, in exploring the perceptions of couples who had received information about prenatal screening within a specific information model

Unit of analysis	Sub-category	Category	Main category
A separate appointment was good, that way you could prepare for it, since it felt hard, this thing with the prenatal screening (woman 11)	Positive about the additional visit, and the time to prepare mentally	A separate visit	Form and content
You're aware of some things from before when you have two children. But like this thing with the ultrasound, that they look very closely, I didn't know that ... and they really emphasized that this was voluntarily (partner 5)	The ultrasound scan is a check-up of the fetus and is voluntary are new knowledge	The content	Form and content
As for me, I haven't given it any thought. When you were there you got an insight into what you wanted to do, but after that no thoughts (partner 2)	Not much thought much after getting the information, no additional concerns	Emotional management	Managing the information

Studies II and III

The analyses originate from the Interpretive Description⁹¹, which is an inductive approach to obtaining a clinically relevant and useful understanding of how people experience issues related to clinical health processes.

The analysis process started with all the interviews being verbatim transcribed (step 1). Then, all the interviews were read through several times to gain a sense of the whole (step 2). Text units, an entire phrase, a specific statement of it, or just words related to the aim were marked out as a next step (step 3), and headings describing aspects of the content were then written down (step 4). The analysis process was guided by the analytic question related to the aim, for example, “What are reasoning and experiences of the participants?” As a next step, related headings were broadly grouped together. Possible interpretations and sub-themes were written down and checked in relation to the text (step 5).

As a final step in study II, all interviews were analysed a second time using all the interviews together for each couple (step 6). An interpretation was made concerning how the different couples’ decision-making processes were related to the different themes and subthemes. Three patterns were developed that together encompassed all couples’ decision-making processes. Because the aim was to obtain the couples’ descriptions of their decision-making process, and because not all interviews contained the partners’ points of view, we took care to ensure that the analysis did not include statements from the women about their partners’ opinions, but rather, only the women’s versions of their mutual conversations. All statements were analysed together, without being divided into women’s or partners’ points of view.

Study IV

Data were anonymously entered digitally into the esMaker Nx2® database and statistically analysed using IBM SPSS®, version 22. For comparison between groups the Mann-Whitney test was used. A p-value of <0.05 was considered as statistically significant. Descriptive data is presented with absolute numbers and percentages.

ETHICAL CONSIDERATIONS

During planning, ethical concerns about the studies were considered. It was discussed that in the group of pregnant women and partners, memories and unprocessed traumas could obviously come up in the interviews, and to be interviewed further about this subject might seem burdensome. For participants of study III who had not taken part in the extended information visit, an interview about how to make decisions could be perceived as questioning. The same concern was present for study IV, with the questionnaire that evaluated the participants' choice in retrospect. We discussed in the research group the number of interviews for each study, and our ambition was to not include more than needed to get a maximum variation sample⁸² of different experiences, and at the same time to avoid having such limited numbers as could lead to an insufficient amount of data. The number of interviews could have been expanded, if needed, but was not found necessary.

There was an interval between the time when consent was granted and the interview or the questionnaire to be completed, and this gave an opportunity for the participants to determine whether or not to participate. The interviewer reminded participants at every interview about the possibility of discontinuing the interview and also took care to create a climate for discussion that was open and inquiring, and not questioning. It was also taken into account that all pregnant women and their partners have an established contact with the Maternal Health Care Programme for psychosocial help and support, if needed.

It can also be argued that it is an obligation for the health care service to find out how recipients of the health care services perceives these services. In the case of introducing a new concept of prenatal screening and information on prenatal screening this may be especially important since this is an issue highly related to ethical values. If not meeting the needs of the population, such concepts must be questioned and reconsidered. Hence, on balance, we found any possible negative effects that could be experienced from taking part in these studies outweighed by the value of the information that could be gained. As described, precautions to minimise negative experiences from participating were also taken into consideration.

The studies of this thesis were carried out in accordance with the Helsinki Declaration⁹² and approved by the Regional Ethical Review Board in Uppsala, Sweden, in 2009, (D nr: 2009/230), and in 2013, (D nr: 2013/411). The participants received both oral and written information about the studies. They were informed that participation was voluntary

and that they could withdraw their participation at any time without consequences. An informed consent form was signed before data collection, and all data were handled confidentially. The presentation of data has been made in such a way that no participant can be identified.

FINDINGS

The findings from the four studies are presented as integrated results; the individual studies can be identified by their numbers I, II, III, and IV. See Appendix 3 for results in the studies; themes/categories, flow chart, figures, and tables.

Experiences of the extended information visit

A majority of the women, 73%, and more than half, of the partners, 58%, had participated in an extended information visit (IV). Different opinions were expressed about the offer of the extended information visit. Some couples, who had attended the extended information visit, had felt obliged to participate in order to take part in the combined test. Despite having already decided about the test and having no wish for further information, they perceived themselves as forced to attend and found it impossible to decline (I). Otherwise, attendance was understood to be voluntary, and easy to decline the extended information visit if not interested by some other couples in study I and the couples in study III (I + III). It was also found that some couples who had declined the extended information visit believed that there was a link between the offer of the extended information visit and the offer of the combined test. These couples did not state separate reasons for why they had abstained from the extended information visit; instead, they presented arguments about why they had abstained from the combined test (III).

There were also variances in how the extended information visit was perceived as a separate visit. The separate visit was welcomed by some couples, as they wanted to prepare for this visit. They needed time to find out more about the subject and to prepare questions. Others needed mental preparation, for what they perceived, as a sensitive subject. Some other couples had, what can be seen as a more rational reason; they wanted to receive all information needed at this separate visit. Those couples who considering themselves obliged to participate in the extended information visit in order to make use of the combined test did not see any advantages in having a separate information visit (I).

Meeting another midwife at the extended information visit was apprehended by some as an advantage and by some as not. For those with a positive attitude, it was perceived that the focus could then be on prenatal screening, as other consultations with the midwife during early pregnancy focused on other issues (I).

The extended information visit was taken up by 58% of the partners of the population in study IV. The partners, in study I experienced this visit as providing more equity compared with the ordinary midwife consultations. They did recognize that obviously during ordinary midwife visits, concerning health information and examinations in early pregnancy, the woman was in focus. However, this visit was different; they recognized themselves to be equally important and felt they got the same attention from the midwife as the woman. The partners also expressed that this information was important to them. The information received at the extended information visit was mostly discussed within the couple and the partners were determined to take part in the decision about prenatal screening (I).

The content of the extended information visit, available methods, what can be obtained from these methods, what kind of further decisions the couple may face and how to take part in the screening, was in line with what most couples needed to make a decision about the test. They also perceived the content as clear and easy to understand. On the other hand, some couples' experienced that they did not get all the answers they had expected at the extended information visit. Statistics on prenatal screening, for example, how many pregnant women participate in the combined test, was something they had felt was lacking in the information. They thought that statistics could reflect other couples' thoughts and also indicate how others make up their minds about prenatal screening. Case reports on how other couples considered prenatal screening were also something these couples thought could have helped them to reflect on the subject. Others had wanted more individual counselling regarding their personal situation (I).

There were views about whether the information should, or should not, include ethical considerations. Some couples expressed appreciation that the extended information visit did not include an ethical discussion, while others considered the absence of a discussion about ethics to be a missed opportunity. They felt that all technical information about prenatal screening was readily available on the Internet but to discuss ethics of prenatal screening with someone non-professional was not that easy, and they expressed that they had missed being able to have this discussion with the midwife (I).

Increased knowledge about chromosomal disorders, received at the extended information visit, was for some, especially younger, couples related to increased worries (I). To avoid increased worries, was a reason to abstain from the extended information visit (III). However, those who took part in the extended information visit did not regret the decision because

of increased worries or emotional suffering. On the contrary, their worries had decreased by time and they worried less about the pregnancy. Some couples had also experienced, that despite the increased worry and need to reach a decision, the situation had been positive. The thoughts and emotions that were brought up, for example, the fear that the expected child would not be healthy, had led the couple to talk with each other. Thus, this situation gave an opportunity to talk in a way they may not have done, otherwise, and this was something that they welcomed (I).

Decision-making about the combined test

Eighty-two percent of the women and 79% of the partners had experiences of the combined test (IV). The decision, to participate or not, was a mutual decision for the vast majority; 95% of the women and 96% of the partners had that perception. Just over 4% of the women had made a decision by themselves, and 4% of the partners perceived that the pregnant woman had made the decision by herself (IV).

The decision-making process about whether to take part in the test or not, was described by some couples, in study II, as a fairly straightforward decision, while for others it was a more complex process that required a great deal of consideration. The decision-making process was, for some couples, characterized as a communicative process within the couple and with others (II). For some of the couples the communication process had started immediately after the extended information visit, but for other couples it was not something to discuss. Some couples had also sought opinions from their parents and siblings and then considered different options, which helped them make their decision (I).

Three different patterns of decision-making processes could be identified in the couples' narratives about their decision (II). In *the open and communicative decision-making process* the couples had formulated their own reasons for choosing to participate or not, for example, avoiding anxiety by declining the test, gaining an opportunity to prepare themselves for a child with trisomy, or having a chance to decide on an abortion. Couples who accepted the combined test had also made, or were prepared to make, a decision about the whole procedure; they had decided what they would do if they received a high-risk assessment from the combined test, and whether they would carry on with the invasive test. Also, in case this invasive test showed a trisomy, the couples had decided whether they would have an abortion or prepare for a life with the child, or for those who had not yet decided, were prepared to make the decision. These cou-

ples had engaged in an on-going discussion together until they reached a joint decision (II).

The closed and personal decision-making process was characterized by the couples' focus on only one argument for participating, and the decision was made at or almost right after the extended information visit. Their argument was about having this opportunity to take the test, and this was something they did not want to miss. The couples who adopted this decision-making pattern related their decision only to the combined test. None of these couples mentioned that the combined test might require further decisions, and no couple following this pattern hesitated to make the decision. Also, they did not mention any consequences of the test or the risk assessments. The couples reasoned that the test did not involve any physical risks for the woman or the foetus, and therefore, there was not much to discuss. The decision, for couples showing this pattern, was immediate, and they had no need to discuss with each other or with anyone else before reaching their decision (II).

In *the searching and communicative decision-making process* the couples had had to give the decision much thought, and they were ambivalent. They could not find a distinct argument for or against participating in the combined test, except that later on in the pregnancy they might regret not having participated. The combined test as a method was also questioned, since the test could not give an exact answer. It was hard for these couples to determine what the decision was all about; was it just the test or possible future invasive testing and abortion? They discussed in depth with each other and tried to communicate with family and friends, and sometimes, they encountered different opinions. These opinions gave them new perspectives and new ideas for how to think about the issue, and it helped them to reach a decision. Other couples regretted not having had the opportunity to discuss the issue with someone else, and they wanted an opportunity to have further contact with the midwife from the extended information visit. Many questions had occurred to them after the session, which were not technical questions about the combined test or risk assessments. They wanted to know how other people and couples debated these matters, since they experienced themselves as locked in their own thoughts and wanted to find new perspectives. Some couples struggled with ethical considerations as to "who was to decide in this matter" and referred to this as "a decision for a higher power". Others thought it was a complicated decision and referred to it as something "for medical professionals to decide" and not a decision "for an ignorant public" (II).

Views on the combined test and mid-pregnancy ultrasound scan

The women participating in the extended information visit had some earlier knowledge from the media or the Internet about the combined test. But their partners stated that it was at the extended information visit that they really understood what the combined test was all about (I). The couples were familiar with the mid-pregnancy ultrasound scan, which was mostly seen as a non-voluntary check-up of the foetus's anatomy (I+III). But some couples, who had abstained from the extended information visit, reasoned that the mid-pregnancy ultrasound scan could detect diseases that could be treated, such as heart failures. They compared this with the combined test, which only detected non-treatable conditions. This was perceived to be a major difference and also an important reason to abstain from the combined test. Some of these couples had also declined the extended information visit because they had arguments against prenatal screening. To deselect a child with a chromosomal abnormality was not an option for most of these couples. They perceived that children with Down syndrome had a good life. However, for one couple, the decision was something that they thought could be changed, if they already had a child with special needs. They considered that in case, and at that time, they might want to know more about the expected sibling, and prenatal screening might then be an option (III).

An apprehension of the test, by some of those who had refrained the extended information visit, was that it was an expression of society's involvement in decisions that belong to the expectant parents. They wished, by rejecting participation in the test, to make a statement, to indicate that they did not line up with this perceived hidden agenda. They also did not want to influence others in that direction of accepting the state's authority in this matter. These couples also questioned the health care service's intentions about the combined test, and they wondered why the test had been developed at all (III).

Satisfaction with the decision about the combined test

The decision to participate or not in the combined test was mostly perceived in the survey study IV as an uncomplicated decision. Ninety-three percent, of both women and partners scored 1 - 3 on the five-point scale (from 1 = very easy to 5 = very difficult). However, the decision was considered as "very difficult" by 2% of both women and partners, and "difficult" by 5% of the women and 4% of partners. Well over 90%, of both women and partners, were satisfied with their decision (IV).

In study II the couples, both acceptors and decliners of the combined test, described themselves as pleased with their decision, showing the patterns *the open and communicative decision-making process* and *the searching and communicative decision-making process*. Couples showing the pattern *the closed and personal decision-making process* thought there was “too much fuss” being made about the test. One woman regretted having participated in the test, because the risk assessment showed different risk figures for the three trisomies, and this was not what she had expected. All the figures were well within the limits for low risk, and although she understood this, it caused her great anxiety. She felt reassured only when the mid-pregnancy ultrasound scan showed a normal result (II).

DISCUSSION

A majority of the women and more than half of the partners had participated in an extended information visit, as shown by study IV. Different opinions were expressed about the offer of the extended information visit. Attendance was mostly understood as voluntary, both by some of those who had accepted the offer and by those who had declined the extended information visit. The separate visit was welcomed by most couples, as they wanted to prepare for this visit and the visit was perceived as providing more equity within the couple compared with the ordinary midwife consultations. An apprehension of the test, by some of those who had refrained the extended information visit, was that it was an expression of society's involvement in decisions that belong to the expectant parents. The decision-making process regarding whether to take part in the test or not was described by most couples as a fairly straightforward decision, while for others it was a more complex process that required a great deal of consideration. Ninety-three percent of both women and partners considered the decision about participating in the combined tests as uncomplicated, and well over 90%, of both women and partners were satisfied with their decision.

Reflections on the findings

The extended information visit

The extended information visit was perceived differently by the couples in this thesis. The procedure with two separate visits had advantages for some of the couples in study I, and they perceived it as positive to have a defined visit with information and discussion about prenatal screening. They could then prepare for the subject and also get all information needed for the decision whether to participate or not in the combined test. After the extended information visit they were also more aware of the purposes of the mid-pregnancy ultrasound scan, which is an improvement from earlier Swedish studies^{37, 93}.

This situation could be discussed in terms of autonomy, and that the autonomy of the couples' in some way was threatened⁵⁵. According to Dworkin⁵⁵ autonomy is the capacity to reflect upon one's motivational structure and to make changes in that structure. However, the couples in study I, who felt obliged to participate in order to take part in the combined test, found themselves forced into a situation which they could not control. On the other hand, according to Juth and Munthe⁵⁶ it could be

said that their autonomy was in having the opportunity to know things about their foetus, so they could plan their life accordingly, and that a screening programme could promote a person's ability to make an autonomous decision. Juth & Munthe⁵⁶ highlights that a side effect of screening could be that the more benefits the screenings offers the more pressure there is to participate, which is problematic from the point of autonomy⁵⁶. This situation was also found in an Icelandic study where the offer of screening had become a routine and time for an autonomous decision was not available⁵⁷. Seavilleklein⁵⁸, drew conclusion opposite to that of Juth and Munthe⁵⁶, that women's autonomy is not being protected in screening and therefore argued that women do not have enough knowledge to make an informed choice⁵⁸, which could be seen as paternalistic view of women's capacity. The findings in this thesis has showed that most of the women and partners made decisions they were satisfied with, and were capable to make these decisions.

Some of the couples in study I saw the main role of their midwife as an information provider, which was also the finding in a British study⁹⁴. Earlier studies have also shown that midwives lack knowledge about prenatal genetic testing^{95, 96}, and that the midwife provided information in a way that generally required only minimal acknowledgement, rather than active participation, and lack of an overt refusal was taken to imply acceptance⁹⁷. It has also been shown that the nonverbal sensitivity of both care providers and patients plays a role in medical communication about genetic testing⁹⁸. However, none of the couples in study I perceived the midwives lacked knowledge about prenatal screening; on the contrary, they felt that they could get all the information they needed in the two-step information model. Still, some couples wanted the midwife to take another role, as they wanted more of a discussion with the midwife. The discussion that the couples were calling for, was about non-technical issues, about decision-making support and ethics. This was also shown in a Dutch study⁹⁹, but such further discussion demands the midwife's ability to guide without exercising control in decision-making. A European network for genetic counsellors has developed a curriculum for nurses and midwives enabling knowledge and skill for that purpose¹⁰⁰. The midwife may have concerns about affecting the couple's decision, and that maybe a reason for holding back in the discussion. A British study showed that the midwives attempted to maintain the normality and avoid discussions about potential scenarios¹⁰¹, and that sometimes the health care professionals and person seeking care have different goals¹⁰². However, a Dutch study showed that neither women's uptake rates, nor their attitudes toward

prenatal screening were significantly predicted by midwives' or gynaecologists' attitudes toward prenatal screening¹⁰³. Furthermore, the ethicists McLeod⁶¹ discussed the idea of self-trust as a major factor in the individual in making an autonomous decision, and Garcia et. al., have also showed that women make decisions following their individual perspectives⁶⁰.

Partners involvement in decision-making

An interesting advantage that should be mentioned of having the extended information visit scheduled as a separate visit, is the perceptions of the partners, in study I. They all, even those partners who had a more negative view about the extended information visit, talked about this visit as an opportunity for equality. They meant equal, both in terms of both gender equality as they saw themselves as equal to the woman in the decision about the combined test, and in the way they were treated by the midwife at the extended information visit. This is a different result from what other studies have shown¹⁰⁴⁻¹⁰⁹. However, our result from study I were supported in study IV, when over 90% of both partners and women saw the decision about the combined test as a mutual decision. Whether this is due to gender equality or due to other reasons is something for further research. Although, studies have shown that men's participation often is inhibited by existing institutional and organizational factors and workplace norms, both of which continue to be influenced by traditional gender role ideology^{110, 111}.

Decision-making

Earlier studies about attitudes towards prenatal screening have shown that a positive attitude towards prenatal screening, is connected with a desire for confirmation of the pregnancy or for reassurance about the health of the foetus^{37-42, 112}. Studies have also shown that a negative attitude towards prenatal screening, is associated with the perception that an abortion, in case of a chromosomal aberration, is not an option^{40, 43, 112}. For the couples in study II, these reasons, desire for confirmation, reassurance about the health of the foetus and attitude towards abortion, were also a central object in the couples' decision-making process. For the couples in *the open and communicative decision-making process* and *the searching and communicative decision-making process* it was crucial to find their own reasons why they should or should not participate in the combined test. As for the couples in *the closed and personal decision-making process* the reason to participate was more about the test being available, and this was the reason why they chose to participate in the extended information visit.

This type of a closed decision-making process was also found in a British study⁹⁴, where the couples reported a strong desire for a joint but ultimately private decision-making process⁹⁴.

The findings in study II, could be discussed according to different decision-making theories or models. The pattern *the open and communicative decision-making process*, which was the most common pattern, showed couples who had considered their whole life situation, which was often an emotional, though rational process and could be related to the expected utility (EU) theory¹¹³. According to the EU theory, individuals aim to maximize utility, and thus choose the behaviour or option with the highest expected utility and for these couples in this situation, “what is the best outcome of participating in, or declining the combined test for me and/or our family”¹¹³.

Emotions were a central attribute for the couples showing the pattern *the searching and communicative decision-making process*, in study II. These couples processed all the facts they received at the extended information visit at an emotional level. This manner of decision-making could be connected to “the risk-as-feelings hypothesis” described by Loewenstein et. al¹¹⁴. According to this hypothesis, the couples could make use of their emotions (worry, fear, and anxiety) and emotional responses as an important factor in the decision-making process¹¹⁴. The couples showing this pattern also questioned the combined test as a method, because they could not expect an exact answer from it. They did not feel comfortable with the answer being presented as a numerical figure representing risk, and this has also been shown in earlier studies⁶⁶⁻⁶⁹. To decide about prenatal screening often involve emotions and this makes it hard to clearly communicate risks to people⁶⁶⁻⁶⁹.

The pattern *the closed and personal decision-making process*, in study II, was adopted by couples who made quick, individual decisions that they did not want to communicate. This way of acting could relate to the theory of planned behaviour (TPB)¹¹⁵. Central constructions of the TPB are attitudes, and according to the TPB, an individual’s behaviour is predicted by three factors, namely, whether the individual’s evaluation is positive, whether the individual believes that important others think they should perform the action, and whether they perceived it as being under their control¹¹⁵. The couples showing this pattern, in study II, were favourably disposed towards the combined test. They did not know what others thought about it, because they did not want to discuss the issue with each other or with others, possibly as a strategy to avoid confronting different opinions about the decision. This way of acting has also been reported in a

British study⁹⁴ in which couples saw themselves as a unit with a shared experience of pregnancy and parenthood. They felt anxious that, if other people had different views, knowing about these would make decision-making too difficult and influence their own decision⁹⁴.

Couples in study III had strong moral opinions about prenatal screening as a basis for their decision to not participate. For them it was a strange thought to have an abortion, because they did not consider Down syndrome to be a severe enough condition. The couples assumed that children with Down syndrome had a good quality of life, and these couples also had a positive attitude towards diversity in society, an attitude shown in earlier studies^{46, 62, 116}. Some couples in study III also interpreted the offer of the combined test as an intrusion of privacy and society's control of the individual, and they actively decided not to participate as a stand against the society. This action could be discussed according to Hirschman's theory of exit, voice, and loyalty¹¹⁷. This minority of couples could be referred to, as actively "voicing" their decision to decline the combined test. They are in contrast to the majority of the couples who passively don't participate, seen as the "exit"¹¹⁷. The challenge is for the society to meet individuals taking this stand, without violating their autonomy. It is therefore important in clinical work to be aware that this group exists, and that culture clashes can occur when different views meet.

Satisfaction with the decision

A Danish study³³ showed that almost all of the women and all partners were satisfied with their decision about participating in the combined test. In Denmark over 90% participate in the combined test. Well over 90% of both the women and the partners in study IV, were satisfied with their decision about the combined test, and 93% also considered the decision to be uncomplicated. Of the women, 73% had participated in an extended information visit, as had 58% of the partners. This can be interpreted as a good outcome of the extended information visit, if major conclusions can be drawn on this small dataset, but anyhow, it indicates that there is a satisfaction with the information model among the pregnant women and partners included in this thesis.

An informed choice about prenatal screening can be defined as, a choice based on relevant knowledge and a choice that the pregnant woman and the partner do not regret later in the pregnancy³³. This definition, can be said to indicate a modern conception of the individual's position in health care decisions, and individuals will decide whether they are satisfied with their own decisions or not. The definition also reflects a vision in which

person-centred care¹⁰ is implemented and an ethical view whereby the individual is competent to make decisions^{60, 61}.

The future of prenatal screening

The progress of medical technologies continues, and despite the fact that not even half¹¹⁸ of all county councils in Sweden offers the combined test, the next test is knocking at the door. Rapid advances in non-invasive prenatal testing (NIPT) based on cell-free foetal DNA in maternal plasma have now made it possible to identify pregnancies affected by trisomy 21 from 10 weeks of gestation, with high accuracy (>99%) and a low false-positive rate (0.1%), via a blood test from the mother¹¹⁹⁻¹²¹. Detection rates are also high for trisomy 18 (>99%) and trisomy 13 (up to 90%)¹²²⁻¹²⁵.

A British study¹²⁶ about users' view on the NIPT showed that 96% thought NIPT was a positive development in prenatal care, with 88% indicating that they would use the test, including respondents who would currently decline prenatal screening¹²⁶. Concerns have been raised that the introduction of NIPT could change the attitudes towards information about prenatal screening, if the decision of NIPT is made too easy¹²⁶⁻¹²⁹, which also was the concern of couples in study III about too easy access to the combined test. However, it is likely to believe that a two-step information model may also be applicable when prenatal screening methods change. An Australian study¹³⁰ showed that in spite of increased online access of health information, both women and partners still prefer to receive information about prenatal testing options face-to-face.

In Sweden, where the health care service is decentralized and the offers of prenatal screening vary between the county councils and regions, there is a need for a national consensus when the NIPT is introduced¹¹⁸. The National Board of Health and Welfare in Sweden introduced guidelines in 2013⁸¹ for information about prenatal testing, and urged for an information model in two steps.

Methodological considerations

This thesis comprises both qualitative and quantitative studies in order to meet the overall aim, to describe pregnant women's and partners' experiences of an information model in a prenatal screening programme, including different views, and achieving valid and reliable results. The multiple methods in this thesis can be seen as a strength, as multiple data strengthen the validity⁸³.

To strengthen the credibility of the studies the members of the research group participated in various steps in the analysis to contribute different

perspectives⁸². Individually manuscripts have been critically reviewed and discussed at research seminars as well as presented at national and international conferences, as a supplement to the discussions in the research group. Interview guides were used to ensure that the same topics was discussed in the interviews, this enhanced the dependability. The transferability and credibility are demonstrated in the studies with representative citations from the narratives, and analysis processes are shown with carefully chosen examples of meaning units, categories, subthemes, themes, and additional tables and flow-chart⁸².

The validity concerning generalizability should be discussed. One aspect to discuss in relation to study IV is that the participants mainly represent a homogenous group, and there was a majority of those who had participated in the extended information visit. Another aspect could be the Hawthorne effect, which means that simply participating in a study could induce a behaviour or perception simply just by virtue of the fact that one is participating. In study IV it could be the case that the participants believed that being satisfied was the right answer to the research question. In all studies I - IV the effect of maturation, that is, the interval between the decision to participate and the measurement, also should be noted. Important events had occurred after the decision, the combined test for some and, maybe an invasive test for a few, and all couples had just participated in the mid-pregnancy ultrasound scan.

Sample

To meet a maximum variation sampling⁸³ in studies I – III, the recruitments were stratified into different groups. Women were divided into three age groups, ≤ 25 , 26–34, and ≥ 35 years, and into different groups for nullipara and multipara. The county was divided into four parts. That intention was fulfilled. However, education as a characteristic was not stratified. In studies I – III, and also in the quantitative study IV, the number of participants with university-level education was much higher than the average in the county. The reasons for this were discussed in the research group but no clear explanation could be identified. The recruitments were followed via charts, and the recruiters, the midwives, did not, as far as we could determine, act as “gatekeepers”⁸³. The main reason for exclusion was facility with the language, since the participants had to be able to speak and understand Swedish. At the first study there were preparations made to use an interpreter, if needed. Unfortunately, at time of the interviews in 2009, it was not common that pregnant women and/or partners who needed an interpreter, accepted the extended information visit. Now,

some years later when the combined test is better known and the extended information visit is available at all Maternal Health Care Programme clinics in Örebro County Council, the picture is different, and midwives at the extended information visits more commonly use interpreters. Therefore, the discussion about the large representation of participants with university education in all studies I - IV has resulted in concerns about other effects. It may be that participation in a study is more appealing to those with high education. Increased education could lead to increased perceived self-efficacy¹³¹ and a trust that the individual could have a voice to affect the society. The highly educated might see participating in research as an opportunity to influence, but those with lower education maybe not feel that they have this ability to lobby and therefore may not have the incentive to participate in research.

The sample sizes in studies I – III should also be discussed. According to Sandelowski¹³², the sample size in qualitative research should be large enough to achieve a variation in experiences but also small enough for the analysis process to be sufficiently deep¹³². The data from the interviews were rich in information, although the interviews were not particularly long; study I, (mean 44 minutes), study II, (mean 52 minutes) and study III, (mean 42 minutes). It was no problem to get the participants to talk about the subject, and no initial information or small talk was necessary. Participants often talked directly about the subject, so almost all of the interviews could be used as data. According to Patton⁸², the validity and insights generated from qualitative studies have more to do with the information richness of the cases selected than with sample size. Therefore the numbers of participants were determined to be adequate in studies I - III⁸².

Data collection

Using a semi-structured interview guide in studies I - III can be a weakness, since important and salient topics can be omitted⁸². Yet, in all interviews in the same study, the main questions were the same and the interviewer was the same person. This may indicate that dependability could be obtained¹³³. The interviews for study I, with the follow-up interviews for study II, ensured credibility⁸² for study I, since these gave an opportunity for clarification, if something had been misunderstood. The time between the interviews gave a chance for reflection and depth. The interviews in studies I - III, with the couples together and the individual interviews with the women, gave rich data, which was an advantage. In these interviews, in most cases, only an opening question was needed to stimulate the couples to discuss with each other and describe their thoughts and experiences

of the subjects. The partners were, in most cases, as active as the women in the discussions. The women, in the individual interviews, talked freely and open, but, of course, only from their own points of view, and the partners' perceptions and experiences were missing, which obviously is a disadvantage and affects the credibility⁸².

In study IV, offering participants the choice of digital questionnaire via e-mail or via traditional mail resulted in something over 50 questionnaires being returned by traditional mail. Use of the digital questionnaire could be the reason for the relatively high, 77%, response rate in a study population comprising mainly younger people. The inclusion period was short, from December - February, with a break for holiday time.

Data analysis

The qualitative analysis processes and the different stages in studies I - III were discussed and scrutinized within the research group to attain credibility⁸². Content analysis with an inductive approach⁹⁰ was used for study I, as the aim was to describe perceptions of the pregnant women and partners about the extended information visit. The data were processed manifestly⁸² and without attempting to interpret the main categories as themes. This process was chosen to maintain fidelity to the participants' narratives.

Interpretive Description⁹¹ was used in studies I and II. According to Thorne⁹¹, Interpretive Description takes advantage of the researcher's experience, which informs the research process, and the questions asked, and how the data are processed and interpreted. Therefore, Interpretive Description⁹¹ was considered as an usable analysis method to make the most of the experiences in the research group. In the research group there were different backgrounds and experiences, which was an advantage in the whole process, in designing the studies and throughout the analysis. Interpretive Description⁹¹ allowed us to use that collective experience to benefit the studies. Experiences gained in study I, when couples expressed the wish to know about other couples' experiences of the decision about the combined test, were used in study II, in describing the decision-making process about the combined test.

For study IV the Decision Regret Scale was chosen. We chose not to present a total score but instead to present the results from each subscale, to give a more complete understanding of the results.

CONCLUSIONS

The conclusions in this thesis, are that the decision whether or not to participate in the combined test is multidimensional and influenced by different views. Most of the pregnant women and partners were satisfied with their decision, but some were not. The two-step information model helped the pregnant woman and the partner to make a decision. The invitation to the extended information visit was in some ways experienced as unclear and not precise, and some couples felt obliged to participate. The extended information visit aid the pregnant woman and the partner to focus on the prenatal screening decision and prepare for the information. By the partners the extended information visit were seen as an opportunity to be involved in the pregnancy and decisions about prenatal screening. At the extended information visit the partners recognized themselves to be equally important and getting the same attention from the midwife as the woman. To decline the extended information visit, was for some couples an action to take stand against the idea of prenatal screening. The decision about prenatal screening is for most couples a fairly straightforward process but for some a more complex process with mixed feelings.

Practical implications

The two-step information model is a model that offers information about prenatal screening on the pregnant woman's and partner's own terms because they are able to decline further information. To fulfil this ambition, health care professionals have to meet every woman and their partners as individuals with individual needs. The invitation to the extended information visit should be clear and precise helping the couple to decide whether to take part or not. This thesis has also showed that some couples are calling for more guidance and discussion about the idea of prenatal screening, as information about the medical and more technical questions could be easily found, for example on the Internet. This demands the midwife's ability to guide without controlling in decision and enhanced skill in counselling.

The two-step information model could be applicable when prenatal screening methods change to more technically simple methods, when the pregnant woman and partner are still needing guidance in their decision.

SVENSK SAMMANFATTNING

Den gravida kvinnan och partnern ställs tidigt i graviditeten inför valet att välja fosterdiagnostik eller inte. Enligt Världshälsoorganisationen är målet med fosterdiagnostik att det erbjuds och finns tillgängligt och att det är kvinnans och partnerns val att delta eller avstå. Statens beredning för medicinsk utvärdering konstaterade 2006, i en systematisk översikt, att kombinerat ultraljud och biokemiskt prov (KUB-test) är den mest fördelaktiga metoden för screening av trisomi i början av graviditeten. KUB-testet ger en sannolikhetssiffra i det enskilda fallet för trisomierna 13, 18 och 21. Detta ger en bättre bedömning av risken än kvinnans ålder, vilken var den tidigare rutinen. KUB-testet är en algoritm bestående av en ultraljudsundersökning med mätning av fostrets nackuppkläring, ett blodprov och kvinnans ålder. Nackuppkläring är ett vätskefyllt utrymme på baksidan av fostrets nacke som bara existerar i början av graviditeten och ett större mått ger misstanke om kromosomavvikelse. Testet utförs i graviditetsvecka 11 - 14 och en beräkning görs av den individuella sannolikheten för att bära ett foster med någon av dessa kromosomavvikelser. I cirka 5 % fås ett resultat med hög sannolikhet och den gravida kvinnan erbjuds då invasiva tester som fostervattenprov eller moderkaksprov för diagnos. De invasiva testerna ger en risk för missfall upp till 1 %.

Enligt svensk lag ska alla gravida kvinnor erbjudas information om fosterdiagnostik. Svensk sjukvård är decentraliserad och därmed varierar erbjudandet om vård mellan olika landsting och regioner. Fosterdiagnostik är ett sådant område. År 2012 erbjöd 16 av 21 landsting och regioner KUB-test, varav sex av dem till alla gravida. Övriga landsting/regioner hade en åldersgräns på 35 år, då risken för kromosomavvikelser ökar med moderns ålder. Även om ett fåtal landsting/regioner har andra kriterier, som också ger yngre kvinnor möjlighet att genomgå testet, är det betydligt fler kvinnor i åldern 35 år och äldre som genomför KUB-test. Om fostret har en kromosomavvikelse ökar risken för missfall eller dödfött barn.

Studier har visat att gravida kvinnor med en positiv inställning till fosterdiagnostik vill söka bekräftelse på graviditeten eller att bli lugnad av undersökningen. Den främsta orsaken till att avstå från KUB-test, är uppfattningen att en abort inte är ett alternativ om testet skulle visa på en kromosomavvikelse. Andra skäl till att avstå kan vara att KUB-testet bara är en beräkning, att testet inte ger någon säkerhet eller uppfattning om att testet inte är tillförlitligt.

Det finns ingen generell definition när det gäller innehållet i informationen om fosterdiagnostik till den gravida kvinnan och partnern. Utifrån

riktlinjer i USA, Storbritannien och Sverige finns en professionell konsensus som innefattar att information ska innehålla 1) vad testerna visar, 2) testernas egenskaper och 3) följderna av möjliga testresultat. Som det första landstinget i Sverige införde Örebro läns landsting i november 2008 KUB-test som ett kostnadsfritt erbjudande till alla gravida kvinnor. Samtidigt introducerades en informationsmodell där kvinnan och partnern inbjuds till en riktad information. Informationen är uppdelad i två steg som börjar med en kort information om fosterdiagnostik som ges av barnmorskan vid den gravida kvinnans första besök i mödrahälsovården. För de kvinnor eller par som vill ha mer information erbjuds ett utökad informationssamtal, som är inriktat på fosterdiagnostik. Detta sker vid ett separat besök och med en specialutbildad barnmorska.

Det övergripande syftet för denna avhandling har varit att beskriva gravida kvinnors och partners erfarenheter och upplevelser av en informationsmodell för att välja eller inte välja tidig fosterdiagnostik med KUB-test.

Delarbete I

Syftet med studien var att beskriva den gravida kvinnans och partnerns uppfattningar om den specifika informationsmodellen om fosterdiagnostik. I studien intervjuades 15 par som hade deltagit i den utökade informationen. För att få en variation i urvalet gjordes en indelning i urvalsgrupper: tre åldersgrupper (≤ 25 , 26–34, och ≥ 35 år), olika grupper för förstföderska och omföderska och Örebro län delades in i fyra områden. De tio barnmorskor som arbetade med utökad informationssamtal i länet ombads rekrytera två par vardera från olika urvalsgrupper. Paret tillfrågades om deltagande i studien direkt efter det utökade informationssamtal och de som accepterade att bli kontaktade uppgav namn och telefonnummer. Tjugotre par tillfrågades, 19 accepterade att bli kontaktade och 15 par samtyckte till deltagande. Datainsamlingen bestod av sammanlagt 26 semi-strukturerade intervjuer med kvinnor/par som deltagit i ett utökad informationssamtal. Intervjuerna genomfördes med kvinnan och partnern var för sig och/eller paret tillsammans. Sammanlagt består materialet av intervjuer med 10 kvinnor och 6 partner (alla män) och 10 par. Intervjuerna genomfördes tre dagar till tre veckor efter det utökade informationssamtal. Data analyserades med innehållsanalys.

Resultatet visar att paret/kvinnan uppskattade att det var ett extra besök och med en annan barnmorska än den ordinarie. Det gav ett fokus på fosterdiagnostik eftersom andra barnmorskebesök har andra syften och fokus. De par som hade bestämt sig för KUB-test före informationssamtal

let upplevde inte utökad informationssamtal som något som de hade valt frivilligt. De hade hellre velat få informationen om fosterdiagnostik tillsammans med all annan information vid ett ordinarie besök. Överlag kände sig partnern mer delaktig i utökad informationssamtal än i övriga graviditetsbesök och upplevde också detta mer som ett besök på lika villkor än övriga graviditetsbesök. Innehållet i informationen uppskattades av flertalet par. En del par tyckte att de fick ny kunskap, medan andra kompletterade sina tidigare kunskaper och såg informationssamtalet som ett tillfälle att ställa frågor. Det fanns hos en del en önskan om ett mer djuplodande och individuellt samtal om bl. a. etiska frågeställningar och hur andra i samma situation tänker och funderar kring fosterdiagnostik. Några par uttryckte att oron över kromosomavvikelse ökade i och med ökad kunskap men att detta var övergående. Det hade också fått till följd att de pratade mer med varandra om sin oro och om hur det skulle bli om de skulle få ett barn med speciella behov. Detta var samtal som de annars inte skulle ha haft, vilket upplevdes som berikande.

Delarbete II

Syftet med studien var att utforska hur den gravida kvinnan och partnern, som hade deltagit i utökad informationssamtal, beskrev beslutsprocessen om att delta i fosterdiagnostik eller inte. I studien ingår intervjuerna från delarbete I kompletterat med en uppföljningsintervju. Vid den första intervjun tillfrågades paren/kvinnorna om de accepterade att bli kontaktade för en uppföljningsintervju efter ultraljudsundersökningen i graviditetsvecka 18. Tolv par samtyckte och två par avstod på grund av tidsbrist. Ett av paren som hade samtyckt avbokade strax före intervjun, utan att ange skäl, varvid elva par samtyckte till en uppföljningsintervju. Den andra intervjun var planerad att genomföras som parintervju, men på grund av tidsbrist för partnern var detta var inte möjligt i fem fall. Sammanlagt ingår 37 intervjuer, varav 15 individuella intervjuer med den gravida kvinnan, sex med partnern (alla män) och 16 intervjuer med paret tillsammans. Tolkande beskrivning har använts som analysmetod.

Av de 15 parens berättelser kunde tre olika mönster av beslutsprocess identifieras. I en "Öppen och kommunikativ beslutsprocess" diskuterade paren tillsammans för att komma fram till sina egna, personliga motiv för att delta i KUB-test eller inte. De vägde olika möjliga svar på KUB-testet och planerade för hanteringen av dessa alternativ. Alla de par som uppvisade detta mönster var i efterhand nöjda med sitt beslut att välja eller inte välja KUB-test. Ett annat mönster var "Stängd och personlig beslutsprocess", vilken innebar att kvinnan och partnern funderade var och en för

sig för att sedan ta ett gemensamt beslut. Beslutet innebar att välja KUB-test eller inte och de talade inte om eventuellt kommande beslutssituationer. De flesta par i detta mönster var nöjda med sitt beslut att välja KUB-test efteråt. En kvinna ångrade sitt beslut eftersom hon hade blivit mycket orolig när hon fick svar trots att svaret visade på låg sannolikhet för kromosomavvikelse. Det tredje mönstret var "Sökande och kommunikativ beslutsprocess". De paren kommunicerade med varandra, men även med andra i sin omgivning, för att få andra tankar på hur de kunde tänka runt beslutet. Paren hade svårt att hitta något eget, personligt motiv till varför de skulle delta i KUB-test eller inte. Det fanns etiska funderingar kring fosterdiagnostik, och de egna värderingarna kunde krocka med önskan att trots allt ha möjligheten att få ett svar om kromosomavvikelse. Alla par som uppvisade i detta mönster var nöjda efteråt med beslutet att välja eller inte välja KUB-test.

Delarbete III

Syftet med studien var att beskriva åsikter om, och erfarenheter av, fosterdiagnostik och information för par som inte hade deltagit i utökad informationssamtal. Rekryteringen gjordes i samband med ultraljudsundersökningen i graviditetsvecka 18. Paren tillfrågades om medverkan i studien direkt efter undersökningen, av barnmorskorna på Specialistmödravården vid Universitetssjukhuset Örebro och Karlskoga lasarett. För att få en variation i urvalet gjordes en indelning i urvalsgrupper: tre åldersgrupper (≤ 25 , 26–34, och ≥ 35 år), olika grupper för förstföderska och omföderska och länet indelat i fyra områden. De som accepterade att bli kontaktade uppgav namn och telefonnummer. Sammanlagt tillfrågades tio par och alla accepterade att bli kontaktade. Av dem samtyckte åtta till att delta, två avböjde på grund av tidsbrist. I ett fall kunde inte partnern delta i intervjun på grund av arbete och intervjun med kvinnan exkluderades. Sju intervjuer analyserades med tolkande beskrivning.

Resultatet beskrev två teman för parens syn på fosterdiagnostik och information om fosterdiagnostik. Det första temat "En individuell syn" visade på erbjudandet om utökad informationssamtal utifrån personliga behov. Det fanns olika anledningar till att tacka nej. En anledning var att paren inte ville veta mer om fosterdiagnostik eftersom det skulle öka oron omkring graviditeten. Andra anledningar var att de redan visste vad de behövde veta för att kunna bestämma sig eller att erbjudandet om utökad informationssamtal inte hade uppfattats av paret. I det andra temat "En samhällelig syn" beskrevs erbjudandet om fördjupat informationssamtal som förenat med ett accepterande av fosterdiagnostik, vilket dessa par

uppfattades som något negativt. Det sågs även som samhällets intrång i familjens egen sfär och som en avspegling av en samhällssyn där bara vissa människor ska få födas. Sjukvårdens ansvar för att erbjuda och utveckla tekniker för fosterdiagnostik ifrågasattes. Frågor ställdes om kravet på att sjukvården ska erbjuda fosterdiagnostik är ett politiskt krav eller ett krav från blivande föräldrar. Det fanns också uppfattningar om att Down syndrom inte är ett allvarligt tillstånd utan att det är möjligt att leva ett gott liv med Downs syndrom.

Delarbete IV

Syftet med studien var att beskriva om gravida kvinnor och partner var nöjda eller inte över beslutet att delta eller inte delta i KUB-test samt deras bedömning om hur svårt detta val var. Rekrytering till studien gjordes direkt efter ultraljudsundersökningen i graviditetsvecka 18 på Specialistmödravården vid Universitetssjukhuset Örebro och i Karlskoga lasarett. Alla gravida kvinnor och partner som talade och läste svenska, var över 18 år gamla och en normal ultraljudsundersökning tillfrågades om deltagande i en enkätundersökning. Rekryteringsperioden var december 2013 till februari 2014. Instrumentet Decision Regret Scale (DRS) användes för att mäta nöjdheten med valet att välja eller att avstå KUB-test, kompletterat med ytterligare fler frågor. Definitionen av att ångra sitt beslut enligt DRS är: ånger eller ångest över ett beslut. Instrumentet utgörs av en femsiffrig skala som mäter ångest eller ånger efter ett sjukvårdsbeslut med fem frågor. De kompletterande frågorna var: "Har du varit på utökat informationssamtal?" (ja/ nej), "Har tidigt fosterdiagnostik med KUB-test utförts?" (ja/nej), "Vem tog beslutet att delta eller inte delta i KUB-test?" (jag själv/min partner/vi tillsammans),"Hur lätt eller svårt tyckte du att det var att fatta beslut om att delta eller inte i KUB-test?" (femgradig svarsskala från 1=mycket lätt till 5=mycket svårt). Demografiska data samlades också in, som födelseår, födelseland, postnummer, högsta avslutade utbildning samt antal barn.

Under undersökningsperioden deltog 488 kvinnor i ultraljudsundersökning på två ställen i Örebro län. Av dessa blev 104 kvinnor inte tillfrågade på grund av de exklusionskriterier som fanns. Information om studien gavs till 384 kvinnor, varav 25 tackade nej till deltagande. Slutligen accepterade 359 kvinnor och 315 partners att delta i studien. Svarsfrekvensen blev 77 % då 295 kvinnor och 223 partner svarade på enkäten. Beslutet att genomföra KUB-test eller inte sågs som parets ömsesidiga beslut av 95 % av kvinnorna och 96 % av partners, och 93 % av både kvinnor och partners uppfattade beslutet som okomplicerat. Beslutet betraktades som

"svårt/mycket svårt" av 6 %. Mellan 93-99 % av kvinnorna och partners var nöjda med sitt beslut i efterhand, medan 1-7 % uppgav att de inte var det.

Avhandlingens slutsatser

Slutsatserna i denna avhandling är att beslutet om att delta eller inte delta i KUB-test är flerdimensionellt och påverkas av olika synsätt. Beslutet om KUB-test var för de flesta par en ganska okomplicerad process medan en mindre grupp upplevde beslutet som komplext. Flertalet var i efterhand också nöjda med sitt beslut.

Två-stegs informationsmodellen uppfattades som värdefull för beslutsfattandet. Det utökade informationssamtalet uppfattades ge möjlighet för den gravida kvinnan och partnern att fokusera på fosterdiagnostik och förbereda för informationen. För partnern var det utökade informations-samtalet en möjlighet att få vara delaktig i graviditeten och i beslutet om fosterdiagnostik, och de upplevde sig vara jämställda kvinnan vid besöket och i beslutet.

Inbjudan till utökat informationssamtal upplevdes ibland som otydlig, och vissa par kände sig tvungna att delta för att få delta i KUB-test. Att avstå från utökat informationssamtal var för vissa par ett ställningstagande mot idén om fosterdiagnostik.

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Frågeformulär: Beslut om fosterdiagnostik

Kod _____

1. Födelseår _____

2. Födelseland _____

3. Bor på postnummer _____

4. Din högsta genomförda utbildning

Grundskola

Gymnasium

Högskola

5. Är gravid Är partner

6. Beräknat datum för förlossning _____

7. Har du barn sedan tidigare? _____

8. Har du varit på besök med fördjupad information om fosterdiagnostik, s.k. Frejasamtal?

Ja

Nej

9. **Har tidig fosterdiagnostik med KUB-test (ultraljud + blodprover) genomförts?**

Ja

Nej

10. **Vem tog beslutet om att göra KUB-test eller inte göra KUB-test?**

Jag

Min partner

Vi tillsammans

11. **Hur enkelt eller svårt tyckte du det var att fatta beslutet om att delta eller inte i KUB-test?** Markera det svarsalternativ av påståendet som du tycker stämmer på dig

Mycket lätt

1

2

3

4

Mycket svårt

5

Fråga 12-16

När du ser tillbaka på beslutet i denna graviditet att välja KUB-test eller inte, hur tänker du idag? Markera det svarsalternativ av påstående som du tycker stämmer på dig.

12. **Det var det rätta beslutet**

Instämmer

helt

1

2

3

4

Instämmer inte

alls

5

13. Jag ångrar det val som jag gjorde

Instämmer

helt

1

2

3

4

Instämmer inte

alls

5

14. Jag skulle göra samma val om jag skulle göra det igen

Instämmer

helt

1

2

3

4

Instämmer inte

alls

5

15. Valet medförde en hel del obehag för mig

Instämmer

helt

1

2

3

4

Instämmer inte

alls

5

16. Det var ett klokt beslut

Instämmer

helt

1

2

3

4

Instämmer inte

alls

5

Sample Tool: Decision Regret Scale

Decision Regret Scale

Please reflect on the first decision you made about _____ after talking you're your physician. Please show how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about your decision. I feel **confident** that I can:

1. It was the right decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
2. I regret the choice that was made	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
3. I would go for the same choice if I had to do it over again	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
4. The choice did me a lot of harm	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
5. The decision was a wise one	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree




Decision Regret Scale © AM O'Connor, 1996 University of Ottawa

Study I.**Categories and sub-categories describing the findings**

<i>Category</i>	Form and content	Managing the information
<i>Sub-category</i>	Voluntariness	Communication within the couple
	A separate visit	Communication with other people
	A special midwife	Emotional management
	The content	
	Missing information	
	Ethical considerations	
	A visit on equal terms	

Study II.

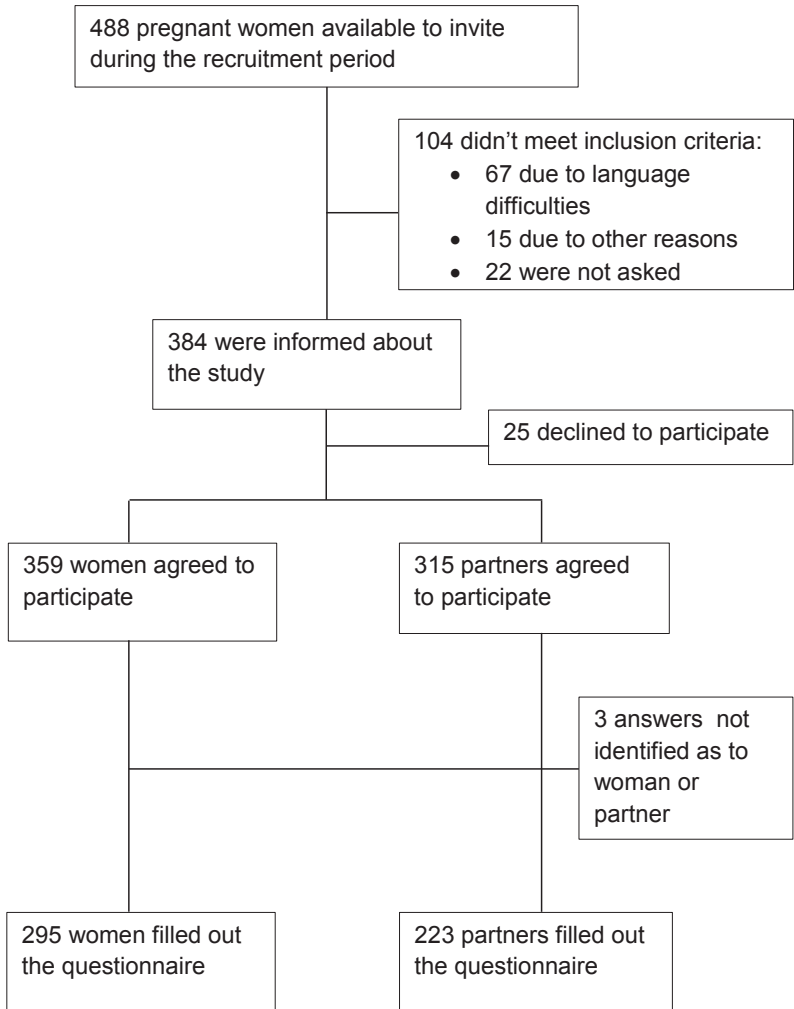
Themes and subthemes developed into pattern

Theme	Subtheme	Subtheme	Subtheme
<i>Why? Reasons for decision</i>	Formulating their own reason	Giving one argument as reason	Struggling to find a reason
<i>What? Options for decision</i>	Deciding about the combined test and further steps	Deciding about the combined test only	Striving to decide about the combined test and further steps
<i>How? Paths for decision making</i>	Communicating with each other and family to reach decisions	No need to communicate about the decision	Communicating with each other and others to reach decisions
			
Patterns	<i>The open and communicative decision-making process</i>	<i>The closed and personal decision-making process</i>	<i>The searching and communicative decision-making process</i>

Study III.**Themes and sub-themes describing the findings**

<i>Theme</i>	From an individual view	From a societal view
<i>Sub-theme</i>	Declining further information	Society has a hidden agenda
	Position taken against prenatal screening	The health care service's responsibilities

Study IV.



Flow chart of the recruitment for study IV

Study IV.**Demographic data for women and partners**

	Women n = 295	(%)	Partners n = 223	(%)	<i>p</i>
<i>Age</i>					
mean years	30.7		33.15		
range	20 - 42		22 - 52		
<i>Parity</i>					
n = 294			n = 220		
0	124	(42)	103	(46.2)	
1-4	170	(57.6)	117	(52.4)	
<i>Education**</i>					
n = 292			n = 221		0.037*
Low	4	(1.45)	6	(2.7)	
Medium	138	(46.8)	121	(54.3)	
High	150	(50.8)	94	(42.2)	
<i>Country of birth</i>					
n = 294			n = 223		
Sweden	273	(92.5)	211	(94.6)	
Other Nordic countries	1	(0.3)			
Rest of Europe	12	(4.1)	5	(2.2)	
Outside Europe	8	(2.7)	7	(3.1)	

**Education: low = up to 10 years, medium = more than 10 years and less than 13 years, and high = at university level

Study IV.

Women's and partners' participating in extended information visit, combined test and perception of who took the decision about the combined test.

	<i>Women</i>		<i>Partners</i>		p
	<i>n =295</i>	<i>(%)</i>	<i>n = 223</i>	<i>(%)</i>	
<i>Participated in extended information visit at any pregnancy</i>	<i>n = 294</i>		<i>n =222</i>		
Yes	216	(73.2)	129	(57.8)	
No	78	(26.4)	93	(41.7)	
<i>Participated in the combined test at any pregnancy</i>	<i>n =295</i>		<i>n = 223</i>		
Yes	242	(82)	177	(79.4)	
No	53	(18)	46	(20.6)	
<i>Who took the decision whether or not to take part in the combined test</i>	<i>n = 294</i>		<i>n = 23</i>		0.572
<i>Myself</i>	13	(4.4)	0		
<i>My partner</i>	0		8	(3.6)	
<i>Mutual decision</i>	281	(95.3)	215	(96.4)	

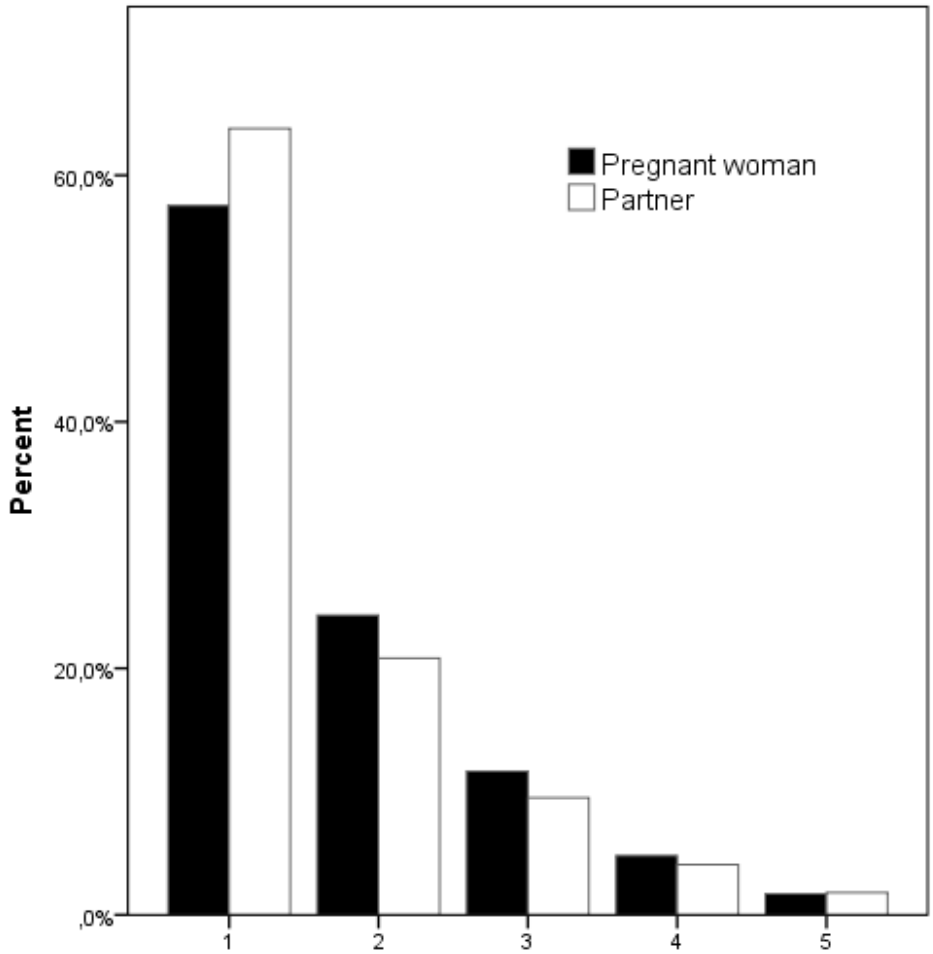
Study IV.

Decision Regret Scale according to pregnant women and partners in the decision about prenatal screening

<i>Decision Regret Scale items</i>	<i>Women</i>		<i>Partners</i>		<i>p</i>
	<i>n = 295</i>	<i>%</i>	<i>n = 223</i>	<i>%</i>	
It was the right decision	<i>n = 295</i>		<i>n = 222</i>		0,436
1	245	(83.1)	179	(80.3)	
2	29	(9.8)	27	(12.1)	
3	14	(4.7)	8	(3.6)	
4	4	(1.4)	7	(3.1)	
5	2	(0.7)	1	(0.4)	
I regret the choice that was made	<i>n = 288</i>		<i>n = 221</i>		0.272
1	5	(1.7)	1	(0.4)	
2	3	(1.0)	1	(0.4)	
3	5	(1.7)	3	(1.3)	
4	14	(4.7)	10	(4.5)	
5	261	(88.5)	206	(92.4)	
I would go for the same choice if I had to do it over again	<i>n = 293</i>		<i>n = 223</i>		0.607
1	252	(85.4)	195	(87.4)	
2	23	(7.8)	17	(7.6)	
3	12	(4.1)	9	(4.0)	
4	4	(1.4)	1	(0.4)	
5	2	(0.7)	1	(0.4)	
The choice did me a lot of harm	<i>n = 292</i>		<i>n = 222</i>		0.045*
1	5	(1.7)	2	(0.9)	
2	13	(4.4)	10	(4.5)	
3	24	(8.1)	16	(7.2)	
4	58	(19.7)	28	(12.6)	
5	192	(65.1)	166	(74.4)	
The decision was a wise one	<i>n = 292</i>		<i>n = 223</i>		0.586
1	232	(78.6)	172	(77.1)	
2	33	(11.2)	30	(13.5)	
3	20	(6.8)	19	(8.5)	
4	6	(2.0)	1	(0.4)	
5	1	(0.3)	1	(0.4)	

1 = Strongly Agree, 2 = Agree, 3 = Neither Agree or Disagree, 4 = Disagree, 5 = Strongly Disagree

Study IV.



How easy or difficult did you think it was to make the decision to participate or not in the combined test? Scoring (range): 1 = very easy to 5 = very difficult

Women's and partners' attitudes towards the decision about the combined test (n = 295 pregnant women, 223 partners)

Study IV

Decision Regret Scale according to pregnant women and partner in decision about prenatal screening

<i>Decision Regret Scale items</i>	<i>Women</i>		<i>Partners</i>		<i>p</i>
	<i>n = 295</i>	<i>(%)</i>	<i>n = 223</i>	<i>(%)</i>	
It was the right decision	n = 295		n = 222		0.436
1	245	(83.1)	179	(80.3)	
2	29	(9.8)	27	(12.1)	
3	14	(4.7)	8	(3.6)	
4	4	(1.4)	7	(3.1)	
5	2	(0.7)	1	(0.4)	
I regret the choice that was made	n = 288		n = 221		0.272
1	5	(1.7)	1	(0.4)	
2	3	(1.0)	1	(0.4)	
3	5	(1.7)	3	(1.3)	
4	14	(4.7)	10	(4.5)	
5	261	(88.5)	206	(92.4)	
I would go for the same choice if I had to do it over again	n = 293		n = 223		0.607
1	252	(85.4)	195	(87.4)	
2	23	(7.8)	17	(7.6)	
3	12	(4.1)	9	(4.0)	
4	4	(1.4)	1	(0.4)	
5	2	(0.7)	1	(0.4)	
The choice did me a lot of harm	n = 292		n = 222		0.045*
1	5	(1.7)	2	(0.9)	
2	13	(4.4)	10	(4.5)	
3	24	(8.1)	16	(7.2)	
4	58	(19.7)	28	(12.6)	
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The decision was a wise one	n = 292		n = 223		0.586
1	232	(78.6)	172	(77.1)	
2	33	(11.2)	30	(13.5)	
3	20	(6.8)	19	(8.5)	
4	6	(2.0)	1	(0.4)	
5	1	(0.3)	1	(0.4)	

1 = Strongly Agree, 2 = Agree, 3 = Neither Agree or Disagree, 4 = Disagree, 5 = Strongly Disagree

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