Psychological consequences of prenatal screening

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# CONTENTS

1. General introduction 7

2. Does prenatal screening influence anxiety levels of pregnant women? 31

3. Prenatal screening for Down syndrome: Pregnant women's perceived risk and emotional well-being 47

4. Does offering and performing prenatal screening influence women's attachment to their unborn child? 61

5. Does informed decision making influence psychological outcomes after receiving a positive screening outcome? 75

6. Does offering prenatal screening influence pregnant women's attitudes regarding prenatal testing? 83

7. The decision for or against prenatal screening in relation to pregnant women's values 97

8. General discussion 109

Summary 127

Samenvatting 135

List of publications 145

Dankwoord 147
Summary

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INTRODUCTION

Prenatal screening tests are being offered in more and more European countries to all pregnant women. Guidelines for screening programmes state that the benefits of these programmes should outweigh any harmful physical or psychological effect as a result of participating. Therefore, the question arises concerning whether offering prenatal screening has an effect on pregnant women’s psychological well-being.

The thesis is divided into two parts: (1) psychological consequences of offering prenatal screening, and (2) informed decision making. In the first part we looked at the effect of offering prenatal screening and receiving a screening outcome on general feelings of anxiety, fear of bearing a physically or mentally disabled child (child-related anxiety), positive and negative emotions, and attachment to the pregnancy and the unborn child. In the second part we looked at the effect of informed decision making on the emotional reaction after receiving an increased screening outcome. An important criterion for informed decision making is that women act in line with their values. When studying informed decision making, attitudes are often used as a reflection of people’s values. As attitudes are not stable, we looked at the effect of offering prenatal screening on pregnant women’s attitudes towards prenatal testing. In addition, we explored what women’s values are concerning various pregnancy outcomes, and whether these are in line with the decisions women made about accepting or declining screening.

In this thesis we aimed at answering the following research questions:

1. Psychological consequences
   a) What is the effect of being offered prenatal screening on anxiety (Chapter 2) and attachment (Chapter 4)?
   b) What is the effect of receiving a screening result on anxiety (Chapter 2), attachment (Chapter 4), and positive and negative emotions (Chapter 3)?
   c) What are the longer-term effects of being offered prenatal screening and receiving a screening result on anxiety (Chapter 2), attachment (Chapter 4), and positive and negative emotions (Chapter 3)?

2. Informed decision making
   a) Do women who made an informed decision and those who did not, differ in their emotional reaction when confronted with a positive screening outcome? (Chapter 5)?
   b) What is the effect of offering prenatal screening on pregnant women’s attitudes towards prenatal testing (Chapter 6)?
   c) What are pregnant women’s preferences in pregnancy outcomes (Chapter 7)?

Prenatal tests can be divided into prenatal diagnostic tests (e.g. amniocentesis and chorionic villus sampling) and prenatal screening tests (e.g. nuchal translucency measurement, maternal
Summary

serum screening test, and the combination test). In virtually all cases, diagnostic tests provide certainty about whether or not the foetus has the abnormality being tested for, whereas screening tests may only give an estimation of the chance that the foetus has the abnormality. If the prenatal screening test indicates an increased risk, women are offered a prenatal diagnostic test to gain certainty. Invasive prenatal diagnostic testing has a procedure-related risk of miscarriage. Therefore, and for practical and financial reasons, these tests are not offered to all pregnant women in the Netherlands, but only to those who are at an increased risk (women of 36 years and older, and women with a medical indication).

Two prevalent congenital abnormalities that can be tested for during pregnancy are Down syndrome (DS) and neural tube defects.

METHODS

The data presented in this thesis were collected in the context of a larger research project: a longitudinal randomised controlled trial, aimed at studying risk perception, decision making, and psychological well-being of pregnant women when offered prenatal screening for DS and neural tube defects.

Setting

We collected our data in the period between May 2001 and May 2003. In the Netherlands, at that time, it was prohibited to offer prenatal screening to women younger than 36 years of age who had no medical indication. We received permission from the Minister of Health to offer prenatal screening in the context of this study.

Participants

Midwifery and gynaecology practices in various parts of the Netherlands were approached until a sufficient number (n=44) consented to participate. These practices consisted of group and individual practices and were located in rural and urban areas. Pregnant women attending one of these practices were asked permission to be sent a research information letter. Only women with a gestational age of at most 16 weeks, and with a command of the Dutch language were approached. The first information letter invited women to participate in a study for evaluating different kinds of pregnancy care. We did not mention prenatal screening tests, since there is a risk that women in the control group might look for more information about it, which would mean that they were no longer a proper control group. Of the 4077 women who were approached, 2986 women (73%) gave informed consent. Sixty percent of these women filled in the questionnaires at all points in time.
Randomisation
After informed consent was granted, women were randomised into three groups: a group that was given information about the nuchal translucency measurement (NTM), a group that received information about the maternal serum screening test (MST), and a group that was not offered screening (control group). Since the NTM can only be performed between the first 10 and 14 weeks of pregnancy, it was necessary to make sure that the pregnancy duration of women who would be offered this test did not fall outside this range. Consequently, women who gave consent after 10 weeks were randomised into either the MST group or the control group.

Intervention
Women received information about the prenatal screening test by means of a booklet sent to their home and a consultation by their midwife or gynaecologist. The booklet had previously been pilot-tested for comprehensibility.

Questionnaires
Participants were asked to fill in five postal questionnaires at various points in time: (1) before any information about screening was given; (2) after they had been offered prenatal screening, or at a comparable point in time for the control group; (3) after the screening result was known, or at a comparable point in time for the control group and women who declined screening; (4) at 28 weeks of pregnancy; and (5) two months after giving birth.

RESULTS AND DISCUSSION
Psychological consequences
Offering prenatal screening influenced certain psychological outcomes. After the screening offer, women showed more attachment towards their pregnancy and the unborn child compared to women who were not offered screening (Chapter 4), and some of the women became more anxious about the health of their unborn child (Chapter 2). Possibly, offering prenatal screening increases women’s awareness of their pregnancy and their unborn child.

Overall, during pregnancy, women who had been offered screening seemed to have more favourable psychological outcomes than women who had not been offered screening (Chapters 2, 3, 4). They showed a higher increase in positive feelings over time, a larger decrease of negative feelings, more attachment and less general anxiety. Overall, our study did not find a difference in psychological outcomes between screening acceptors (who received a negative screening outcome) and decliners, nor a difference between women who had had a screening test in which the child was visible (NTM) and women who had had a screening test in which the child was not visible (MST). So, it seems as if offering prenatal screening is psychologically beneficial for most women, compared to not being offered screening, regardless of whether
Summary

or not women choose to accept the test, and regardless of the specific test offered. Possibly, giving women the possibility to decide themselves about the course of the pregnancy and pregnancy outcome makes them feel more in control. Other studies have shown that a sense of control is related to higher emotional well-being, whereas women who experience the course of their pregnancy as uncontrollable have an increased fear of bearing a physically or mentally disabled child.

Even though the differences in our study were statistically significant, the differences between the groups in our study were small. Therefore, at the population level, offering prenatal screening may have some beneficial influence for pregnant women, whereas the clinical significance of these differences for an individual pregnant woman can be questioned.

Even though for most women prenatal screening does not seem harmful, positively screened women do experience negative consequences. Our study found that after women received a positive screening outcome, their level of general anxiety rose. However, their anxiety decreased later in pregnancy (most women had had a diagnostic test done, with all results being favourable).

Women who received a positive screening result in our study knew for which anomaly the risk was increased, and were given the choice to gain certainty about its presence by means of diagnostic testing. Currently, women are offered, among others, the standard anomaly scan (SAS), which can indicate a wide range of abnormalities, the clinical significance of which is not always clear. The test characteristics of the SAS raise questions concerning its psychological effects. How do women respond to an abnormal finding if the consequence of the anomaly is not clear? How do they deal with an abnormal result during the rest of their pregnancy if diagnostic testing cannot give certainty? These questions remain to be answered.

The study outlined in Chapter 2 implies that receiving a favourable diagnostic test outcome can lessen the worries caused by a positive screening outcome. It would therefore be beneficial for women to receive the diagnostic test result more quickly. Traditionally, prenatal diagnostic testing of chromosome abnormalities took 1-3 weeks before producing the test outcome. Currently, MLPA (multiplex ligation-dependent probe amplification) is being implemented as a prenatal screening technique, which enables a diagnosis of aneuploidy in 2-4 days. Therefore, the period of tension between receiving a positive screening result and receiving a diagnostic test outcome is likely to be shortened in the future.

Informed decision making

Our study outlined in Chapter 5 suggests that, when confronted with a positive screening outcome, women who had made an informed decision have a more favourable emotional reaction (variables that were measured: regret, shock, disappointment, feeling insecure), and felt better able to decide about invasive diagnostic testing. Because only a few women in our
study had received a positive screening outcome, this is a preliminary conclusion. Results will 
have to be replicated in a broader sample and for a wider variety of outcome measures before 
firm conclusions can be drawn.

Chapter 6 describes that attitudes towards prenatal testing may change when women are 
offered information about prenatal screening; these attitudes came more into line with the 
decision women made. It is possible that, because women had gained more knowledge 
about prenatal testing, their ideas about it changed. This may be unfavourable concerning 
the presently-used guidelines for prenatal screening in the Netherlands. These guidelines 
state that the health professional first has to check whether the woman wishes to be informed 
about screening for DS. If that is the case, she will receive more information. So it may be 
that a woman declines information about screening because she does not hold a 
positive attitude, whereas, if she had known more about screening, she might have chosen 
to have the test performed. In future however, this situation is probably less likely to 
occur. Now that all women have the option to be informed about prenatal screening, knowl-
edge about prenatal testing will become more widespread among the population as a 
whole.

Some health professionals and policy makers feared that because prenatal screening tests are 
safe for the child, women would very easily choose to have such a test done without considering 
what they would do in the case of a positive screening outcome. After receiving a positive 
outcome, women may feel drawn further into the screening trajectory and make choices that 
do not correspond to their values. In Chapter 7 we tried to gain insight into whether or not 
this fear is justified. The results of our study are twofold. On the one hand, screening acceptors 
assigned a lower value to having a child with DS than to a chosen abortion of such a child. This 
is in line with what could be expected if one considers the decision to have prenatal screening 
done as the first step in a trajectory that may end with a decision about termination of the 
pregnancy. This result implies that women who accept screening are aware of the possible 
consequences of their decision. On the other hand, acceptors assigned the lowest value to 
losing a healthy child by means of a procedure-related miscarriage. This finding requires 
attention when considering the cut-off that is used for offering invasive prenatal diagnostic 
testing. In the Netherlands, the cut-off for labelling a screening outcome as ‘increased’ is set 
at a chance of 1:200 at 12 weeks of pregnancy. This cut-off is equal to the risk of a procedure-
related miscarriage for the chorionic villus sampling, implying that having a child with DS has 
the same value as having a procedure-related miscarriage (which in most cases will be the 
miscarriage of a healthy child). However, our study showed that screening acceptors do not 
value these outcomes as equal. Therefore, after women receive an increased screening result, 
it is important that they understand that prenatal diagnostic testing is not a self-evident next 
step. During counselling, special attention should be paid to the values an individual woman 
attaches to the possible pregnancy outcomes.
Summary

Chapters 5 and 7 suggest that it is important that pregnant women make an informed decision on prenatal screening, and that special attention should be paid to the values women attach to the various possible pregnancy outcomes. With the future development of screening techniques, parents will probably be able to have access to more, and sometimes uncertain, information about the (future) health of their foetus. Facilitating informed decision making will therefore become even more important. Decision aids are a useful supplement to counselling.

CONCLUSION

The present thesis suggests that prenatal screening is not psychologically harmful for most women; it does not cause anxiety, nor decrease attachment to the pregnancy and unborn child, nor lead to less positive, or more negative emotions. There are adverse effects, however, in women who receive an increased screening result, although these seem to reduce after a favourable diagnostic test result is received. The thesis presents the preliminary findings that making an informed decision is associated with a more favourable emotional outcome when confronted with a positive screening result.