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Accepting or declining the offer of prenatal screening for congenital defects: test uptake and women's reasons

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Objectives Prenatal screening for Down syndrome has become standard practice in many western countries. In the Netherlands, however, prenatal screening tests for congenital defects are not offered routinely. The present study aims to assess test uptake in a large, unselected population of pregnant women, and to give more insight into the decision for or against prenatal screening through nuchal translucency measurement or maternal serum screening.

Patients and Methods The study is part of a randomized controlled trial with two groups, each being offered a different prenatal screening test, and a control group. Pregnant women received postal questionnaires at three stages of their pregnancy.

Results Of the women being offered the nuchal translucency measurement or the second trimester maternal serum test, 53 and 38% respectively accepted the test offer. The main reasons for accepting were 'gaining knowledge about the health of the foetus/curiosity' (50%), 'favourable characteristics of the screening test' (18%), and 'increased risk of having a child with DS' (15%). The main reasons for declining were 'unfavourable characteristics of the screening test' (42%), 'not applicable/not necessary' (35%), 'anxiety/uncertainty' (36%), 'adverse characteristics of the invasive tests' (32%), and 'being against abortion' (15%).

Discussion The uptake of prenatal screening was relatively low, and different distributions of reasons were reported, compared to other studies. These differences may be due to the specific Dutch situation in which prenatal screening is not part of standard prenatal care. The question arises as to whether informed decision-making would be reduced if prenatal screening became routinised. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS: prenatal screening; Down syndrome; decision-making; uptake; reasons

INTRODUCTION

Prenatal screening can identify a high-risk subgroup within a population of pregnant women. Prenatal screening for Down syndrome (DS) and neural tube defects (NTD) provides an individualized risk estimation of having a child with one of these disorders. The subgroup of women with an increased risk can be offered prenatal diagnostic testing in order to provide a certain diagnosis.

Two of the available methods of prenatal screening for congenital defects are the nuchal translucency measurement (NTM) and the maternal serum screening test (MST). Although both screening tests result in a risk estimation, it should be stressed that these tests have different characteristics: NTM screens only for DS in the first trimester of pregnancy, and is performed through ultrasound scanning (Nicolaides *et al*., 2002). The MST ('triple test') is a blood test in the second trimester of pregnancy, and tests for both DS and NTD (Benn, 2002).

Although prenatal screening for DS and NTD has become standard practice in many western countries, this is not the case in the Netherlands. In July 1996, the Population Screening Act (PSA) became law in the Netherlands. Its purpose was to protect the population against screening programmes that could be a threat to the psychological and physical health of the person being screened. One of the categories of the population screening that requires ministerial approval is screening for 'serious disorders that can neither be treated nor prevented'. Prenatal screening for congenital disorders comes under this category, since the legislature considers termination of pregnancy as being neither treatment nor prevention (Health Council of the Netherlands: Committee on the Population Screening Act, 1996). Since there is no approval for this type of screening in the Netherlands, it is forbidden to offer prenatal screening to pregnant women, unless they request it. However, permission is granted to offer prenatal diagnostic tests to pregnant women only if they are over 35 years of age.

In contrast to the practice in other western countries, in the Netherlands the prenatal care system is strongly decentralized: midwives operate as autonomous medical practitioners (Smeenk and ten Have, 2003). Generally, physiological pregnancies are taken care of by midwives,

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and it is only in cases where pathology is suspected or identified that the pregnancy is managed by a gynaecologist (Pajkrt *et al*., 1998).

In the United States, prenatal screening has been offered as part of customary prenatal care for decades, and having such a screening test done has become common (Markens *et al*., 1999; Press and Browner, 1997). On the basis of interviews and observations, Markens *et al*. and Press and Browner concluded that prenatal screening ceases to be something about which a deliberate decision needs to be made. A recently published review by Green *et al*. on psychosocial aspects of prenatal and newborn screening, which included 106 publications from 12 different countries, also concluded that women's understanding of screening is poor and that most women are not making informed choices about screening (Green *et al*., 2004). Accepting prenatal screening is not a result of a considered, conscious decision, but rather perceived as something self-evident: 'Thus, the acceptance of routines *because* they are routine means that pregnant women do not necessarily make an informed decision [. . .] '(Green and Statham, 1996). A Scottish report, which presents a technology assessment concerning ultrasound scanning before 24 weeks of pregnancy (this includes NTM), also concluded that many women did not feel that they were being offered a choice about testing, and did not consider their decision-making as being informed (Ritchie *et al*., 2004). This lack of informed decision-making conflicts with the commonly held belief that the objective of prenatal screening is to enable people to make their own, informed decision regarding whether to have the screening test done or not, rather than preventing as many affected children as possible from being born (Health Council of the Netherlands, 2001; Marteau *et al*., 2001).

Uptake rates of screening tests are generally high in countries where prenatal screening is part of usual care, for example, in the United Kingdom, uptake percentages were 87% for the second-trimester MST, and over 95% for NTM combined with first-trimester serum biochemistry (Spencer, 1999; Spencer *et al*., 2000; Spencer *et al*., 2003). Studies from other countries also reported high uptake rates (Browner and Press, 1995; Jorgensen, 1995a; Press and Browner, 1998; Salonen and Ammala, 1997; Sanden and Bjurulf, 1988). However, uptake rates vary considerably across health care settings, even in the same region (Dormandy *et al*., 2002b).

Several studies that have been done to assess motivations concerning prenatal screening, focused solely on reasons for declining the screening test (Bennett *et al*., 1980; Berne-Fromell *et al*., 1984; Jorgensen, 1995b; Liamputtong *et al*., 2003; Sher *et al*., 2003). These studies reported religious and moral reasons as the main reasons for declining a screening test, as well the unreliability of the test. Some other studies examined only reasons for accepting prenatal screening (Browner and Press, 1995; Press and Browner, 1993; Roelofsen *et al*., 1993; Santalahti *et al*., 1998; Weinans *et al*., 2000). The most frequently mentioned reason in the majority of these studies was reassurance (see also Green *et al*., 2004).

Most of the above-mentioned studies were performed in countries where prenatal screening is part of customary prenatal care. Given the questions about informed choice in these countries, our study—which is performed in a situation where this screening is not a routine or implicit decision—offers a unique opportunity to investigate uptake and reasons for accepting or declining the screening offer in an unbiased way. According to the PSA, ministerial approval was needed for this study, since it involves offering prenatal screening.

The aim of this study is to assess the uptake of prenatal screening tests offered to an unselected population of pregnant women, and to assess how uptake differs across the background variables. The second aim of the study is to investigate reasons for either accepting or declining prenatal screening for congenital defects.

PATIENTS AND METHODS

Women attending one of 44 participating midwifery and gynaecology practices from May 2001 to May 2003 before 16 weeks' gestation were asked permission to be sent a research information letter and an informed consent form. Women who granted informed consent were randomized into one of two intervention groups or into the control group. Women in the first intervention group were offered the NTM, and women in the other randomization group were offered the MST. Participants in the control group received the customary care. As the NTM has to be performed in the first trimester of pregnancy, women whose first contact with their midwife or gynaecologist occurred later than 10 weeks into the pregnancy could be randomized solely in the MST group or the control group.

The test offer consisted of a sent-home booklet with information about the particular test, and an oral explanation by the woman's midwife or gynaecologist during a personal consultation. The following topics were covered in the information booklets: characteristics of DS and NTD (information about NTD was covered only in the MST booklet), age-specific risks of DS, population risk of NTD, procedure of the screening test, options available following a positive test result, and procedure of the diagnostic tests (amniocentesis and chorionic villus sampling). The last section of the booklet was entitled as follows: 'to decide whether or not to undergo the screening test'. This section listed some advantages and disadvantages of having the prenatal screening test done. The booklets were pilot-tested for clarity. Women who gave birth in the VU University Medical Center during the year preceding the start of the study ($n = 659$) were asked to read the booklet and fill in a questionnaire. Of these women, 368 (58%) returned the questionnaire. It appeared that the booklets were comprehensible and suitable to be used as information booklets in our study. After this pilot, the wording of the booklets was adapted in some areas. The oral explanation was standardized by means of a plasticized paper consultation guide, which covered the same topics as the information booklets as well as some counselling

guidelines. These guidelines included issues of non-directiveness: 'avoid giving your own opinion', 'it has to be the pregnant woman's own decision'. A separate visit to the hospital was required to have the screening test done.

Data collection took place using five questionnaires. For the present article, only data of the first three questionnaires were used. The first questionnaire was filled in before the pregnant women received the screening information booklet, and the second questionnaire was filled in after they had read the booklet and decided for or against prenatal screening, but (if applicable) before they received the result of the screening test. The third questionnaire was sent after receiving the result (or at a comparable point in time).

The first questionnaire contained questions about background variables such as age, education, parity, and religion. The second questionnaire contained open-ended questions in which participants were asked for their personal reasons (including a decisive one) for accepting or declining the prenatal screening offer. The third questionnaire asked whether participants had had the screening test done or not. Overall, these answers matched the official result forms. The self-reported test uptake rates were used in the analyses.

During the recruitment period, 4076 women were asked to participate in the study; 2978 (73%) women gave informed consent and returned the first questionnaire. Of these women, 74% ($n = 2203$) also filled in and returned the second questionnaire (after one reminder letter). The third questionnaire was returned by 1968 women. For the present article, only data of the respondents in the intervention groups were used ($n = 1399$). For analysis of non-response, all women who were asked to participate between September 2002 and January 2003 were sent a short questionnaire. Of these 259 women, 130 (50%) replied. It appeared that the main reason for not participating in the study was lack of time or lack of interest.

Analysis

Categories and sub-categories for given reasons for accepting or declining prenatal screening were created by the first author on the basis of a selection of hundred answers, and discussed by others (JHK, EG, DRMT). After some adaptations had been implemented, all answers were coded by three persons (MB, JHK, EG). At random, 20% of the answers were double-coded into the main categories by one of the authors (DRMT). The correspondence rate was 94%. Most non-corresponding codes were a result of a systematically different interpretation by the double-coder of the meaning of three of the 16 main categories. After some discussion, these differences in interpretation were resolved.

To compare the distributions of test uptake with respect to the background variables (age, education, parity, and religion), and with respect to the two different screening tests, χ^2 tests were used. Ordinal variables were analysed using a χ^2 test for trend (χ^2_{trend}). Multiple logistic regression was used for multivariate analysis.

Approvals

According to the Dutch Population Screening Act, the Minister of Health, Welfare, and Sports had to grant permission for this study to be performed. After receiving advice from the Health Council, the permission was granted (Health Council of the Netherlands: Committee on the Population Screening Act, 1999). The present study was also approved by the Ethical Committee of the VU University Medical Center.

RESULTS

To assess the representativeness of the sample, background variables (age, education, and parity) were compared with data of the general pregnant population in the Netherlands (Statistics Netherlands, 2004). The only relevant difference was that women in our sample had higher education levels (19 and 43% for the general pregnant population and our study sample respectively). The mean age of the participants was 31 years.

Uptake

The overall test uptake was 46%. Table 1 shows the distribution of acceptors and decliners for the two screening tests. Test uptake was significantly higher among women being offered the NTM compared to those being offered the MST ($\chi^2 = 32.4$, 1 df, $p < 0.001$). Table 2 shows that test uptake was significantly lower for women who reported being more actively religious and for women who were highly educated. Using a model that started with all four background variables, multiple logistic regression analysis revealed that the degree of religiosity and level of education remained significantly and independently associated with test uptake (see Table 3).

Reasons for accepting or declining the screening test

The mean number of reasons for accepting or declining prenatal screening that participants specified was 1.9. The test acceptors gave significantly fewer reasons compared to the test decliners (1.7 versus 2.0, $t = 7.5$, $p < 0.001$). The participants were also asked to give one

Table 1—Numbers of participating pregnant women accepting or declining the nuchal translucency measurement or the maternal serum test

	Accepted screening *n* (%)	Declined screening *n* (%)	Total *n*
NTM[a]	387 (53)*	342 (47)	729
MST[b]	254 (38)	416 (62)	670
Total	641	758	1399

[a] NTM, nuchal translucency measurement.
[b] MST: maternal serum screening test.
* $\chi^2 = 32.4$, $p < 0.001$.

Table 2—Background characteristics of the participating pregnant women who accepted or declined prenatal screening

	Total *n* (%)	Accepted screening *n* (%)	Declined screening *n* (%)
Age[a]			
<26	89 (7)	39 (44)	50 (56)
26–30	499 (37)	215 (43)	284 (57)
31–35	639 (47)	316 (50)	323 (50)
>35	123 (9)	49 (40)	74 (60)
		$\chi^2_{trend} = 0.54$, $p = 0.463$	
Number of children			
0	602 (43)	287 (48)	315 (52)
1	574 (41)	247 (43)	327 (57)
2	163 (12)	79 (49)	84 (51)
≥3	60 (4)	28 (47)	32 (53)
		$\chi^2_{trend} = 0.15$, $p = 0.701$	
Degree of religiosity[a]			
Actively	58 (4)	12 (21)	46 (79)
Somewhat actively	255 (18)	105 (41)	150 (59)
Not actively	412 (30)	213 (52)	199 (48)
Not religious	668 (48)	306 (46)	362 (54)
		$\chi^2_{trend} = 6.3$, $p = 0.012$	
Educational level[a]			
Low	165 (12)	95 (58)	70 (42)
Middle	616 (45)	280 (46)	336 (54)
High	579 (43)	244 (42)	335 (58)
		$\chi^2_{trend} = 10.1$, $p = 0.001$	

[a] The totals of age, degree of religiosity, and educational level do not add up to 1399 because of missing values on these questions.

Table 3—Multiple logistic regression analysis: two significant factors associated with test uptake

	OR	95% CI	
Degree of religiosity			$p < 0.001$
Not religious	1.00		
Not actively	1.29	1.00–1.66	
Somewhat actively	0.82	0.61–1.11	
Actively	0.34[a]	0.17–0.65	
Educational level			$p = 0.005$
Low	1.00		
Middle	0.61[a]	0.42–0.87	
High	0.55[a]	0.38–0.78	

[a] significant at 0.01 level.

decisive reason, but 45% of the test acceptors and 33% of the test decliners failed to give a decisive reason. The respondents either did not fill in this question, or they indicated that there was not one decisive reason. So, the numbers of participants giving a decisive reason are as follows: 353 (55% of 641) acceptors and 500 (66% of 758) decliners. Women's (decisive) reasons for accepting or declining prenatal screening are shown in Table 4 and 5 respectively.

There were no differences in frequencies of decisive reasons between the NTM group and the MST group, except for the category 'research/science' with regard to the acceptors (3% versus 13%, $\chi^2 = 12.4$, 1 df, $p < 0.001$) and the category 'unfavourable test characteristics of the screening test' with regard to the decliners (17% versus 26%, $\chi^2 = 5.9$, 1 df, $p < 0.05$)

Table 4—Reasons to accept the offer of a prenatal screening test

Reasons to accept screening	One of the reasons ($n = 641$) %	Decisive reason ($n = 353$) %
Gaining knowledge/curiosity	50	29
Favourable characteristics of screening test	18	15
Increased risk (age, family history)	15	12
Research/science	13	7
Reassurance	8	4
Wanting a healthy child	5	5
Reasons against testing	21	6
Other	36	21

Table 5—Reasons to decline the offer of a prenatal screening test

Reasons to decline screening	One of the reasons ($n = 758$) %	Decisive reason ($n = 500$) %
Unfavourable characteristics of screening test	42	22
Anxiety/uncertainty	36	13
Not applicable/not necessary	35	12
Adverse characteristics of invasive test	32	11
Against abortion	15	13
Acceptance/destiny	16	10
Reasons in favour of testing	17	12
Other	7	6

Test acceptors

The most frequently mentioned reason for accepting a screening offer was 'gaining knowledge about the health of the foetus' (50 and 39% as decisive reason). This category included sub-categories such as 'I just want to know whether or not the child has Down syndrome', 'I want more certainty about the health of the foetus', and 'It's just out of curiosity'. Of the women who accepted the screening offer, 18% mentioned that they did so because of the favourable test characteristics (15% as decisive reason). This category consisted of two subcategories: 'The test does not involve any risk', and 'There's no harm in trying'. Another group (15 and 12% as decisive reason) decided to have the screening test done because (they thought) they had an increased risk of having a child with congenital defects, either because of their age or because of family history. Reassurance was mentioned by 8% of the women. The 'Other' category involved reasons such as 'to be prepared' and

'the ability to make a better choice concerning invasive diagnostic testing'.

Test decliners

The main reasons for declining a screening test were 'unfavourable characteristics of the screening test' (42%), 'anxiety/uncertainty' (36%), 'not applicable/not necessary' (35%), and 'adverse characteristics of the invasive tests' (32%). Almost a quarter of all women mentioned 'unfavourable characteristics of the screening test' as their decisive reason for refusing prenatal screening. This reason contained three sub-categories: 'It is just a calculation of probability', 'The test gives no certainty', and 'The test is not reliable'. Another important reason concerned the feeling in women that screening causes anxiety and uncertainty. The three most frequent sub-categories were 'I do not want to become unnecessarily anxious', 'The test result will make me uncertain and anxious', and 'I am afraid of a positive test result'. Relevant sub-categories within the group of women who considered screening as 'not applicable' or 'not necessary' were 'I am not in a risk group' and 'I have already done a prenatal test'. The fourth main reason women gave was coded as 'adverse characteristics of invasive tests'. This category included the following sub-categories: 'I will not do diagnostic testing because of the risk of miscarriage that is involved' and 'I do not want to make a possibly difficult decision'.

Among the reasons for declining the screening test, two ethical reasons could be discerned: women who were opposed to selective abortion (15%), and women who see the health status of the baby as destiny or fate, and would accept the child anyway (16%). This last reasoning included the following sub-categories: 'The child is welcome, whether it is disabled or not' and 'I want nature to take its course'.

Ambivalence in reasoning

Of the test accepters, 21% also mentioned reasons against prenatal screening, in addition to reasons in favour of prenatal screening (Table 4). The most frequently mentioned reasons were 'adverse characteristics of invasive test', and 'anxiety/uncertainty'. On the other hand, 17% of the women who declined the screening offer also mentioned reasons in favour of screening (Table 5). The contra-reasons among test decliners included 'gaining knowledge/curiosity', 'increased risk of having a child with DS', and 'favourable characteristics of the screening test'.

DISCUSSION

The overall uptake of prenatal screening for congenital defects was 46%. This is considerably lower than most other studies report. Some studies presented uptake rates of 90% and above (Spencer *et al*., 2003). These differences in uptake are probably related to the different situation in the Netherlands compared to other countries. Generally in the Netherlands, prenatal care is not considered as something 'medical', and the natural character of pregnancy is highly valued (Roelofsen *et al*., 1993). This is evident not only from the high rate of home deliveries and the low rate of epidural analgesia during labour in the Netherlands but also from the fact that prenatal screening is not part of customary care. Consequently, accepting the screening test offer is not a routine decision for Dutch pregnant women. These factors might account for the relatively low uptake rates of prenatal screening. Nevertheless, two Dutch studies did report high uptake rates of around 80% (Kamerbeek *et al*., 1993; Muller *et al*., 2002). The study of Kamerbeek *et al*. was performed in a particular region of the Netherlands, where prenatal screening was offered routinely even though this is not allowed formally. In contrast to our study, in the study of Muller *et al*., no separate visit was required to have the screening test done. Dormandy *et al*. have shown that higher uptake of serum screening was seen at hospitals that offered the test as part of a routine visit than at those where screening required a separate visit (Dormandy *et al*., 2002a, b). It might be that prenatal screening as part of a routine visit stimulates test uptake without giving too much thought to it (Press and Browner, 1997; Tymstra *et al*., 1991). However, it could also reflect barriers to testing incurred by requiring a separate visit (Dormandy *et al*., 2002a).

In our study, uptake rates of 53% for the NTM and 38% for the MST were found. Because there were hardly any differences in given reasons between the two groups, other factors may be relevant in explaining these different uptake rates. It might be related to the fact that the NTM is performed by ultrasound scanning, resulting in the visualization of the foetus, which is often seen as an advantage of this screening test. In general, pregnant women consider ultrasound examination as a benign procedure, allowing them to see their baby, and they attach positive value to being able to see it (Baillie *et al*., 1999; Green and Statham, 1996; Ritchie *et al*., 2004). Another contributing factor could be women's preferences for screening in the first trimester of pregnancy (NTM) compared to screening in the second trimester (MST) (de Graaf *et al*., 2002; Kornman *et al*., 1997).

The three most frequently mentioned reasons for accepting the screening test offer (obtaining knowledge, good test characteristics, increased risk) did not include reassurance. However, other studies (Santalahti *et al*., 1998; Browner and Press, 1995; Roelofsen *et al*., 1993) reported reassurance as the most important reason for having a screening test done. This might be due to a difference in information given in the booklet women received, or in the counselling by their midwife or gynaecologist. In our study, participants received well-balanced information about the pros and cons of the screening tests, while this may not always be the case in countries where prenatal screening is part of customary prenatal care. Consequently, it could be that women participating in our study were more aware of the fact that a screening test is not able to give reassurance by itself, since it provides merely a risk estimation.

Two of the main arguments for declining the screening test offer (mentioned by three quarters of the participants) were linked to disadvantageous test characteristics. The unfavourable characteristic of the screening tests is that they provide only a risk estimation, and cannot give certainty. On the other hand, a risk of induced miscarriage of the foetus is inherent in diagnostic testing. Women specifying one of these reasons were not opposed to prenatal screening in general, and did not consider it problematic to know the health status of their baby, but they basically said 'the test isn't good enough', or they just did not want to put their baby at risk. These data suggest that many pregnant women will make a different decision when a risk-free screening test providing a certain diagnosis is available. Accordingly, we expect higher uptake rates in the future when better screening tests will have been developed.

Of the women, 23% mentioned reasons against screening that could be interpreted as ethical in nature. This percentage is considerably lower than reported by Sher *et al*. (2003). Cultural and religious differences may be responsible for this difference. Furthermore, it might be due to the fact that at the time the study by Sher *et al*. was carried out, screening had already become widely accepted. In such a situation, declining prenatal screening may mainly be based on strong moral values. Again, the well-balanced information booklets may also play a part here.

Over 25% of the women also gave reasons in support of the opposite decision option. On the one hand, this could be an indication of ambivalence: the choice of whether or not to screen is not a clear-cut decision, but rather one that is imbued with mixed feelings. In this case, these women need to be given special attention during the counselling process. On the other hand, it may also be an indication of someone balancing the pros and cons of a decision. In this situation, giving opposite reasons might be a sign of a rational, informed decision (Bekker *et al*., 2003).

To conclude then, offering prenatal screening in a context where it is not part of routine prenatal care resulted in lower uptake rates and different reasons for accepting or declining such a screening test than in a situation in which screening is offered routinely. This raises the question as to what extent a high uptake rate involves a high number of informed choices. Are all test acceptors making considered, deliberate decisions?

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REFERENCES

Baillie C, Hewison J, Mason G. 1999. Should ultrasound scanning in pregnancy be routine? *J Reprod Infant Psychol* **17**: 149–157.

Bekker HL, Hewison J, Thornton JG. 2003. Understanding why decision aids work: linking process with outcome. *Patient Educ Couns* **50**: 323–329.

Benn PA. 2002. Advances in prenatal screening for Down syndrome: I. General principles and second trimester testing. *Clin Chim Acta* **323**: 1–16.

Bennett MJ, Gau GS, Gau DW. 1980. Womens attitudes to screening for neural-tube defects. *Br J Obstet Gynaecol* **87**: 370–371.

Berne-Fromell K, Josefson G, Kjessler B. 1984. Who declines from antenatal serum alpha-fetoprotein screening–and why? *Acta Obstet Gynecol Scand* **63**: 687–691.

Browner CH, Press N. 1995. The normalisation of prenatal diagnostic screening. In *Conceiving the New World Order: The Global Politics of Reproduction*. Ginsburg FD, Rapp R (eds). University of California Press: Los Angeles; 307–322.

de Graaf IM, Tijmstra T, Bleker OP, van Lith JM. 2002. Womens' preference in Down syndrome screening. *Prenat Diagn* **22**: 624–629.

Dormandy E, Hooper R, Michie S, Marteau TM. 2002a. Informed choice to undergo prenatal screening: a comparison of two hospitals conducting testing either as part of a routine visit or requiring a separate visit. *J Med Screen* **9**: 109–114.

Dormandy E, Michie S, Weinman J, Marteau TM. 2002b. Variation in uptake of serum screening: the role of service delivery. *Prenat Diagn* **22**: 67–69.

Green JM, Hewison J, Bekker HL, Bryant LD, Cuckle HS. 2004. Psychosocial aspects of genetic screening of pregnant women and newborns: a systematic review. *Health Technol Assess* **8**: 1–124.

Green JM, Statham H. 1996. Psychosocial aspects of prenatal screening and diagnosis. In *The Troubled Helix: Social and Psychological Implications of the New Genetics*. Marteau TM, Richards M (eds). Cambridge University Press: Cambridge; 140–163.

Health Council of the Netherlands: Committee on the Population Screening Act. 1996. Population screening act: the assessment of permit applications, 1996/09WBO. The Hague, Health Council of The Netherlands.

Health Council of the Netherlands: Committee on the Population Screening Act. 1999. Population screening act: prenatal screening and risk perception, 1999/04WBO. The Hague, Health Council of the Netherlands.

Health Council of the Netherlands. 2001. Prenatal screening: Down's syndrome, neural tube defects, routine-ultrasonography, 2001/11. The Hague, Health Council of the Netherlands.

Jorgensen FS. 1995a. Attitudes to prenatal screening, diagnosis and research among pregnant-women who accept or decline an alpha-fetoprotein test. *Prenat Diagn* **15**: 419–429.

Jorgensen FS. 1995b. Declining an alpha-fetoprotein test in pregnancy, why and who? *Acta Obstet Gynecol Scand* **74**: 3–11.

Kamerbeek LI, Roelofsen EE, Beekhuis JR, Tijmstra T, Mantingh A. 1993. How women cope with the results of maternal serum screening for fetal neural tube defects and Down syndrome? *Ned Tijdschr Geneeskd* **137**: 1308–1311.

Kornman LH, Wortelboer MJ, Beekhuis JR, Morssink LP, Mantingh A. 1997. Women's opinions and the implications of first- versus second-trimester screening for fetal Down's syndrome. *Prenat Diagn* **17**: 1011–1018.

Liamputtong P, Halliday JL, Warren R, Watson LF, Bell RJ. 2003. Why do women decline prenatal screening and diagnosis? Australian women's perspective. *Women Health* **37**: 89–108.

Markens S, Browner CH, Press N. 1999. 'Because of the risks': how US pregnant women account for refusing prenatal screening. *Soc Sci Med* **49**: 359–369.

Marteau TM, Dormandy E, Michie S. 2001. A measure of informed choice. *Health Expect* **4**: 99–108.

Muller MA, Pajkrt E, Bilardo CM. 2002. Ultrasound screening for Down's syndrome early in pregnancy: nuchal translucency thickness. *Ned Tijdschr Geneeskd* **146**: 793–798.

Nicolaides KH, Heath V, Cicero S. 2002. Increased fetal nuchal translucency at 11–14 weeks. *Prenat Diagn* **22**: 308–315.

Pajkrt E, van Lith JMM, Mol BWJ, Bleker OP, Bilardo CM. 1998. Screening for Down's syndrome by fetal nuchal translucency measurement in a general obstetric population. *Ultrasound Obstet Gynecol* **12**: 163–169.

Press NA, Browner CH. 1993. Collective fictions—similarities in reasons for accepting maternal serum alpha-fetoprotein screening

among women of diverse ethnic and social-class backgrounds. *Fetal Diagn Ther* **8**: 97–106.

Press N, Browner CH. 1997. Why women say yes to prenatal diagnosis? *Soc Sci Med* **45**: 979–989.

Press N, Browner CH. 1998. Characteristics of women who refuse an offer of prenatal diagnosis: Data from the California maternal serum alpha fetoprotein blood test experience. *Am J Med Genet* **78**: 433–445.

Ritchie K, Boynton J, Bradbury I, *et al*. 2004. Routine ultrasound scanning before 24 weeks of pregnancy. Health Technology Assessment Report 5. NHS Quality Improvement Scotland: Glasgow.

Roelofsen EEC, Kamerbeek LI, Tymstra TJ. 1993. Chances and choices. Psycho-social consequences of maternal serum screening. A report from The Netherlands. *J Reprod Infant Psychol* **11**: 41–47.

Salonen R, Ammala P. 1997. Prenatal diagnosis in Finland. *Eur J Hum Genet* **5**: 22–25.

Sanden ML, Bjurulf P. 1988. Pregnant womens attitudes for accepting or declining a serum-alpha-fetoprotein test. *Scand J Soc Med* **16**: 265–271.

Santalahti P, Aro AR, Hemminki E, Helenius H, Ryynanen M. 1998. On what grounds do women participate in prenatal screening? *Prenat Diagn* **18**: 153–165.

Sher C, Romano-Zelekha O, Green MS, Shohat T. 2003. Factors affecting performance of prenatal genetic testing by Israeli Jewish women. *Am J Med Genet Part A* **120A**: 418–422.

Smeenk ADJ, ten Have HAMJ. 2003. Medicalization and obstetric care: An analysis of developments in Dutch midwifery. *Med Health Care Philos* **6**: 153–165.

Spencer K. 1999. Second trimester prenatal screening for Down's syndrome using alpha-fetoprotein and free beta hCG: a seven year review. *Br J Obstet Gynaecol* **106**: 1287–1293.

Spencer K, Spencer CE, Power M, Dawson C, Nicolaides KH. 2003. Screening for chromosomal abnormalities in the first trimester using ultrasound and maternal serum biochemistry in a one-stop clinic: a review of three years prospective experience. *Br J Obstet Gynecol* **110**: 281–286.

Spencer K, Spencer CE, Power M, Moakes A, Nicolaides KH. 2000. One stop clinic for assessment of risk for fetal anomalies: a report of the first year of prospective screening for chromosomal anomalies in the first trimester. *Br J Obstet Gynaecol* **107**: 1271–1275.

Statistics Netherlands. 2004. Statistics Netherlands. www.cbs.nl. date of access: 23-03-2004.

Tymstra TJ, Bajema C, Beekhuis JR, Mantingh A. 1991. Women's opinions on the offer and use of prenatal diagnosis. *Prenat Diagn* **11**: 893–898.

Weinans MJN, Huijssoon AMG, Tymstra T, Gerrits MCF, Beekhuis JR, Mantingh A. 2000. How women deal with the results of serum screening for Down syndrome in the second trimester of pregnancy? *Prenat Diagn* **20**: 705–708.