



Inequalities in Obstetric Care

A mixed method approach in a multi-ethnic population

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Artwork on the cover: 'Ciranda Sophia' 100x140cm Oil on Linen 2008. The Ciranda dancers are free and unconstrained; they turn, twirl, jump and stretch. There is no beginning and no end to their movement. Their energy is captured in this moment: celebrating who they are!

About the artist: Júlia dos Santos Baptista was born and raised in Brasília, the capital of Brazil. She currently lives and works in The Netherlands and Brazil. Júlia's work reflects on universal themes such as urbanization, cultural roots and social relevancy. Júlia believes that art and science stimulates the dialogue and enables us to recognize and pass on the very best that life has to offer to our children. www.juliadossantosbaptista.com

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Inequalities in Obstetric Care

A mixed method approach in a multi-ethnic population

Ongelijkheden in de geboortezorg

Mixed methods-onderzoek in een multi-etnische populatie

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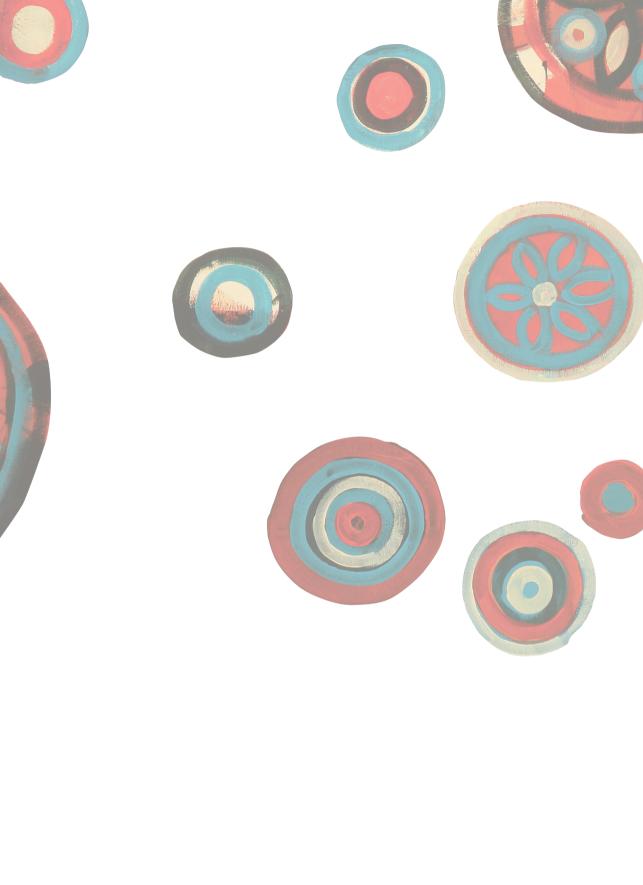
CONTENT

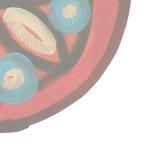
Chapter 1	General introduction	11
PART I	SATISFACTION WITH CARE, INEQUALITIES IN USE AN PROVISION OF ANTENATAL AND MATERNITY CARE IS MULTI-ETHNIC POPULATION	
Chapter 2	Satisfaction with obstetric care in a population of low-educated native Dutch and non-western minority women Peters IA, Posthumus AG, Steegers EAP, Denktaş S. Submitted for publication.	27
Chapter 3	Ethnicity and language proficiency differences in provision and of intentional use of prenatal screening Peters IA, Heetkamp KM, Ursem NTC, Steegers EAP, Denktaş, Knapen MFCM. Maternal and Child Health Journal. 2018;22(3):343-354.	57
Chapter 4	Inequalities in uptake of prenatal screening according to ethnicity and socio-economic status in the four largest cities of the Netherlands (2011-2013) Posthumus AG, Peters IA, Borsboom GJJM, Bonsel GJ. Prenatal Diagnosis. 2017; 37(10): 959-967.	85
Chapter 5	Having an unwanted pregnancy and being illiterate are strongly associated with a first antenatal visit after the first trimester: results from a prospective cohort study. Heetkamp KM, Peters IA, Steegers EAP, Bertens L, Knapen MFCM. Submitted for publication.	103

PART II PERFORMANCE ASSESSMENT OF PRENATAL COUNSELLING AND FETAL ANOMALY SCAN

Chapter 6	Novel quality assessment method for the health educational component of counselling about prenatal screening	121
	Peters IA, Reijerink-Verheij JCIY, Knapen MFCM, Ursem NTC.	
	Submitted for publication.	
Chapter 7	An audit of second-trimester fetal anomaly scans based on a novel image-scoring method in the Southwest region of the Netherlands	141
	Ursem NTC, Peters IA, Kraan-van der Est MN, Reijerink-Verheij JCIY, Knapen MFCM, Cohen–Overbeek TE.	
	Journal of Ultrasound in Medicine. 2017; 36: 1171-1179.	
PART III	IMPROVING INFORMED DECISION MAKING (IDM),	
	HEALTHCARE KNOWLEDGE AND HEALTHY BEHAVIO	UR
Chapter 8	Reproductive health peer education for multicultural target groups	163
	Peters IA, Schölmerich VLN, van Veen DW, Steegers EAP, Denktaş S.	
	Journal of Multicultural Education. 2014;8(3):162–78.	
Chapter 9	Effect of culturally competent educational films about prenatal screening on informed decision making of pregnant women in the Netherlands	183
	Peters IA, Posthumus AG, Reijerink-Verheij JCIY, Knapen MFCM, Denktas S.	
	Patient Education and Counseling 2017: 100 (4) 780-786.	

Chapter 10	General discussion	205
Addendum	Summary	229
Addendum	Summary	229
	Samenvatting	235
	Authors and affiliations	241
	List of publications	243
	PhD portfolio	249
	About the author	253
	Dankwoord	255









General introduction







GENERAL INTRODUCTION

From the moment of birth, and ideally from the moment of conception, all human beings have the fundamental right to receive the highest level of healthcare. This right is consolidated in the Dutch law and has a strong anchorage with the legislative framework of the international human rights treaties. Since 1980 the issue of health inequalities has been on the political agenda in the Netherlands. The agenda setting and national policy was mainly aimed at the behavioral change of Dutch citizens in order to improve individual and general health in able to avoid and decrease health inequalities in Dutch society. These policy programs were mainly focused on targeted so-called high risk groups such as youth, citizens living in deprived areas, and immigrants. Despite these policies health disparities still exist. 4

Health inequalities are also present in the Dutch antenatal and maternity healthcare setting. There are disparities noticeable in the *provision of care, healthcare utilization* and *healthcare outcomes* in terms of perinatal morbidity and mortality.

Provision of care: inadequate provision of antenatal care may also play a role in these adverse perinatal outcomes. Communication and socio-economic problems, suboptimal health literacy, lack of knowledge about the antenatal and maternity care system, and substantive differences in expectations between care provider and patient about used language (proficiency, use of professional or relative interpreter), cultural competence of the prenatal care provider and the type of care provided can cause insufficient provision of antenatal and maternity care.^{5, 6}

Healthcare utilization: especially Dutch women with an non-western immigrant and a low socio-economic status background have to deal with limited access to antenatal and maternity healthcare. The quality of the provided antenatal and maternity care in terms of responsiveness, the way individuals are treated, and the environment in which they are treated during health system interactions, determines access to and utilization of care. The existing cultural competence of the antenatal and maternity care system can also play a decisive role in the access and quality of care. Before

In the Netherlands, non-western pregnant women make inadequate use of antenatal care (e.g. concerning a delayed first antenatal visit and a lower frequency of antenatal care consultations) twice as often in comparison to pregnant women with a native Dutch background. Pregnant women with a low social economic status background experienced the same aforementioned difficulties concerning care utilization. He most frequently reported impeding factors for healthcare utilization are insufficient periconceptional and prenatal prevention, lack of knowledge about general hygiene and the healthcare system, and poor language proficiency. 12, 14

Healthcare outcomes: perinatal mortality was substantially higher in the Netherlands compared to other European countries.^{17, 18} Especially nonmedical characteristics of

pregnant women, such as non-western ethnicity and a low Social Economic Status (SES) background, have been negatively associated with perinatal morbidity and mortality. $^{18,\,19}$

What is already known

The practice of antenatal and maternity care and scientific research within a multiethnic population has already provided valuable insights so far. A lot is already known about determinants known to be associated with healthcare provision, the effect of health education interventions, healthcare utilization and women's experiences with antenatal and maternity care.

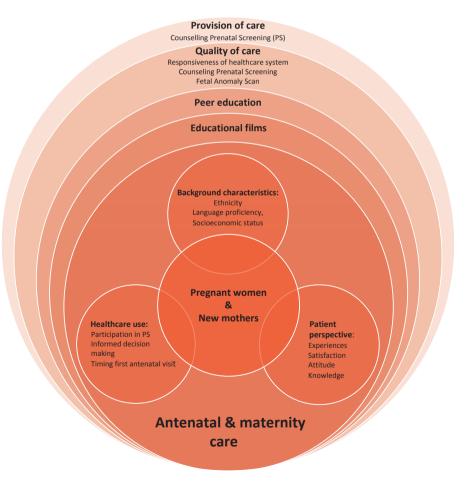


Figure 1.1 Exploring antenatal and maternity care provision and utilization in a multi-ethnic population

Figure 1 shows the research context of this thesis. Its various elements and figure composition were derived from and based on previous findings in this field. A summary of these findings will follow below. In the center of the figure the pregnant woman/new mother is shown surrounded by the characteristic background, use of healthcare and variable opinions that have been researched for this thesis. They are embedded in the measured components of the provision of antenatal and maternity care, such as the quality of care and healthcare interventions.

Provision of antenatal care

Individual characteristics, for example age, gender, educational level, ethnicity, level of knowledge (health literacy), and the attitude towards specific subjects concerning both immigrant women and care providers, influence the provision of antenatal and maternity care. ^{6,13,20-23}

The Dutch prenatal screening program consists of *counselling* for screening for Down's, Edwards' and Patau's syndrome, the screening of structural fetal anomalies, and the actual execution of the prenatal screening tests, namely the first trimester combined test, Non Invasive Prenatal Test (NIPT) (since April 2017), and the second trimester fetal anomaly scan. Several studies underline the fact that information provision about prenatal screening, consisting of prenatal counseling and providing leaflets only, is not sufficient for pregnant women with a non-western immigrant and low social economic status background.^{24, 25} These women more frequently make an insufficiently informed decision concerning participation in an antenatal screening.²⁶ Previous research calls for improvements in the information provision procedure of prenatal screening when it comes to used information materials and bridging language proficiency, culture, religious and health illiteracy barriers.^{23,27-29}

A small part of research in this thesis elaborates on the puerperium. Therefore, also information about the provision of maternity care within a multi-ethnic women's population is provided. Sufficient communication, consistent information, continuity of care, trust in the relationship with the new mother and her social network all are important components to increase quality of maternity care for a new mother with an immigrant background. ^{8, 21, 30, 31}

Previous research shows that the absence of language proficiency, a low educational level, health illiteracy, differences in expectations and limited trust between pregnant women and the care provider as well as short medical consultations can lead to miscommunications with pregnant women with an immigrant background.^{32, 33} The antenatal care providers experience the use of the professional interpreter as the most successful means to be able to explore the health situation of the pregnant women that have a low language proficiency level and the most effective way to provide adequate

care in terms of objective communication and to create the possibility to discuss sensitive and complex subjects. ^{6, 34}

In the maternity care setting the social network of the new mother with an immigration background can play a dominant role in the communication with the patient. Often, the social network gives well intended and harmless support, advice and information which might partially be based on cultural and religious beliefs, but can sometimes lead to health risks for mother and child. Of the new mother with an immigration background can play a dominant role in the communication with the patient.

Health education interventions

Previous research shows that the level of general knowledge about health, diseases and healthcare is lower in women with an immigrant background in comparison with native women. There is especially a low level of knowledge concerning the Dutch system of antenatal and maternity care among this segment of the population, which can result in limited access to antenatal and maternity care, as well as utilization problems. The effectiveness of health education in relation to antenatal and maternity care can be increased when peers are involved and when the content and organizational format is adjusted to the whole obstetric care chain. The results of a Dutch health educational project for immigrant women shows that these women especially have the need for health education about pregnancy and genetics. Adjusting health education to the health literacy level of the participant, verbal and non-verbal communication, and individual culture and religious values of the participant, can contribute to a positive effect of health education for immigrant target groups.

Healthcare utilization

Pregnant women with a non-western, first generation, immigrant background, are ,'too late' (\geq 11 weeks gestational age) for their first antenatal visit, which is three times as often than is the case for native Dutch women, and one and a half times as often as second generation immigrant women. ^{11, 39, 40} Non-medical determinants such as a limited or absent Dutch language proficiency level, a first immigrant generation background, a relatively young age, a low educational attainment level, and living in a highly urban area, are factors associated with a late antenatal start. ³⁹

For pregnant women with a first generation immigrant background demographic, pregnancy-and socio-economic factors such as having a young age, an unplanned pregnancy, an adverse previous pregnancy outcome, a low socio-economic status, and the absence of a healthcare insurance play a role in the inadequate use of antenatal care. ^{11, 41} Responsiveness of healthcare factors that influence the use of antenatal care are the organization of care (location and setting), the role of the various care providers (general practitioners, midwives, gynecologists), how appointments can be made and the means of communication. ^{20, 42}

An existing language barrier between the antenatal or maternity care provider and the patient does not automatically lead to healthcare utilization problems.⁴² A possible migration background of pregnant women and new mothers has a more determining effect on the use of antenatal and maternity care than the existing language barriers. ^{6, 12} Cultural factors may also influence the use of antenatal and maternity care, such as convictions concerning health and provided healthcare, related rituals and behavior, culturally determined family dynamics, as well as the religious and cultural beliefs of the women and their social network. 12, 20, 27 More specific, having a non-western immigrant background often is associated with a lower uptake for the combined test when compared to native Dutch pregnant women. ^{26, 43, 44} Religious (Islamic / Protestant Christian) pregnant women and women with a low language proficiency level have a lower uptake rate for the Fetal Anomaly Scan. 43-45 Also differences exist in the use of maternity care, comparing new mothers with a non-western immigrant background with western immigrant women and women with a Native Dutch background. Women with a non-western immigrant background and / or a low socio-economic status less frequently make use of maternity care at home and use fewer maternity care hours. 16,46,47

Experiences with antenatal and maternity care

The analysis concerning responsiveness of the Dutch perinatal care services from the women's perspective shows that' client orientation' components, for instance *choice* and continuity, prompt attention, quality of basic amenities and social consideration need improvements to positively facilitate the provision of antenatal and maternity care. This discovery shows a similarity with other international research, which can be explained by the difficulty to conduct changes in the organization of care required for 'client orientation' domains. On the difficulty to conduct changes in the organization of care required for 'client orientation' domains.

AIMS OF THIS THESIS

The aim of this thesis is to increase insight in the existing adjustment of obstetric care with the healthcare utilization needs of the Dutch multi-ethnic reproductive women's population and to propose strategies that can contribute to enhancing the provision and utilization of care within this population. This thesis addresses this aim in three parts:

- Part I *Aim:* to investigate the level of satisfaction concerning obstetric healthcare, inequalities in use and provision of care related to antenatal and maternity healthcare in a multi-ethnic women's population.
- Part II Aim: to assess the quality of counseling in relation to prenatal screening and the ultrasound fetal anomaly scan which is made in the second trimester.

Part III Aim: to evaluate interventions that have the goal to improve informed decision making, healthcare knowledge, and healthy behavior.

These aims have been translated into the following research questions:

- What is the level of satisfaction with antenatal, birthing and maternity care of multiethnic and overall low social-economic status urban women in Rotterdam?(Part I, chapter2)
- 2. What inequalities exist in the information provision procedure of prenatal screening, uptake of prenatal screening according to ethnicity, language proficiency and socio-economic status in the urban areas of the Netherlands? (Part I, chapter 3 and 4)
- 3. Which maternal determinants and self-reported reasons are associated with delay in timing of the first antenatal visit of pregnant women that receive an information offer about prenatal screening? (Part I, chapter 5)
- 4. Which quality assessment methods can contribute to a standardized, easy to reproduce and reliable quality assessment counseling concerning prenatal screening and the second-trimester ultrasound fetal anomaly scan? (Part II, chapter 6 and 7)
- 5. Which interventions can contribute to improvement of knowledge about antenatal and maternity care, healthy behavior and informed decision making about participation in prenatal screening? (Part III, chapter 8 en 9)

OUTLINE OF THIS THESIS

This thesis is structured by the three before mentioned aims.

Part I addresses the investigation of satisfaction and inequalities of use and provision of care related to antenatal and maternity healthcare in a multi-ethnic women's population. Chapter 2 describes the satisfaction with antenatal, birthing and maternity care of low-educated native Dutch and non-western minority urban women. Chapter 3 gives an overview of the existing associations between the information provision procedure of prenatal screening for Down's syndrome and congenital anomalies in the Netherlands and the intention to participate in prenatal screening of ethnic groups and Dutch language proficiency groups. Chapter 4 presents the existing inequalities in uptake of prenatal screening according to ethnicity and socio-economic status in the urban areas of the Netherlands. The first part of this thesis is completed by Chapter 5 which describes the association between maternal determinants and self-reported reasons for delay in timing of the first antenatal visit of pregnant women that get an information offer about prenatal screening.

Part II focusses on the assessment of the quality of antenatal care performances of counseling about prenatal screening and the second-trimester ultrasound fetal anomaly scan. **Chapter 6** presents a reproducible and reliable study of a new developed assessment method counselling for prenatal screening for the assessment of the health educational part of a counselling session. The following **Chapter 7** shows the scanning performance of all sonographers in the southwestern region of the Netherlands using a standardized image-scoring method.

The final *part III* of the thesis consists of an evaluation of interventions improving informed decision making, healthcare knowledge and healthy behavior. **Chapter 8** describes which recruitment method is the most successful to reach specific disadvantaged target groups for Reproductive Health Peer Education. It also shows the effect of Reproductive Health Peer Education on knowledge about perinatal health within a multi-ethnic participant population. The final chapter of part III, **Chapter 9** presents a study which aims to evaluate the effect of a culturally competent educational film on informed decision making regarding prenatal screening in a multi-ethnic pregnant women's population.

To complete this thesis, **Chapter 10** provides a summary of the main findings, methodological considerations and implications for the provision of antenatal and maternity care and policy making in this field.

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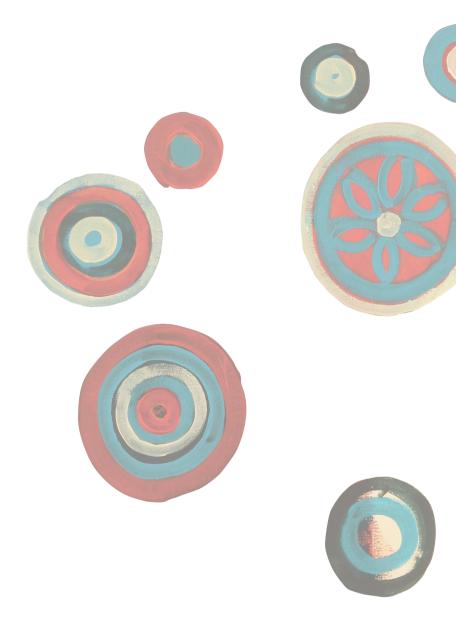
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PART I

Satisfaction with care, inequalities in use and provision of antenatal and maternity care in a multi-ethnic population





Ethnicity and language proficiency differences in provision and of and intentional use of prenatal screening for Down's syndrome and congenital anomalies. A prospective, non-selected, register-based study in the Netherlands.

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ABSTRACT

Objective: we aimed to conduct an analysis of the associations between the information provision procedure of prenatal screening for Down's syndrome and congenital anomalies and the intention to participate in prenatal screening (PS) of ethnicity groups and Dutch language proficiency groups.

Design: using a prospective web-based registration form, we asked counselors (midwives, general practitioners, nurses and gynecologists) to report whether and how they offered information about PS to pregnant women.

Duration: the study was conducted from 2008 to 2010. Participants We collected data on the characteristics of the women who received an information offer about PS from counselors.

Measurements: measures included socio-demographic and language proficiency level (LPL) characteristics, key elements of the provision procedure of PS, and intentional participation in PS.

Findings: the dataset represents 37% of the total population in the study area. Women with a non-native Dutch background and/or insufficient Dutch LPL received fewer information offers about PS, faced a reduced chance of receiving counseling, and showed lower intentional participation rates for PS.

Key Conclusions: women with a nonnative Dutch background and/or with an insufficient LPL are underserved in the Dutch PS program. These findings present evidence indicating that the fundamental principle of the Dutch Population Screening Act, namely, equal access to PS for all pregnant women, is not being realized.

Implications for Practice: therefore, the study findings are important for national and international healthcare, policy makers and governmental professionals to allow ethnic and LPL-related differences in the provision and intentional uptake of PS.

Significance

What is already known on this topic? Several studies have shown that there are disparities in Dutch prenatal screening (PS). Ethnic minority groups are less likely to make an informed decision and participate in antenatal care due to the existence of possible language, cultural, and religious barriers; health illiteracy; being relatively underserved in terms of health services; and the absence of culturally sensitive information within the health services.

What does this study add? This study shows that pregnant women with a non-native Dutch background and/or with insufficient Dutch language proficiency (LPL) are underserved more often within the Dutch PS program. These women are less likely to receive an information offer about PS and to receive counseling. The Population

3

Screening Act 'prenatal screening' calls for equal access to the program. Therefore, these study findings are important for healthcare practitioners, policy makers and governmental professionals.

INTRODUCTION

Since 2007, a nationwide prenatal screening program was introduced in the Netherlands. The program is supported by a legislative framework (the Population Screening Act), providing standards for regional and nationwide coordination and quality assessment of prenatal screening. The Screening Act calls for equal access to the program for all pregnant women. According to this act, pregnant women who indicate that they require information should be counseled on the first trimester combined test (CT) for Down's syndrome and the second trimester fetal anomaly scan (FAS) for congenital anomalies. 1-3 The aim of offering counseling is to foster informed decision making (Marteau et al. 2001). For an overview of the Dutch prenatal screening program, see Fig. 3.1. International differences in screening policies (for example, CT as an extra option in the Netherlands or as part of routine care in other countries) have affected the provision procedures and, therefore, the informed decision making and the uptake of CT among women. 5-8 In the Netherlands, advanced maternal age-related risk perception, the financial threshold for younger women for the CT (until 2014) and the relatively positive attitude towards Down's syndrome are likely to have a negative effect on CT uptake. 9, 10 The FAS is considered standard care by non-Dutch pregnant women, which possibly influences the current participation rate, which is comparable with that of the native Dutch population (89 vs. 90%, respectively, during the Deliver study 2009–2011). 11, 37 The legislative framework of the Dutch prenatal screening program prescribes that all pregnant women, regardless of their ethnic background or Dutch language proficiency, must have equal access to the prenatal screening program. Nevertheless, several studies have shown that there are disparities in Dutch prenatal screening. Ethnic minority groups are less likely to make an informed decision and participate in antenatal care due to the existence of possible language, cultural, and religious barriers; health illiteracy; being relatively underserved in terms of health services; and the absence of culturally sensitive information within the health services. ^{9, 11-17} Multiple studies endorse the association between lower intentional and actual participation in the CT and partly endorse the association between ethnicity and language proficiency level (LPL); however, research on these outcomes for the FAS is lacking. 10,16, 18 The aim of this study is to analyze the association between the individual offer of prenatal screening with the CT and FAS and ethnic and language proficiency groups within a population of pregnant women and their intention to participate in prenatal screening.

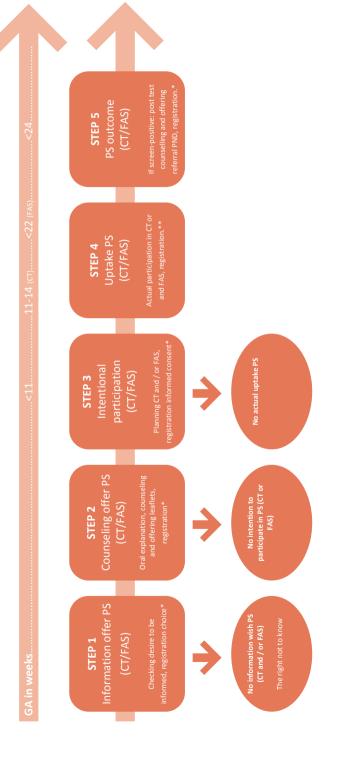


Figure 3.1 Dutch prenatal screening for Down's syndrome and congenital anomalies

GA: Gestational age

PS: Prenatal Screening

CT: first trimester combined test FAS: second trimester Fetal Anomaly Scan

^{*} Action counselor

^{**} Action counselor, sonographer and laboratory

PND: Prenatal Diagnostics; detailed utrasound or chorion villus biopsy / amniocentesis

METHODS

Data Collection

The study was performed in the southwestern region of the Netherlands, the largest prenatal screening region in the country. In comparison to other Dutch regions, the southwestern region is characterized by a larger urban and suburban area and a relatively high percentage (24%) of non-western immigrants.¹⁹ In this prospective study, we used data obtained through a web-based registration form, in which the regional center for prenatal screening asked counselors (midwives, nurses and gynecologists) to report for each pregnant woman in their practice whether and how they were offered information about prenatal screening during the period between June 2008 and December 2010. This registration form was primarily intended for quality control of the contracted healthcare professionals by the regional center in the southwestern part of the Netherlands. The legal use of anonymous data from the registration form was based on the 'implied consent' of pregnant women who had received an information offer of prenatal screening and/or who participated in the program. From April to December 2010, the regional center included four extra variables in the registration form, including voluntary registration of the ethnicity of the pregnant women. Healthcare professionals eligible for this study practiced in one of the hospitals or community midwifery practices contracted by the regional center for PS in the southwestern region of the Netherlands. Fifty-two contracted organizations contributed to registration, which corresponds to 50% of the total number of contracted counseling organizations, including five general practitioner practices, two secondary hospitals and 45 midwifery practices.

Measurements

For more detailed information about the registration of women's socio-demographic and pregnancy characteristics, see Appendix 3.1. The registration form was based on the criteria for comprehensive counseling. The three key elements of counseling were registered. These key elements included the following: (1) pregnant women's 'wish to be informed' and, if desired, (2) the actual provision of information about the CT and FAS ('counseling') and (3) the obtaining of 'informed consent'. Because reliable uptake numbers for the CT and FAS were lacking during the study period, the intention to participate in the CT and FAS (planning uptake) was registered. For this study, we used the data of pregnant women who primarily received an information offer about prenatal screening. The dataset contained information on 37% of the total population of pregnant women in the southwestern region of the Netherlands (Table 1). Information on the provision of information about prenatal screening (counseling) was obtained using several multiple-choice questions: "Is the willingness to receive information on the CT/FAS verified?" [yes/no/not applicable], "Have the women already

Table 3.1 Background characteristics of pregnant women who were offered counseling about prenatal screening

	June 2008	=			Exact numbers (n= 60.038) ^a	
	N	%	Median (range)	N	%	
Age (years)	30.095		30 (11-50)			
≤ 19	550	2				
20-29	13.394	44				
30-39	15.375	51				
40-50	776	3				
Age category						
< 36	25.911	86 ^b		47.791	80	
≥ 36	4.184	14		12.247	20	
Ethnic origin ^e	6.083			17.990 ^c		
Dutch	4.018	66		11.133	62	
Surinamese	187	3		817	5	
Antillean	150	2		484	3	
Cape Verdean	64	1		187	1	
Turkish	307	5		974	5	
Moroccan	470	8		1.116	6	
Other	887	15		3.279	18	
Generation ^e	6.083			17.990 ^c		
First-generation immigrants	1.880	31		4.430	25	
Second-generation immigrants	185	3 ^d		2.427	13	
Native Dutch	4.018	66		11.133	62	
Parity	30.229		1 (0-14)			
Nulliparity	15.065	50				
Multiparity 1-3	14.635	48				
Multiparity 4-14	529	2				
Gravidity	30.182		2 (0-20)			
1-2 pregnancies	21.707	72				
>2 pregnancies	8.475	28				
Gestational age (first booking visit)	29.007		9 (5-41)			
0-11 weeks (on time)	22.894	79				
12-41 weeks (too late)	6.113	21				

Table 3.1 Background characteristics of pregnant women who were offered counseling about prenatal screening (continued)

	Web application registrations June 2008 – December 2010 (n= 30.549)			Exact numbers (n= 60.038) ^a	
	N	%	Median (range)	N	%
Dutch language proficiency level	28.043				
Absent	583	2			
Limited	1.259	5			
Fluent	26.201	93			
Urbanity	30.549				
not or less urban	6.397	21			
moderately urban	4.841	16			
highly urban	19.311	63			

^a Exact numbers of mothers that gave birth to a living child in the study area from June 2008 to December 2010 [Data request. CBS Statistics Netherlands 2013].

been counseled for the CT/ FAS?" [Yes, already counseled or will receive counseling in special counseling consultation/Yes, but not in a special counseling consultation/No or Not applicable] and "How is information on the CT/FAS actually provided?" [The multiple-choice question allows respondents to select more than one answer. Selection of options: 'leaflet', 'counseling, verbal explanation', 'website' and 'other']. The results for intentional participation in PS were obtained with two multiple-choice questions: (1) "Does the pregnant woman wish to participate in CT?" and (2) "Does the pregnant woman wish to participate in the FAS? [Yes/No/Not asked/woman thinks about it/not applicable].

Statistical Analysis

To describe the baseline characteristics, frequency tests were performed. Chi square tests were applied to identify differences in the provision procedure and the intention to participate across origin, immigrant generation and Dutch language proficiency. Associations among background characteristics, the information provision procedure of prenatal screening, the desire for information and the intention to participate in prenatal screening were examined using multivariate logistic regression. For the

^b Higher representation of pregnant women <36 years old due to more inclusion by midwifery practices (low risk population)

^c Exact ethnicity distribution for the study area. To make the study outcomes comparable with the denominator data. only nine months of the year 2010 were explored.

^d Under-reporting second generation caused by the strict definition of second generation (country of birth of the pregnant women and both parents most be known).

e Ethnicity and immigrant generation variables only registered from April 2010 to December 2010'

subanalyses of intentional participation of ethnic and language groups after adequate counseling, we used Chi square tests and multivariate logistic regression. Categorical variables related to the provision of prenatal screening and intention to participate were set as dependent variables (dependent box). Predictive variables such as age, urbanity, ethnicity, generation and language proficiency were introduced simultaneously (enter method) into the regression analyses. 'Goodness of fit' of the models was tested using the Hosmer–Lemeshow test. All analyses were performed using IBM SPSS statistical software version 21 (SPSS Inc., Chicago, IL, USA). For all analyses, a p-value of <0.05 was considered statistically significant.

RESULTS

During the study period, 31,573 registrations were collected (Table 3.1). Almost 5% of all cases (n = 1477) were excluded from the analysis as a result of incomplete registration, e.g., lacking a year of birth or gestational age, or lacking information on the provision and intention to participate in PS. 86% of the women were younger than 36 years old. 31% of pregnant women were first-generation immigrants. 21% had their first antenatal visit after eleven (11 + 0) weeks of gestational age. Finally, 7% had an 'absent' or a 'limited' Dutch LPL. Table 3.2 shows that the first-generation immigrants were significantly more likely to be 'too late' for antenatal visits (first antenatal visit ≥11 + 0 weeks of gestational age) compared to the native Dutch and second-generation immigrants. Also, the results indicated that pregnant women with 'absence of LPL' were significantly more (41%) likely to be 'too late' for their first antenatal visit. The information about the CT was offered significantly less often to the first generation immigrant group (ranging from 10 to 19% less) and to the 'absent' and 'limited LPL' groups (19 and 12% less, respectively) compared to the native Dutch, second generation immigrant and 'fluent LPL' groups. Counseling about the CT and FAS was offered significantly less often to the 'absent LPL' group compared to the 'fluent LPL' group (12% less for the CT and 11% less for the FAS). The first generation immigrants and 'absence of LPL' groups received the explanatory leaflet about the CT as part of the counseling process significantly less often than the other native Dutch, second-generation immigrant, and language groups (ranging from 5 to 16% less). Compared to the other LPL groups, the 'absent LPL' group received an explanatory leaflet about the FAS significantly less often (ranging from 10 to 12% less).

Table 3.3 shows that pregnant women with an 'absence of LPL' were less likely to get an information offer about the CT (OR 0.40; 95% CI 0.23–0.71) and to be given counseling about the CT (OR 0.48; 95% CI 0.38–0.68). A non-urban or less urban maternal residency was associated with a lower chance that information about the FAS was offered (OR 0.65; 95% CI 0.45–0.96) and that counseling was received about the

Table 3.2 Provision of prenatal screening and intentional participation in prenatal screening with CT and FAS

Total Native Dutch immigrant immigrant First-gen. Immigrant immigrant Total immigrant </th <th></th> <th>Я</th> <th>ithin n</th> <th>ative D</th> <th>utch an</th> <th>immi þ</th> <th>within native Dutch and immigrant generations</th> <th>eneratic</th> <th>suc</th> <th>Ż</th> <th>ithin k</th> <th>nguag</th> <th>e profi</th> <th>ciency 1</th> <th>level (LF</th> <th>within language proficiency level (LPL) groups</th> <th>S</th>		Я	ithin n	ative D	utch an	immi þ	within native Dutch and immigrant generations	eneratic	suc	Ż	ithin k	nguag	e profi	ciency 1	level (LF	within language proficiency level (LPL) groups	S
(%) n (%) (28) e8 40 (22) e8 (84) e8 161 (89) 8 3 (95) e 176 (98) 4 (72) 130 (76) 7 (96) 171 (97)		Total	1	Vative L	Jutch	First-ge immigra	n. ant	Second Immigi	d-gen. rant	Total	, ,	Absent Dutch LF	7.	Limited Dutch LPL	TbT	Fluent Dutch LPL	7 _d
(28) °8 40 (22) °8 2 (84) °8 161 (89) 8 3 (95) ° 176 (98) 4 (72) 130 (76) 7 (96) 171 (97)		u	1 (%)				(%)	u	(%)	u	(%)	(%) u (%)		u	(%)	u	(%)
(28) e8 40 (22) e8 (84) e8 161 (89) 8 (95) e 176 (98) 1 (72) 130 (76) 7 (96) 171 (97)	First antenatal visit																
g desired 5.103 (90) 3.450 (94) * 1.492 (84) * 161 (89) * 5.470 (96) 3.571 (97) * 1.723 (95) * 176 (98) 3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	- Late (>11 weeks gestational age)	1.175	(19)) 609	(15) ef		(28) eg	40	(22) eg	5.765	(21)	235 (41) bc .	416	(34) ^{b d}	$5.765 (21) 235 (41)^{\; b c} 416 \ \ (34)^{\; b d} 5.114 \ (20)^{\; c d}$	(20) ^{c d}
g desired 5.103 (90) 3.450 (94) * 1.492 (84) * 8 161 (89) 8 5.470 (96) 3.571 (97) * 1.723 (95) * 176 (98) 3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	STEP 1																
g desired 5.103 (90) 3.450 (94) * 1.492 (84) ** 161 (89) * 5.470 (96) 3.571 (97) * 1.723 (95) * 176 (98) 3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	Information offer																
g desired 3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	- CT (yes)	5.103		3.450 (.94) e	1.492	(84) eg	161	g (68)	24.030	(68)	373 ()	71) b c	937	_{p q} (82)	$24.030 \ \ (89) \ \ 373 \ \ (71)^{\; b \; c} \ \ 937 \qquad (78)^{\; b \; d} \ \ 22.720 \ \ (90)^{\; c \; d}$	р э (06)
g desired 3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	- FAS (yes)	5.470	(96)	3.571	62) e	1.723	(62) е	176	(86)	25.163 (94) 485 (90) ^{b c} 1.123 (93) ^b	(94)	485 (э q (06	1.123	(63) p	23.555	(94) ^c
3.960 (73) 2.626 (73) 1.204 (72) 130 (76) 5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	Counseling desired																
5.377 (96) 3.499 (96) 1.707 (96) 171 (97)	- CT (yes)	3.960	(73)	2.626		1.204	(72)	130	(92)	17.996 (76) 287 (80) ^{bc} 732 (87) ^b	(92)	287 (8	30) pc	732	(87) b	16.977 (90) ^c	₅ (06)
	- FAS (yes)	5.377	(96)	3.499 ((96)	1.707	(96)	171	(26)	23.351 (98) 465 (97)	. (86)	465 (1.075 (99)	(66)	21.811 (99)	(66)

Table 3.2 Provision of prenatal screening and intentional participation in prenatal screening with CT and FAS (continued)

	И	ithin	native D	utch an	d immi	grant ge	within native Dutch and immigrant generations	su	И	ithin	angna	ge prof	iciency	level (LF	within language proficiency level (LPL) groups	ş
	Total		Native Dutch		First-gen. immigrant	n. ant	Second-gen. Immigrant	<i>l</i> -gen. ant	Total		Absent Dutch LPL	nt 1. LPL	Limited Dutch LPL	I LPL	Fluent Dutch LPL	PL
		(%)	_ c	(%)	_ c	(%)	ء	(%)	ء	(%)	ء	(%)		(%)	ء	(%)
STEP 2																
Counseling																
- CT (yes)	4.009	(92)	(76) 2.668 (76) ^e		126	(77) e	(77) e 1.215 (74)	(74)	19.503	(24)	303	(79) 303 (67) ^{b c} 789	789	(75) ^{b d}	(75) ^{b d} 18.411	_{p 2} (62)
- FAS (yes)	3.956		(77) 2.522	(75) ef	(75) ef 1.284 (79) eg 150	8 a (6Z)		g _j (06)	17.477	(74)	296	(74) 296 (64) ^{b c}	755	_{p q} (02)	(70) ^{b d} 16.426	$(75)^{cd}$
Counseling setting																
- Specific counseling consult	1.294	(24)	829	(24)	428	(26)	37	(23)	1.749	(23)	74	(37) ^{b c}	104	(27) ^{b d}	571	(23) cd
- Other	4.009	(92)	2.668	(92)	1.215	(74)	126	(77)	5.826	(77)	126	(63) b c	277	(73) ^{b d}	5.423	(77) cd
Counseling CT																
- Leaflets	3.495	(09)	2.834 (61) e		1.033	(56) eg 122		₂ (99)	16.089	(59)	238	(44) bc	85	_{p q} (99)	5.611	р э (09)
- Counseling (verbal explanation)	3.511	(61)	2.329	(62) e	1.063	(57) e	119	(65)	17.441	(64)	237	(43) bc	719	_{p q} (99)	16.485	(65) cd
- Website	945	(16)	979	(17) ef	303	(16) eg	16	g _j (6)	4.673	(17)	64	(12) ^{b c}	208	(17) ^b	4.401	(17) с
- Other	17	$\widehat{\underline{\zeta}}$	_	(<1) e	10	(<1) e	0	(0)	204	$\widehat{\overline{>}}$	21	(4) b c	19	(2) b d	164	(1) cd
Counseling FAS ^a																
- Leaflets	4.776	(83)	3.072	(82)	1.544 (84)	(84)	160	(87)	6.753	(82)	170	(70) b c	343	q (08)	6.240	(82) ^c
- Counseling (verbal explanation)	4.683	(81)	3.001	(80) f	1.521	(82)	161	(87) f	21.956	(82)	428	(78) с	1.003	(82)	20.525	(82) ^c
- Website	988	(17)	637	(17) ^f	331	(18) ^g	20	(11) fg	3.952	(15)	75	(14)	192	(16)	3.685	(15)
- Other	110	(2)	77	(2)	32	(2)	_	(<1)	433	(5)	27	(11) b c	32	(Z) p	374	(2) c
- Omer		(7)				(7)	_	(>)	45	2		/7 (c)	/7 (c)	(5) 27 (11) 32	(5) 27 (11) 32	(5) 27 (11) 32 (7)

Table 3.2 Provision of prenatal screening and intentional participation in prenatal screening with CT and FAS (continued)

	2	ithin	native L	Outch an	mui pi	within native Dutch and immigrant generations	eneration	ons		/ithin	langu	age pro	ficiency	within language proficiency level (LPL) groups	L) group	Si
	Total		Native Dutch	Dutch	First-gen. immigrant	en. ant	Second-gen. Immigrant	d-gen. rant	Total		Absent Dutch	Absent Dutch LPL	Limited Dutch LPL	d d	Fluent Dutch LPL	PL
	=	(%)	_ c	(%)	_ c	(%)	2	(%)	=	(%)	_	(%)	ء	(%)	_ c	(%)
STEP 3																
Intention to participate in CT ^a																
- Yes	1.250 (22)	(22)	996	(26) ef 259	259	(15) eg 25	25	(14) efg	6.084	(23)	99	(13) ^c	124	(11) ^d	5.894	(24) cd
- No	2.524	(44)	1.638 (44) ef 810	(44) ef	810	(46) eg	9/	(42) efg	11.733 (44)	(44)	199	(40) c	551	(47) ^d	10.983	(44) ^{c d}
- Thinking about	1.338	(23)	849	(23) ef	429	(25) eg	09	(33) efg	6.310	(24)	102	(21) ^c	270	(23) ^d	5.938	(24) cd
- Inapplicable / not asked	581	(10)	255	(7) e f	255	(14) eg	21	(11) efg	2.526	(6)	127	(26) ^c	227	(19)	1.879	14 ₂ (8)
Intention to participate in FAS a																
- Yes	5.009		(88) 3.286 (89)	(88)	1.562	(88)	161	(88)	22.312 (84) 439	(84)	439	(84) ^c	993	(82)	20.880	(85) c
- No	49	<u><</u>	31	(< <u>1</u>	17	(1)		<u>></u>	443	(2)	10	(2) c	19	(2)	414	(2) c
- Thinking about	412	(261	(7)	137	(8)	4	(8)	2.423	(6)	38	(7) c	103	(6)	2.282	₂ (6)
- Inapplicable / not asked	220	(4)	128	(3)	98	(5)	9	(3)	1.470 (5)	(2)	33	(9) с	09	(2)	1.046	(4) c

Significant differences = p-value between 0.001 and 0.05

PS Prenatal screening, CT Combined test, FAS Fetal anomaly scan, gen generation

^a More than one answer is possible

^b Significant difference between Absent Dutch language proficiency level and Limited Dutch language proficiency level

^c Significant difference between Absent Dutch language proficiency level and Fluent Dutch language proficiency level

^d Significant difference between *Limited* Dutch language proficiency level and *Fluent* Dutch language proficiency level

^e Significant difference between native Dutch and first-generation immigrants.

Significant difference between native Dutch and second-generation immigrants.

⁸ Significant difference between first- and second-generation immigrants

CT (moderate urban: OR 0.64; 95% CI 0.45-0.75 and non-urban/less urban: OR 0.79; 95% CI 0.64-0.97). Pregnant women with an absence of Dutch LPL were associated with a lower desire for counseling about prenatal screening for both the CT (OR 0.45; 95% CI 0.31–0.63) and the FAS (OR 0.45; 95% CI 0.23–0.91). There was an association found between pregnant women living in non-urban or less urban areas and a reduced wish for counseling about the FAS (OR 0.39; 95% CI 0.27-0.58). Compared to the native Dutch (OR 0.39; 95% CI 0.27-0.58). Compared to the native Dutch group, a substantially increased desire for counseling on the CT was found for the Cape Verdean ethnic group (OR 2.48; 95% CI 1.09-5.68). Pregnant women with a first-generation immigrant background were associated with a higher chance of receiving counseling about the FAS (OR 1.91; 95% CI 1.11-3.30). Living in non-urban or less urban areas was associated with lower intention to take up PS with the CT (OR 0.55; 95% CI 0.44-0.68). When a pregnant woman had Surinamese, Dutch Antillean, Turkish or Moroccan ethnicity, there was a significant negative association with intention to participate in the CT. An 'absent' and 'limited LPL' status had a significantly negative association with intention to participate in the CT (range OR 0.46-0.48) and the FAS (range OR 0.45-0.49). Table 4.4 shows that having a 'limited and absent LPL' was significantly associated with a lower chance of receiving an information offer about the CT (-14%, OR 0.44 (0.33-0.58 p < 0.001) compared to the 'fluent' language group. If the information provision procedure about the CT is executed adequately, the intentional participation in the CT is significantly lower within the non-Western immigrant and the 'limited and absent LPL' groups compared to the native and Western groups and 'fluent LPL' group (21 and 19% less, respectively). After an adequate information offer about the FAS to pregnant women with a non-Western immigrant and a 'limited and absent LPL' background, these groups showed significantly lower percentages of counseling about the FAS in comparison with the native and Western groups and 'fluent LPL' group (5 and 6%, respectively).

DISCUSSION

The results of this study indicate that there are disparities in the provision of prenatal screening (PS) across ethnic and language proficiency subpopulations. These disparities can possibly result in insufficient access to prenatal screening. This insufficient access may be explained by (1) cultural barriers, (2) language barriers, (3) delays in attending the first antenatal visit, (4) unfamiliarity with diversity by practitioners, and (5) the attitude of the counselor. The literature suggests that the growth of the number of patients born abroad with a variety of social, cultural and religious affiliations and migration histories and statuses influences healthcare provision and reception. ^{15, 20,21, 28} This growth could explain the lack of the provision of and wish for counseling about the CT and the FAS

Table 3.3 Multivariate association between background characteristics and provision and intentional participation in prenatal screening with CT and FAS

				ST	EP 1			
	Info	rmation offer CT		ounseling esired CT	Info	rmation offer FAS	Couns	seling desired FAS
	n= 5,	386	n= 5,	189	n= 5,	429	n= 5,3	12
	OR	CI (95%)	OR	CI (95%)	OR	CI (95%)	OR	CI (95%)
ge	*		*					
30-39	ref		ref		ref		ref	
< 19	0.41	(0.24-0.70) ^c	0.96	(0.59-1.57)	0.73	(0.29-1.85)	0.85	(0.30-2.40)
20-29	0.87	(0.71-1.05)	0.82	$(0.72 \text{-} 0.93)^{\text{ b}}$	1.00	(0.76-1.34)	1.21	(0.90-1.64)
40-50	0.36	(0.22-0.57) ^c	0.91	(0.59-1.40)	0.45	(0.23-0.91) a	0.75	(0.32-1.76)
J rbanit y			*				*	
Highly	ref		ref				ref	
Moderately	1.05	(0.82-1.36)	0.75	(0.64-0.87) ^c	0.90	(0.63-1.30)	0.65	(0.45-0.95) ^a
Not or less	1.08	(0.81-1.46)	0.62	(0.52-0.75) ^c	0.65	(0.45-0.96) ^a	0.39	(0.27-0.58) °
thnicity			*					
Dutch	ref		ref		ref		ref	
Surinamese	0.61	(0.32-1.18)	1.42	(0.85-2.36)	1.11	(0.36-3.48)	1.84	(0.44-7.69)
Antillean	0.56	(0.28-1.14)	0.94	(0.55-1.60)	1.07	(0.31-3.66)	0.85	(0.23-3.08)
Cape Verdean	0.78	(0.31-1.98)	2.48	(1.09-5.68) a	1.20	(0.24-6.06)	n.a.	n.a.
Turkish	0.74	(0.39-1.35)	1.09	(0.70-1.71)	1.05	(0.39-2.85)	1.24	(0.40-3.82)
Moroccan	0.60	(0.34-1.05)	0.83	(0.55-1.26)	1.08	(0.43-2.76)	0.89	(0.33-2.42)
Other	0.67	(0.38-1.16)	1.59	(1.05-2.40) ^a	0.89	(0.38-2.17)	1.20	(0.45-3.19)
Generation d								
Native Dutch	ref		ref		ref		ref	
First	0.74	(0.40-1.35)	0.84	(0.57-1.24)	0.81	(0.34-1.92)	0.85	(0.33-2.21)
anguage profici	ency le	vel (LPL)	*		*			
Fluent	ref		ref		ref		ref	
Limited	0.55	$(0.37 \text{-} 0.82)^{\text{ b}}$	0.76	(0.57-1.01)	0.61	(0.36-1.03)	0.98	(0.49-1.95)
Absent	0.38	(0.23-0.61) ^c	0.45	(0.31-0.63) ^c	0.40	(0.23-0.71) a	0.45 a	(0.23-0.91)

Adjusted for all predictor variables in the table

CT Combined test, FAS Fetal anomaly scan

Bold is significant: *Significant difference p <0.05 within predictor variable; a p <0.05 b p<0.01 c p <0.001 d Results of second-generation immigrants were not applicable.

	STE	P 2			STE	P 3	
Co	unseling CT	Соц	inseling FAS		itention to icipate in CT		tention to cipate in FAS
n= 5,05	56	n= 4,92	27	n= 5,42	25	n= 5,42	.2
OR	CI (95%)	OR	CI (95%)	OR	CI (95%)	OR	CI (95%)
*		*		*		*	
ref		ref		ref		ref	
0.85	(0.51-1.39)	0.96	(0.57-1.63)	0.21	(0.10-0.45) ^c	0.37	(0.22-0.61) ^c
0.85	(0.75-0.97) a	0.73	$\textbf{(0.64-0.85)}^{\text{ c}}$	0.33	$(0.29 \text{-} 0.39)^{\circ}$	0.76	$(0.64\text{-}0.91)^{\ b}$
0.58	$(0.39 \text{-} 0.86)^{\ b}$	1.32	(0.86-2.03)	2.18	(1.49-3.19) ^c	0.72	(0.42-1.22)
*		*		*		*	
ref		ref		ref		ref	
0.64	(0.45-0.75) §	1.05	(0.90-0.23)	0.68	$\textbf{(0.58-0.80)}^{\text{ c}}$	0.56	$\textbf{(0.56-0.68)}^{\text{ c}}$
0.79	(0.64-0.97) a	0.06	(0.04-0.10)	0.55	(0.44-0.68) ^c	0.90	(0.69-1.16)
*		*		*			
ref		ref		ref		ref	
1.22	(0.72-2.09)	0.31	(0.16-0.60) ^c	0.40	$(0.21 \text{-} 0.75)^{\text{ b}}$	0.81	(0.43-1.54)
0.66	(0.38-1.14)	0.44	(0.22-0.87) ^a	0.25	(0.11-0.55) ^c	1.64	(0.71-3.76)
1.82	(0.79-4.18)	0.29	$(0.12 \text{-} 0.70)^{\text{b}}$	0.75	(0.35-1.63)	1.26	(0.45-3.49)
1.05	(0.66-1.68)	0.47	(0.25-0.85) a	0.39	$(0.22\text{-}0.71)^{\ b}$	0.85	(0.47-1.51)
0.81	(0.53-1.26)	0.30	(0.16-0.54) $^{\circ}$	0.14	$(0.07-0.27)^{\circ}$	0.94	(0.54-1.63)
1.11	(0.73-1.70)	0.49	(0.28-0.85) a	0.90	(0.55-1.47)	0.91	(0.54-1.54)
		*					
ref		ref		ref		ref	
0.90	(0.60-1.36)	1.91	(1.11-3.30)†	1.04	(0.63-1.70)	1.04	(0.63-1.72)
*				*		*	
ref				ref		ref	
0.75	(0.56-1.00) ^a	0.90	(0.65-1.24)	0.46	(0.31-0.68) §	0.49	(0.35-0.69) ^c
0.48	(0.38-0.68) ^c	0.74	(0.48-1.15)	0.48	(0.30-0.77) ‡	0.45	(0.30-0.37) ^c

Table 3.4 Intentional participation of ethnicity and language groups after adequate information provision prenatal screening

			STEP 1	.P 1		STEP 2		STEP 3
	Total	Informa	Information offer CT	Counseli	Counseling desired CT	Counseling	Intention to	Intention to participate in CT
		Yes n (%) ^g	OR CI (95%) ^h	Yes n (%) ^{g a}	OR CI (95%) ^h	Yes n (%) ^{g b}	Yes n (%) ^{g c}	OR CI (95%) ^h
Ethnicity 12								
Native/Western	3,877	3,606 (93) §	ref	2,761 (77) ‡	ref	2,653 (96)	879 (32)) [§]	ref
Non-Western	889	756 (85)	1.05 (0.65-1.71)	571 (76) [‡]	0.70 (0.46-1.05)	538 (94)	64 (11) [§]	1.61 (0.84-3.10)
Language ³								
Fluent	25,244	22,720 (90) §	ref	16,997 (75) ‡	ref	16,638 (98)	4,977 (46) [§]	ref
Limited/absent	1,723	1,310 (76) [§]	$0.44 (0.33-0.58)^{\S}$	1,019 (78)	0.62 (0.49-0.79) [§]	988 (97)	167 (27) [§]	1.93 (1.29-2.88)
			STEP 1	P 1		STEP 2		STEP 3
	Total	Informa	Information offer FAS	Counseli	Counseling desired FAS	Counseling	Intention to	Intention to participate in FAS
		Yes n (%) ^g	OR CI (95%) ^h	Yes n (%) ^{g a}	OR CI (95%) ^h	Yes n (%) ^{g b}	Yes n (%) ^{g c}	OR CI (95%) ^h
Ethnicity 1 2								
Native/Western	3,865	3,749 (97) §	ref	3,674 (98)	ref	863 (23) ‡	813 (94)	
Non-Western	902	ş (96) 998	1 (0.41-2.44)	857 (99)	0.71 (0.42-1.22)	158 (18) ‡	141 (89)	n.a.
Language ³								
Fluent	25,058	23,555 (94) §	ref	21,811 (93)	ref	15,766 (72) §	14,015 (89)	ref
Limited/absent	1,748	1,608 (92) §	1.92 (1.24-2.99) ‡	1,540 (96)	1.41 (0.97-2.04)	1,021 (66) §	921 (90)	2.26 (0.17-30)

CT Combined test, FAS Fetal anomaly scan, n.a. not applicable

Bold is significant: \pm p<0.01 § p<0.001

^b Percentage based on the number of pregnant women that desired counseling about CT / FAS

^a Percentage based on the number of pregnant women that had an information offer about CT / FAS

- ^c Percentage based on number of pregnant women that was counseled about CT / FAS
- ^d Adjusted for age, gravidity, parity, immigrant generation, urbanity and language proficiency.
- e The 'other' ethnicity category, presented in different analyses in this article, is excluded from analyses due to uncertainty about Western and non-Western backgrounds because the country of birth of the parents of pregnant women is missing.
 - Adjusted for age, gravidity, parity, immigrant generation, urbanity and ethnicity.
 - ^g Chi² testing
- ^h Logistic regression analyses.

among non-Western women in this study. Several studies show that language barriers are a threat to the effective provision and actual use of health services, which is in line with the positive association between the demand for counseling for the CT and the FAS and Dutch language proficiency found in this study. ^{20, 23, 24, 25} Immigrant women's underutilization of midwifery services may be linked to the delay in the first antenatal visit. ²⁶

Along with other studies, our study shows a higher percentage of first-generation immigrant women and women with an absence of limited language proficiency who are late for their first antenatal visit. ²⁷

A late start of antenatal care could be a reason for less frequent offers of information about PS and a lower provision of counseling about PS, especially about the first trimester CT. This lower provision of counseling can decrease the chance for accurate participation in prenatal screening. Additionally, specific behaviors and attitudes by healthcare providers towards immigrants cause mutual mistrust. Practitioners fear that they might unintentionally discriminate against immigrant patients because they think they are not knowledgeable and/or have no skills to address the varied social, political and cultural backgrounds of these patients. This apprehension might be responsible for the deficiency in the information provision procedure for prenatal screening of non-Western pregnant women in our study. ²³ An interesting outcome of this study is the significant association between having a Cape Verdean ethnicity and an increased wish for counseling on the CT. A possible explanation for this finding is the general negative attitude towards the phenomenon of 'disability' within the Cape Verdean culture.²⁸ Another explanation could be the fact that in comparison to other non- Western Dutch pregnant women, a high percentage of the Dutch Cape Verdean community lives in highly urbanized areas. ^{19,29} In highly urbanized areas, an increased demand for counseling about the CT is generally observed. In addition, since the total percentage of Cape Verdean women in the study is very small, this finding might be coincidental. The legislative framework of the Dutch prenatal screening program requires 'verbal explanation' and (translated) 'leaflets' about prenatal screening as a minimum necessary element of pretest counseling. An interpreter is not available free of charge. In this study, pregnant women with an 'absent or limited LPL' received an informational prenatal screening leaflet about the CT or FAS less often, which indicates that part of the population of pregnant women is being underserved in terms of receiving written information about prenatal screening. ³⁰ This finding can be explained by (1) a potentially negative attitude among practitioners towards the use of leaflets based on previous outcomes regarding the ineffectiveness of leaflets in a medical setting ^{31, 32}, (2) a lack of knowledge of the counselors about the availability of multilingual leaflets, and (3) a possible lack of motivation or time to give these leaflets to patients (multilingual leaflets must be downloaded and printed). ³³ These assumptions can be confirmed by the actual use of translated leaflets about prenatal screening within the Netherlands during 2014 (see Appendix 3.2).

An association between a relatively low rate of intention to participate in the CT among Dutch immigrant women and women with an absent or limited Dutch LPL was partially confirmed in previous papers. ^{13, 18, 33} Most Dutch pregnant women with an absent or limited LPL usually have an immigrant background ³⁴; therefore, we will only discuss outcomes for pregnant immigrant women as they relate to intention to participate. Low intention to participate among immigrant women can be explained by (1) socio-economic background, (2) age of immigrant women, (3) low awareness of prenatal screening with the CT and (4) more acceptance of a child with Down's syndrome within the non-Western pregnant women's population. Since Dutch citizens of Antillean, Surinamese, Turkish and Moroccan descent generally have lower incomes, they possibly experience a resistance to participate in the CT because of the obligation to pay for PS for women under the age of 36 years. ^{18,35} An average income or a lack of income provides an explanation for the lower uptake for the CT. 11 In our study and in general, the population of pregnant women with these ethnic backgrounds was predominantly younger than 36 years old compared to the native Dutch population.¹⁹ Earlier studies reported that Turkish pregnant women read written information less often, had little knowledge about Down's syndrome and prenatal screening and did not make well-informed decisions as often. ^{12,13} Several studies have reported that when pregnant women with a non-Western background do not participate in prenatal screening, a more positive opinion about birth defects based on religious beliefs play a role. 9,13,36 In this study, an association was found between intention to participate and 'absent' and 'limited' Dutch LPL groups in the FAS, such that these groups showed less frequent participation. This finding contrasts with previous data on FAS uptake, which indicates almost similar uptake rates between Dutch and non-Dutch pregnant women. 11

Strengths and Limitations

Comparing the demographic data of our study population to those from the general population shows an almost equal distribution in terms of age and ethnicity, which highlights the representativeness of the study (see Table 3.1). ¹⁹ The strengths of the study are the exploration of outcomes concerning ethnicity and language proficiency differences in the provision and (intentional) participation for both the CT and the FAS, which has not been frequently studied before. The risk of confounding effects on study outcomes is less likely because the data were registered during a period in which the Dutch prenatal screening program was already implemented for one and a half years.

The program was not subject to changes and there were no major socio-demographic trends in the southwestern region of the Netherlands. This study has several limitations. First, LPL is classified subjectively. Differences in interpretation may well exist between

the approximately 200 prenatal healthcare providers included in our dataset. Second, as a result of the strict definition of a second-generation immigrant, data from pregnant women with this background were underrepresented in this study. ¹⁹ Third, a significant limitation of the study is that the data consist of intention to participate in prenatal screening and not actual participation. There may be a difference between hypothetical and actual uptake within the study population, but rates of intention to take up the CT and FAS in this study show similarities with actual CT and FAS uptake rates in the Netherlands, which is promising for the representativeness of the study results. ^{7,11}

Generalizability

The Population Screening Act for prenatal screening calls for equal access to the prenatal screening program. Therefore, the findings of this research are important for healthcare providers, policy makers and governmental professionals involved in the Dutch prenatal screening program. The study results support the development of interventions aiding in the provision of transcultural healthcare that are directed to professional counselors settled in highly urbanized areas, which are strongly multiethnic. The results of this study can teach health professionals outside the Netherlands more about the influence of ethnicity and language proficiency differences in the PS provision procedures and intention to participate in screening. Furthermore, culturally and socio-economically competent visual information materials, such as educational films that are sensitive to differences in culture and language proficiency, should be developed. Healthcare professionals should be encouraged to find better ways to inform their patients. Additional qualitative research among health professionals is desirable to explore why non-native Dutch women and women with limited LPL are less likely to be offered counseling on the CT and FAS. Future research should determine LPL based on several parameters: indication of LPL by both professionals and pregnant women and an optional language skill test.

CONCLUSIONS

This study shows that pregnant women with a non-native Dutch background and/or with insufficient Dutch language proficiency are underserved more often within the Dutch prenatal screening program. These women are less likely to receive an information offer about the CT and FAS and to receive counseling about prenatal screening. In addition, these women exhibit a profoundly lower rate of intention to participate in the CT and FAS. The Population Screening Act 'prenatal screening' calls for equal access to the prenatal screening program. Therefore, these study findings are important for healthcare practitioners, policy makers and governmental professionals involved in the Dutch prenatal screening program.

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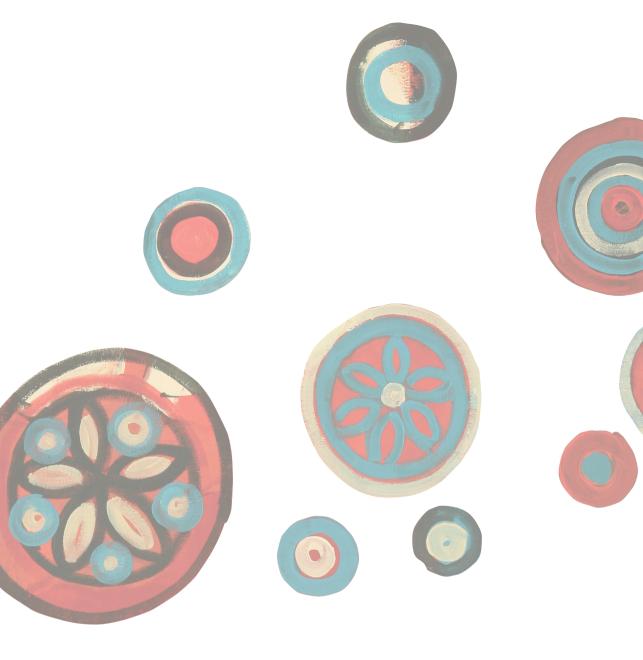
APPENDIXES

Appendix 3.1 Registration of women's socio-demographic and pregnancy characteristics in the web-based form

Variable	Defined on	Answer options / categories
Age	year of birth	
Ethnic background	Country of birth of the woman and her parents	First generation: ethnic background determined by the country of birth of the pregnant woman. Second generation: ethnic background determined by the country of birth of her mother. If her mother is born in the Netherlands, then the country of birth of her father is leading (Statistics Netherlands, 2015).
Migrant generation	Country of birth of the woman and her parents	First-generation immigrants are born abroad; second-generation immigrants are born in the Netherlands and have at least one parent born abroad (Statistics Netherlands, 2014a).
Parity	Number of live births	Nulliparous, multiparous 1-3 or 4-14, gravidity
Gravity	Number of pregnancies	0-2 or >2 pregnancies
Gestational age	Gestational age during first booking visit. Weeks of gestation dated by last menstrual period (LMP)	
First booking visit	Gestational age during first booking visit	On time: 0-11 weeks gestational age (counseling for combined test possible) Too late: ≥11 (11+0) weeks gestational age
Dutch language proficiency level (LPL)	Determined and registered by a prenatal healthcare professional	'Fluent': woman speaks Dutch sufficiently, or 'Limited': woman speaks Dutch with difficulty or 'Absent': woman does not speak Dutch and/or communication is impossible without a translator (Perinatal Registration the Netherlands, 2014).
Urbanity	The four digit zip code of the healthcare organization was used to determine the urbanity category of the pregnant women.	Not or less urban: mean area address density (aad) <500-1000 addresses per square km, moderately urban: aad 1000 tot < 1500 addresses per km² and highly urban: aad \geq 1500- >2500 addresses per square km (Statistics Netherlands, 2014 ^b).

Appendix 3.2 Use of translated hardcopy and downloaded leaflets about Dutch prenatal screening in 2014

Language	Birth rates ^a	First immigrant generation	Difficulty with reading Dutch ^d	Use of leaflet CT ^e	Possibly no translated leaflets CT provided	Use of leaflets FAS ^e	Possibly no translated leaflet FAS provided
	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)
Dutch	126.259 ^b (74)			170.542 f (98)		170.138 f (99)	
Total Western immigrants	17.635 (10)	10.406 (59) ^a					
English				1.090 (0,6)		593 (0,3)	
Spanish				208 (0,1)		128 (0,1)	
French				149 (0,1)		80 (0)	
German				141 (0,1)		76 (0)	
Total non- Western immigrants	27.447 (16)	18.961 (69) ^g					
Turkish	5.873 (3)††	2.978 (51) ^g	983 (33) ^g	345 (0,2)	638 (65) ^h	168 (0,1)	815 (83) ^h
Arabic (Moroccan)	7.424 (4)††	4.432 (60) ^g	1.063 (24) ^g	320 (0,2)	743 (70) ^h	257 (0,1)	806 (76) ^h
Chinese				268 (0,2)		167 (0,1)	
Portuguese (Cape Verdean)				134 (0,1)		65 (0)	
Papiamento (Antillean)	2.199 (1)††	1.371 (62) ^g	41 (3) ^g	109 (0,1)	adequate	45 (0)	adequate
Total	171.341			173.306		171.717	







4



Posthumus AG
Peters IA
Borsboom GJ
Knapen MFCM
Bonsel GJ

Prenatal Diagnosis 2017, Oct; 37 (10) 959-967.



ABSTRACT

Objectives: in the Netherlands, all women are claimed to have equal access to prenatal screening (PS). Prior research demonstrated substantial inequalities in PS uptake associated with socioeconomic status (SES) and ethnic background. The suggested pathway was a lack of intention to participate in PS among these subgroups. We studied the background of inequalities in PS participation, challenging intention heterogeneity as the single explanation.

Methods: multivariable logistic regression analyses of the national PS registry, focusing on the four largest cities in the Netherlands (n = 4578, years 2011-2013), stratified by SES.

Outcome measures: (1) any uptake of PS (yes/no) and (2) uptake (one/two tests) for women who intended to participate in two tests. Determinants included intention, ethnicity, practice, and age.

Results: of non-Western women, 85.7% were screened versus 89.7% of Western women. Intention was an important explanatory factor in all models. However, after correction for intention, ethnicity remained a significant determinant for differences in uptake. Ethnicity and SES also interacted, indicating that non-Western women in low SES areas had the lowest uptake (corrected for intention).

Conclusions for practice: socioeconomic status and ethnicity related inequalities in PS uptake are only partially explained by intention heterogeneity; other pathways, in particular provider-related determinants, may play a role.

INTRODUCTION

In 2007, a nationwide program on prenatal screening (PS) for congenital anomalies was introduced in the Netherlands, supported by a legislative framework (Population Screening Act.¹ PS informs pregnant women and their partners in a timely manner about the likelihood of having a child affected by Down's syndrome or structural congenital anomalies. If the fetus is diagnosed with a syndrome or disorder, prospective parents have the opportunity to either prepare for the birth of a child with this disorder or to consider termination of pregnancy.

Under Dutch law, all pregnant women should be offered the opportunity to receive information from a certified counselor, on the possibility of having PS.² Only if the pregnant woman indicates she wants to be informed on PS, the initial consultation is followed by counseling on the first trimester Combined Test (CT) and the second trimester Fetal Anomaly Scan (FAS). This information 'triage' stage, preceding the actual screening, embodies the principle of 'the right not to know'.

For those consenting, the first option, the CT calculates the chance of carrying a child with Down's syndrome or the lethal syndromes of Patau and Edwards based on biochemistry, serum concentrations of PAPP-A and $f\beta$ -hCG, the sonographic fetal nuchal translucency measurement, and maternal age. ³ The FAS, an ultrasound screening test for fetal anomalies at 20 weeks of gestation, primarily aims at the detection of fetal neural tube defects. ⁴ If the result of the PS is suggestive for a syndrome or disorder, women are offered additional prenatal diagnostic tests.

All women have to pay approximately €165 for the participation in CT; however, before 2015 (data shown in this paper) women over 36 years were exempted from this copayment because of their supposed higher chances of having a positive test. The FAS is freely available. See figure 4.1 for an overview of the Dutch PS program.

Despite the assumption of a barrier free choice for PS in the Netherlands, available data suggest selective barriers to exist as substantial heterogeneity in participation rates are present. Fransen *et al.* showed that non-Western women were less likely to make an informed choice and were less likely to participate in the CT, without any evidence of a different attitude to PS as such.^{5,6} In other western countries women from low socioeconomic status (SES) or non-Western ethnic backgrounds were less likely to receive PS, even in the absence of out-of-pocket costs.⁷⁻¹¹ Generally, contributing factors to these inequalities could be patient-related (i.e. language barriers, the inability to afford the deductible, or preference effects following one's cultural or personal background) and provider-related (lack of time for proper counseling, logistic barriers, personal view of the professional). Only heterogeneity due to true preference of the client should be present.

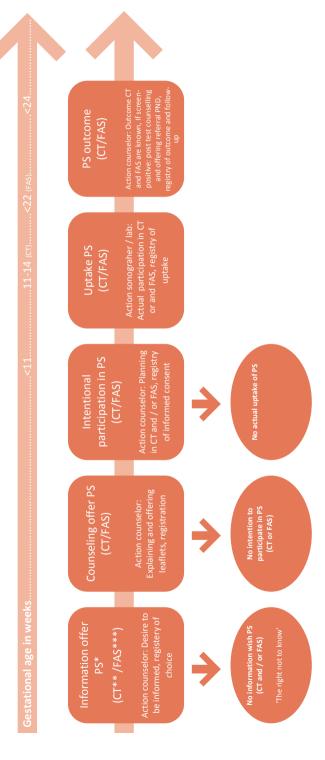


Figure 4.1. Dutch prenatal screening on Down's syndrome and congenital anomalies

PS: Prenatal Screening

CT: first trimester combined test

FAS: second trimester Fetal Anomaly Scan

The aim of this study was to investigate the presence of inequalities in the actual uptake of both CT and FAS as related to SES and ethnicity in the four largest cities in the Netherlands. These cities harbor large non-Western subpopulations (>15%). Also substantial SES gradients are present in these cities. Because prior studies revealed significant differences in perinatal health outcomes and care utilization within these areas ^{12, 13}, registry data on PS in these cities were regarded suitable to investigate whether ethnicity- and SES-related PS inequality were present here, and whether heterogeneity in preference of these groups was the single explanation for inequalities.

METHODS

To investigate the presence of inequalities in women's uptake of PS in relation to SES and ethnicity in the four largest cities in the Netherlands, we extracted records with a small set of individual-level variables from the national Peridos database for the years 2012 to 2013. This web-based database contains data on different aspects of PS in the Netherlands. This includes information on patient characteristics, counseling, informed choice (preference), and actual uptake of the CT and of the FAS. Data are provided by healthcare professionals involved in PS (counselors and sonographers). Not all data fields in Peridos are mandatory and internal validation of the data is yet to be carried out.

The completeness of recording showed practice variation. We excluded practices with more than 10% missing overall information in the client records, as for our analyses data needed to be reasonably complete on the procedural steps. Additionally we excluded individual cases with missing information on gravidity, ethnicity, postal code and uptake of prenatal screening. See figure 4.2 for an overview of exclusions.

Outcome variable

In our analyses we focused on two outcome variables. The first variable was 'actual uptake of PS'. The response variable was dichotomous (non-participation in PS: 0; having participated in some form of PS: 1). The latter could be the CT solely, the FAS solely, or both tests.

As an intermediate variable we included the woman's preference for PS as expressed after being counseled. The options were: no screening, CT, FAS, or both tests.

The second dichotomous outcome variable was the 'comprehensiveness of PS' in women who preferred both forms of screening after counseling (uptake of both the CT and the FAS: 1; uptake of only one test (CT or FAS): 0).

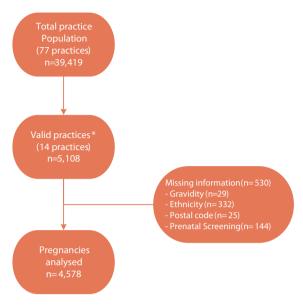


Figure 4.2 Exclusion of pregnancies.

* Practices with <10% missings in registry
This figure shows the number of pregnancies excluded from the analysis.

Determinants

Based on previous studies on the association of maternal covariates and actual uptake of PS, we included the following maternal covariates: maternal age (in categories, as a strictly linear relationship could not be assumed in the statistical models) and ethnicity. In Peridos the ethnic categories were not mutually exclusive. Therefore we dichotomized ethnicity into being from 'Western' or 'non-Western' descent. Moreover this dichotomization usually provides the most contrasting results in the Netherlands. Gravidity was included because prior experience with pregnancy is known to influence behavior in the current pregnancy. Data on neighborhood SES were obtained from the Netherlands Institute for Social Research. ¹⁵ The status scores were calculated based on (1) average income, (2) proportion of people with low income, (3) proportion of people with a low education and (4) proportion of unemployed people in a neighborhood. Higher values of this continuous variable indicate a higher SES. Because the maternal zip codes were missing in 85% of the records, we used the address of the counseling practice as a proxy for the woman's neighborhood of residency. Lastly, an uptake variable at the practice level was included. For each counseling practice in the study we calculated a CT-ratio: number of women who participated in the CT divided by the total number of women in this counseling practice. In this way, we obtained an indication of uptake of PS at practice level. This may be relevant because caregivers may unintentionally influence uptake themselves.

Ethics and consent

The legal use of Peridos data is based on 'implied consent'. Pregnant women who received an information offer on PS were informed about the use of the anonymized data for quality assessment and research purposes and the right to object to information disclosure for this purpose (opt out). Permission for the current analysis was obtained from the 'Centraal Orgaan Prenatale Screening', the national steering committee.

Analytical strategy

We started with descriptive analyses of the maternal demographic characteristics. Hereafter, in all explanatory analyses the study population was stratified according to SES (low SES: ≤50th percentile of all SES values, high SES: >50th percentile of all SES values). The first set of explanatory analyses was based on the entire study population. Univariate logistic regression analyses established the crude odds ratios (OR, 95% CI) between the demographic characteristics and the uptake of PS (model 1). The same determinants were subsequently included in a multivariable logistic regression model (model 2).

Our second set of analyses focused on the subgroup of women who preferred both forms of PS (CT *and* FAS). Again, at first univariate logistic analyses were performed to determine the crude odds ratios (OR, 95% CI) between the demographic characteristics and the participation in either one (CT *or* FAS) or both tests (CT *and* FAS) of PS (model 3). The determinants were subsequently included simultaneously in a multivariable logistic regression model. All analyses were performed using IBM SPSS Statistics version 20.0 (IBM Corp., Armonk, NY, USA) or SAS 9.3 (SAS Institute, Cary, NC, USA).

RESULTS

Demographic characteristics

Between 2012 and 2013, 96.6% of pregnant women in our study sample had indicated after counseling that they wanted any PS. 88.3% actually received either one or both tests.

Table 4.1 shows the demographic characteristics of the study population. Western women received PS slightly more often than non-western women (89.6% versus 85.7%, p<0.01). In non-western women, the uptake of CT was only 12.2%. This was 31.4% in western women. A similar, yet more subtle pattern was seen for SES with CT uptake being lower in low SES women. The proportion of women preferring a CT (with or without FAS) increased with age. Additionally in primigravid women, the uptake of PS was slightly higher than in multigravid women.

Table 4.1 Population Characteristics

		Actual upta	ke of screenin	g at 24 week	s of gestatio	n
4578	Total N (column %)	Combined Test (CT)	Fetal Anomaly Scan (FAS)	Both CT and FAS	No Screening	p-value
		N (row %)	N (row %)	N (row %)	N (row %)	
Age		138 (3.0)	3030 (66.2)	876 (19.1)	534 (11.7)	< 0.01
<20 years	89 (1.9)	0 (0)	75 (84.3)	1 (1.1)	13 (14.6)	
20 - 30 years	1640 (35.8)	19 (1.2)	1267 (77.3)	137 (8.4)	217 (13.2)	
≥30 - 36 years	2155 (47.1)	84 (3.9)	1327 (61.6)	526 (24.4)	218 (10.1)	
≥36 years	694 (15.2)	35 (5.0)	361 (52.0)	212 (30.5)	86 (12.4)	
Gravidity						< 0.01
Primigravida	2042 (44.6)	64 (3.1)	1347 (66.0)	424 (20.8)	207 (10.1)	
Multigravida	2536 (55.4)	74 (2.9)	1683 (66.4)	452 (17.8)	327 (12.9)	
Ethnicity						< 0.01
Non-Western	1563 (34.1)	19 (1.2)	1176 (75.2)	145 (9.3)	223 (14.3)	
Western	3015 (65.9)	119 (3.9)	1854 (61.5)	731 (24.2)	311 (10.3)	
Socioeconomic Status						< 0.01
SES <50 th percentile	2224 (48.6)	48 (2.2)	1571 (70.6)	335 (15.1)	270 (12.1)	
SES ≥50 th percentile	2354 (51.4)	90 (3.8)	1459 (62.0)	541 (23.0)	264 (11.2)	
Stated screening prefere	ence at 10 wee	eks of gestation	on			< 0.01
FAS	2711 (59.2)	0 (0)	2332 (86.0)	58 (2.1)	321 (11.8)	
CT + FAS	1727 (37.7)	138 (8.0)	652 (37.8)	813 (47.1)	124 (7.2)	
Unknown	140 (3.1)	0 (0)	46 (32.9)	5 (3.6)	89 (63.6)	

CT. Combined Test

FAS, Fetal anomaly scan

The stated screening preference was strongly associated with the actual uptake of screening. In advance 37.7% of women preferred both CT and FAS: in these women the uptake of both tests was 47.0%, the uptake of CT or FAS was 45.8% and 7.2% declined all tests. This means that more than half of the women who preferred both tests after counseling, participated in only 1 or none. Also, women who had not stated their preference after counseling, did not receive screening in 63.6% of the cases. In table 4.2 the stated screening preference at ten weeks of gestation is indicated per SES stratum and per ethnicity stratum. A considerably lower proportion of non-western women wanted both screening tests, in favor of FAS only. Preference in low SES women showed the same pattern.

Table 4.2 Stated screening preference at 10 weeks of gestation, according to ethnicity and socioeconomic status.

	Total N (column %)	FAS N (row %)	Both tests (CT+FAS) N (row %)	Unknown N (row %)	p-value
Total	4578	2711 (59.2)	1727 (37.7)	140 (3.1)	< 0.01
Ethnicity					< 0.01
Non-Western	1563 (34.1)	1197 (76.6)	317 (20.3)	49 (3.1)	
Western	3015 (65.9)	1514 (50.2)	1410 (46.8)	91 (3.0)	
Socioeconomic Status					< 0.01
SES <50 th percentile	2224 (48.6)	1602 (72.0)	553 (24.9)	69 (3.1)	
SES >50 th percentile	2354	1109 (47.1)	1174 (49.9)	71 (3.0)	

CT, Combined Test FAS, Fetal anomaly scan

Logistic regression

Tables 4.3a and b show the univariate and multivariable logistic regression analyses for the outcome variable 'no screening' in low (Table 4.3a) and high (Table 4.3b) SES women respectively. In low SES women non-Western ethnicity was strongly associated with higher odds of receiving no PS (OR 1.77). Advanced maternal age, primigravity and a preference for either FAS or both types of screening were associated with reduced odds of no screening. Counseling practice appeared to be a strong provider related determinant as well. Univariate and multivariable regression results were comparable. In high SES women, the individual's preference and the counseling practice both were significant determinants, and only the first remained significant in the multivariable model. Unlike the low SES model, other determinants showed little effect. Therefore, the patterns in significant determinants for non- participation in screening were quite different for the two SES strata.

Table 4.4a shows the univariate and multivariable logistic regression analyses on 'uptake of one or two types of screening tests' for low SES women who preferred two types of screening after counseling. Non-Western women had higher odds of participating in only one type of screening test than Western women. The opposite effect was seen for primigravida, who had lower odds of participating in one type of screening test. These effects remained significant in the multivariable model. Counseling practice again was a significant provider related factor in both models. The same analyses for the high SES stratum is presented in table 4.4b. Non-Western ethnicity and advanced maternal age were associated with higher odds of receiving only one type of screening in the univariate model. However this effect did not remain significant after correction for the other determinants. This means that non-Western ethnicity was not an additional factor for the uptake of PS in high SES women.

Table 4.3a Logistic regression models of individual level determinants and uptake of prenatal screening (no / yes, reference category) for low socioeconomic status women.

	N = 2224	Model 1	(crude)	Model	2 (Forced entry)
Determinants		OR	95% CI	OR	95% CI
Age (ref. 20 – 30 years)	30 - 36 years	0.68	(0.51-0.92)*	0.69	$(0.51 - 0.95)^{+}$
	≥36 years	0.86	(0.58-1.28)	0.79	(0.51 - 1.22)
Gravidity (ref. Multigrav.)	Primigravida	0.54	(0.41 - 0.72)**	0.58	(0.43 - 0.78)**
Ethnicity (ref. Western)	Non-Western	1.77	(1.33 - 2.35)**	1.47	(1.09 - 1.98)*
Preference (ref. Other)	FAS	0.19	(0.11 - 0.31)**	0.15	(0.09 - 0.26)**
	Both	0.14	(0.08 - 0.25)	0.13	(0.07 - 0.23)
Practice		0.00	(0.00 - 0.00)**	0.00	(0.00 - 0.00)**

 $(Odds\ ratios,\ 95\%\ confidence\ intervals\ in\ parentheses)$

Table 4.3b Logistic regression models of individual level determinants and uptake of prenatal screening (no / yes, reference category) for high socioeconomic status women.

	N = 2354	Model 1 (crude) Model 2 (Forced entry)			
Determinants		OR	95% CI	OR	95% CI
Age (ref. 20 – 30 years)	30 - 36 years	0.80	(0.59 - 1.10)	1.02	(0.71 - 1.46)
	≥36 years	1.02	(0.69 - 1.50)	1.35	(0.84 - 2.16)
Gravidity (ref. Multigrav.)	Primigravida	1.04	(0.81 - 1.35)	1.14	(0.85 - 1.53)
Ethnicity (ref. Western)	Non-Western	1.34	(0.86 - 2.09)	1.40	(0.86 - 2.28)
Preference (ref. Other)	FAS	0.03	(0.01 - 0.05)**	0.03	(0.01 - 0.05)**
	Both	0.01	(0.01 - 0.02)	0.01	(0.01 - 0.03)
Practice		0.10	(0.02 - 0.64)*	0.40	(0.06 - 2.93)

(Odds ratios, 95% confidence intervals in parentheses)

Level of significance:

Level of significance:

^{*} p<0.10,

^{*} p<0.05,

^{**} p<0.01

^{*} p<0.01.

^{**} p<0.05.

Table 4.4a Logistic regression models of individual level determinants and uptake of one *or* two forms of prenatal screening (CT *or* FAS / CT *and* FAS, reference category) in low socioeconomic status women who preferred both types of screening.

	N = 553	Model 1 (crude)		Model 2 (Forced entry)	
Determinants		OR	95% CI	OR	95% CI
Age (ref. 20 – 30 years)	<20 years	1.12	(0.24 - 5.28)+	8.88	(1.09 - 72.32)
	30 - 36 years	0.25	(0.05 - 1.27)	0.49	(0.31 - 0.79)**
	≥36 years	0.62	(0.13 - 3.07)	0.73	(0.43 - 1.23)
Gravidity (ref. Multigrav.)	Primigravida	0.31	(0.16 - 0.60)**	0.78	(0.52 - 1.16)
Ethnicity (ref. Western)	Non-Western	2.24	(1.23 - 4.08)**	2.37	(1.59 - 3.52)**
Practice		0.00	(0.00 - 0.00)**	0.00	(0.00 - 0.00)**

(Odds ratios, 95% confidence intervals in parentheses) Level of significance:

Table 4.4b Logistic regression models of individual level determinants and uptake of one *or* two forms of prenatal screening (CT *or* FAS / CT *and* FAS, reference category) in high socioeconomic status women who preferred both types of screening.

	N = 1174	Model 1 (crude)		Model 2 (Forced entry)	
Determinants		OR	95% CI	OR	95% CI
Age (ref. 20 – 30 years)	30 - 36 years	2.16	(1.28 - 3.67)*	0.69	(0.46 - 1.04)
	≥36 years	2.19	(1.10 - 4.34)	0.65	(0.41 - 1.04)
Gravidity (ref. Multigrav.)	Primigravida	0.84	(0.52 - 1.36)	0.79	(0.61 - 1.02)**
Ethnicity (ref. Western)	Non-Western	3.02	(1.42 - 6.42)***	1.41	(0.80 - 2.50)
Practice		0.14	(0.00 - 4.70)	0.00	(0.00 - 0.00)***

(Odds ratios, 95% confidence intervals in parentheses) Level of significance:

^{*} p<0.10,

^{**} p<0.01

^{*} p<0.05.

^{**} p<0.10.

^{***} p<0.01.

DISCUSSION

Our study demonstrated that inequalities in the actual uptake of PS are present in pregnant women living in the four largest cities of the Netherlands. These inequalities persisted after correction for screening preference. Ethnicity and SES showed an interacting effect: women with a non-Western ethnic background from low SES areas were the least likely to take PS. Stratifying for SES showed different patterns for the remaining risk factors, essentially suggesting that participation in the tests in women with low SES was due to material and personal constraints, and was more personal in the high SES group.

Our findings concerning a barrier effect of lower SES and a lower preference for and uptake of PS in women with a non-Western ethnic background (corrected for SES) are both in line with previous studies. Dormandy et al. investigated attitudes on and uptake of PS in the UK and also concluded that participation was less in low SES women. ⁸ Alderdice et al reported that individual level SES did not significantly predict uptake of screening, but area level deprivation did.(Alderdice et al., 2008) In our study we used area level deprivation to define SES as well.

By contrast, in another study from the UK in pregnancies affected by Down's syndrome, there was no significant difference between the SES quintiles in uptake of PS. ¹⁰ However, this group of women carrying a fetus with proven Down's syndrome is possibly not comparable to the general pregnant population. Rowe et al. did not find a difference according to SES either. ¹⁷ This study also investigated ethnicity and found that in the UK Asian women were less likely to prefer PS. A Dutch study focusing on the CT found a lower uptake in Non-Western women after adjustment for SES. ⁶ This study was carried out in part of the same geographical area as our study. Dormandy et al. investigated attitudes and uptake of PS in the UK and also found that participation was lower in non-Western women. ⁸

Lastly, a recent Dutch study by Gitsels et al. also found contrasting results, with non-Western women being more likely to prefer screening.¹⁸ This study included participants by means of purposive sampling, therefore the study population may not reflect the general population. Moreover, in this study no results were reported on preference. Preference was an important determinant for participation in PS in our study. Compared to Western women, a smaller proportion of non-Western women preferred to receive PS. This has previously been attributed to lower levels of education, lower levels of knowledge and religious background.¹¹ We do not have information on these determinants in our study population, but it is plausible that these factors also play a significant role in our study population. Concerning preference, we also saw that low SES women preferred FAS only (without CT), more often than high SES women. One of the possible explanations for this difference is the costs of the CT for younger

women. High SES women may experience less of a financial threshold to participate, thus leading to an inequality in access. However this inequality is unlikely to have major implications: Until 2015 the CT was reimbursed in pregnant women of advanced maternal age (>= 36 years of age) as an alternative for invasive prenatal testing.

Our study showed that preference is not the only explanation for differences in the uptake of PS. After correction for preference, the unequal outcome for non-Western women remained. In these women a stronger deviation was present than in Western women between stated preference for PS after counseling and the actual uptake of PS at the time of testing. There are a number of possible explanations. First, women might reconsider their initial choice after discussing it with her partner, family or peers. Because family ties in many non-Western cultures are often stronger, opinions of significant others mays be valued more. Secondly, in non-Western women language-barriers are more prevalent. Women may not always understand the counseling, make a non-informed choice and then opt out at the time of testing.⁵ Another underlying mechanism may be that these women have difficulties navigating the health care system. The actual PS test is performed on a separate appointment, mostly at another location than where they were counseled. This may form an extra barrier for some women, which they will not always discuss with their care provider.

Our data suggest that health care professionals also play a role in the inequalities. By failing to reduce potential logistic barriers experienced by women, they may unintentionally make access to care more difficult for certain groups of women. Additionally, because of an experienced lack of time to explain what PS entails and what the results mean, or by overestimating the understanding women have of PS, care providers may contribute to the deviation between preference and realization. By knowing that these women are at higher risk of receiving less care, and that this is not solely based on their preference, care providers may place more emphasis on guiding women through the counseling process. However, improving support should not merely depend on the goodwill of health caregivers directly involved. Structured support by means of culturally competent leaflets are available, but not widely used. Innovative methods such as audiovisual tools are currently being explored and show promising results.

In all models except the high SES yes/no screening model, practice was a significant determinant for PS, albeit with a very small effect size. In high SES women no effect was found. This was either because caregiver support was perfectly in accordance with their needs concerning PS or if this was not the case, these women still managed. For the other groups of women this was less so, even though the influence was minimal.

Our study has a number of strengths that merit discussion. Firstly, the Peridos registry is filled out at the time of counseling and at the time of screening. Therefore there is little

risk of recall bias and there is no need to depend on self-report by the participating women. Secondly, by using a stratified approach to SES in our analysis, we were able to tease apart the interaction between SES and ethnicity.

Our study should also be viewed in the light of its limitations. The large number of missing values may reduce the generalizability of our findings to the rest of the population. The proportion of women with non-Western ethnicity and a low SES status are however comparable to the numbers in other national databases, suggesting the population may be comparable. ¹² The large number of missings in Peridos is partly caused by the newness of the system, and registration is expected to improve in the coming years. Additionally, only women who gave consent for counseling on PS and gave permission to use their data are included in the database. Therefore we have no information on the number and characteristics of the women who did not wish to receive information on PS or of those who denied the use of their data (following informal communication the latter is a small fraction).

Because postal codes were missing in the majority of the records, we assigned the postal code of the practice or hospital to the pregnant woman. It is reasonable to assume that women seek obstetric care in their direct vicinity. Especially for low SES women, the travelling distance to a practice of choice would entail an additional financial burden. If high SES women did choose to travel a greater distance to a 'low SES' practice, this would mean that the effect we found in the study is a dilution of the true effect. Concerning information on prior pregnancies, the registry only contained information on gravidity, not parity. Ideally both would be available, because it gives insight in the occurrence of fetal demise. This may in turn influence choices in PS. The information on gravidity is however a good starting point.

Because the ethnic categories were not mutually exclusive, we had to reduce ethnicity to a dichotomous variable (crude dichotomization). This may have led to grouping together women from distinctively different ethnic and cultural backgrounds. Different backgrounds may in turn have led to differences in uptake of PS, as was demonstrated by Fransen *et al.*⁶ Our inability to distinguish between these subgroups, does not detract from the fact that overall substantial differences in uptake between Western and non-Western women are present, justifying dichotomization if - like here - focus is on the potential role of provider factors.

Conclusions for practice

In all, our study rejects the assumption that the WHO universal health care coverage principle is applicable to PS in the Netherlands. There is unequal participation in PS between non-Western and Western women and women from low and high SES areas, at least in the four largest cities of the Netherlands that cover about 15% of all pregnancies. The pattern of observed effects suggest cumulative disadvantage for women

combining vulnerability characteristics. Most disturbing is that these inequalities exist after full account of the woman's' preference. In a health system that claims equal access, these outcomes urge for further follow-up and improvement, in particular as these inequalities are part of the perinatal outcome gap in the four large cities. All stakeholders should take responsibility here, caregivers, screening organizations and health insurance parties.

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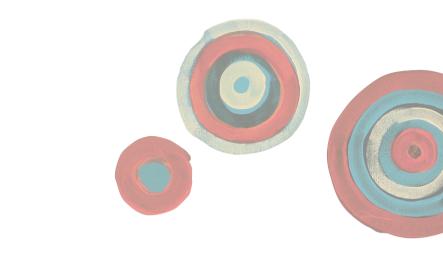
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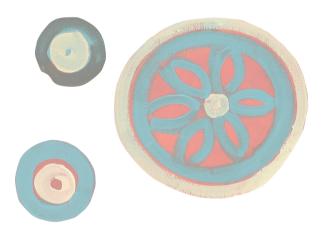


PART II

Performance assessment of prenatal counselling and Fetal Anomaly Scan













Novel quality assessment method for the health educational component of counselling about prenatal screening

6

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ABSTRACT

Objective: Informed decision-making on participation in prenatal screening (PS) for Down's, Edwards' and Patau's syndrome and structural anomalies is the cornerstone of the prenatal screening program in the Netherlands. Since the introduction of the Non Invasive Prenatal Test (NIPT) in the Netherlands counseling on PS became more complex. The importance of adequate counseling and the absence of a quality assessment method for the counseling urged to develop a new assessment method that could assess the quality of the 'health educational' part of the counseling for prenatal screening.

Methods: the reliability of this assessment method was studied in two hospitals and one ultrasound centre. On the basis of 56 transcribed audio-recordings of counseling sessions concerning the combined test and/or the second trimester Fetal Anomaly Scan an item scoring was conducted on each record by three different assessors by using two developed assessment tools for CT and FAS counseling.

Results: the intraclass correlation coefficients of the three assessments of the counseling about PS showed to be significantly above 0.80 (p <0.001), which indicates excellent agreement between the assessments.

Conclusion and practice implications: This method proved to be a reproducible and feasible assessment method and is useful in a broader health care perspective.

INTRODUCTION

The Dutch Ministry of Health, Welfare and Sports (VWS) granted eight regional centers (RC's) a permit for coordination and quality assessment of prenatal screening with regard to the Population Screening Act in 2007.¹ The screening program consists of counseling for screening for Down's, Edwards' and Patau's syndrome and screening for structural fetal anomalies and the actual execution of the prenatal screening tests, being the first trimester combined test (CT), Non Invasive Prenatal Test (NIPT) (since April 2017) and the second trimester fetal anomaly scan (FAS). Every obstetric caregiver that wishes to perform one of the previously mentioned tasks has to be certified to do so ²⁻⁵ and must have a quality contract with a RC. The RC's are responsible for the regional coordination and quality of prenatal screening in their targeted region in the Netherlands. There are nationwide uniform quality requirements for prenatal screening on the content of the counseling, basic qualifications of the counselor on knowledge, skills and conditions for offering counseling. ²⁻⁶

The concept of counseling in the national prenatal screening program implies that all women will be informed, both written and verbally, in the first trimester of their pregnancy on the option for prenatal screening and the implications and the possible advantages and disadvantages of prenatal screening.^{1, 2} The purpose of this counseling is to enable the pregnant woman to freely make an informed decision on whether or not to participate in prenatal screening.¹⁻³ The counseling for prenatal screening occurs in midwifery practices, sonographic centers and hospitals.

By national evaluations and scientific research it was evident that there are specific points of attention regarding counseling, such as (1) the relatively frequent insufficient counseling of multiparous pregnant women, (2) the fact that non-western and low-educated pregnant women more often make an uninformed decision and (3) that from the perspective of the pregnant woman during counseling more attention should be paid to the screening procedures and the social and risk aspects of the screening which contribute to an informed decision. ⁷⁻¹⁰

Since April 1st 2017 the NIPT is available in the Netherlands in a study setting (TRIDENT 2). The NIPT, besides the combined test, is available as an optional first trimester screening test primarily for Down's, Edwards' and Patau's syndrome. Due to the availability of the NIPT in the Netherlands the procedure of provision of prenatal screening becomes complicated and requires for a higher standard of counseling and therefore more knowledge and skills on prenatal screening.

Quality assessment counseling

The quality of counseling is assessed by the RC's through written audits in which questions regarding organization of the counseling and the level of training of the counselor

were included. Besides this, counselors were also assessed on the number of counseling sessions per year. Moreover, informed decision making of pregnant women about participation in prenatal screening was evaluated on a national level. ^{9, 11} International research shows several methods to measure the quality of counseling: (1) evaluating client satisfaction focuses on the experience and opinions of the client with use of the Client Satisfaction Questionnaire and Service Satisfaction Scale¹², (2) evaluating informed decision making after counseling through questionnaires, but occasionally also through audio recordings ^{11, 13, 14} and (3) evaluating the standards of care by assessing if the counseling session is up to the latest standard. ¹² The before mentioned proceedings give outcomes on quantity of the counseling, the quality of the organization of the counseling and informed decision making of pregnant women rather than the quality of the content of the counseling.

The absence of an assessment tool on the content and the increased interest for the quality of the counseling was the motivation to develop a novel method to assess the quality of the 'health education' component of the counseling. The developed method was based on the assessment of the content of audio-recordings of counseling sessions. With our study we will answer the question whether a 'New assessment method counseling for prenatal screening' offers the possibility of providing a reproducible and reliable assessment of the information provision of a counseling session. With regard to the aim of this study, this article will not comment on the quality assessments of the content of the conducted counseling sessions.

METHOD

The study regarding the assessment method was conducted in the screening region of Southwest of the Netherlands. Ten counselors working in two hospitals and one ultrasound center were prepared to take part in the study.

Use of audio-recordings was preferred above video-recordings for several reasons: (1) making audio-recordings diminishes privacy related issues of the counselor and the pregnant woman, (2) an audio-recording of the counseling session is an adequate source for enabling assessment of the health education component of the counseling and (3) the counselor is able to make the recording herself. The method in this study consisted of the following phases (see also figure 6.1):

A) Inclusion pregnant women: in the period February to April 2016 the to be counselled pregnant women within the participating organizations were notified with regard to the study through an information letter, through which from both the pregnant woman and the counselor written informed consent was obtained.

- B) Recording counseling session: using a voice-recorder the counselor recorded the counseling session.
- C) Registration counseling and pregnancy details: several anonymous details were registered [date counseling, gravidity, age and Dutch language proficiency of the pregnant woman [good, average, none]].
- D) Transcribing audio-recordings: the recordings were transcribed and the timeframe was registered.
- E) Assessment audio-recordings: the transcripts were assessed with use of the assessment frameworks for the CT and the FAS counseling. For each counseling session the outcomes of the assessment per item, sub-item and the total overall score were registered in the study dataset as well as the timeframe of the assessment.

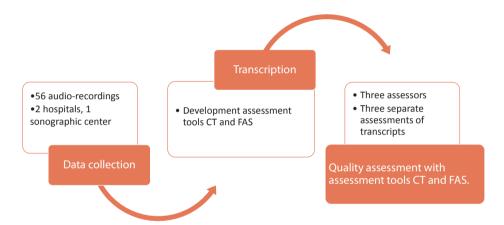


Figure 6.1 Study design: Novel quality assessment method for counseling about prenatale screening.

CT: Combined Test FAS: Fetal Anomaly Scan

Assessment framework

The assessment framework consisted of two assessment tools for a qualitative measurement of the quality of the content of the counseling for the CT and the FAS. See supplements 6.1 and 6.2 for the assessment tools CT and FAS. The assessment tool for the counseling of the CT was based on the nationally implemented checklist of what an adequate counseling session for screening on Down's, Edwards's and Patau's syndrome should consist of. For the development of the assessment tool for the FAS, a checklist of what an adequate counseling session for the FAS should consist of developed by the SPSZN was used, as such a checklist was lacking on a national level. The checklists consisted of items which indicated the minimum information to be given during a

Table 6.1 Baseline characteristics

		Ν	(%)
Organisation			
Counselling sessions		56	(100)
Counsellors		10	(100)
Location counselling session	Ultrasound center	20	(36)
	Hospital	36	(64)
Profession counsellor	Midwife	6	(11)
	Nurse	30	(54)
	Sonographer	20	(35)
Time frame counselling session	Median 9,22		
	0-5 minutes	12	(21)
	>5-12 minutes	21	(38)
	12-23 minutes	23	(41)
Type counselling	FAS	9	(16)
	Combined test	1	(2)
	Both	46	(82)
Pregnant women			
Gravidity	Primigravida	19	(34)
	Multigravida	37	(66)
Age	<36	47	(84)
	≥36	9	(16)
Dutch language proficiency	Good	53	(95)
	Average	1	(2)
	None	2	(4)

counseling session. With use of the assessment tools counseling for the CT and the FAS, a set score could be assigned on the level of the discussed items and sub-items. The assessment tool clearly stated, word by word, what was needed to be discussed in order to be assigned a certain score. For the CT counseling a maximum score of 14 points could be assigned and for the FAS counseling a maximum score of 12 points could be assigned. Within an item, it was possible to assign a part of the maximum points when only a part of the sub-items were discussed.

Statistical analysis

In order to gain insight into the characteristics of the study dataset, descriptive statistical analysis was conducted. The same method was used to analyze the differences in

assessments of the counseling sessions. To analyze intra-observer variability between the three assessors, the Intraclass Correlation Coefficient (ICC) analysis method was used for which a minimum sample size of 50 is required. Analysis of the determinants regarding the feasibility, such as timeframe of transcription and quality assessment per audio-recording, were conducted with use of descriptive statistical frequency analysis. All analyses were conducted in IBM SPSS statistics software version 21 (SPSS Inc., Chicago, IL, USA). A p-value of <0.05 was considered significant in this study.

RESULTS

Of the participating hospitals and ultrasound center 58 audio-recordings of counseling sessions regarding the combined test and/or the FAS were retrieved. Two audio-recordings were excluded from the study. One due to missing characteristics of the pregnant woman and another one because it concerned a post test counseling session.

Table 6.2 Quality assessments Combined test and Fetal Anomaly Scan counselling

	Max. Score	Median	(min-max)
Total item score CT counselling	14	9.15	(3.28-13.09)
- Information CT	2	2.00	(0.67-2.00)
- Chance of trisomy 18 and trisomy 13	2	1.00	(0.00-2.00)
- Information down syndrome, trisomy 18 and 13	2	1.00	(0.33-2.00)
- Further research	2	1.67	(0.00-2.00)
- NIPT	2	1.60	(0.00-2.00)
- Provision of RIVM flyer ¹	1	0.00	(0.00-1.00)
- Referral letter	1	1.00	(0.00-1.00)
- Communication test results	2	0.33	(0.00-1.33)
Total item score FAS counselling	12	4.33	(1.73-8.24)
- Purpose FAS	2	0.96	(0.00-2.00)
- Limitations FAS	2	0.33	(0.00-2.00
- Sonographic markers / additional findings	1	0.00	(0.00-1.00)
- Time frame FAS	2	0.33	(0.00-2.00)
- Further research	1	0.67	(0.00-1.00)
- Communication test results	2	0.33	(0,00-1.33)
- Provision RIVM flyer ¹	1	0.00	(0.00-1.00)
- Referral letter	1	1.00	(0.00-1.00)

CT: Combined Test

FAS: Fetal Anomaly Scan

¹ In practice the flyer is not standard provided during the counseling session.

Table 6.2 shows the median score of the assessments of the counseling items due to the inventory assets of the method. The median overall score of the counseling for the combined test is 9.15 of a maximum score of 14. The counseling for the FAS reached a median score of 4.33 of a maximum score of 12.

Table 6.3 shows that the coefficients of the three assessments by the three assessors for the counseling for the CT and the FAS were significantly above 0.80 which indicates excellent agreement between the assessments. Additionally, on item level the agreement between the three assessors and the assessor pairs were generally high with significant coefficients of over 0.70. Several assessed items, with a coefficient of <0.70 on all levels of analysis, showed a disagreement between the assessments. The CT counseling agreement between the assessors was least significant for the item 'communication of

Table 6.3 Intraclass Correlation Coefficient analysis

	A1/A2/A3	
	ICC	P-value
Total Combined test counselling	0.88	0.001
- Information CT	0.10	0.289
- Chance of trisomy 18 and trisomy 13	0.86	0.001
- Info down syndrome, trisomy 18 and trisomy 13	0.93	0.001
- Further research	0.90	0.001
- NIPT	0.89	0.001
- RIVM flyer	0.94	0.001
- Referral letter	0.88	0.001
- Communication of results	0.47 1	0.003
Total Fetal Anomaly Scan counselling	0.82	0.001
- Purpose FAS	0.97	0.001
- Limitations FAS	0.76 ²	0.001
- Sonographic markers	0.95	0.001
- Time frame FAS	0.30^{3}	0.001
- Further research	0.93	0.001
- RIVM flyer	0.94	0.001
- Referral letter	0.22	0.006
- Communication of results	0.57 1	0.001

CT= Combined test, FAS= Fetal Anomaly Scan

B1= Assessment 1, B2= Assessment 2, B3= Assessment 3.

Coefficient \geq 0,70 adequate agreement between the assessments [11]

 $^{^1}$ Significant inadequate agreement between 1 assessor pair, 2 between 2 assessor pairs and 3 between 3 assessor pairs.

results'. The items 'time frame FAS', 'referral letter' and likewise the 'communication of results' significantly showed the largest difference in assessments for the counseling of the FAS.

Table 6.4 gives an overview of the feasibility determinants for the execution of the assessment method. For each minute of an audio-recording of the counseling, the median time investment for transcription was close to 10 minutes.

Table 6.4 Time investment assessment method counseling

A. Transcribing	Median	min-max
Per transcript (total minutes)	97.50	(10.00-195.00)
Per minute counseling	9.61	(5.75-21.74)
B. Assessments content counseling	Median	min-max
Per transcript (total minutes)	12.80	(1.70-20)
Per minute counseling	1.28	(0.67-3.20)
Assessments CT counseling n=47	9.15	(3.28-13.09)
Assessment FAS counseling n=55	4.33	(1.73-8.24)

CT: Combined test FAS: Fetal Anomaly Scan

DISCUSSION AND CONCLUSION

Discussion

To our knowledge this is the first developed and evaluated method that was able to assess the quality of the content of the health educational component of the counseling based on audio recordings. This method offered the ability to assess the conversation held in the counseling session in a standardized and a reproducible manner. The primary outcomes of the assessment were the quality assessments for the health educational part of the counseling, and the secondary outcome was an evaluation of counselor specific characteristics and any shortcomings in the counseling. The method was therefore complementary regarding the developed observation method with which the communication skills of the counselor can be studied.⁸

The method assessed the quality of the 'information supplying component' (health education) of the counseling while the 'support in decision-making' is not part of the assessment. Considering the purpose of this study and the low representativeness of the sample size, this article will not supply quality assessments on the content of the conducted counseling sessions. The required sample size of 50 counseling sessions to enable execution of a valid ICC was reached with a sample of n=56.¹¹ Based on the significant agreement between overall assessments for both tests of the counseling

supplied by the three assessors, the reliability of the method has been established. The outcomes confirm that for the overall assessment for each type of counseling it does not matter which assessor has executed the assessment. However, on a few items there was less of an agreement between supplied assessments by the assessors, with the item assessments for the FAS counseling showing the least agreement. Based on further study of the sub-items for both assessment tools, it appears that a lack of explicitness in the sub-items is the cause. The study findings give implications for improvement of the method. The items and sub-items with the lowest level of agreement are ought to be made more explicit in their description in the assessment tools. This will further optimize the method.

The assessment method was based on audio-recordings of the counseling session conducted by the counselor. Transcription of the audio-recordings contributed to a reliable assessment of the counseling. Solely use of the audio-recordings is less objective to determine on which parts of the conversation the scored and assessed items are based. Furthermore the listening and elaborating by the counselor themselves of the conducted counseling session will lead to further insight and awareness on the quality of the conducted counseling session and create a learning experience. For this reason it is, not only with regard to the feasibility of this method from the perspective of the auditor, recommended to enable transcription by the counselor, despite the timely investment.

Based on the transcripts, the counseling can be evaluated accordingly to the described method, which will enable the auditing organization to report on the quality of the counseling.

CONCLUSION

The developed assessment tool showed to be an adequate instrument to assess the quality of the 'health education' component of the counseling session in a uniform and reproducible manner. The method additionally offers the ability to gain insight in the structure of the counseling and shortcomings in the transmission of information. Hereby a reliable method is available to primarily assess the health educational part of the counseling on an individual level and secondary give the opportunity to inventory the omissions in the counseling in national perspective.

Practice implications

Implementation of this new assessment method for counseling is feasible seeing (1) the method and the used assessment tools are transmissible and useful in a broader health care perspective, (2) the used assessment tools are easily adjustable and (3) the time investment for the counselor and auditor is realistic. Implementation of the

assessment method appears to be worthwhile. This method could be used as a quality evaluation of the counseling session and can, after professional development adjusted to the outcomes of the assessment, result in contribution to improvement in the quality of the counseling.

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SUPPLEMENTS

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Score-code	Item	Required content	Score		Comments
S_1_CT	Wish for information Combined test	Do you wish to get information about screening for Down syndrome?	Z.A.		This question is likely to be askes prior to the counselling session.
S_2_CT	Information Combined test: blood test, Nuchal translucency (NT) measurement to enable pregnant woman to make an informed decision.	CT: (1) blood test at 9-14 weeks pregnancy. (2) NT measurement for child during ultrasound within week 11-14 of pregnancy.	2 themes = 2 points mentioned (good) 1 theme mentioned = 1 point - = 0 (inadequa	= 2 points (good) = 1 point = 0 (inadequate)	(1): score when blood test and a timeframe is mentioned. (2): Timeframe of 12 weeks is adequate.
S_3_CT	Combined test: Besides chances for DS, also chances for trisomy 13 (patau and 18 (edwards).	Combined test: (1) Besides chances for DS results too show Besides chances for chances for t18 (edwards) and t13 (patau). DS, also chances for (2) Pregnant woman will only get all three trisomy 13 (patau results if she wishes to.	2 themes = 2 points mentioned (good) 1 theme mentioned = 1 point - = 0 (inadequate	= 2 points (good) = 1 point = 0 (inadequate)	

SUPPLEMENT 6.1 - ASSESSMENT TOOL COUNSELING COMBINED TEST (continued)

Score-code	Item	Required content	Score		Comments
S_4_CT	Information trisomy 21, 13 and 18.	T21 (Down): (1) It is a congenital disease (2) Caused by extra chromosome 21. (3) Slow and limited development of the child. T18 (edwards)/T13 (patau): (4) Caused by extra chromosome 18/13. (5)Most children pass away during the pregnancy or within the first year after birth. (6) severe mental disability and specific physical abnormalities.	all 6 themes mentioned 5 themes mentioned 4 themes mentioned 3 themes mentioned 2 themes mentioned 1 theme mentioned	= 2 points (good) = 1.66 points = 1.33 points = 1 point = 0.5 point = 0.3 point = 0.3 point = 0.3 point	When pregnant woman does not wish to receive information on T13 & T18, then maximum points must be divided over T21. (1): chromosomal abnormality = adequate
S_S_CT	Information various result options and potential referral for further research.	Information various (1) The results of the blood test + NT + age result of result options and + exact length of the pregnancy = result of mentioned potential referral for chance (no certainty) 3 themes further research. (2) With a chance of 1:200 or higher for DS: mentioned further research. (3) Further research consists of NIPT, mentioned Chorionic villus sampling, amniocentesis. 1 theme m. (4) Chorionic villus sampling and amniocentesis gives definitive result.	All 4 themes = 2 points mentioned (good) 3 themes = 1.5 points mentioned = 1 point 2 themes = 0.5 point mentioned = 0 1 theme mentioned (inadequate)	= 2 points (good) = 1.5 points = 1 point = 0.5 point = 0. (inadequate)	

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Score-code	Item	Required content	Score		Comments
S_6_CT	Information Non Invasive Prenatal Test	 With higher chance opportunity to take part in NIPT study. Take blood to test DNA child for DS, Edwards and Patau syndrome. Advantage NIPT: no risk of miscarriage. Disadvantage NIPT: no 100% certain result. Further research. 	All 5 themes mentioned 4 themes mentioned 3 themes mentioned 2 themes mentioned 1 theme mentioned 1	= 2 points (good) = 1.6 points = 0.96 point = 0.8 point = 0.4 point = 0 (inadequate)	(2): Mention of blood test + three syndromes = adequate (3): Mention of non-invasive as part of name NIPT = inadequate
L7_CT	Offering support to the pregnant woman to digest the information and come to a decision.	(1) Answer options: - Contact via call; - Extra consultation; - Decision making support / website; - Other.	N.A. (No scoring, but inventory)	rentory)	
S_8_CT	Mention of flyer 'Information about Down screening'	Has the flyer been mentioned yes/no?	mentioned not mentioned	= 1 point (good) = 0 (inadequate)	

SUPPLEMENT 6.1 - ASSESSMENT TOOL COUNSELING COMBINED TEST (continued)

Score-code	Item	Required content	Score		Comments
S_9_CT	If pregnant woman decides to take part in the	(1) Referral letter given/explained (2) Digital referral in the patient system in the case that the CT will be executed	given/registered/ explained	= 1 point	1 point can be scored when one of the situation applies.
	prenatal screening programme, a referral letter must be given in which is stated that the counselling session has been conducted.	internally. (3) In the case that pregnant woman does not yet commit to taking part in the CT, explain further steps and when her final decision is due.	not given /not registered/not explained	0	When pregnant woman decides not to do the CT, no referral letter can be given. In that case score 1.
S_10_CT	If pregnant woman decides to take part in screening programme, mention how she will receive the results from the Combined test.	(1) Explanation of <u>how</u> the results are communicated. (2) Explanation of <u>who</u> will communicate the results.	2 themes mentioned 1 theme mentioned If pregnant woman hasn't decided whether or not to take part yet.	= 2 points (good) = 1 point = 0	When pregnant woman has decided not (yet) to take part in the CT score 2 for item \$_11_CT
S_11_CT	If pregnant woman hasn't decided whether or not to take part yet.		Yes	= 2 points = 0	
CALCULATION			Max 14 points Total score: 1,4 = final score	nal score	

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Score-code	item	Required content	Score		Comment
S_1_FAS	Wish for information Fetal Anomaly Scan	Do you wish to get information about the FAS?	· · · ·		This question is likely to be askes prior to the counselling session.
S_2_FAS	Information goal Fetal Anomaly Scan	(1) neural tube defect (open spine, spinal cord or brain) (2) development of organs (3) other physical abnormalities (4) growth of the child (5) amount of amniotic fluid	5 themes mentioned 4 themes mentioned 3 themes mentioned 2 themes mentioned 1 theme mentioned	= 2 points (good) = 1.6 points = 0.96 points = 0.8 points = 0.4 points = 0 (inadequate)	
S_3_FAS	Limitations of the Fetal Anomaly (1) FAS is not able to find all Scan abnormalities (2) No certainty for healthy/unhealthy child	(1) FAS is not able to find all abnormalities (2) No certainty for healthy/unhealthy child	2 themes mentioned 1 theme mentioned	= 2 points (good) = 1 point = 0 (inadequate)	
S_4_FAS	Chance of unexpected findings (Sono-markers)	Mention that during the FAS unexpected findings can be found.	Mentioned not mentioned	= 1 point (good) = 0 (inadequate)	
S_5_FAS	Timeframe Fetal Anomaly Scan	(1) Between 18-22 weeks of pregnancy.(2) Best before week 21.	2 themes mentioned 1 theme mentioned -	= 2 points (good) = 1 point = 0 (inadequate)	= 2 points (good) 20-weeks as part of the name = 1 point for the FAS = inadequate = 0 (inadequate)
S_6_FAS	Information further research	Further research: expert ultrasound	mentioned not mentioned	= 1 point (good) = 0 (inadequate)	

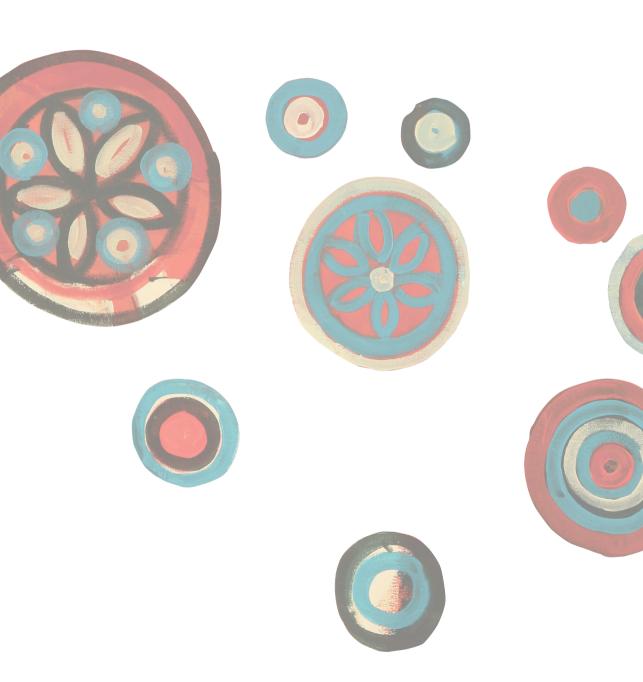
SUPPLEMENT 6.2- ASSESSMENT TOOL FETAL ANOMALY SCAN (continued)

Score-code	item	Required content	Score		Comment
S_7_FAS	If pregnant woman decides to take part in screening programme, mention how she will receive the results from the Fetal Anomaly Scan	(1) Explanation of <u>how</u> the results are communicated. (2) Explanation of <u>who</u> will communicate the results.	2 themes mentioned 1 theme mentioned - This option must be chosen as well in the case that the pregnant woman hasn't decided whether or not to take part yet)	= 2 points (good) = 1 point = 0 (inadequate)	When pregnant woman has decided not (yet) to take part in the CT score 2 for item:
L_8_FAS	Offering support to the pregnant woman to digest the information and come to a decision.	Answer options: - Contact via call; - Extra consultation; - Decision making support / website; - Other:	N.A. (No scoring, but inventory)		
S_9_FAS	Mention of flyer Fetal Anomaly Scan	Has the flyer been mentioned yes/no?	mentioned not mentioned	= 1 point (good) = 0 (inadequate)	
S_10_FAS	If pregnant woman decides to take part in the prenatal screening programme, a referral letter must be given in which is stated that the counselling session has been conducted.	(1) Referral letter given/ given/register explained (2) Digital referral in the patient system in the case not given /not that the FAS will be executed not explained internally. (3) In the case that pregnant woman does not yet commit to taking part in the FAS, explain further steps and when her final decision is due.	given/registered/ explained not given /not registered/ not explained	= 1 point = 0	

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Score-code item	item	Required content	Score	Comment
S_10_FAS	No referral letter is given when the pregnant woman has not decided whether or not to take		1=No referral letter due = 1 point to no decision	
	part.		0=Referral letter given/ = 0 no referral letter given when decision has	
			already been made.	
CALCULATION	7		Max 12 points Total score:1,2 = final score	







An audit of second-trimester fetal anomaly scans based on a novel image-scoring method in the Southwest region of the Netherlands

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ABSTRACT

Objective: Since 2007 the second trimester fetal anomaly scan is offered to all pregnant women as part of the national prenatal screening programme in the Netherlands. Dutch population-based screening programmes have in general a well described system to achieve quality assurance. Due to the absence of an uniform system monitoring the actual performance of the fetal anomaly scan in 2012, we developed a standardised image-scoring method. The aim of this study was to evaluate the scanning performance of all sonographers in the southwestern region of the Netherlands using this image-scoring method.

Methods: Each sonographer is requested to set up a digital portfolio. A portfolio consists of five logbooks from five different pregnant women, each containing 25 fetal anatomical structures and six biometric measures of randomly selected fetal anomaly scans.

Results: During the study period, 425 logbooks of 85 sonographers were assessed as part of the audit process. Seventy-three out of 85 sonographers (86%) met the criteria in the primary audit and twelve sonographers required an individual hands-on training. A successful assessment was achieved for eleven sonographers in the re-audit and one sonographer ceased her contract. Moreover, 2.1% of the required images were not digitally stored and could therefore not be reviewed.

Conclusions: Quality assessment using the image-scoring method demonstrated that the majority of sonographers met the expectations of the audit process but those who had subpar performance met expectations after re-training.

INTRODUCTION

In 2007, a nationwide prenatal screening programme was introduced in the Netherlands for Down syndrome risk assessment in the first trimester of pregnancy and the detection of fetal structural anomalies in the second trimester of pregnancy. This programme is supported by a legislative framework, the Population Screening Act and perpetuates equal access for any pregnant woman to these screening entities. Its main goal is to enable pregnant women to make well informed reproductive choices.

Dutch population-based screening programmes have in general a well described system to achieve quality assurance, including accreditation requirements, quality assurance standards and quality control guidelines.^{1, 2} National quality standards for the Down syndrome screening programme were available in June 2012 and have been implemented in the audit program to assess the quality of the individual sonographer for the nuchal translucency measurement.³

Despite the fact that general requirements for individual sonographers, such as attending CME (continuing medical education) activities and minimum number of scans were already described and incorporated, a uniform system monitoring the actual performance of the second trimester fetal anomaly scan was lacking.

Guidelines for the performance of the second trimester fetal anomaly scan , further referred to as 'anomaly scan' are issued by several international 4,5 and national organisations. All guidelines emphasize the need for documentation of ultrasound examinations and their importance for quality assurance.

Scoring methods of the anomaly scan⁷⁻⁹ and the fetal cardiac scan¹⁰, based on fetal images were developed and are an objective and reproducible tool to assess the quality of ultrasound examinations. Recently a new scale for assessment of obstetric ultrasound competence, the Objective Structured Assessment of Ultrasound Skills (OSAUS) has been described by Tolsgaard *et al.*¹¹ Until now, such scoring systems were never applied to large groups of sonographers and only delineated a proof of principle.

The aim of this study was to evaluate a newly developed score-based audit method for quality assessment⁹ of the second trimester anomaly scan and to evaluate the scanning performance of all sonographers in the southwest region of the Netherlands.

MATERIALS AND METHODS

The Dutch prenatal screening programme on fetal anomalies is a programme that is delegated to eight Regional Organisations and is coordinated by the National Institute of Public Health and Environment (RIVM). The Regional Organisation is among other things responsible for the quality control of the screening programme and auditing is

one of its quality instruments. All sonographers within the screening programme are properly trained in certified institutes. Sonographers only may perform anomaly scans when they have a quality agreement with the Regional Organisation. Certification, ongoing training and being subject to auditing are essential conditions to maintain their contract. In addition to the cost of the anomaly scan, ten percent of the reimbursement is charged and allocated to the Regional Organisation to enable execution of the prenatal screening program.

A score-based audit method for quality assessment of the anomaly scan was developed and briefly described in a national journal ⁹. For each sonographer working in a screening unit, five recent cases preceding the actual audit were randomly selected by the audit team from the national prenatal screening database 'Peridos'. Data are provided by healthcare professionals involved in prenatal screening (contracted midwives, sonographers and obstetricians), all of whom are connected with Peridos. Cases were limited to singleton pregnancies and did not reveal any anomalies on the scan. All ultrasound equipment met the national quality requirements. During the audit individual data from each sonographer, such as number of scans per year, sonographic experience and working environment (kind of organisation, number of sonographers) were collected. According to the national guidelines, sonographers with less than two years of experience ('new') should perform more than 250 anomaly scans per year and others ('experienced') should perform more than 150 anomaly scans per year.

A sonographic digital portfolio consists of five logbooks, from five different pregnant women, each containing 25 anatomical structures and six biometric measures that should be recorded and evaluated during an anomaly scan, according to the Dutch Society of Obstetrics and Gynecology (NVOG).⁶ The required images represent the structures and biometric measurements assessed in the fetal anatomical survey described by International Society of Ultrasound in Obstetrics and Gynecology (ISUOG), with the addition of the outflow tracts of the heart and the anterior - posterior inner to inner measurement of both renal pelvis.⁴ For each anatomical structure one point for the correct plane and one point for the proper magnification can be obtained. A fetal structure should be depicted in a full-screen view, meaning that at least two-third of the monitor is occupied by the area of interest (Figure 7.1). In the Netherlands fetal biometry is assessed as described by Verburg et al. (2008). 12 For six biometrical images one point can be obtained for a correct calliper position. Images that are missing from the logbook will be classified as 'absent' and scored zero points. The maximum score is 56 points for each logbook ($25 \times 2 + 6$). For this study a threshold score of 42 out of 56, corresponding to 75% of the total score was used to discriminate between an adequate and an inadequate score. Next to the evaluation of the above mentioned fetal structures and biometrical measurements, an annotation on the ultrasound image to distinguish right from left for kidneys and extremities was documented.

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Figure 7.1 Four-chamber view showing inadequate magnification (A) and adequate magnification (full-screen view) (B).





The image-scoring is performed by a team consisting of four experienced sonographers from the division of Prenatal Medicine of the Erasmus Medical Centre, Rotterdam (T.C.O., M.H. and E.S.) or the department of Obstetrics and Gynecology of the Reinier de Graaf Hospital, Delft (C.R.). All five logbooks are reviewed, and the three best scoring logbooks will be selected for the final assessment. All selected logbooks should have an adequate score for a successful performance. For every rejected image (plane, magnification and placement of the callipers) a written explanation is provided and during the visit to the ultrasound practice, feedback on the performance based on these scores is given to the individual sonographer. When a portfolio is scored as 'inadequate', the portfolio is subject to a second opinion by the most experienced reviewer (T.C.O.). This reviewer has more than 30 years of experience in performing fetal medicine scans in a tertiary centre. To obtain inter-observer variability, twelve logbooks, each consisting of 25 images were selected randomly and were independently assessed by all four reviewers.

Sonographers with an unsuccessful final assessment should attend a hands-on training provided by the Erasmus Medical Centre or other qualified training institute. Following the hands-on training a re-audit will be performed according to conditions as described above. If the re-audit is unsuccessful again, the Regional Organisation has the ability to dissolve the contract.

Portfolios were obtained and assessed from October 2012 to March 2015. During this period, the whole audit cycle of all participating centres in the Southwest region of the Netherlands was completed.

Inter-observer variability was assessed by calculating intra-class correlation on the logbook scores of the four reviewers. The Wilcoxon test was used to compare individual scores (fetal and biometric measures) and the total audit score between the primary audit and the re-audit. We estimated the association of the total audit score with all studied variables (characteristics of individual sonographers and organisations) as adjusted unstandardized regression coefficients (B) with 95% confidence interval using multiple linear regression analysis. For data analysis SPSS (version 21, Chicago, IL, USA) was used. For all tests, a value of p<0.05 was considered as statistically significant.

RESULTS

During the study period, 85 sonographers participated and 425 logbooks were assessed as part of the audit procedure. Since three out of five portfolios were selected for the final assessment, the results of 255 portfolios were analysed. The characteristics of the audited sonographers are shown in Table 1. Most of the sonographers (57%) worked in a medium size practice consisting of three to seven sonographers, 14% worked in

Table 7.1 Baseline characteristics of the individual sonographers and organisation

	Audited sonographers
	n (%)
Setting	
Hospital	33 (39%)
Independent ultrasound practice	43 (50%)
Independent midwifery practice with ultrasound facilities	9 (11%)
Number of sonographers within an ultrasound practise	
1-2 sonographers	12 (14%)
3-7 sonographers	48 (57%)
>7 sonographers'	25 (29%)
Sonographic experience	
Experienced	63 (74%)
New	22 (26%)
Accomplished the annual number of scans per year	
Yes	60 (71%)
No	25 (29%)
Audit period	
1 (Oct 2012 – Sept 2013	27 (32%)
2 (Oct 2013- Sept 2014)	37 (43%)
3 (Oct 2014 - April 2015)	21 (25%)

a smaller practice and 29% worked in a large ultrasound practice. From the audited sonographers, 74% had more than two years of experience in obstetric ultrasound and 71% of them yielded the goal of the annual number of scans required (Table 7.1).

An overview of the evaluated anatomical structures and biometric measurements are depicted in Table 7.2. Missing results occurred in approximately 0.25% (36/14,280) of the items because the reviewer had forgotten to document their score. The intraclass correlation was 0.974 (95% CI: 0.936 - 0.991) indicating that the inter-observer variability of the scoring method between the four reviewers was excellent. The head circumference and femur length were correctly measured in 94.5% (240/254) and 94.7% (233/246), respectively. Callipers for abdominal circumference were correctly placed in 86.6% (214/247). For the correct anatomical plane the best scoring structure was the bladder (94.5% (241/255)) and the worst scoring structure was the sagittal view of the fetal profile (75.5% (193/255)). For the correct magnification the best scoring structure was the axial and suboccipitobregmatic view of the fetal head (93.3% (238/255)) and the poorest scoring structure was the four chamber view of the fetal heart (78.4% (200/255)). All images of fetal head, brain, spine, four chamber view of

Table 7.2 Ultrasound evaluation of fetal structures and biometric measurement. Ultrasound evaluation of fetal structures and biometric measurement

	Plane	ıe	W	Magnification		Placen	Placement callipers	
Total n = 255	Adequate	əteupəbenl	Adequate	əteupəbenl	Jn9sdA	ejenbəp∀	ətsupəbenl	Jn∋sdA
Central Nervous System								
Axial view head	237 (92.9%)	18 (7.1%)	238 (93.3%) 17 (6.7%)	17 (6.7%)	,	215 (84.6%) * 39 (15.4%)	39 (15.4%)	
Suboccipitobregmatic view	234 (91.8%)	21 (8.2%)	238 (93.3%)	17 (6.7)	ı	247 (97.2%) *	7 (2.8%)	,
Spine	217 (85.1%)	38 (14.9%)	217 (85.1%) 38 (14.9%) 237 (92.9%) 18 (7.1%)	18 (7.1%)	1		,	,
Face								
Sagittal view profile	193 (75.7%)	45 (17.6%)	193 (75.7%) 45 (17.6%) 209 (82.0%) 29 (11.3%) 17 (6.7%)	29 (11.3%)	17 (6.7%)			1
Orbital diameters	234 (91.8%)	8 (3.1%)	231 (90.6%) 11 (4.3%) 13 (5.1%)	11 (4.3%)	13 (5.1%)	,	,	,
Coronal view nose, lips and chin	219 (85.9%)	34 (13.3%)	34 (13.3%) 236 (92.5%)	17 (6.7%)	2 (0.8%)	,	,	,
Thorax								
Shape and echogenicity lungs	213 (83.5%)	36 (14.1%)	217 (85.1%) 32 (12.5%)	32 (12.5%)	6 (2.4%)			1
Diaphragm	200 (78.4%)	50 (19.6%)	216 (84.7%) 34 (13.3%)	34 (13.3%)	5 (2.0%)		1	
Four chamber view	223 (87.4%)	32 (12.5%)	200 (78.4%)	55 (21.6%)	ı		1	
Heart: left outflow tract	223 (87.4%)	31 (12.2%)	211 (82.7%) 43 (16.9%) 1 (0.4%)	43 (16.9%)	1 (0.4%)		1	
Heart: right outflow tract	223 (87.5%)	29 (11.4%)	220 (86.3%) 32 (12.5%)	32 (12.5%)	3 (1.2%)	1	1	,
Heart: three vessel view	237 (92.9%)	17 (6.7%)	222 (87.1%) 32 (12.5%) 1 (0.4%)	32 (12.5%)	1 (0.4%)	1	1	1

Table 7.2 Ultrasound evaluation of fetal structures and biometric measurement. Ultrasound evaluation of fetal structures and biometric measurement (continued)

	Plane	эı	W	Magnification		Placen	Placement callipers	
Total n = 255	əteupəbA	əteupəbenl	Adequate	əteupəbenl	Jn9sdA	əteupəbA	ətsupəbenl	tnəsdA
Abdomen								
Abdominal circumference	230 (90.6%) *	24 (9.4%)	234 (92.9%) [†]	18 (7.1%)		214 (86.6%) #	33 (13.4%)	1
Abdominal wall	221 (87.0%) *		28 (11.0%) 216 (85.0%)* 33 (13.0%)	33 (13.0%)	5 (2.0%)			,
Bowels	210 (82.4%)	24 (9.4%)	212 (83. 2%)	22 (8.6%)	21 (8.2%)			1
Kidney left	227 (89.0%)	28 (11.0%)	28 (11.0%) 220 (86.3%) 35 (13.7%)	35 (13.7%)		166 (65.9%) [†] 86 (34.1%)	86 (34.1%)	1
Kidney right	210 (82.3%)	43 (16.9%)	212 (83.1%)	41 (16.1%)	2 (0.8%)	154 (61.1%) ⁺	97 (38.5%) 1 (0.4%)	1 (0.4%)
Bladder	241 (94.5%)	9 (3.5%)	222 (87.0%)	28 (11.0%)	5 (2.0%)		,	,
Extremities								
Femur	238 (93.3%)	14 (5.5%)	229 (89.8%)	23 (9.0%)	3 (1.2%)	233 (94.7%) §	10 (4.1%)	3 (1.2%)
Left leg and foot	202 (79.2%)		44 (17.3%) 226 (88.6%)	20 (7.9%)	9 (3.5%)	1	1	1
Right leg and foot	204 (80.0%)	43 (16.9%)	229 (89.8%)	18 (7.1%)	8 (3.1%)		1	1
Left arm and hand	229 (89.8%)	18 (7.1%)	229 (89.8%)	17 (6.7%)	9 (3.5%)	1	1	1
Right arm and hand	220 (86.3%)	24 (9.4%)	229 (89.8%)	15 (5.9%)	11 (4.3%)		1	1
Umbilical cord	240 (94.5%)*	12 (4.7%)	237 (92.9%)	16 (6.3%)	2 (0.8%)	1	1	ı
Relationship between placenta and internal cervical os	199 (78.0%)	42 (16.5%)	42 (16.5%) 226 (88.6%)	15 (5.9%)	14 (5.5%)	1	1	1
$S = \{ S : S : S : S : S : S : S : S : S : S$								

*= 1 missing, t = 3 missing, t = 8 missing, t = 9 missing.

the heart and one kidney were present in the portfolios. Of all other required images between 0.8% (umbilical cord) and 8.2% (bowel echogenicity) had not been stored and could not be reviewed and scored zero points. Overall, 2.1% (136/6375) of the images were not stored.

In the primary audit 73 sonographers (86%) had a successful image quality assessment and twelve sonographers (14%) failed to meet the criterion of three adequate scores out of five portfolios and therefore had an unsuccessful image quality assessment. After the primary audit one sonographer ceased working as a sonographer, the remaining eleven sonographers participated in the re-audit after individual feedback and handson training. All of them had a successful final assessment. The total audit score of these eleven sonographers was significantly higher (p < 0.001) in the re-audit compared to the primary audit (Figure 7.2). A more detailed analysis for each evaluated fetal anatomical structures and biometric measurements in the primary and re-audit is presented in the supplementary table.

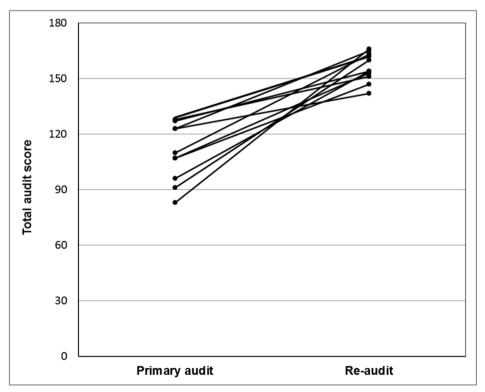


Figure 7.2 Individual sonographers' total audit score in the primary and re-audit of fetal ultrasound structures and biometric measurements.

Table 7.3 The association between total audit score and characteristics sonographers and organisation.

	Mean total audit score	Regression - coefficient (B)	p value	95%-CI
Setting				
Hospital	145	0.00		reference
Independent ultrasound practice	144	-5.62	0.31	-16.5 – 5.3
Independent midwifery practice with ultrasound facilities	147	12.67	0.09	-1.9 – 27.2
Number of sonographers within an ultrasound p	ractise			
1-2 sonographers	130	0.00		reference
3-7 sonographers	145	21.4	0.001	8.8 – 34.0
>7 sonographers	151	26.9	< 0.001	12.2 – 41.6
Sonographic experience				
Experienced	144	0.00		reference
New	146	6.2	0.25	-4.4 – 16.7
Accomplished the annual number of scans per y	ea <i>r</i>			
Yes	147	0.00		reference
No	138	-14.0	0.009	-24.53.6
Audit period				
1	138	0.00		reference
2	148	11.0	0.04	0.6 - 21.5
3	148	6.8	0.23	-4.3 – 17.9

During the primary audit an annotation of the ultrasound image ('to depict right or left side') was present for kidneys in 142 out of 254 (56%) cases and for upper and lower extremities in 88 out of 245 (36%) cases. In the re-audit the percentages for an annotation on the ultrasound image were similar for the kidneys (73%; p = 0.07), but did improve for the upper (67%; p = 0.001) and lower extremities (70%; p < 0.001). The number of sonographers working within an ultrasound practice and fulfilment of required annual number of scans was positively associated with a higher total audit score after adjustment for all study variables (Table 7.3).

DISCUSSION

This study is the first published audit on the performance of the anomaly scan in the Netherlands since the beginning of the nationwide screening programme in 2007. This audit was conducted in southwestern region of the Netherlands consisting of both

highly urbanized and countryside areas. Seventy-three out of 85 sonographers met the audit criteria in the primary audit, and performance was largely similar considering the setting of the ultrasound unit, years of experience of the individual sonographer and the period of the audit. Sonographers who failed the first audit were subject to an individual hands-on training and succeeded in the re-audit, except for one sonographer, who ceased her contract.

The legislative framework for the nationwide prenatal screening programme mandates this programme and financing of the quality control system. Clear quality criteria were set and only sonographers meeting those criteria were legally permitted to perform anomaly scans by means of being contracted to a regional organisation. Auditing the individual sonographer on qualitative issues was commenced five years after starting the programme, implying that most sonographers had executed a substantial number of scans. Our study showed that the initial performance in our region was good (73/85; 86%) and could easily be improved to 100%.

Contracted sonographers were obliged to perform a minimum number of scans per year, but a substantial part of them (29%) did not meet this criterion. We demonstrated a significant correlation between number of scans executed per year and the total audit score, implying the relevance of setting a minimum number of scans, which is in line with an improvement in quality with increasing numbers of NT measurements.¹³ Moreover, a recent study demonstrated that the level of experience and working volume of the sonographer performing the anomaly scan influence rates for revision and referral to a centre for prenatal diagnosis.¹⁴

A significant correlation between the individual performance and the number of sonographers in an ultrasound unit, in favour of large units was demonstrated. Larger units often have implemented internal quality control systems, that probably result in significantly better scores. A Cochrane Review on audit and feedback confirmed this observation.¹⁵ It was suggested that feedback from a supervisor or colleague is shown to be more effective than from an outsider, that might explain why larger units perform better.¹⁵

Quality control of nuchal translucency measurements, based on an image-scoring method demonstrated that an implementation of an ongoing audit *itself* leads to an improvement of image quality. It was shown before in the United States and Canada that a voluntary accreditation of ultrasound practices leads to an improvement of their quality of work. The sonographers in our study compiled their own portfolio which resulted in awareness of image acceptability and lacking images. Previous studies showed that sonographer's own assessment of image acceptability facilitated quality improvement. Most sonographers with an inadequate score acknowledged the judgement by the auditor during audit visit. Realising that failing to continuously keep

adapting the magnification and the correct plane of a structure during the scan of a moving fetus results in storing of inadequate images.

Approximately 2.1% of the required images for the digital portfolio were not available for assessment. Both ISUOG⁴ and NVOG⁶ recommend permanent storing of all images and delineating the results and conclusions of the scan. A proper storage can help the sonographer to avoid litigation and to defend against it ²⁰, as stated by the American College of Obstetrics and Gynecology (ACOG), 'Absence of visual image documentation eliminates the possibility of future review and weakens the defense against an allegation that an incomplete or inadequate study was performed'.^{21, 22}

The incorrect placement of callipers for abdominal circumference in 13.4% of cases is a serious issue. Inaccurate fetal biometry measurements could result in growth estimation errors. ^{19, 23} Due to the audit sonographers became aware of the necessity to improve their accuracy both in fetal anatomical structures and fetal biometry.

After the introduction of the fetal anomaly scan in the Netherlands, detection rates of several anomalies, such as structural heart disease²⁴⁻²⁶, cleft lip²⁷ and open spina bifida²⁸ have increased. However, a quality assessment study for the individual sonographer based on detection rates is not feasible since 2.3% of all pregnancies is affected with congenital anomalies.²⁹ During one year of scanning, sonographers may only encounter occasionally an abnormal finding, therefore, other methods are required to assess and maintain quality preferably supported by legislative framework.

This study had several strong points and limitations. We were able to use actual scans from the actual work situation and scans were randomly selected by the Regional Organisation. All sonographers in our region were obligated to participate in the quality assessment and this was not performed on voluntary basis. Although the quality standards were defined and communicated before starting the audit, the majority of the sonographers did not fully appreciate these new requirements of their practice. Only 38/87 (44%) of the sonographers had experience with image auditing due to nuchal translucency assessment but in that case sonographers may select their own images³⁰ contrary to our method were the audit team randomly selects the examinations.

A limitation of the study was that it took 2.5 years to complete the whole audit cycle. Sonographers evaluated at the end of the audit cycle could have been better informed about the audit method, although the audit score was not significantly dependent of the audit period. Secondly, we were unable to correlate the individual audit score with actual clinical performance because of the low prevalence of congenital anomalies. Another limitation was that we did not ask for annotations as a standard performance. Annotations can improve the interpretation of scans and increase the reliability of the image storage. Annotations are common practice in radiologic imaging.

CONCLUSION

In conclusion, we developed an objective score-based method for quality assessment of fetal images⁹ and evaluated the scanning performance of the sonographers in the southwest region of the Netherlands, being the largest screening region in the Netherlands. Four out of five sonographers met the criteria in the primary audit and after an individual hands-on training all sonographers had a successful assessment. This quality assessment might make sonographers more aware of their performance.

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SUPPLEMENT

Supplementary table 7.1 Ultrasound Evaluation in Primary Audit and Re-audit of Fetal Structures and Biometryupplementary table 1. Ultrasound Evaluation in Primary Audit

	Primary	Primary Audit ($N = 33$)	V = 33)						Re-audit (N = 33)	(N = 33						
	Plane		Magnification	cation		Placeme	Placement Calipers		Plane		Magnification	ation		Placement Calipers	nt Calip	ers
	ə3eupəb∤	əţenbəpeul	ətsupəbA	əteupəbenl	in∍sdA	əţenbəp∀	əteupəbenl	ınəsd∧	əteupəbA	ətsupəbsal	ə₃enbəp∀	əteupəbenl	in∍sdA	əţenbəp∀	əteupəbenl	≀n∋sdA
Central Nervous System																
Axial view head	29 (888%)	4 (12%)	28* (85%)	5 (15%)	1	21* (64%)	12 (36%)	1	28 (85%)	5 (15%)	33* (100%)	1	1	32* (97%)	1 (3%)	ı
Suboccipitobregmatic view	28 (85%)	5 (15%)	27 (82%)	6 (18%)	1	31 (94%)	2 (6%)	1	30 (91%)	3 (9%)	31 (94%)	2 (6%)	ı	31 (94%)	2 (6%)	1
Spine	25 (76%)	8 (24%)	22* (67%)	11 (33%)	1	1	1	ı	23 (70%)	10 (10%)	32* (97%)	1 (3%)	ı	1	ı	1
Face																
Sagittal view profile	14* (42%)	12 (37%)	15* (46%)	11 (33%)	7 (21%)	•		1	25* (76%)	7 (21%)	31* (94%)	1 (3%)	1 (3%)		1	1
Orbital diameters	23* (70%)	4 (12%)	24* (73%)	3 (9%)	6 (18%)	1	1	1	32* (97%)	1	31* (94%)	1 (3%)	1 (3%)	1		1
Coronal view nose, lips and chin	24 (73%)	9 (27%)	29 (88%)	4 (12%)	ı	1	1	1	30 (91%)	3 (9%)	31 (94%)	2 (6%)	1	1	ı	1
Thorax																
Shape and echogenicity lungs	23* (70%)	7 (21%)	16* (49%)	14 (42%)	3 (9%)			1	30*	3 (9%)	32* (97%)	1 (3%)	1	1	1	1

Supplementary table 7.1 (continued)

																١
	Primary	Primary Audit ($N=33$)	N = 33						Re-audit (N = 33)	(N = 33)	(
	Plane		Magnification	cation		Placeme	Placement Calipers		Plane		Magnification	ation		Placement Calipers	nt Calip	ers
	ə₃enbəp∀	əteupəbenl	əteupəbA	əteupəbenl	in∍sdA	ə1supəbA	əteupəbenl	≀uəsq∀	ətsupəbA	əteupəbenl	ətsupəbA	əteupəbenl	≀uəsq∀	ətsupəbA	əteupəbenl	₃uəsq∀
Diaphragm	28 (85%)	3 (6%)	14* (42%)	16 (49%)	3 (9%)	ı	1	1	31 (94%)	3 (6%)	32* (97%)	1 (3%)	1	1		
Four chamber view	24 (73%)	9 (27%)	19* (58%)	14 (42%)	ı	1	ı	1	28 (85%)	5 (15%)	30* (91%)	3 (9%)		1	ı	
Heart: left outflow tract	28 (85%)	5 (15%)	20* (61%)	13 (39%)	ı	1	ı	1	30 (91%)	3 (9%)	31* (94%)	2 (6%)	1	ı	ı	1
Heart: right outflow tract	28 (85%)	5 (15%)	20* (61%)	13 (39%)	ı	1	ı	1	31 (97%)	1 (3%)	31* (94%)	2 (6%)	1	ı	ı	1
Heart: three vessel view	26 (79%)	7 (21%)	20* (61%)	13 (39%)	1	1	1	1	29 (88%)	4 (12%)	30* (91%)	3 (9%)	1	1	1	1
Abdomen																
Abdominal circumference	27 (82%)	6 (18%)	23* (70%)	10 (30%)	ı	26 (84%) [‡]	5 (16%)	1	28 (85%)	5 (15%)	33* (100%)	1		32 (97%)	1 (3%)	
Abdominal wall	24* (75%) [†]	5 (16%)	15* (47%) [†]	14 (44%)	3 (9%)	ı	1	1	32* (97%)	1 (3%)	33* (100%)	1		ı		1
Bowels	19* (58%)	5 (15%)	16* (49%)	8 (24%)	9 (27%)	1	1	1	33* (100%)	0	33* (100%)	1	1			1
Kidney left	26 (79%)	7 (21%)	19* (58%)	14 (42%)	ı	11* (34%) [†]	21 (66%)		31 (94%)	2 (6%)	32* (97%)	1 (3%)		24* (80%) [§]	6 (20%)	

Supplementary table 7.1 (continued)

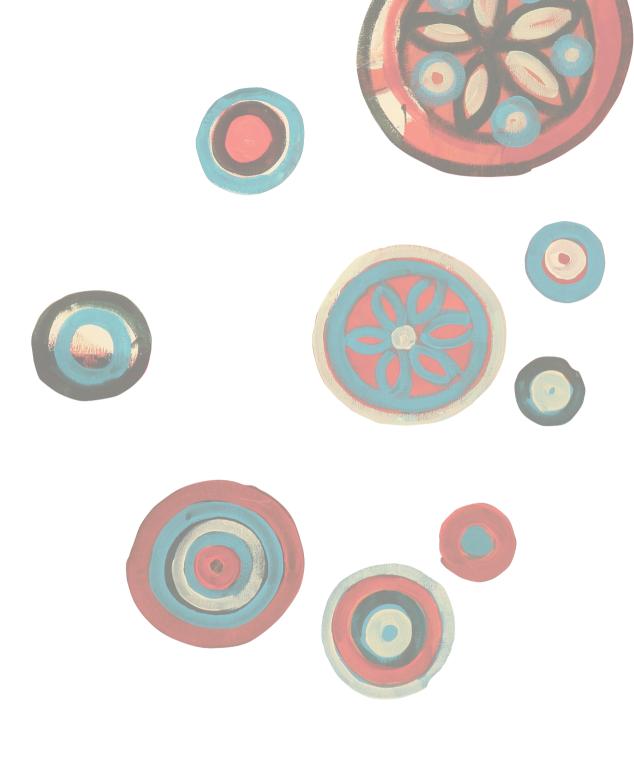
	Primary	Primary Audit (N =	N = 33						Re-audit (N	(N = 33)	(
	Plane		Magnification	ication		Placeme	Placement Calipers		Plane		Magnification	ation		Placement Calipers	nt Calipe	ers
	əĭsupəbA	əteupəbenl	ə₃enbəp∀	əteupəbenl	≀n9sdA	ə₃enbəp∀	əteupəbenl	tn9sdA	ətsupəbA	əteupəbenl	ətsupəbA	ətsupəbsal	in∍sdA	ə1supəbA	əteupəbenl	tn∋sdA
Kidney right	22 (67%)	10 (30%)	14* (42%)	18 (55%)	1 (3%)	9* (28%) +	23 (72%)	1	29 (88%)	4 (12%)	31* (94%)	2 (6%)	1	24* (80%) [§]	6 (20%)	
Bladder	27* (82%)	2 (6%)	19* (58%)	10 (30%)	4 (12%)	1	1	1	32* (97%)	1	30* (91%)	2 (6%)	1 (3%)	ı	1	
Extremities																
Femur	28* (85%)	3 (9%)	20* (61%)	11 (33%)	2 (6%)	24 (80%) [§]	4 (13%)	2 (7%)	33* (100%)	1	32* (97%)	1 (3%)	1	28 (85%)	5 (15%)	1
Left leg and foot	20* (61%)	5 (15%)	18* (55%)	7 (21%)	8 (24%)	1	1	1	31* (94%)	2 (6%)	33* (100%)	1	1	1	1	
Right leg and foot	18* (55%)	7 (21%)	20* (61%)	5 (15%)	8 (24%)	1	1	1	29* (88%)	4 (12%)	32* (97%)	1 (3%)	1	ı	1	
Left arm and hand	23* (70%)	3 (9%)	17* (52%)	8 (24%)	8 (24%)	1	1	1	31* (94%)	2 (6%)	32* (97%)	1 (3%)	1	1	1	
Right arm and hand	21* (64%)	2 (6%)	19* (58%)	4 (12%)	10 (30%)	1	1	1	31* (94%)	2 (6%)	32* (97%)	1 (3%)	1	ı	1	1
Umbilical cord	29 (88%)	3 (9%)	20* (61%)	12 (36%)	1 (3%)	1	1	1	32 (97%)	1 (3%)	33* (100%)	1	1	ı	ı	1
Relationship between placenta and internal cervical os	19* (58%)	8 (24%)	25* (76%)	2 (6%)	6 (18%)	1	1		32* (97%)	1 (3%)	32* (97%)	1 (3%)	1	1	1	1

*Statistically significant difference (P < .05) between primary and re-audit scores for plane, magnification, or placement calipers. t = 1 missing, t = 2 missing, t = 3 missing.



PART III

Improving informed decision making, healthcare knowledge and healthy behaviour



Reproductive health peer education for multicultural target groups

8



Peters IA Schölmerich VLN van Veen DW, Steegers EAP Denktaş S

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ABSTRACT

Purpose: Dutch perinatal mortality rates are relatively high compared to other European countries. Non-Western ethnic minorities show particularly adverse outcomes. They seem to have low health literacy and less access to health care. We studied the characteristics of the participants and the success of the recruitment methods and increase in knowledge of participants in Reproductive Health Peer Education (RHPE). *Design:* we targeted specifically these groups, and developed reproductive health education covering the full spectrum of obstetric care, led by specifically trained female peer educators coming from the targeted communities.

Findings: 'Active' recruitment methods were the most successful methods. 1896 women and 275 men were recruited and participated in the intervention. 65% of the total female participants had a first generation immigrant background. Significant knowledge improvements were found on all five measurements of reproductive behaviour and antenatal and postnatal health care system knowledge (24% average knowledge increase in already knowledgeable participant group and 46% in the not knowledgeable group).

Conclusion: active interpersonal recruitment methods were most successful in reaching the target groups. Peer education resulted in knowledge increase in these groups. Practice implications: invest in training of educators for peer education reproductive health. Organize recruitment by verbal advertising by community organizations and social networks of peer educators.

Originality: to our knowledge, no studies have been conducted combining investigation of the results of specific recruitment methods, the characteristics of reached participants in a multi-ethnic population and their increase in knowledge about reproductive health and care.

INTRODUCTION

Perinatal mortality rates are relatively high in the Netherlands when compared to all other European countries. ¹ This is in particular the case for large cities where perinatal mortality rates are 20 to 50% higher than in rural areas.^{2, 3} Within large cities, substantial inequalities can be found. For instance, in Rotterdam, neighborhood perinatal mortality rates range from 2 to 34‰.³ Inequalities can also be found when considering the perinatal health of different ethnic groups. Among non-western ethnic minority women, the perinatal mortality rates are higher than those of western minorities and the native Dutch. ³ Non-western ethnic minorities represent 11,4% of the population of the Netherlands and 32% of the inhabitants of the four largest cities in the Netherlands.⁴ Many studies have shown that ethnicity and socio-economic deprivation are strongly related to adverse perinatal outcomes such as preterm birth and too small for gestational age.⁵⁻⁷ These trends are not unique to perinatal outcomes, but can also be seen when considering the general health of non-western ethnic minorities in a socio-economic disadvantaged position. ⁸

When compared to Dutch natives and western minorities, non-western ethnic minorities groups not only show poorer general health, but are also underserved by health care (RIVM, 2007). This means that they have insufficient access to health care, as evidenced by not timely use of health services which can affect their health outcomes. Ample studies have indicated a relationship between access to health care and general health. Some studies even claim that limited access to health care resources is the most important contributing factor for ethnic disparities in health. In the area of reproductive health, one third of Moroccan and Antillean women book their first antenatal visit with an obstetric caregiver after 14 weeks of pregnancy, which is often too late to allow for routine first trimester prenatal screening and provision of other prenatal healthcare. Health literacy is also problematic as these groups have e.g. low awareness of folic acid supplementation and of the negative effect of smoking during pregnancy. Limited knowledge of health services in general and reproductive health services specifically can be a major barrier to use health care services.

In 2009 an urban perinatal health programme called 'Ready for a Baby' was initiated in Rotterdam, the second largest city of the Netherlands. Rotterdam has a population of more than 600.000 citizens. 52% of the inhabitants have a native Dutch background, 11% have a western minority background and 37% have a non-western minority background. In International Interna

The aim of the city wide Ready for a Baby programme is to tackle perinatal health inequalities and to improve perinatal health outcomes. Timely reaching of women with a high risk profile is an important aim of this programme. Therefore, we developed -

as a part of this program - an intervention aimed at improving the low reproductive health (care) literacy of non-western ethnic minority groups in socially disadvantaged neighbourhoods.

We hypothesized that 1) active recruitment methods based on interpersonal interaction are more effective methods in reaching the target groups for reproductive health education than passive methods, and 2) for the target groups customized peer education is an effective method to increase knowledge about reproductive health and the healthcare system.

METHODS

Reproductive health peer education: theoretical framework

Health related peer education is an approach whereby community members are supported to promote health-enhancing change among their peers. A more conventional method would be to train (non-peer) health professionals to address the needs of specific target groups. Proponents of peer education argue that specifically trained lay people are in a better position to encourage healthy behavior amongst their peers. Turner and Shepherd listed 10 commonly cited and review based arguments for the use of peer education (see box 8.1).²²

Box 8	3.1
1	Peer education can be used to educate those who are hard to reach through conventional methods
2	It utilises an already established means of sharing information and advice
3	Education presented by peers may be acceptable when other education is not
4	Peer education is beneficial for those involved
5	Peer educators act as good role models
6	It is more cost effective then other methods
7	Peers are more successful than professionals in passing on information because people identify with their peers
8	Peer education is empowering for those involved
9	Peers are a credible source of information
10	Peers can reinforce learning through ongoing contact

Phase I: training peer educators

The first phase of the intervention started in September 2010. 16 bilingual women with a non-western ethnic minority background, and a high school diploma were trained during a full-time six month course (intermediate vocational educational level 4) to become peer educators. The course covered a wide range of topics, including communication and health education skills, basic knowledge about diseases and the Dutch health care system. The focus of the course was on reproductive health. The students were trained to lead four educational meetings: preconception, antenatal, intrapartum and postpartum health and care (see box 8.2). During the course, the students were also trained to translate the (biomedical) messages of caregivers into the language and cultural framework of an ethnically diverse target group. In 2011, 12 students graduated as peer educators perinatal health. The educators had different backgrounds: Moroccan (Dutch/Arabic/Berber language proficiency (LP), Turkish (Dutch/Turkish LP), Antillean (Dutch/Portuguese LP), Surinamese-Creole (Dutch/Scranantango LP), Brazilian (Dutch/Portuguese LP), and Cape Verdean (Dutch/Portuguese LP).

Box 8.2 Peer education modules & topics

1 Preconception health and care

Folic acid, alcohol, drugs, cigarette use, healthy nutrition intake, sexual transmitted diseases, medication, lifestyle of male partner, preconception health care system.

2 Antenatal health and care

Healthy lifestyle, the three trimesters of pregnancy, pregnancy symptoms, necessity of pregnancy checks and preparation for childbirth, organization of antenatal care,

3 Intrapartum health and care

Starting of the delivery, contractions, rupture of membranes, childbearing process, placenta, complications, painkillers.

4 Post partum health and care

The delivery, risk signals, a healthy start for mother and child, motherhood, infant and youth centres, post partum health care system

Phase II: recruiting participants and execution of the peer educational Meetings

Phase II started in July 2011 and ended in April 2012. Primarily women were targeted, but men who were interested to participate were not excluded. Inspired by previous studies ²², the participants were recruited by two active and two passive methods (see figure 8.1).

Peer educational meetings

After recruitment of the participants the meetings were organized. The meetings always had the same structure:

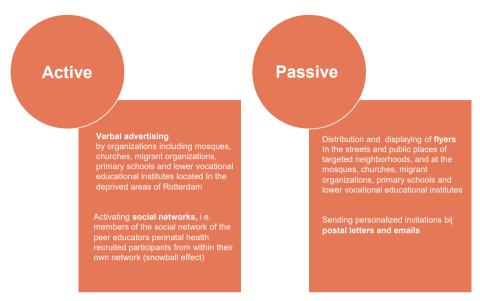


Figure 8.1 Active and passive recruitment methods

- Start: acquaintance and fill in pre-test questionnaires by participants;
- *Peer Education:* customized knowledge transfer using presentations, role-play, discussions, images (e.g. in case of very low educated groups), educational video clips and games (e.g. in case of an adolescent group).
- End: verbal evaluation and fill in post-test questionnaires by participants.
 In order to create a safe and open atmosphere women's and men's groups were separated.

Measurements

To collect data on the characteristics of the individuals reached by this pilot, participants were asked to fill in questionnaires. Twenty-five percent of the 2171 individuals who filled in the questionnaire received assistance from the peer educators because of their low language proficiency level. The questionnaires were specifically adjusted for the four aforementioned peer education meetings (see box 8.2).

The questionnaires obtained information about the participants' socio-demographic characteristics: age [year of birth], ethnic background [participant's country of birth and that of his or her parents], generation [first generation immigrants are born outside the Netherlands, second generation immigrants are born in the Netherlands and have at least one parent born abroad] ²³, marital status [yes/no], children [yes/no], educational attainment level [from low: not completed education, primary school to high: higher vocational education, university, other: residual category], place of residence [four digit zip code]. Information about residence made it possible to infer their neighborhood

social-economic classification by using the 'Social Index'. This index is calculated annually for the Rotterdam municipal authorities by the Centre for Research and Statistics Rotterdam. The Social Index is a composite multidimensional variable indicating neighborhood social quality on a 1-10 scale.^{24, 25} Self-reported information about the Dutch language proficiency of the participants was also obtained ["When you have a conversation in the Dutch language do you have difficulty with it?'[low: often/always difficulty, intermediate: frequently but not always difficulty, high: never difficulties].

Information was also obtained about the way participants were recruited by the openended question "How were you recruited for this meeting?" Answers were categorized into 'verbal advertising by organizations', 'flyers', 'mailing' and 'social network'. Furthermore, participant's preferences for healthcare providers or other caregivers when seeking advice about preconception, antenatal, intrapartum and postpartum health and care were asked. Finally, information was obtained about knowledge of reproductive health and the health care system before and after the meeting. For example, before the meetings on preconception we asked whether the participant knew what preconception care is and after the meetings we asked whether she/he had learned new information about preconception care.

Analysis

First we described the participants by socio-demographic and socio-economic status, according to ethnic background. Chi-Square testing was performed to detect significant differences. To evaluate whether reproductive health (care) knowledge had increased, the non-parametric statistical McNemar test was used. All analyses were performed using IBM SPSS Statistics 20.

RESULTS

Response

In less than ten months, 1896 women and 275 men were recruited and participated in the intervention (table 8.1). Eighty four participants were excluded from the analyses because of missing or incomplete questionnaires, e.g. missing gender variable. 88% of the male participants were adolescents (<19 years). 90% of the female and 66% of the male participants had an ethnic minority background. 71% of the female participants lived in a neighbourhood classified as 'problematic' or 'vulnerable' by the Social Index. Relatively more men (65%) lived in a neighbourhood classified as social 'sufficient'. Only 17% of the female participants had 'insufficient' language proficiency.

	Women		Men	
Variable	N	%	N	%
Total	1896	87	275	13
Age (years)	1658		267	
,19<<19	449	27	236	88
20-29	252	15	10	4
30-39	412	25	7	3
40-59	412	25	11	4
≥60	133	8	3	1
Ethnic origin	1807		263	
Native Dutch	181	10	90	34
Surinamese	180	10	41	16
Antillean	74	4	30	11
Cape Verdean	55	3	5	2
Turkish	452	25	36	14
Moroccan	669	37	31	12
Other	192	11	30	11
Generation	1803		264	
First generation immigrant	1172	65	50	19
Second generation immigrant	444	25	124	47
Native Dutch	187	10	90	34
Married	1767		220	
Yes	1096	62	20	9
Children	1719		224	
Yes	1230	72	29	13
Educational attainment level	1692		442	
Low	795	47	151	62
Intermediate	718	38	88	36
High	67	4	1	1
Other	112	7	2	1
Social Index Score	1906		166	
Problematic 3.9 - 4.9	204	13	10	6

Table 8.1 Background characteristics of participants in Reproductive Health Peer Education N=217 (continued)

	Women		Men	
Variable	N	%	N	%
Vulnerable 5.0 – 5.9	932	58	33	20
Sufficient 6.0 – 7.0	449	28	107	65
Strong ≥7.1	24	1	16	10
Language proficiency	1519		221	
Insufficient	250	17	21	10
Sufficient	593	39	28	12
Good	676	44	172	78

Preferences of participants for health care professionals

Figure 8.2 shows the preferences of female participants for health care professionals or other caregivers with respect to the various reproductive stages. The results indicate the predominant preference for the midwife and the general practitioner during the periconceptional and antenatal period. In the post partum period midwifes and maternity nurses are reported as the preferred care providers followed by the family. Most men preferred the general practitioner during the preconception period, and the GP and the gynaecologist during the antenatal period. Because of the small size of the male participants results are not shown in the figure.

Results recruitment methods

Figure 8.3 shows the results of the four recruitment methods for each of the reproductive health meetings. The coloured lines with percentages show the contribution of a method for recruitment of participants for each of the four educational meetings. The peer educators organized 105 network meetings together with community organizations to achieve cooperation of these organizations in the recruitment. 75% of these network meetings directly resulted in inclusion of participants in the reproductive health meetings. 800 Flyers were distributed and 350 postal- and e-mails were send which accounted for 2% of the participants in the meetings. The interpersonal methods 'verbal advertising by organizations' and 'social network' were the most successful. Almost all participating men (91%) had been reached by 'Verbal advertising by organizations' (not shown in figure).

In addition to figure 8.2, table 8.2a and b show ethnic and generational differences in recruitment. Native Dutch and ethnic minority women both were most effectively recruited by 'verbal advertising by organizations'. The 'social network' method was particularly successful in recruiting ethnic minority women. No major generational

differences were found in recruitment except that the flyer method was more successful in reaching the second than first generation participants.

Knowledge improvements of participants in RHPE

Finally, figure 8.4 shows significant improvements that were found on all five measurements of knowledge of adequate reproductive behaviour and the antenatal en postnatal

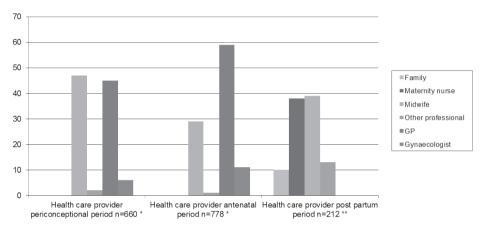


Figure 8.2 Preferences of female participants for perinatal healthcare professional

^{**} Answer options: GP, Midwife, Maternity nurse and Family

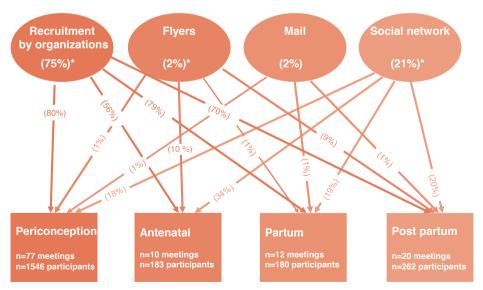


Figure 8.3 Recruitment of participants for Peer Education by four methods *P-value <0.001

^{*} Answer options: GP, Midwife, Gynaecologist and Other professional

Table 8.2a. Recruitment results of female native Dutch and first and second generation minority group participants for Reproductive Health Peer Education n=1.388 (in absolute numbers and percentages)

	Dutch N=172	Surinamese N=122	Antillean N=57	Cape Verdean N=38	Turkish N=337	Moroccan N=510	Other ¹²³ N=152
Verbal advertising by organizations	153 (89) abcd	95 (77) ^a	47 (82) ^e	31 (82)	236 (70) ^b	363 (70) ^{ce}	107 (70) ^d
Flyers	2 (1)	1 (1)	0 (0)	4 (10)	9 (3)	18 (3)	6 (4)
Mailing	0 (0)	2 (2)	0 (0)	0 (0)	1 (0)	10 (2)	1 (1)
Social network	17 (10) ^{abcd}	24 (20) ^a	10 (18)	3 (8)	91 (27) ^b	119 (23) ^c	38 (25) ^d

Non-Western Asian and African immigrants

Table 8.2b. Recruitment results of female immigrant generations for Perinatal Health Peer Education n= 1.235 (in absolute numbers and percentages)

	First generation n=880	Second generation n=355
Verbal advertising by organizations	626 (71)	253 (71)
Flyers	17 (2)*	23 (6)*
Mailing	12 (1)	2 (1)
Social network	225 (26)	77 (22)

^{*} Significant (<0.001) difference between first and second immigrant generation

health care system. For example, participants who did not know what folic acid and preconception care were before the reproductive health meeting had a significantly self-reported knowledge increase on this subjects of respectively 69% and 70%.

DISCUSSION AND CONCLUSION

Discussion

Non Western immigrant women are commonly difficult to reach, especially the first generation. In our study 65% of the total female participants had a first generation immigrant background. The recruitment results confirmed our first hypothesis that, active recruitment methods based on interpersonal interaction are more effective methods in reaching the target groups for reproductive health education than passive methods.

^a Significant (<0.05) difference between native Dutch and Surinamese group

^b Significant (<0.001) difference between native Dutch and Turkisch group

^c Significant (<0.001) difference between native Dutch and Moroccan group

^d Significant (<0.001) difference between native Dutch and Other group¹

^e Significant (<0.05) difference between Antillean and Moroccan group

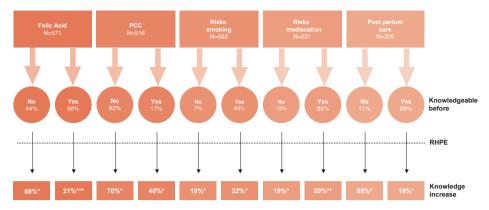


Figure 8.4 Knowledge before and after Reproductive Health Peer Education (RHPE)

Of all recruitment methods used, the active recruitment method 'verbal advertising by organizations' and 'social network' were most successful.

A comparison of demographic data of our participants with those from the general population confirmed that we reached our target group, i.e. participants with a nonwestern minority background living in socially deprived areas with potentially limited access to receive adequate antenatal and postnatal health care. A large majority (90%) of the participants were from a female immigrant background and lived in a neighbourhood receiving a 'problematic' or 'vulnerable' Social Index score. These neighbourhoods are at increased risk for adverse perinatal outcomes (perinatal mortality and perinatal morbidity).²⁵ According to data from the Centre of Research and Statistics Rotterdam (COS), these types of neighbourhoods show low scores for experienced health and high scores for registered use of primary care (but not for reproductive health care). 14, 26 These low health scores are associated with low income, a low language proficiency level, unemployment, weak social network and social cohesion and poor housing. ²⁶ These findings and our study results indicate that the target group needs support for healthy motherhood. The project successfully reached non-western ethnic minority females from deprived neighbourhoods. A majority of the participants lived in a neighbourhood (n=33) with a low Social Index score, 85% reported a low or intermediate educational level, and 17% of the females reported insufficient language proficiency. In these neighborhoods, a mean percentage of 2,4 [range 0,4 to 9,3%] among the target population [non Western female immigrants, aged between 18 and 42] was reached. 27 Compared to the native Dutch population more children are born in the non-Western immigrant groups. ²⁷ The Dutch National Institute for Public Health and the Environment has indicated that preventive lifestyle

^{*} P-value <0.001 PCC: Preconception Care

^{**} P-value <0.05 Risks smoking: health risks of smoking before and during pregnancy

^{***} P-value >0.05 Risks medication: health risks of medicaton use before and during pregnancy

interventions are not able to reach low SES groups, let alone non-western immigrant groups. ²⁸ Most Dutch publications about lifestyle interventions show a lack of absolute numbers of participation of specific target groups caused by the absence of registration of background characteristics like SES and ethnicity variables in these intervention programmes. ²⁹

The change of knowledge results confirm our second hypothesis that for the target groups customized peer education is an effective method to increase knowledge about reproductive health (care). After participating in the educational meetings a knowledge increase regarding adequate folic acid use, preconception care, smoking and medication intake was observed.

Health peer education has become very popular in the broad field of HIV prevention and it is also used to reduce tobacco, drug or alcohol abuse among young people. While not commonly used within the field of reproductive health, several international examples can be found of prenatal and postnatal peer led educational programmes focused on preconception health, HIV prevention for pregnant woman, nutrition, mental health, breastfeeding and smoking.^{30, 31} Most of the pregnancy-related peer education programmes were developed and evaluated for single health issues such as nutritional intake ³² in contrast to slightly broader education programmes in the United States of America, Nepal and India.^{33, 33} To our knowledge, this is the first time that a peer-led reproductive health education project spans the entire chain of obstetric care, ranging from the preconception to the postnatal health period.

Participants

The majority of participants were female which can be explained by (1) the pilot design (inclusion criteria: directed primary at women and secondary at men) and (2) the content of the meetings. Reproductive health is commonly perceived by both men and women as primarily "women's" issues. ^{35, 36} Nevertheless relatively high number of male adolescent participants can be explained by the fact that some of the meetings were organized in a school for intermediate vocational education. Three out of nine peer educators had a Moroccan background, which probably explains the higher proportion of Moroccan participants.

The higher number of first generation female participants is probably due to (1) the first generation immigrant status of most of the peer educators who might have more first generation females in their social network ^{37,2} the low employment rates of first generation immigrants which could provide more time for participating in the sessions ^{3,16,38} the higher educational level of second generation immigrants, who tend to feel that they are already knowledgeable enough ³⁸ and (4) the involvement of several immigrant organizations in the recruitment.

Recruitment

In our study the 'active' recruitment methods were by far the most successful method, which is in line with other studies ^{35,39,40} As expected, the passive methods (flyer and invitation by mail) were less successful, especially for first generation immigrants, probably due to insufficient language skills of these groups, which makes it difficult to read and understand text in Dutch.^{41,43}

Preferences for health care provider

Midwives, gynaecologists and general practitioners (GPs) are the designated professionals to offer preconception care in the Netherlands.⁴⁴ About 45% of the participants had a preference for seeing a midwife, whilst about the same percentage of the participants preferred a GP. A cross-sectional study found that 70% of the population of one of the districts of Rotterdam preferred a GP. ⁴⁵ Our study showed that GPs were also the mostly preferred choice for the first booking visit during pregnancy. Possible reasons for this are that (1) GPs are located in closer proximity than designated obstetric professionals (2) citizens are more familiar with GPs (3) ethnic minorities are less aware of the existence of midwifery care (in a non-hospital setting).¹³

Knowledge

Non-western ethnic minorities in the Netherlands tend to have low awareness of folic acid supplementation and of the negative effect of smoking during pregnancy. ^{13, 14} About half of our participants indicated that their knowledge of folic acid usage had increased after the educational meetings. This might suggest that the public campaigns and advice offered by governmental organizations and healthcare providers about folic acid use in the Netherlands did not fully reach our target group. The limited effectiveness of these methods might be caused by (1) the passive and impersonal nature of campaigns and (2) the lack of adaptation to people with low/intermediate educational levels ⁴⁶ In the educational meetings, participants learned about the negative effects of smoking before and during pregnancy. Despite of mass-media campaigns about the detrimental health effects of smoking for the general health, the meetings delivered new information. ⁴⁷ As expected, the majority of the participants indicated that they heard new information about preconception care. Other studies have shown that preconception care is not a very well known type of care. ^{48, 49}

Points of improvement

Registration forms were only available in the Dutch language. This might have caused a barrier for participants with poor Dutch language proficiency. Four percent of the questionnaires were incomplete (missing of gender variable and missing of more than five respondent characteristics) that were excluded from the analysis. We cannot fully oversee the consequences that these omitted questionnaires have for results of this

study. However, given the small number of exclusions (4%) we do not expect a bias. For future research we recommend translating the forms in the relevant languages or deployment of research assistants who can primarily focus on assisting participants in filling in the forms.

CONCLUSION

The peer led educational format used in this study was successful in reaching and educating non-Western ethnic minorities - a typically underserved population - for reproductive health education. Cornerstones of the success were 1) the active recruitment strategies 'verbal advertising by organizations' and 'social network', 2) the involvement of bicultural peer educators as recruiters and 3) a customized knowledge transfer using an eclectic peer educational method.

Practice Implications

In line with the results of this pilot study, we recommend educational programmes to invest in: a) training of educators for peer education about peer education reproductive health; training of educators with a Central African and Eastern European background are highly needed in the Netherlands as well as native Dutch peer educator; b) recruitment for peer education by verbal advertising by organizations and social networks of peer educators.

Future research

This pilot study showed that it is possible to reach first and second generation non-Western ethnic minority groups via reproductive health peer education. The success of this pilot is the starting point for a scaling-up of this method to other cities in the nationwide perinatal health program called 'Healthy Pregnancy 4 ALL' which started in 2011.

We recommend the following future research: (1) a network study of how recruiters / educators use their social network to recruit participants and (2) a study on how community organizations such as churches, mosques, schools and community centres are able to recruit participants.

Acknowledgements

Data collection and recruitment of participants for the educational sessions for this study was carried out by the reproductive health peer educators. In cooperation with the community organisations in the deprived neighbourhoods of Rotterdam, two of the recruitment strategies were performed. 'Zorgcampus' was together with the Erasmus MC responsible for coaching, training and employing the peer educators. We would

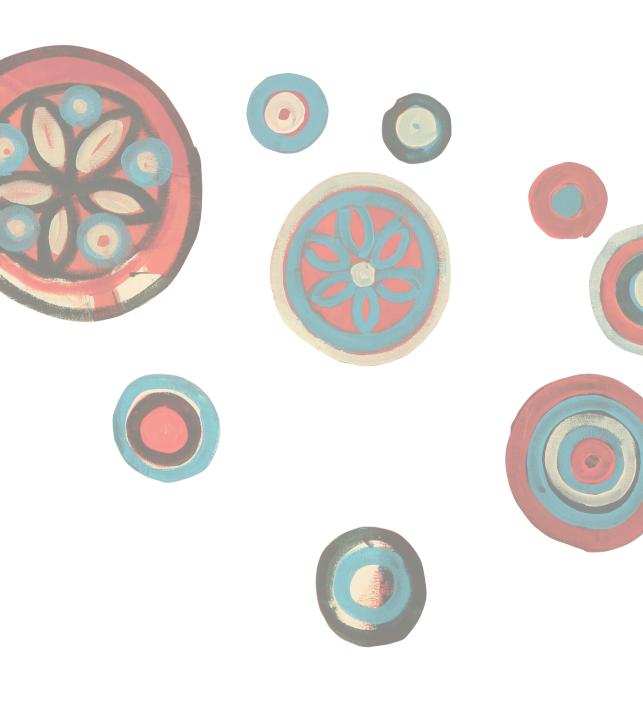
like to thank the Rotterdam Centre for Research and Statistics (COS, www.cos.rotter-dam.nl) for their cooperation.

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Effect of culturally competent educational films about prenatal screening on informed decision making of pregnant women in the Netherlands

A cross sectional study

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ABSTRACT

Objective: To evaluate the effect of a culturally competent educational film (CCEF) on informed decision making (IDM) regarding prenatal screening (PS) in a study population consisting of multicultural pregnant women.

Methods: A cross-sectional study with 262 women in the control group and 117 in the intervention group. All counselled participants received a self-report questionnaire to obtain data on IDM and only the intervention group received the CCEF. Twenty two percent of the study population had an ethnic minority background and 52% had a low or medium educational level. Results: After exposure to the CCEF, knowledge about the Fetal Anomaly Scan (FAS) was significantly increased in ethnic minority women and in 'medium' and 'highly' educated women. Among women in the intervention group who had the intention to participate in FAS, there was an increase of 11% in IDM and a decrease of 12% in uninformed decision making.

Conclusion: CCEF leads to a significant increase in the level of knowledge in medium and highly educated groups as well as non-western ethnic minority groups. The increase in IDM among intentional participants in the FAS is promising as well. CCEF's are a valuable complement to counseling about PS.

INTRODUCTION

The Dutch nationwide Prenatal Screening (PS) programme, supported by a legislative framework is unique in the world.^{1,2.} In the Netherlands, all pregnant women should actively be offered counselling about PS, consisting of the first trimester Combined Test (CT), a test for prenatal screening on Down syndrome ^{1,3}and the second trimester Fetal Anomaly Scan (FAS), screening for structural fetal anomalies.¹ The aim of counselling is to contribute to the autonomous Informed Decision Making (IDM) of pregnant women on participation in PS. An informed decision is made when a woman has adequate decision-relevant knowledge and her attitude towards participating in PS is consistent with her actual participation.⁴⁻⁶

In Dutch participants there is a strong association between a lower level of IDM on PS and inadequate information provision about PS. Other contributing factors are a non-Western background, low socioeconomic status (SES) or insufficient Dutch language proficiency.⁷⁻¹⁷ International studies on IDM in PS show that pregnant women, especially within ethnic minority groups²¹⁻²⁵, experience insufficient information provision¹⁸⁻²⁰ and reported a high percentage of low knowledge and IDM about PS.

Interventions to improve IDM in non-Western or low SES pregnant women should particularly aim to overcome cultural, language and 'information' barriers. ^{7, 26-28} Peer educators ^{21, 28, 29} and the use of educational films ^{30, 31} are promising methods to cope with these barriers. Therefore we combined the strengths of both, by developing CCEF's with peer educators to provide information about PS. We hypothesized that adding a CCEF to regular counselling would increase IDM on participation in PS of non-western pregnant women. With two consecutive cross sectional studies (the IDM-Intervention study) we assessed whether pregnant women made an informed decision more often after seeing the CCEF (Figure 9.1).

METHODS

The Culturally Competent Educational Films (CCEF's) were developed by the Foundation for Prenatal Screening in the Southwest region of the Netherlands (SPSZN). The films contained decision-relevant information about PS and were recorded in the four different languages that are spoken most often amongst non-western groups in the Netherlands (Dutch, Turkish, Moroccan-Arabic or Moroccan-Berber). Dutch, Turkish and Moroccan peer educators provided standardized information in the CCEF's (Supplement 9.1). To validate the content of the films, expert meetings were organized with experts on language, culture and obstetrics. We performed two consecutive cross sectional studies in the Southwestern region of the Netherlands. Pregnant women were included from December 2013 to June 2014 (control group) and from September

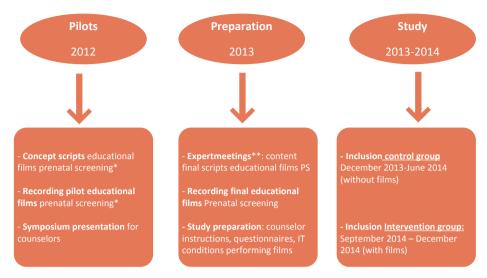


Figure 9.1 Study design IDM-Intervention study

- * In four languages: Dutch, Turkish, Maroccan-Berber and Maroccan-Arabic
- ** Separate meetings Focused on Dutch, Turkish, Maroccan-Berber and Maroccan-Arabic language and culture.

PS: prenatal screening

to December 2014 (intervention group) (Supplement 9.2). Participating counsellors (n=33) including midwives, sonographers, physicians and nurses working in hospitals, midwifery practices or sonographic centres included women with a gestational age of up to 24 weeks with a Dutch, Turkish or Moroccan ethnic background [women's country of birth and her parents' country of birth]³². Subsequently, we also included women with other ethnic backgrounds. To obtain data on Informed Decision Making (IDM), all respondents received a self-report questionnaire in the language of choice (Dutch, Turkish or Arabic) after counselling. Only the intervention group received the CCEF in the language of choice. The legal use of anonymous data of pregnant women was based on digital informed consent. After the study the participating counsellors filled out a questionnaire to report their experiences with the CCEF's (Supplement 9.3). IDM was measured by a questionnaire which was previously used ^{9, 33-35} with a general part containing questions on the pregnant woman's background and an IDM specific part with questions about knowledge, attitude and intentional participation in Prenatal Screening (PS) with the Combined Test (CT) and the Fetal Anomaly Scan (FAS). 9, 34, 35 Knowledge was measured using twelve statements about the CT and ten about the FAS with response options 'true', 'not true', and 'do not know'. The total knowledge score ranged from 0 to 10. Attitude towards undergoing the CT or the FAS was measured using a seven point scale, transformed into a 1-10 scale (Supplement 9.4).4 Intentional participation was measured by asking respondents whether they intended to participate

in the CT and the FAS. We combined *knowledge*, *attitude* and *intentional participation* to calculate the level of IDM.⁴ An informed decision was defined as having adequate knowledge (total score > 6.0), a positive attitude towards undergoing the screening (total score > 6.0) and an intention to participate consistent with this attitude. Chi-square tests were used for the associations and differences between maternal characteristics of the control and intervention group and knowledge, attitude towards participating in PS and IDM. To strengthen the comparability between both study groups for the analysis of IDM, we created a separate dataset. In this set we matched two equally large groups of records of control and intervention group women with similar background characteristics on ethnicity, gravidity, parity, educational level and age.

RESULTS

Table 9.1 shows that the respondents in the control and intervention groups were comparable in terms of background characteristics. Knowledge about the Fetal Anomaly Scan (FAS) was significantly increased in first generation (39% and 50% knowledgeable in respectively control group (CG) and intervention group (IG);p<0.001) and second generation (60% and 67% knowledgeable in resp. CG and IG;p<0.001) ethnic minority groups and 'medium' (70% and 80% knowledgeable in respectively CG; p<0.001 and IG; p<0.05) and 'highly' educated pregnant women (89% and 93% knowledgeable in respectively CG; p<0.001 and IG; p<0.05) (Table 9.2). Non-Western (67%, p<0.01) and medium educated (59%, p<0.05) intervention group women had significantly more often a positive attitude towards Combined Test (CT) (table 9.3).

There was an 11% increase of women who made an Informed Decision Making about intentional participation in FAS and a 12% decrease in uninformed decision making about whether or not to participate in FAS in the intervention group (table 9.4).

DISCUSSION

This study elucidated that Culturally Competent Educational Film (CCEF's) as part of the counseling on Prenatal Screening (PS) do lead to an increase in knowledge and Informed Decision Making (IDM) in specific groups. In comparison with other promising interventions to improve IDM, like group counseling and education ^{36,37} and the use of decision aids ³⁸⁻⁴⁰, CCEF's seem to be more suitable for women with a language barrier and lower health literacy levels. Presumably, the overall knowledge increase about the Fetal Anomaly Scan (FAS) in the intervention group can be explained by inadequate counseling about FAS ⁴¹ and reduced motivation to be informed about FAS due to misconception that FAS is routine obstetric care ¹¹, the relatively high Dutch uptake

Table 9.1 Background characteristics of pregnant women who participated in the 'IDM Intervention study'

	Conti	ol grou	p – no í	ilm ¹	Inte	rvention	group	– film 1
	Respo		NR n	=266	Resp n=1	oonse 17	NR	n=120
	Ν	(%)	N	(%)	Ν	(%)	Ν	(%)
Age (years)	2	249	2	200		113		81
≤ 19-29	108	(43)	92	(47)	49	(43)	42	(51)
30-35	114	(46)	84	(43)	55	(49)	32	(40)
≥ 36	27	(11)	20	(10)	9	(8)	7	(9)
Ethnic origin ²	2	248	2	234		113		109
Dutch	193	(78)	143	(61)	84	(74)	71	(65)
Surinamese, Antillean, Cape Verdean	15	(6)	-		4	(4)	-	
Turkish	9	(4)	24	(10)	6	(5)	13	(12)
Moroccan	7	(3)	27	(12)	2	(2)	14	(13)
Other Western	11	(4)	33	(14)	6	(5)	8	(7)
Other non-western	13	(5)	7	(3)	11	(10)	3	(3)
Native / Western / non-Western immigrant ²	2	248	2	234		113		109
Native	193	(78)	143	(61)	84	(74)	71	(65)
Western immigrant	15	(6)	7	(3)	12	(11)	3	(3)
Non-Western immigrant	40	(16)	84	(36)	17	(15)	35	(32)
Generation ²	2	44 ²				117 ²		
First generation immigrant	24	(10)			13	(11)		
Second generation immigrant	27	(11)			19	(16)		
Native Dutch	193	(79)			85	(73)		
Gravidity	2	243	1	90		105		75
primigravida	91	(37)	64	(34)	33	(31)	28	(37)
multigravida	152	(63)	126	(66)	72	(69)	47	(63)
Parity ²	2	261				117		
Nulliparous	125	(48)			48	(41)		
Primi/multiparous	136	(52)			69	(59)		
Religion ²	2	259				117		
Roman Catholic	39	(15)			13	(11)		
Protestant Christian	53	(20)			25	(21)		
Islam	26	(10)			17	(15)		

Table 9.1 Background characteristics of pregnant women who participated in the 'IDM Intervention study1397969521 (continued)

	Conti	ol grou	p – no í	film ¹	Interv	vention	group	– film ¹
	Response n=249		NR n=266		Response n=117		NR n=120	
	N	(%)	Ν	(%)	Ν	(%)	Ν	(%)
Hinduism, other religion, no wish to answer	12	(5)			7	(6)		
No religion	129	(50)			55	(47)		
Dutch language proficiency ²	262			1	116			
Fluent	250	(95)			111	(95)		
Limited	7	(3)			2	(2)		
Absent	5	(2)			3	(3)		
Education	2	249			1	112		
Low	14	(6)			7	(6)		
Medium	107	(43)			59	(53)		
High	128	(51)			46	(41)		
Urbanity	2	249	2	266	1	113		120
Rural	30	(12)	41	(15)	12	(11)	15	(13)
Urban	100	(40)	93	(35)	52	(46)	42	(35)
Highly urban	119	(48)	132	(50)	49	(43)	63	(52)

¹ Overview of missing baseline characteristics see Supplement 9.2. ² Data only available for response –group. Chi² testing gave no significant differences in background characteristics comparing control and intervention groups (response and non-response population.

rates of FAS ¹⁰, funding of FAS by health insurance companies and ¹⁰ incorrect assumptions about the purpose and performance of the FAS. ^{15, 16} Especially non-Western and first generation ethnic minority intervention group women are more knowledgeable about FAS than their control group counterparts. Possible explanations are a higher rate of health illiteracy and a decreased level of knowledge about PS within ethnic minority groups ^{7, 26, 42, 43}, a reduced provision of counseling and educational leaflets about PS (supplement 9.5) and difficulties experienced by healthcare professionals ^{14, 27, 41} in the counselling of non-western groups. We only found minor attitude changes in intervention group women, suggesting that the films do not change the basic attitude towards PS. This is in contrast with a comparable study in Sweden which used educational films about PS in one language. ⁴⁴ The analyses of the 'matched dataset' demonstrated an increased IDM in intervention group women who intended to participate in FAS. We believe that the increase of knowledge of intervention group women explains the increase of IDM in both participating and non-participating groups. IDM about inten-

tional participation in the Combined Test (CT) shows contradictory results. A possible explanation is that women tend to receive more detailed information on CT, making

Table 9.2 Knowledge of Prenatal Screening for control and intervention group

	Knowledge	CT		Knowledge FAS		
	Control 1	Intervention ²		Control 1	Intervention ²	
	N (%)	N(%)		N(%)	N(%)	
	Adequate knowledge	Adequate knowledge	Chi ²	Adequate knowledge	Adequate knowledge	Chi ²
	N=233	N=106		N=196	N=102	
Total group ³	198 (85)	87(82)	0.20	151 (77)	85 (83)	0.20
Age	N=233	N=105		N=196	N=101	
≤35	179(86)	79 (82)	0.45	134 (78)	77 (83)	0.34
≥36	19 (79)	8 (89)	0.52	17 (71)	8 (100)	0.08
Native/western / non-western	N=229	N=106		N=193 ***	N=102 ***	
Native	163 (90)	71 (90)	0.96	127 (85)	70 (91)	0.18
Western	14 (74)	6 (67)	0.70	10 (67)	6 (75)	0.68
Non-western	18 (62)	10 (56)	0.66	12 (43)	9 (53)	0.51
Generation ⁴	N=48 ***	N=27***		N=43***	N=25 ***	
First	10 (56)	7 (64)	0.66	7 (39)	5 (50)	0.57
Second	22 (73)	9 (56)	0.23	15 (60)	10 (67)	0.67
Education	N=232***	N=105**		N=195 ***	N=102 *	
Low	7 (58)	4 (57)#	0.96	4 (36)	3 (50)#	0.58
Medium	78 (77)	42 (75)	0.75	60 (70)	45 (80)	0.16
High	113 (95)	40 (95)	0.94	87 (89)	37 (93)	0.51
Urbanity	N=233	N=106		N=196	N=105	
L-m urban	19 (73)	3 (60)#	0.55	15 (75)	5 (83)	0.67
highly urban	179 (86)	84 (83)	0.44	136 (77)	83 (83)	0.24

Adequate knowledge: score of ≥ 6 points in knowledge assessment

Chi 2: comparison between Control and Intervention groups

[#] chi 2 cell count less than 5.

¹ Chi ² test within control group for differences in knowledge CT/FAS

 $^{^{\}rm 2}$ Chi $^{\rm 2}$ test within intervention group for differences in knowledge CT/FAS

³ Separate Chi ² testing shows significant differences in level of knowledge about CT and FAS comparing the overall control and intervention population. Significant increase of knowledge within intervention group about 'Content of combined test', 'Screening on neural tube defects with FAS' and 'The fact that FAS is not required' and a decrease of knowledge within the intervention group about 'Risks of invasive prenatal testing'.

⁴ No performance of native group in 'generation variable' because similarity with native group 'variable native/ western/non-western'.

Significance levels * P <0.05, ** P<0.01 , *** P<0.001

them more knowledgeable *before* watching the films, thus leaving less opportunity for improvement by means of the CCEF's. The fact that 50% of the study population had a low or medium educational level is a unique result in comparison with comparable research which included mostly higher educated women.^{44, 45} A limitation of the study is the short inclusion period of the intervention group women. We had to take

Table 9.3. Attitude of Prenatal Screening for control and intervention group

	Attitude C	T		Attitude FAS			
	Control 1	Intervention ²		Control 1	Intervention ²		
	N(%)	N(%)		N(%)	N(%)		
	Positive attitude	Positive attitude	Chi ²	Positive attitude	Positive attitude	Chi ²	
	N=234	N=106		N=198	N=102		
Total group	121 (52)	59 (56)	0.50	186 (94)	95 (93)	0.79	
Age	N=234	N=105		N=198	N=101		
≤35	104 (50)	51 (53)	0.58	163 (95)	87 (94)	0.68	
≥36	17 (68)	7 (78)	0.58	23 (89)	7 (88)	0.94	
Native/western / non-western	N=230 *	N=106		N=195 **	N=102		
Native	97 (54)	42 (53)	0.91	144 (96)	72 (94)	0.40	
Western	12 (63)	5 (56)	0.70	15 (100)	8 (100)	n.a.	
Non-western	9 (29)	12 (67)	0.01	24 (80)	15 (88)	0.47	
Generation ³	N=50	N=27		N=45**	N=25		
First	10 (50)	7 (64)	0.46	15 (75)	9 (90)	0.40	
Second	11 (37)	10 (62)	0.09	24 (96)	14 (93)	0.33	
Education	N=233	N=105		N=197	N=102		
Low	8 (62)	3 (43)#	0.42	11 (92)	5 (83)	0.60	
Medium	43 (43)	33 (59)	0.05	80 (92)	52 (93)	0.84	
High	69 (58)	23 (55)	0.72	94 (96)	38 (95)	0.81	
Urbanity	N=234 **	N=106		N=198	N=102		
Low-medium urban	6 (23)	2 (40)#	0.43	20 (100)	6 (100)	n.a.	
highly urban	115 (55)	57 (56)	0.85	166 (93)	89 (93)		

[#] Chi ² cell count less than 5.

Positive attitude towards undergoing CT / FAS: score of ≥ 6 points in knowledge assessment

Chi²: comparison between Control and Intervention groups

¹ Chi ² test within control group for differences in attitude CT/FAS,

² Chi ² test within intervention group for differences in attitude CT/FAS,

³ No performance of native group in 'generation variable' because similarity with native group 'variable native/ western/non-western'

Significance levels * P < 0.05, ** P < 0.01, *** P < 0.001

Table 9.4 Informed decision making in prenatal screening

	General p	articipation 1 2					
		Control group		Intervention group			
	N (%)			N(%)			
	CT	FAS	Chi 2	СТ	FAS	Chi 2	
	N=235	N=243		N=100	N=106		
Yes	103 (43)	240 (99)	0.22	51 (51)	105 (99)	0.81	
No	132 (57)	3 (1)		49 (49)	1 (1)		
	IDM - CT	1	Chi 2	IDM - FAS 1		Chi 2	
	Control	Intervention		Control	Intervention		
	N(%)	N(%)		N(%)	N(%)		
	N=218	N=94	_	N=187	N=94	_	
IDM - Participation	86 (39)	41 (44)	0.78	142 (76)	78 (83)	0.12	
IDM - Non-participation	96 (44)	38 (40)		0 (0)	1 (<1)		
No-IDM	36 (17)	15 (16)		45 (24)	15 (16)		
	Match- IE	DM CT 1	Chi 2	Match-IDM	FAS 1	Chi ²	
	Control	Intervention		Control	Intervention		
	N(%)	N(%)	_	N(%)	N(%)	_	
	N=100	N=92	_	N=102	N=92	_	
IDM - Participation	48 (48)	40 (44)	0.80	73 (72)	76 (83)	0.08	
IDM - Non-participation	39 (39)	38 (41)		0 (0)	1 (1)		
No-IDM	13 (13)	14 (15)		29 (28)	15 (16)		

¹ Intentional participation during IDM Intervention study

 $IDM = Informed\ Decision\ Making:\ participation\ with\ sufficient\ knowledge\ and\ a\ positive\ attitude\ or\ non-participation\ with\ sufficient\ knowledge\ and\ a\ negative\ attitude\ towards\ CT\ /\ FAS$

No-IDM: participation and non-participation with insufficient knowledge about prenatal screening and a non-matching attitude towards prenatal screening with participation and non-participation.

CT= Combined Test

FAS= Fetal Anomaly Scan

Match= matching on similarity in determining characteristics (ethnicity, gravidity, parity, educational level and age) n=111 control and n=111 intervention respondents.

the upcoming availability of the Non-Invasive Prenatal Test (NIPT) and change in the threshold of the CT in the Netherlands (since 2015 all women most pay for the CT), into account. Lastly, we had to reduce ethnic background to a dichotomous variable, Western and non-Western women because of absence of large enough ethnic minority subgroups for reliable statistical analyses.

^{*} During IDM Intervention study

Chi ²: comparison between Control and Intervention groups

CONCLUSION

Adding Culturally Competent Educational Film (CCEF's) to counseling about Prenatal Screening (PS) has a significant effect on the increase of knowledge within medium and highly educated groups and non-western immigrant groups. Promising results were seen for the increase of Informed Decision Making among intentional participants in the Fetal Anomaly Scan (FAS) and decrease of uninformed decision making of participants and non-participants in FAS. We recommend an update of the the CCEF's to the current context of PS (including the Non Invasive Prenatal Test, NIPT). A randomized controlled trial would be useful to further build on the evidence for the films.

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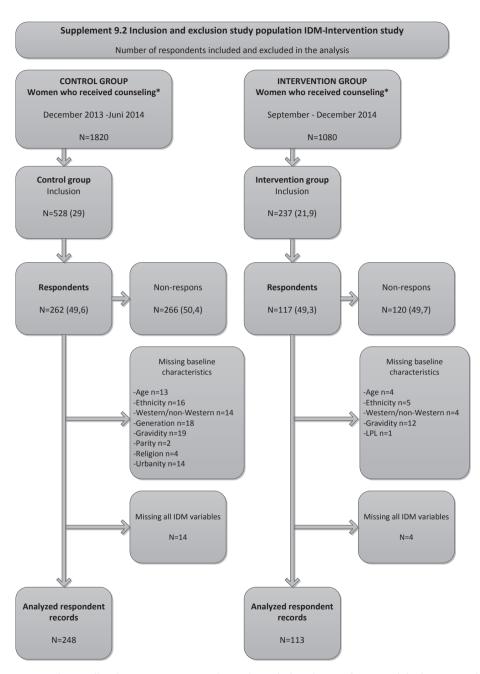
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SUPPLEMENTS





^{*} Registered counselling for participating counselors in the study (based on Peridos national database Prenatal Screening).

Supplement 9.3 Survey counsellors: Use of educational films on prenatal screening

CHARACTERISTICS OF COUNSELORS		Total OPINION ABOUT EDUCATION N=28 FILMS		Total N=28	
	N	%		N	%
Age category counselors			Personal experience with educational films		
20-29	2	(7)	Very good	8	(28
30-39	9	(32)	Good	18	(64
40-49	8	(29)	Neutral	1	(4)
50-59	6	(21)	Bad	1	(4)
60-69	3	(11)	Very bad	0	(0)
Counselors organization			Experience of pregnant women with educational films $^{\rm 12}$		
Midwifery practice	5	(18)	Very good	9	(32
Midwifery practice + ultrasound	6	(21)	Good	17	(61
Hospital	17	(61)	Neutral	2	(7)
Profession of counselor *			Educational film is useful addition to routine practice?		
Midwife	5	(18)	Yes	26	(93
Midwife & sonographer	8	(29)	No	2	(7)
Sonographer	7	(25)	Benefits of the educational films*	26	
Nurse	7	(25)	Standardized information provision	10	(38
Gynecologist / obstetrician	1	(3)	Time efficient	12	(46
Years of experience in profession			Appropriate for language barriers	7	(27
≤5 years	6	(21)	More calm information provision	4	(15
6 - ≤ 10 years	6	(21)	Visualization benefits information prov.	2	(8)
11 – ≤ 20 years	11	(40)	Disadvantages of the educational films*	27	
> 21 years	5	(18)	ICT complications	6	(22
Years of experience with counseling PS			Other languages needed ³	3	(11
1 - ≤ 2 years	4	(14)	Time investment	8	(30
$3 - \leq 4 \text{ years}$	7	(25)	Educational films incomplete	3	(11
5 - ≤ 8 years	13	(47)	Other	2	(7)

9 - > 11 years	4	(14)	None	7	(26)
Vision on counseling about PS in general			Time investment use educational film		
Necessary	15	(54)	5-7 minutes	19	(68)
Necessary, but time-consuming & difficult	6	(21)	7-10 minutes	7	(25)
Ambivalent	2	(7)	> 10 minutes	2	(7)
Other	5	(18)	Preferred use of educational films in future*		
Knowledgeable about:			On organizational website	7	(25)
Existence of translated leaflets "Yes"	25	(89)	Before counseling	17	(61)
Acquiring translated leaflets "Yes"	18	(64)	During counseling	9	(32)
Languages of translated leaflets "Yes"	8	(29)	After counseling	2	(7)

¹ Observed by counselor ² Also answer categories 'bad' and 'very bad', but none of the respondents marked this answer *Multiple answer options possible

³ English and Polish.

9

Supplement 9.4 Questionnaire IDM-Intervention study

Used questionnaires in Dutch, Turkish and standard-Arabic language



II Attitude measure CT and FAS used in the questionnaire

Participating in prenatal screening for Down syndrome / fetal anomaly screening: What is your opinion? ¹

What is your opinion of participating in prenatal screening for Down syndrome / fetal anomalies? Please indicate this in the following four questions by marking for each line one of the boxes under the numbers one through seven.

Example

If you are of the opinion that participating in prenatal screening for Down syndrome / fetal anomalies would be 'a bad idea' for you, mark box 1 in the first line. If your opinion is that it is not such a bad idea, then you should choose one of the numbers more towards the right when making the assessment. If your opinion is that participating in prenatal screening for Down syndrome / fetal anomalies is 'not a bad idea' for you, you should then mark box 7. The other three questions should be answered in the same way.

Participating in first trimester prenatal screening for Down syndrome / fetal anomalies is, in my opinion:

A bad idea								Not a bad idea
	1	2	3	4	5	6	7	
Useful								Not useful
	1	2	3	4	5	6	7	
Harmful								Not harmful
	1	2	3	4	5	6	7	
A good idea								Not a good ide
	1	2	2	4	-	_	7	

Supplement 9.5 Use of translated hardcopy and downloaded leaflets Dutch prenatal screening 2014

Language	Birth rates *	First generation *†	Difficulty with reading Dutch §	Downloads leaflet CT ¹	Possible no provision translated leaflets CT	Downloads leaflets FAS ¹	Possible no provision translated leaflet FAS
	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)
Dutch	126.259 † (74)			170.542 **(98)		170.138 ** (99)	
Total Western immigrants	17.635 (10)	10.406 (59)*					
English				1.090 (0,6)		593 (0,3)	
Spanish				208 (0,1)		128 (0,1)	
French				149 (0,1)		80 (0)	
German				141 (0,1)		76 (0)	
Total Non- westen immigrants	27.447 (16)	18.961 (69)††					
Turkish	5.873 (3)††	2.978 (51)††	983 (33)††	345 (0,2)	638 (65) ‡‡	168 (0,1)	815 (83) ‡‡
Arabic (Maroccan)	7.424 (4)††	4.432 (60)††	1.063 (24)††	320 (0,2)	743 (70) ‡‡	257 (0,1)	806 (76) ‡‡
Chinese				268 (0,2)		167 (0,1)	
Portugeuse (Cape Verdean)				134 (0,1)		65 (0)	
Papiamento (Antillean)	2.199 (1)††	1.371 (62)††	41 (3)††	109 (0,1)	adequate	45 (0)	adequate
Totaal	171.341			173.306		171.717	

^{*} Statistics Netherlands Statline: birth rates by etnicity until December 31 2013. Ref: http://stat-line.cbs.nl/Statweb/publication/?DM=SLNL&PA=37884&D1=a&D2=0&D3=0-2,4-9&D4=14-17&HDR=T&STB=G2,G1,G3&VW=T

[†] Dutch and Surinamese; both Dutch speaking

[#] More need for translated leaftlets within first generation Immigrant groups

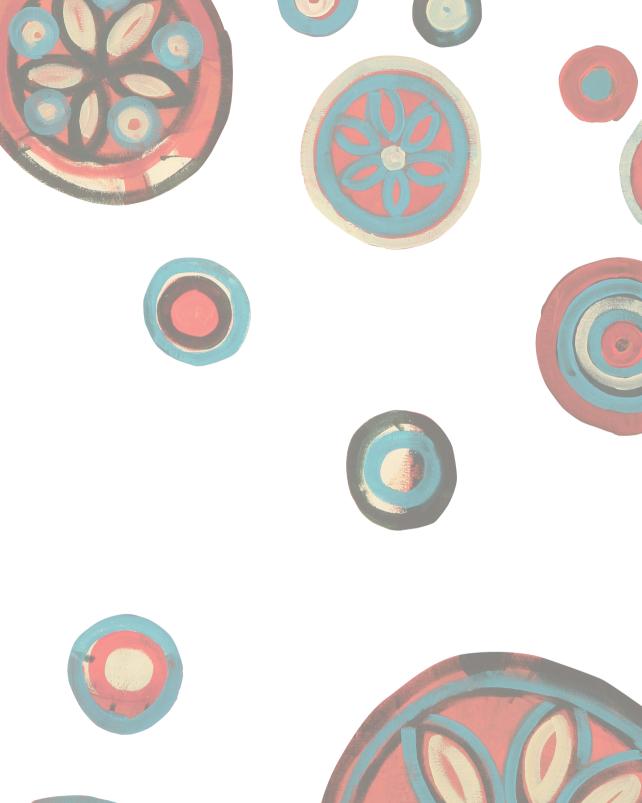
[§] Statistics Netherlands; difficulty with reading in Dutch, first generation 2006 Ref: http://www.cbs.nl/nl-NL/menu/themas/dossiers/allochtonen/publicaties/artikelen/archief/2008/2008-2570-wm.htm

[¶] Data request: National Institute for Public Health & Environment (2014).

^{**} Inclusive 170.000 Dutch hardcopy leaflets both CT and FAS

^{††} Percentage within ethnicity / language group

^{##} Percentage number pregnant women with difficulty to read in Dutch **minus** number of downloads transleted leaflet CT/FAS gave number and percentage of absence







General discussion 10



GENERAL DISCUSSION

Reflection on the principal findings

Part I - Satisfaction with care, inequalities in use and provision of antenatal and maternity care in a multi-ethnic population.

The studies of **Part 1** explored satisfaction with the provided antenatal, obstetric and maternity care using, among others things, the concept of a healthcare system's responsiveness with regard to measuring quality of care – as illustrated in figure 10.1. These studies also explored the reasons for delay in the first antenatal visit, the provision of antenatal screening in the Netherlands, intentional participation in screening

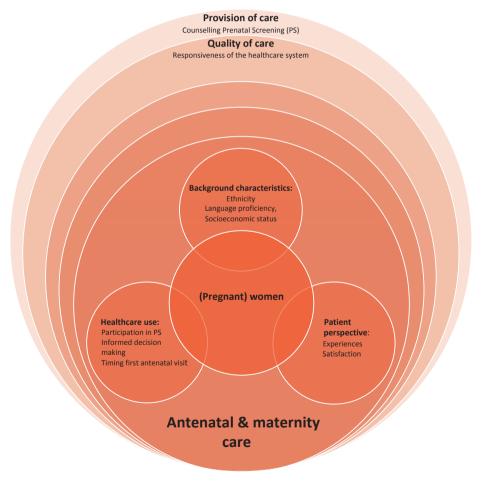


Figure 10.1, Exploring satisfaction and inequalities related to antenatal, birthing en maternity healthcare in a multi-ethnic women's population

and inequalities in the actual uptake of antenatal screening. Furthermore, the possible interaction between healthcare system factors was studied as well as the influence of individual characteristics of (pregnant) women and new mothers in a multi-ethnic population on the perceived satisfaction with care, inequalities in use and provision of antenatal, obstetric and maternity care.

In **chapter 2** it is shown that the 'respect for persons' responsiveness domain category was the most influential on the satisfaction with antenatal, birthing and maternity care in the studied low-educated native Dutch and non-western minority women. The study population was mostly positive about the provided care during the antenatal phase. They were less positive about the other two phases of care. Moreover, the obstetric healthcare systems' responsiveness in all phases of care (antenatal, birthing and maternity) did not meet these women's needs. The 'respect for persons' domains 'autonomy', 'communication' and 'dignity' and the 'client orientation' domain 'prompt attention' were judged most negatively.

The study described in **chapter 3** study shows that women in a disadvantaged position, those with a non-native Dutch background and/or with an insufficient language proficiency level, were underserved in the Dutch prenatal screening program. They were less likely to receive an information offer about the Combined Test (CT) and Fetal Anomaly Scan (FAS) and to be counselled about prenatal screening. In addition, the rate of intention to participate in CT and FAS among these women was considerably lower than the rate among women with a native Dutch background. These findings seem to indicate that the fundamental principle of the Dutch Population Screening Act – equal access to prenatal screening for all pregnant women – has not yet been realized.

In this line, our study on the presence of inequalities in the actual uptake of both the CT and the FAS in the four largest cities in the Netherlands as related to socioeconomic status and ethnicity (**chapter 4**) indicated that non-Western women in low socioeconomic areas had the lowest uptake. The pattern of observed effects suggests cumulative disadvantages for women with multiple risk factors.

Based on these findings we can conclude that pregnant women and new mothers with a non-Western immigrant and low socioeconomic status background, and not well proficient in the Dutch language, have a higher chance of being underserved with care in the Netherlands. There seems to be a mismatch between the provided antenatal, birthing and maternity care and the actual Dutch population mix. The existing inequalities call for further improvement efforts, in particular as they reflect the perinatal outcome gap in the Netherlands (see policy recommendations).

This thesis and the literature underline that the provision of antenatal and maternity care is subject to the women's individual characteristics, like age, educational

attainment, ethnicity, level of knowledge (health literacy), as well as the care providers' and immigrant women's attitudes towards subjects concerning health and healthcare. ¹⁻⁶ More specifically, language barriers threaten the effective provision and actual use of health services, ^{3, 7-9} and immigrant women's underutilization of obstetric care services and level of health literacy are linked to the delay in the first booking visit. ^{10, 11} Intervention strategies focussing on individual factors such as insufficient language proficiency and health literacy among both non-Western and low socioeconomic status groups are needed (see policy recommendations).

Furthermore, the Dutch obstetric healthcare for pregnant women and new mothers seem not sufficiently take into account the growth in the number of patients born abroad with a variety of social, cultural and religious affiliations, migration histories and status. It is known that this ethnic and cultural variety of the patient population influences health care provision and reception.^{3, 12-15} In light of the situation in the Netherlands, where we see an increasing diversity in the population, the outcomes of this thesis provide recommendations for cross-cultural communication and cultural competence improvements of the antenatal, birthing and maternity healthcare system (see policy recommendations). By taking up these recommendations, the obstetric healthcare system can sustainably meet the changed needs of the Dutch patient population and provide equal access to care for everyone.

Another key finding of **part 1** concerned the main reason for delay of the first antenatal visit (after week 12+0 of gestation). This was found to be an unplanned or unwanted pregnancy (**chapter 5**) was. The association was significant, in line with previous research. The delay was most common in adolescents, older women (≥40 years of age), high order multiparous women (P≥3), women with a previous miscarriage and women who were not well proficient in the Dutch language. Plausible reasons for the delay are, therefore, misunderstanding of the Dutch healthcare system (health illiteracy), a language barrier, a more expectant attitude towards a new pregnancy (in the case of a previous miscarriage) and women in non-Western ethnicity groups not always being wont to timely plan their first antenatal visit. The delay of the plant their first antenatal visit. The delay of the previous miscarriage and women in non-Western ethnicity groups not always being wont to timely plan their first antenatal visit. The delay of the previous miscarriage and women in non-Western ethnicity groups not always being wont to timely plan their first antenatal visit. The delay of the previous miscarriage and women in non-Western ethnicity groups not always being wont to timely plan their first antenatal visit.

In the Netherlands, autonomy and individual responsibility to health and healthcare use are considered important. Individuals should be free to decide what is best for their own health. Still, not everyone is able to make a well-considered decision regarding timing of their first antenatal visit. The above-mentioned self-reported delaying factors for the first antenatal visit may guide caregivers and policymakers in developing intervention strategies to provide timely prenatal care to all patients. Interventions should focus on education about (1) the Dutch healthcare system and (2) the necessity of timely antenatal care (see policy recommendations).

Part II – Performance assessment of prenatal counselling and Fetal Anomaly Scan
The two studies in **part II** evaluate methods for standardized quality assessment of
the counselling about prenatal screening and the second-trimester Fetal Anomaly Scan
provided in the context of the Dutch prenatal screening program – as illustrated in
figure 10.2. Furthermore, these studies evaluate how these quality assessment methods
can contribute to a standardized, easy-to-reproduce and reliable quality assessment of
the counselling.

A novel method for the assessment quality of prenatal screening counselling is described in **chapter 6.** This method involves two newly-developed assessment tools for the CT and the FAS, respectively, applied by three different assessors. The intraclass correlation coefficients of the three assessments was significantly above 0.80 (p <0.001), which

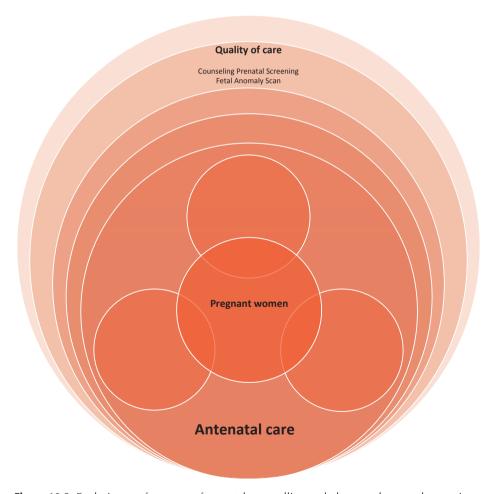


Figure 10.2, Exploring, performance of prenatal counselling and ultrasound prenatal screening

indicates excellent agreement between the assessment outcomes of the assessors. This method proved to be a reproducible and feasible assessment method and is useful in a broader health care perspective. Despite these promising results the method includes two restrictive elements for possible implementation in the Dutch prenatal screening program. First, the assessment spectrum is small because the focus is on the health educational element of counselling about prenatal screening. Second, the required transcription of the audio-recorded counselling session by the assessed counsellor is too time-consuming in the opinion of an advisory board of antenatal healthcare professionals (Foundation Prenatal Screening Southwest Netherlands, SPSZN) and an expert team of the National Institute for Public Health and the Environment (RIVM). New insights have revealed, however, that the method should not be used on its own but is particularly suitable when combined with a method that assesses the counselling competence. Examples of such methods are the one developed by Martin et al. (2015) and a brand-new method developed by TrainTool and expert groups of RIVM that uses digital roleplays. ^{18, 39}

The study in chapter 7 addresses the implementation in the Southwest region of the Netherlands of a standardized image-scoring method developed in 2012. We found that most of the sonographers met the expectations of the audit process; and those whose performance was subpar met the expectations after retraining. The Dutch population-based screening programs generally have a well-described system to achieve quality assurance, but a uniform system to monitor the actual performance of the FAS was lacking. When repeating the assessment cycle in a specific region every two years, this method enabled not only to measure the scanning performance of the FAS but also to investigate the interaction with organizational level factors (e.g., size of organization, patient population) and professional level factors (e.g. years of working as sonographer, educational background). Exploring these outcomes can be useful for quality assessment, but can also benefit scientific research in the field of sonography antenatal screening. The method is still in use in the Southwest region of the Netherlands and elements of the method are being implemented in other screening regions in the Netherlands. This shows that this method is useful and is supported within the prenatal screening program, under the condition that the FAS scanning performance assessment is standardized.

Part III - Improving informed decision making (IDM), healthcare knowledge and healthy behaviour

As illustrated in figure 10.3, the studies of **part III** investigate the effects of interventions that could help improve women's knowledge about antenatal and maternity care provision, healthy behaviour and informed decision making about prenatal screening

participation. In particular, the effects of two health educational interventions within an overall multi-ethnic and low socioeconomic status population were explored.

In **chapter 8** we demonstrate that 'Active' interpersonal recruitment methods were the most successful methods to recruit participants with a non-Western immigrant background (90% of the participants) for Reproductive Health Peer Education (RHPE). Non-Western immigrant women are considered difficult to reach, especially the first generation. Nevertheless, we found that 65% percent of the participants in RHPE have a first generation immigrant background, which is an encouraging result. Not only the use of the active interpersonal recruitment method 'verbal advertising by organizations' and involving the 'social network' were determining in the recruitment process, but bicultural peer educators as recruiters particularly played an important

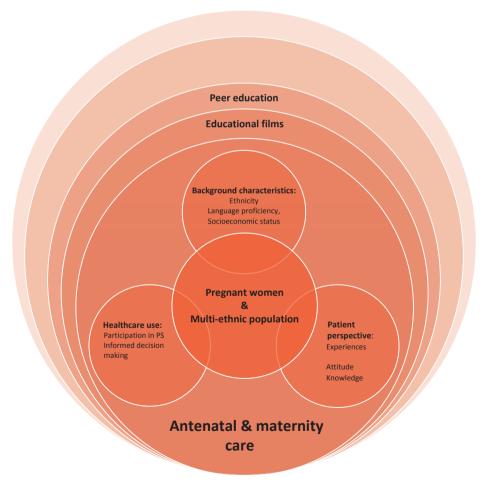


Figure 10.3, Exploring, improving informed decision making, healthcare knowledge and healthy behaviour

role. The success of 'active' recruitment is in line with other studies 19-21, but the involvement of the bicultural peer educators was innovative and recommendable to recruit participants with an immigrant background for (Peer) Health Education. Almost a decade ago participants and healthcare professionals were enthusiastic about the performance of Peer Health Educators (In Dutch: 'Voorlichters Eigen Taal en Cultuur') but the government meanwhile has ended subsidizing these educators. ^{22, 23} In chapter 8, too, a positive effect is shown of peer health education on the knowledge increase within a non-Western immigrant participant population. All measurements of reproductive behaviour and antenatal and maternity care system knowledge had improved after the intervention. In the already knowledgeable participant group the knowledge had increased on average by 24% and in the not knowledgeable group by 46%. Despite the proven effectiveness of RHPE, also this peer health educational initiative is not embedded in the Dutch public health system and is not financed in a structured way. Peer health education focussing on general health, healthy behaviour and the Dutch healthcare system for in particular first-generation immigrants and asylum seekers deserves to be integrated in the Dutch public health system (see policy recommendations). If, in addition, efforts should be made to stimulate learning the Dutch language, the inequalities in satisfaction, provision and utilization of Dutch antenatal care as described in part I of this thesis could be further bridged.

In chapter 9 we demonstrate promising effects of cultural competent educational films (CCEFs) about prenatal screening in the Dutch, Turkish, Moroccan-Arabic and Moroccan-Berber languages. Ethnic minority women and 'medium' and 'highly' educated women showed significantly increased knowledge about the FAS after having watched a movie. An increase of 11% in informed decision making and a decrease of 12% in uninformed decision making were measured among women who had the intention to participate in the FAS. The CCEFs are a valuable complement to the provision of counselling and flyers, which on their own do not fully contribute to the informed decision making of women with a non-Western and low socioeconomic background.^{6, 24} After our effectiveness study, antenatal healthcare professionals in the Southwest region of the Netherlands working in the primary, secondary and tertiary obstetric care sectors started to use the CCEFs as well during their consultations in the first trimester. In the year 2017 the films were updated to the current context of the Dutch prenatal screening (including the Non-Invasive Prenatal Test; NIPT). The RIVM provided funding for the update but due to cost reductions the updated films are only available in Dutch spoken word and with Dutch subtitles. The lack of updated films in the Turkish, Moroccan-Arabic and Moroccan-Berber languages was troublesome from the perspective of the antenatal health care professionals who used the different language versions of the films. The films are accessible through a health educational website about prenatal screening targeting Dutch pregnant women (www.onderzoekvanmijnongeborenkind.nl). Based

on a qualitative research of all health educational materials within the Dutch prenatal screening program commissioned by RIVM in 2018, the CCEFs were judged as suitable health education instruments. The respondents found the films useful to communicate elementary information about prenatal screening, especially for pregnant women and their partners with a language barrier.²⁵ Our study findings, the positive opinions of antenatal healthcare professionals and the suitability of the CCEFs as health educational instrument about prenatal screening from the patient perspective underline that it is well worth to implement watching these films in the Dutch screening program.

METHODOLOGICAL ISSUES

Study population

The study populations described in **chapter 2** and **chapter 8** shows an oversampling of respondents with a non-Western and low socioeconomic status background – which is a logical consequence of the inclusion criteria that especially targeted those respondents. We succeeded to include these vulnerable groups to explore the satisfaction with obstetric care in all phases (antenatal, birthing and postpartum) as well as the effect of Reproductive Health Peer Education Reproductive Health. These study samples did not reflect, however, the distribution of ethnicity groups within the population of the city of Rotterdam. ²⁶ Due to the inclusion criteria, the same phenomenon held true with regard to the population of the southwest region of the Netherlands studied in **chapter 9**.

The presence of a (very) limited language proficiency level (LPL) of parts of the overall non-Western immigrant study populations included particularly in the studies in chapters 2, 3, 8 and 9 may have resulted in a possible bias in the study results. Despite translations by other respondents, community workers and peer educators in the focus groups (chapter 2) for respondents with a (very) limited LPL, some respondents may not have understood all the questions asked. However, the outcomes for these respondents were rather similar to those of others respondents with similar background characteristics, which indicates a minimal bias. For the same reason, the outcomes of the study in **chapter 3** on the information provision procedure of the Dutch prenatal screening may have been biased through, for example, not fully understanding the questions from the counsellor concerning their wish for counselling or intentional participation in prenatal screening. The data-registration was web-based and primarily intended for quality control of the contracted counsellors in the context of the Dutch Population Screening Act, which gave minimal opportunities to prevent such a bias. Therefore, we possibly judged the Dutch prenatal counselling provision procedure too negatively. The Dutch LPL and native language of respondents of the population of the studies described in chapter 8 and chapter 9 can also have affected the responses to

the questions posed on reproductive health after participation in reproductive health peer education and on informed decision making in prenatal screening after watching or not watching a cultural competent educational film. The registration forms used in the study of **chapter 8** were only available in the Dutch language, which was not an ideal match with the study population. The questionnaires used in the study in **chapter 9** were provided in the Dutch language and as well in the Turkish and standard-Arabic languages, but this provision cannot rule out difficulties to read the questions inherent to low literacy. The respondents had been encouraged (verbally and written) to ask for assistance if filling in the questionnaire was problematic, but may have been hesitant to ask for help. Reading problems may have led to a small number of missed questions concerning knowledge and attitude about reproductive health and prenatal screening, but there is no indication that this has affected the study results.

The **chapters 4**, **8** and **9** of this thesis show a few limitations concerning the data registration. In **chapter 4** the number of missing values may have reduced the generalizability of our findings to the rest of the population. The proportions of women with a non-Western ethnicity or a low socioeconomic status are comparable, however, to the proportions in other national databases, suggesting the populations may be comparable.²⁷ The number of missing values in Peridos (the national Dutch prenatal screening database) is partly caused by the newness of the system during the study period. In the study described in **chapter 8**, only a small part (4%) of the questionnaires were incomplete (missing of gender variable and missing of more than five respondent characteristics) and these were excluded from the analysis. We cannot fully oversee any consequences of this exclusion on the results of this study. However, given the small number of exclusions we do not expect a bias.

Other limitations regarding the data collection in **chapter 4** are the following. First, only women who wanted counselling about prenatal screening and gave permission to use their data were included in the database. The numbers and characteristics of the women who did not wish to receive information on prenatal screening or of those who denied the use of their data are not known. Second, most of the respondents' personal postal codes were missing. Instead, the postal code of the visited practice or hospital was assigned. It is reasonable to assume that women seek obstetric care in their immediate environment. Especially for women with limited financial budget, the traveling distance to a practice of choice would entail an additional financial burden.

Used methodology

Some overall methodological considerations concerning the studies in this thesis deserve mention. In the focus group study described in **chapter 2** it was possible to obtain a more personal contextual and differentiated analysis on background characteristics in relation to determining factors for satisfaction with care. The focus group interview

methodology enabled us to find more in-depth explanations, like the influence of culture and migration history, compared to previous quantitative research in the field of responsiveness of prenatal and maternity care. The prospective register-based studies described in **chapter 3** and **chapter 4** and the cross-sectional study described in **chapter 9** investigated on a large scale and in a structured and quantitative manner the influence of ethnicity and language proficiency on the participants' intention to participate in prenatal screening and their attitudes towards screening. It was not possible, however, to uncover any first-generation immigrant respondents' experiences in the country of birth that may have influenced the study outcomes.

In **chapter 7** we underline that it took 2.5 years to complete the whole audit cycle. This may have been a limitation, as the sonographers who were evaluated at the end of the audit cycle could have been better informed about the audit method, although the audit score was not significantly dependent on the audit period. In contrast, the study described **chapter 9** had a shorter inclusion period than predetermined. We had to take into account the upcoming availability of the NIPT and the threshold change for the Combined Test (CT) in the Netherlands (since 2015 all women must pay for the CT). The predetermined longer inclusion period could perhaps have resulted in more positive significant outcomes of the effect of the educational films on informed decision making and attitudes concerning prenatal screening.

The studies presented in **chapter 3** and **chapter 5** were both prospective, register-based studies in the South-west region of the Netherlands and made use of different subsets of the same prospective dataset. Both studies share several similar methodological limitations. One, the respondents' language proficiency level was classified by the antenatal healthcare provider. Differences in interpretation may well exist between the approximately 200 prenatal healthcare providers included in our dataset. Due to this human subjective factor, it is realistic to take into account possible limitations resulting from non-standardization of the data input. Second, as a result of the strict definition of a second-generation immigrant, data from pregnant women with this background were underrepresented. ²⁸ Third, the data concern intention to participate in prenatal screening rather than actual participation. The hypothetical and actual uptakes within the study population may well differ, but rates of intention to take up the CT and Fetal Anomaly Scan (FAS) in this study show similarities with actual CT and FAS uptake rates in the Netherlands, which is promising for the representativeness of the study results. ^{29, 30}

When it comes to methodological considerations on data analysis, in **chapters 4, 5** and **9** ethnicity was dichotomized into Western and non-Western for a part of the analysis, because the ethnic categories were not mutually exclusive to conduct in-depth regression analysis. This may have led to the grouping of women from distinctively different ethnic

and cultural backgrounds. Different backgrounds may in turn account for differences in uptake of prenatal screening ³¹, may have masked the actual associations between different non-native Dutch ethnicities and the timing of the first antenatal visit^{32, 33} and ethnic differences in informed decision making about prenatal screening after seeing a cultural competent educational film. Nevertheless, overall substantial differences between Western and non-Western women were found, justifying the dichotomization. Concerning the methodology used in the studies described in chapters 6 and 7 to assess the quality of counselling about prenatal screening and the FAS, we propose specific limitations. It appeared that the sub-items in the novel assessment tools of the quality assessment method counselling were not explicit enough and led to poor interrater reliability (chapter 6). We made these sub-items more explicit, after which it was possible to obtain also reliable assessment outcomes on these themes. The standardized image-scoring method as described in **chapter 7** did not provide for annotations. Annotations are common practice in radiologic imaging as a means to improve the interpretation of scans and increase the reliability of the image storage. This is why it was an important missing variable.

RECOMMENDATIONS

Future research

Based on the outcomes of the study described in **chapter 2** it would be interesting to repeat the focus group study with exclusive inclusion of multi-ethnic low-educated pregnant women and women who recently gave birth. This would enable to explore more recent experiences with the responsiveness of the antenatal healthcare system. Such a prospective study design would reduce the risk of recall bias. ³⁴ Also it is recommendable to conduct a new focus group study focussing on the extra care and interventions needed by vulnerable subgroups such as low-educated non-Western women. In this way the prerequisites of adequate obstetric care provision to these groups can be determined.

Qualitative study designs create opportunities to explore aspects of context-based medicine. Most of the healthcare provided in the Netherlands is based on protocols and guidelines grounded in an evidence--based medicine approach. In this approach, 'good healthcare' is that which has been proven adequate in mainly randomised experimental scientific research. As underlined by the Dutch Council for Health and Society, this kind of evidence is not related to the healthcare professionals and patients as persons and does not take into account the differences between patients' personal values and the dynamic settings of healthcare provision.³⁵ For each individual patient, good healthcare provision is different within a specific situation.³⁶ In addition, views on

the definition of good healthcare are influenced by ongoing changes in society and in patients' needs. Furthermore, recently a Dutch professor of 'Health Care Governance' stated that a digital dataset for registration of the healthcare performance is over trusted and does not automatically provide clues for innovation and improvements in care.³⁷ In the light of this statement, it is recommendable to explore adequate context-based medicine methods for establishing the responsiveness of the Dutch obstetric healthcare system.

The study findings described in **chapter 3** show the desirability of additional qualitative research among antenatal caregivers (counsellors) exploring why non-Native Dutch women and women with a limited language proficiency level are less likely to be offered counselling on the combined test and Fetal Anomaly Scan.

The study outcomes described in **chapter 4** underline that future research in this field should focus on potential inequalities in the uptake of prenatal screening in the new cell-free DNA test (NIPT) which was recently introduced in the Netherlands. Because counselling will become more complex, equity in healthcare offer and usage will become more important and inequalities in informed decision making and uptake may become more profound. Additional research on the influences of socioeconomic status and ethnic background on the intention to participate in prenatal screening and the actual uptake at a more detailed level (four digit postal code area, subgroup analyses of women with different ethnic backgrounds) may help to gain new insights.

Last, the studies in **chapter 3** and **chapter 4** show that the precise roles of healthcare organisations and caregivers in inequalities in uptake of prenatal screening need to be elucidated. Future research should investigate possible healthcare system factors and antenatal caregivers' factors that influence the uptake of prenatal screening. A more context-based medicine approach is recommended for exploring the healthcare system factors, because this gives a more realistic view on the underlying organisational mechanisms. Self-observation, self-recording, and self-evaluation can give insight in the antenatal caregivers' professional behavior and attitude and in addition point at areas for improvement. This approach enhances self-esteem, develops self-awareness and it may help to identify the transferable skills.³⁸

The findings from the study in **chapter 5**, about the association between several maternal determinants and the reasons for delay of the first antenatal visit, provide directions for future research. It is recommendable to investigate maternal factors related to the most determining delaying factor for planning the first antenatal visit; i.e., an 'unplanned pregnancy'. A mixed methods strategy of both qualitative scientific research and a more context-based medicine approach would be most suitable to this aim. Intervision meet-

ings of antenatal caregivers should be planned to discuss what healthcare and patient factors may be related to a delayed antenatal visit (see healthcare recommendations).

The 'Novel assessment method for counselling about prenatal screening' described in **chapter 6** was complementary to the previously developed observation method with which a counsellor's communication skills.¹⁸ It would be interesting to combine both methods in one new quality assessment method along the lines of the digital RolePlay method as develop by TrainTool and to study the reproducibility and reliability of this method (see also healthcare recommendations).³⁹

From the findings in **chapter 7** we conclude that it would be interesting to repeat the evaluation of the sonographers' scanning performance based on the images-scoring method of the second trimester FAS. This may provide more insight in the sustained effect of the assessment method and the scanning performance monitoring. It is even more interesting to perform an evaluation on a national instead of regional level. Currently, however, a uniform FAS assessment method is not yet in use in the Netherlands.

The pilot study focussing on 'Reproductive Health Peer Education' (**chapter 8**) showed that it is possible to reach first- and second-generation non-Western ethnic minority groups through health peer education. This finding can be a starting point for a network study of how peer educators use their social networks to recruit participants. Such a study could be embedded in the nationwide perinatal health programme "Healthy Pregnancy 4 ALL-phase 3".

Based on the findings in **chapter 9** we conclude it would be useful to use a randomized controlled trial study design to further build on evidence for the effect of culturally competent educational films on pregnant women's informed decision making. Furthermore, to gain real insight in the effectiveness of using these films in the context of healthcare provision, obstetric healthcare organizations themselves would do well to evaluate this educational instrument.

Policy recommendations

This thesis brought to light inequalities in the provision and utilization of obstetric care and inequities in healthcare between groups of women. Furthermore, the perceived satisfaction with antenatal, birthing and maternity care hints at disparities. Especially non-Western first and second generation immigrants and women with a low socioeconomic status tend to find the provided obstetric care as inadequate.

Since 1980, the Dutch government's political agenda and national policy concerning 'health inequalities' was mainly aimed at avoiding and decreasing health inequalities in the Dutch society. Policy was mainly targeted on what had been labelled high-risk groups, such as youth, citizens living in deprived areas and immigrants. Despite good examples of Dutch governmental policies ^{35, 40, 41} and research efforts, the outcomes

of this thesis and other research findings show that obstetric healthcare and health disparities still exist in the Netherlands.^{13, 18} Especially non-Western immigrant and low educated pregnant women and new mothers are disadvantaged by the Dutch obstetric healthcare system in which self-reliance plays an important role.

Therefore we recommend the Dutch government health policy makers to provide strong incentives for obstetric health educational institutes and obstetric care organizations to focus on bridging the health inequality gaps between pregnant women and new mothers with and without immigrant background and a low socioeconomic status.

This thesis concludes that the obstetric training programmes and the obstetric healthcare system in the Netherlands, which is based on self-reliance, do not equip healthcare professionals with the necessary skills to provide sufficient care for vulnerable pregnant women and new mothers. Therefore, the Dutch government should encourage and embed in policy (1) initiatives for restructuring care which contributes to patient-centred obstetric care; (2) the implementation of cultural competence as part of the curricula of health educational institutes and training for obstetric and midwifery healthcare professionals, and (3) the use of preventive and care intervention strategies to decrease disparities in the provision and utilization of obstetric healthcare.

In the Netherlands, several strategies are available to influence policy making in the field of obstetric healthcare. The most direct way is approaching high-positioned civil servants in the Ministry of Health, Welfare and Sport. Interest groups like the Dutch university medical centres and professional associations (KNOV and NVOG) have proved to be successful in influencing obstetric policy making concerning the 'perinatal mortality' topic in 2008-2010. Also on a local level it is possible for interest groups to influence policy making. Convincing the responsible alderman, local governmental civil servants and the local public health service that it is essential to tackle a specific obstetric health topic can contribute to the desired policy programs. A successful example of such policy making supported by an interest group, in this case the Erasmus University Medical Centre, was the program Ready for a Baby. In both more direct ways of influencing policy making, perinatal mortality rates triggered a policy process to change perinatal care.

For national and more structural long-term policy making, political agenda setting is the first step to accomplish the above-mentioned desired policy making goals. To this aim, it is important to involve interest groups like patients, migrants, welfare and obstetric health organizations. But seeing that more vulnerable interest groups, such as patients and migrants, may be less capable of influencing policy making, interest groups are recommended to join forces. For example, while obstetric healthcare organisations take the lead, other less well organized and capable interest groups may assume a supportive position in the lobbying coalition. It is essential that consensus should have

been reached between the most important actors about the topics for influencing the political and eventually the policy agenda.

As shown in a Dutch research paper that analysed policy towards improvement of perinatal mortality, policy makers and interest groups are most successful in influencing first the political and second the policy agenda setting if social developments around the lobbying topic are receiving persistent media attention.⁴²

Influencing the political and policy agendas is possible by provision of petitions, positioning as an important actor and collocutor and publishing reports that summarize the existing inequalities in obstetric care in terms of costs and effects on a societal and individual level, but also best practices to fix these disparities. It is recommendable for interest groups to get informed about relevant elements of the research- and advice reports of the Dutch Council for Health and Society and the Health Council of the Netherlands. Lobbying is best targeted at political parties that have a focus on improvement of healthcare in their election programmes, but also to the Minister of Health, Welfare and Sport and the civil servants of this Ministry.⁴⁴

A decentral strategy, as recommended by a former Minister of Health Welfare and Sport, is to focus on the local government when it comes to policy making that can solve problems in the healthcare provision to immigrants. Interest groups can seek liaison with Dutch local governments that conduct 'best practice' with regard to decreasing health disparities within the reproductive women's population. Through national political parties that participate in the coalition of these local governments it is possible to influence the national political and policy agenda. Also a bottom-up lobbying strategy is possible through the Dutch multi-level governance (local, provincial and national) if a local government has the opportunity to present the success of their implemented policy. 44

Healthcare recommendations

The outcomes of this thesis urge for improvements in the obstetric healthcare system in order to decrease the inequalities and inequities in the provision and utilization of the care for all Dutch pregnant women and new mothers.

In this thesis we propose two intervention strategies that can contribute to enhancing the provision and utilization of care within a multi-ethnic population, which ultimately reduces health inequalities. In line with the results of the pilot study 'Reproductive health peer education for multicultural target groups' (**chapter 8**) we recommend local governments and obstetric healthcare organizations to invest in training of educators for peer education about reproductive health. Especially educators with a Central African and Eastern European background are highly needed in the Netherlands, as well as native Dutch peer educators. The empowerment of reproductive health peer educators

can help increase non-Western immigrant and low socioeconomic status groups' knowledge about the health care system. This is particularly important for groups with a 'late' or 'very late' first antenatal visit and groups with healthcare utilization problems. Additionally it is recommendable for obstetric healthcare organisations to make use of reproductive peer educators. These can function as cultural sensitive healthcare experts and advisors on the provision of obstetric care in a multi-ethnic population. **Chapter 9** shows that adding culturally competent educational film to counselling about prenatal screening has a significant effect on the increase of knowledge within medium- and high- educated groups and non-Western immigrant groups. Therefore, we recommend the Dutch government to add the educational films to the existing national information materials about prenatal screening. Ideally, this should be combined with an evaluation by the obstetric healthcare organisations of the pros and cons of using the films in the context of healthcare provision for pregnant women with a low educated and non-Western background (context-based medicine).

From a broader context than only that of the intervention strategies as elaborated in this thesis, we make some recommendations that can contribute to reduce health disparities and improve the provision and utilization of obstetric healthcare.

First, the quality of healthcare systems should be measured by the organisations concerned (context-based medicine), using the classic World Health Organization concept of the responsiveness of healthcare. This provides opportunities for increasing awareness about the level of responsiveness of provided care, which contributes to reducing inequalities in the perceived responsiveness of obstetric care within the Dutch population.⁴⁶

Second, all healthcare professionals working in the setting of antenatal, birthing and maternity care – like midwives, gynaecologists, sonographers, obstetric and maternity nurses – should know how to provide cultural competent care. To achieve this goal, the educational institutions should provide curricula for all basic supplementary training programs that offer a solid theoretical and practical basis related to ethnic-cultural diversity in the provision and utilization of obstetric healthcare. The involvement of trainers with an immigrant background is recommendable. The trainers of 'Stichting Voorlichters Gezondheid' in Rotterdam, for example, proved useful for making healthcare professionals more knowledgeable about diversity and the provision of obstetric care. ^{47, 48}

Third, based on the findings in this thesis a two-way strategy is recommended for improving medical communication, with implications for both obstetric caregiver and pregnant women behavior. Training of the (candidate) obstetric caregivers in cultural competence and cross-cultural communication is a direction for a possible solution. We recommend obstetric professional associations like the NVOG and KNOV to list

training about cross-cultural communication as a periodical required and accredited professionalization. The training should focus on increasing the obstetric caregivers' awareness that (1) culture affects the way in which pregnancy, childbirth and the postpartum period is framed and affects the experiences of pregnant women and new mothers; (2) cross-cultural communication starts with self-awareness and respect for the pregnant women's and new mothers' beliefs and values; and (3) communication with the woman about her culture and a cultural sensitive attitude of the caregiver is preferable.⁴⁹

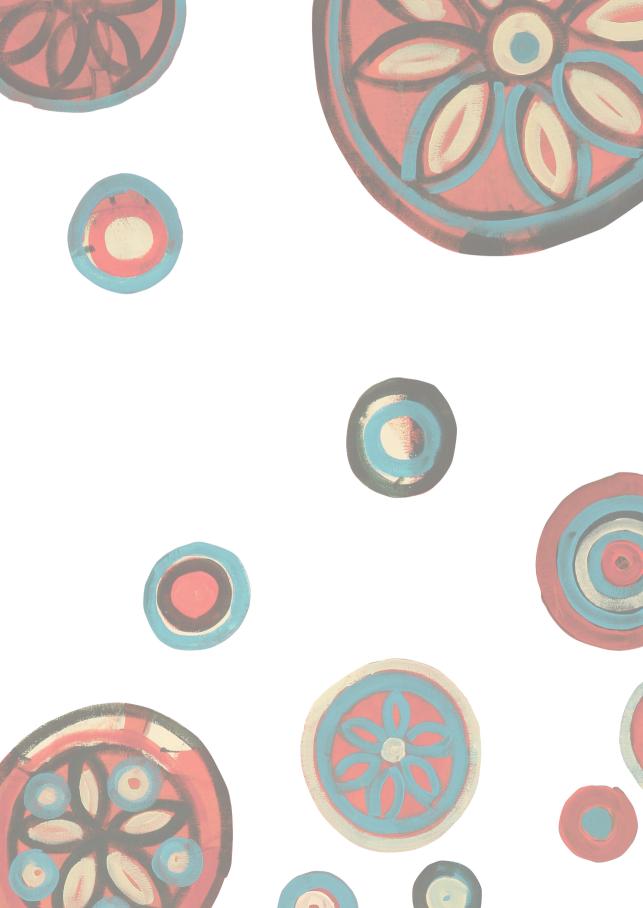
Fourth, our study findings show the need for self-assessment (as described in the 'future research' section) of obstetric caregivers and intervision between obstetric caregivers about providing obstetric care to low educated and non-Western pregnant women. Chapters 2, 3, 4 and 5 show that obstetric caregivers provide obstetric care to vulnerable pregnant women in different ways. This is partly caused by the healthcare system, but it is also related to caregivers' beliefs, attitudes and behaviours. The deeper understanding of their own beliefs, attitudes and behaviour obtained through self-assessment will enable them to investigate areas for improvement with regard to the responsiveness of obstetric care. Intervision meetings provide the opportunity to discuss: (1) how they counsel non-native Dutch women and women with a limited language proficiency level; (2) the precise role of the counsellors in the inequalities in uptake of prenatal screening; and (3) patient, caregiver and healthcare organizations factors that are related to a late antenatal visit.

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Addendum

Summary
Samenvatting
Authors and affiliations
List of publications
PhD portfolio
About the author
Dankwoord

SUMMARY

Health inequalities are present in the Dutch antenatal and maternity healthcare setting. There are disparities noticeable in the *provision of care, healthcare utilization* and *healthcare outcomes* in terms of perinatal morbidity and mortality.

Provision of care: inadequate provision of antenatal care may also play a role in these adverse perinatal outcomes. Communication and socio-economic problems, suboptimal health literacy, lack of knowledge about the obstetric care system, insufficient cultural competence of the prenatal care provider and lack of responsiveness of the healthcare system can cause insufficient provision of antenatal, birthing and maternity care.

Healthcare utilization: women with a non-Western ethnic background and a low socioeconomic status more often have reduced access to antenatal, birthing and maternity care. Dutch research shows that non-Western women are twice as likely to make inadequate use of antenatal care when compared with their native counterparts. Both women with a low socioeconomic and with a non-Western ethnic background are at an increased risk for late recognition of pregnancy and entry in antenatal care, decreased participation in antenatal screening, and postpartum complications. The most frequently reported impeding factors for healthcare utilization are insufficient periconceptional and prenatal prevention, lack of knowledge about the healthcare system, and poor language proficiency.

Healthcare outcomes: perinatal mortality was substantially higher in the Netherlands compared to other European countries. Especially nonmedical characteristics of pregnant women, such as non-western ethnicity and a low socioeconomic status (SES) background, have been negatively associated with perinatal morbidity and mortality.

The aim of this thesis is to increase insight in the existing adjustment of obstetric care with the healthcare utilization needs of the Dutch multi-ethnic reproductive women's population and to propose strategies that can contribute to enhancing the provision and utilization of care within this population. This thesis addresses this aim in three parts. *Part I* investigates (a) the level of satisfaction concerning care, (b) inequalities in use and provision of antenatal and maternity care in a multi-ethnic population. *Part II* assesses the quality of counselling in relation to prenatal screening and the Fetal Anomaly Scan. And *part III* evaluates interventions that stimulate (a) informed decision making, (b) healthcare knowledge, and (c)healthy behaviour.

Part I - Satisfaction with care, inequalities in use and provision of antenatal and maternity care in a multi-ethnic population.

First, in part I of this thesis the level of satisfaction with antenatal and maternity care within a multi-ethnic and overall low socioeconomic status urban women's population in the Netherlands was investigated.

Chapter 2, describes a focus group research combining the World Health Organization conceptual framework of healthcare responsiveness to measure satisfaction with antenatal, birthing and maternity care of women with a non-Western ethnic background and low socioeconomic status. It shows that within a low-educated native Dutch and non-western minority women population the 'respect for persons' responsiveness domains has the most influence on the satisfaction with antenatal, birthing and maternity care. The study population was mostly positive about the provided care during the antenatal phase. They were less positive about the other two phases of care. Moreover, the obstetric healthcare systems' responsiveness in all phases of care (antenatal, birthing and maternity) did not meet these women's needs. The 'respect for persons' domains 'autonomy', 'communication' and 'dignity' and the 'client orientation' domain 'prompt attention' were judged most negatively.

Second, an exploration was conducted of the existing inequalities in the information provision procedure of prenatal screening, uptake of prenatal screening according to ethnicity, Dutch language proficiency and socioeconomic status in the urban areas of the Netherlands.

Chapter 3 shows an analysis of the associations between the information provision procedure of prenatal screening for Down's syndrome (combined test) and congenital anomalies (Fetal Anomaly Scan) and the intention to participate in prenatal screening of ethnicity groups and Dutch language proficiency groups. Key conclusions were that women with a non-native Dutch background and/or with an insufficient language proficiency level were underserved in the Dutch prenatal screening program. These findings present evidence indicating that the fundamental principle of the Dutch Population Screening Act, being equal access to prenatal screening for all pregnant women, is not realized.

Chapter 4 shows an investigation of the presence of inequalities in the actual uptake of both the combined test and the Fetal Anomaly Scan as related to socioeconomic status and ethnicity in the four largest cities in the Netherlands. Intention to participate was an important explanatory factor in all models. However, after correction for intention, ethnicity remained a significant determinant for differences in uptake. Ethnicity and socioeconomic status also interacted, indicating that non-Western women in low socioeconomic areas had the lowest uptake. The pattern of observed effects suggests cumulative disadvantages for women combining characteristics that make them vulnerable

Finally, the first part of this thesis ends with an investigation of the maternal determinants and self-reported reasons that are associated with a delay in timing of the first antenatal visit of pregnant women who receive an information offer about prenatal screening.

Chapter 5 shows a study focusing on the association between the reasons for delay and several maternal determinants in the timing of the first antenatal visit. Key findings of this study first of all were that an unplanned or unwanted pregnancy was the main reason for the first visit being delayed. Secondly, a 'late' first antenatal visit was more common for adolescents, older women (≥40 years of age), high order multiparous women (P≥3), women with a previous miscarriage, and women with an absent Dutch language proficiency level compared to those without this background. And finally, an absent Dutch language proficiency level showed the strongest association with a 'very late' first antenatal visit.

Part II - Performance assessment of prenatal counselling and Fetal Anomaly Scan

The second part of this thesis explores which quality assessment methods can contribute to a standardized, easy to reproduce and reliable quality assessment of counselling concerning prenatal screening and the second-trimester ultrasound Fetal Anomaly Scan.

Chapter 6 describes the development of a new assessment method that could assess the quality of the 'health educational' part of the counselling for first and second trimester prenatal screening. A novel assessment method was developed with the following elements: (1) recording a counselling session by the counsellor using a voice-recorder, (2) the counsellor transcribing the audio-recording, (3) the transcripts being assessed by three assessors with use of the assessment frameworks for the health education part of counselling about the combined test and the Fetal Anomaly Scan. Intra-observer variability analysis proved that this method is a reproducible and feasible assessment method which is useful in a broader health care perspective.

Chapter 7 elaborates on an evaluation of an auditing method of performing second-trimester Fetal Anomaly Scans based on a novel image-Scoring method in the Southwest region of the Netherlands. Because of the absence of a uniform system to monitor the actual performance of the Fetal Anomaly Scan in the Netherlands, a standardized image-scoring method in the Southwest region was developed. Each sonographer was requested to set up a digital portfolio. A portfolio consists of five logbooks of five different pregnant women, each containing 25 fetal anatomical structures and six biometric measures of randomly selected Fetal Anomaly Scans.Quality assessment using the image-scoring method demonstrated that most of the sonographers met the expectations of the audit process, but those who had subpar performance only met the expectations after retraining.

Part III - Improving informed decision making (IDM), healthcare knowledge and healthy behaviour

The third part of this thesis investigates interventions that can contribute to improvement of knowledge about antenatal and maternity care, healthy behaviour and informed decision making about participation in prenatal screening.

Chapter 8 describes a study focusing on the characteristics of the participants for Reproductive health Peer Education and the success of the recruitment methods and increase in knowledge of participants in reproductive health peer education. Active interpersonal recruitment methods were most successful in reaching participants with a first-generation immigrant background. Significant knowledge improvements were found on all in this study measured knowledge themes concerning reproductive behaviour and antenatal and maternity care system knowledge.

Chapter 9 shows an evaluation of the effect of a culturally competent educational film about prenatal screening on informed decision making regarding prenatal screening in a multi-ethnic pregnant women study population. After exposure to the cultural educational films, knowledge about the Fetal Anomaly Scan increased significantly in woman who were part of an ethnic minority and in 'medium' and 'highly' educated women. Among women in the intervention group who had the intention to participate in the Fetal Anomaly Scan, an increase in informed decision making and a decrease of uninformed decision making was measured. The cultural competent educational films are a valuable complement to counselling about prenatal screening.

CONCLUSION

The elaborated studies in this thesis show that there are existing inequalities and inequities in the provision and utilization of and the satisfaction with care for pregnant women and new mothers when comparing women with a non-western immigrant and low socioeconomic status (SES) background and women with a native and higher SES background. The two in this thesis elaborated promising intervention strategies (1) 'Reproductive Health Peer Education' and (2) 'Cultural Competent Educational Films' can contribute to the improvement of knowledge about antenatal and maternity care, healthy behaviour, and informed decision making. This thesis advises the Dutch government, obstetric healthcare organizations, caregivers and health insurance parties(1) to measure and improve the quality of the obstetric healthcare system from a context-based medicine approach using the WHO concept of responsiveness of healthcare and (2) to focus on *cultural competence* and *cross-cultural communication* of (candidate) caregivers.

SAMENVATTING

Er bestaan gezondheidsverschillen in de Nederlandse antenatale, obstetrische en postpartum zorg. Er zijn ongelijkheden aanwezig in het *aanbod, het gebruik* en de *geboorte-uitkomsten* van de Nederlandse geboortezorg in termen van perinatale morbiditeit en mortaliteit.

Aanbod van zorg: inadequaat aanbod van geboortezorg kan een rol spelen in de slechte perinatale geboorte-uitkomsten. Communicatie- en sociaaleconomische problemen, lage gezondheidsvaardigheden, gebrek aan kennis over de Nederlandse geboortezorg, onvoldoende culturele competentie van de verloskundig zorgverlener en het gebrek aan responsiviteit van het antenatale-, obstetrische- en postpartum-zorgsysteem kan leiden tot een inadequaat zorgaanbod.

Zorggebruik: vrouwen met een niet-westerse migratieachtergrond en een lage sociaaleconomische status hebben vaker beperkter toegang tot antenatale, obstetrische en postpartum zorg. Nederlands onderzoek toont aan dat niet-westerse vrouwen twee keer zo vaak niet adequaat gebruik maken van antenatale zorg in vergelijking tot de Nederlandse vrouwen. Zowel vrouwen met een lage sociaaleconomische status als vrouwen met een niet-westerse migratieachtergrond hebben een verhoogd risico op het in een later stadium ontdekken van de zwangerschap, een late start van antenatale zorg, een lagere deelname aan prenatale screeningsonderzoeken en postnatale complicaties. Belemmerende factoren voor zorggebruik tijdens de zwangerschap zijn onvoldoende periconceptionele en prenatale preventie, gebrek aan kennis over het Nederlandse gezondheidszorgsysteem en gebrekkige Nederlandse taalvaardigheid.

Zorguitkomsten: perinatale mortaliteit is substantieel hoger in Nederland vergeleken met een groot deel van de andere Europese landen. Vooral de niet-medische karakteristieken van de zwangere vrouw zoals een niet-westerse migratie-achtergrond en een lage sociaaleconomische status zijn negatief geassocieerd met perinatale morbiditeit en mortaliteit.

Het doel van dit proefschrift is het verwerven van inzicht in de aanwezige afstemming tussen de aangeboden antenatale, obstetrische en postpartum zorg met de zorgbehoefte van de multi-etnische Rotterdamse populatie en tevens het bieden van interventiestrategieën die bij kunnen dragen aan het verbeteren van het zorgaanbod en zorggebruik door deze populatie. Dit proefschrift behandelt dit vraagstuk in drie delen. **Deel I** onderzoekt (a) het niveau aan tevredenheid met de zorg en (b) de ongelijkheid in het gebruik en het aanbod van antenatale, obstetrische en postpartum zorg. **Deel II** behandelt de kwaliteit van de counseling over prenatale screening en het Structureel Echoscopisch Onderzoek (SEO, 20-wekenecho). Deel III omvat een evaluatie van interventies die bijdragen aan (a) geïnformeerde besluitvorming, (b) kennis over de gezondheidszorg en (c) gezond gedrag.

Deel I – Tevredenheid met zorg, ongelijkheden in gebruik en aanbod van antenatale en postpartum zorg in een multi-etnische populatie

Ten eerste wordt in deel I van dit proefschrift de mate van tevredenheid met de antenatale, obstetrische en postpartum zorg binnen een Nederlandse multi-ethnische en lage sociaaleconomische vrouwenpopulatie onderzocht.

Hoofdstuk 2 beschrijft een studie waarin focus groep interviews zijn gecombineerd met het responsiviteitsconcept van de Wereld Gezondheidsorganisatie (WHO), waarmee de tevredenheid met de zorg gemeten is. Dit hoofdstuk toont aan dat in een laagopgeleide Nederlandse en niet-westerse studiepopulatie de responsiviteitscategorie 'Respect voor personen' de meeste invloed heeft op de tevredenheid met de antenatale, obstetrische en postpartum zorg. De studie populatie was het meest tevreden over de aangeboden antenatale zorg. Zij waren minder positief over de ontvangen zorg tijdens de geboorte en kraamperiode. Over het algemeen was de geboortezorg responsiviteit in alle fasen van de zorg (antenataal, obstetrisch en postnataal) niet in overeenstemming met de zorgbehoefte van de onderzochte vrouwen. De 'Respect voor personen' domeinen 'autonomie', 'communicatie' en 'waardigheid' en het 'cliënt georiënteerde' domein 'directe aandacht' werden met betrekking tot de aangeboden geboortezorg het meest negatief beoordeeld.

Ten tweede worden in het eerste deel van dit proefschrift de bestaande ongelijkheden in de aanbiedingsprocedure prenatale screening, de deelname aan prenatale screening naar etniciteit, Nederlandse taalvaardigheid en sociaaleconomische status geëxploreerd.

Hoofdstuk 3 geeft een analyse weer van de associatie tussen de aanbiedingsprocedure prenatale screening op downsyndroom (combinatietest) en het Structureel Echoscopische Onderzoek (SEO, 20-wekenecho) en de intentie tot deelname aan screening naar etniciteit en Nederlandse taalvaardigheid. De belangrijkste conclusies zijn dat vrouwen met een migratie-achtergrond en / of met een insufficiënte Nederlandse taalvaardigheid minder toegang hebben tot het Nederlandse prenatale screeningsprogramma. Deze uitkomsten laten zien dat de gelijke toegang tot het nationale screeningsprogramma, zoals op basis van de Wet op het Bevolkingsonderzoek dient te bestaan, niet wordt gerealiseerd.

Hoofdstuk 4 beschrijft een onderzoek naar de aanwezigheid van ongelijkheden in deelname aan de combinatietest en het SEO in relatie tot etniciteit en sociaaleconomische status van zwangeren woonachtig in de vier grootste Nederlandse steden. De studieuitkomsten tonen aan dat de intentie tot deelname een belangrijke verklarende factor bleek in alle analysemodellen. Toch bleek na correctie voor intentie tot deelname aan screening dat etniciteit een significante determinant is voor de verschillen in deelname. Etniciteit en sociaaleconomische status hebben een wisselwerking, aangevende

dat vrouwen met een niet-westerse migratie-achtergrond en vrouwen met een lage sociaaleconomische status de laagste deelname percentages laten zien. De patronen van de geobserveerde effecten van etniciteit en sociaaleconomische status suggereren een opeenstapeling van nadelen voor kwetsbare vrouwen.

Tenslotte wordt het eerste deel van dit proefschrift afgerond met een onderzoek van de maternale determinanten en (zelf gegeven) redenen die geassocieerd zijn met een te laat antenataal consult van zwangeren die informatie aangeboden kregen over prenatale screening.

Hoofdstuk 5 beschrijft een studie naar de associatie tussen de redenen voor een te late start van antenatale zorg en diverse maternale determinanten in relatie tot het tijdstip van het eerste antenatale consult. De belangrijkste uitkomst van deze studie was allereerst het feit dat een ongeplande of ongewilde zwangerschap de meest voorkomende reden was voor een te laat eerste antenataal consult. Ten tweede komt een late eerste antenataal consult vaker voor bij adolescenten, 'oudere' vrouwen (≥40 jaar), een hogere pariteit (P≥3), vrouwen met een voorgaande miskraam en vrouwen met een afwezige Nederlandse taalvaardigheid in vergelijking tot vrouwen zonder deze achtergrond. Tot slot laat een afwezige Nederlandse taalvaardigheid de sterke associatie met een 'heel laat' eerste antenataal consult zien.

Deel II – Kwaliteitstoetsing van prenatale counseling en het Structureel Echoscopisch Onderzoek

Het tweede deel van dit proefschrift onderzoekt welke methodes kunnen bijdragen aan een gestandaardiseerde, goed herhaalbare en betrouwbare kwaliteitstoetsing van de counseling over prenatale screening en het Structureel Echoscopisch Onderzoek (SEO, 20-wekenecho).

Hoofdstuk 6 beschrijft de ontwikkeling van een nieuwe methode waarmee de kwaliteit van het voorlichtingsdeel van de counseling over eerste en tweede trimester prenatale screening kwalitatief kan worden getoetst. De ontwikkelde kwaliteitstoetsingsmethode bestaat uit de volgende elementen: (1) het maken van een geluidsopname van het counselingsgesprek, (2) transcriptie van de geluidsopname door de counselor, (3) beoordeling van de inhoud van het transcript door drie auditors met gebruikmaking van twee scoringsinstrumenten voor het beoordelen van de voorlichting over de combinatietest en het SEO. De uitkomsten van de intraobserver variabilititeitsanalyse laten zien dat de methode een reproduceerbare en haalbare kwaliteitstoetsingsmethode is die bruikbaar is binnen de brede context van de gezondheidszorg.

Hoofdstuk 7 omvat een evaluatie van een nieuwe methode voor het toetsen van de kwaliteit van het SEO. De methode is ontwikkeld in Zuidwest Nederland en op een beeldbeoordelingsmethodiek gebaseerd. Omdat er tot op heden een uniform systeem

voor de monitoring van de actuele kwaliteit van het SEO in Nederland ontbrak is er in Zuidwest Nederland een nieuwe methode ontwikkeld. Elke echoscopist werd gevraagd een digitaal SEO portfolio samen te stellen dat bestond uit vijf SEO logboeken afkomstig van vijf willekeurig geselecteerde SEO's, verricht bij vijf verschillende zwangeren. Elk logboek bestond uit 25 foetale anatomische structuren en zes metingen van de biometrie. Kwaliteitstoetsing van het SEO met gebruikmaking van de beeldbeoordelingsmethode laat zien dat de meeste echoscopisten voldeden aan de landelijke kwaliteitseisen en degenen die in eerste instantie als onvoldoende werden beoordeeld na hands-on training voldeden.

Deel III – Verbeteren van de geïnformeerde besluitvorming, kennis over de gezondheidszorg en gezond gedrag

Het derde deel van dit proefschrift onderzoekt interventies die kunnen bijdragen aan de verbetering van kennis over antenatale en postpartum zorg, gezond gedrag en geïnformeerde besluitvorming over prenatale screening.

Hoofdstuk 8 beschrijft een studie die zich richt op de karakteristieken van deelnemers aan reproductieve gezondheidsvoorlichting gegeven door voorlichters met een gelijke taal en cultuur, het effect van verschillende wervingsmethodes voor deelnemers aan gezondheidsvoorlichting en kennistoename als gevolg van deelname aan de voorlichting. Actieve interpersoonlijke wervingsmethode waren het meest succesvol in het bereiken en werven van deelnemers met een eerste generatie migratie-achtergrond. De studie toonde een significante kennistoename aan op alle in de studie gemeten reproductieve gezondheid gerelateerde kennisgebieden zoals reproductief gedrag en het prenatale- en kraamzorgsysteem.

Hoofdstuk 9 omvat een evaluatie van het effect van cultureel competente voorlichtingsfilms over prenatale screening op de geïnformeerde besluitvorming over al dan niet deelname aan screeningsonderzoeken binnen een multi-etnische studiepopulatie. Na het zien van de cultureel competente films nam de kennis over het Structureel Echoscopisch Onderzoek (SEO) significant toe van zwangeren met een migratie-achtergrond en van vrouwen met een gemiddeld tot hoog opleidingsniveau. Binnen de populatie vrouwen die de intentie hadden om deel te nemen aan het SEO was na het zien van de voorlichtingsfilm de geïnformeerde besluitvorming toegenomen en de geïnformeerde besluitvorming afgenomen. De cultureel competente voorlichtingsfilms zijn een waardevolle toevoeging op de counseling over prenatale screening.

CONCLUSIE

De uitkomsten van de in dit proefschrift weergegeven studies laten zien dat er binnen de Nederlandse multi-etnische populatie ongelijkheden bestaan in het aanbod aan, gebruik van en tevredenheid met de zorg voor zwangere, moeders en hun (ongeboren) kinderen. De twee in dit proefschrift behandelde interventiestrategieën: (1) 'reproductieve gezondheidsvoorlichting gegeven door voorlichters met een gelijke taal en cultuur' en (2) 'cultureel competente voorlichtingsfilms' kunnen bijdragen aan de verbetering van de kennis over antenatale en postpartum zorg, gezond gedrag en geïnformeerde besluitvorming. Dit proefschrift beveelt de Nederlandse overheid, geboortezorg organisaties, verloskundig zorgverleners en zorgverzekeraars aan (1) de kwaliteit van de Nederlandse geboortezorg vanuit een 'context-based medicine' benadering te meten en te verbeteren op basis van het WHO concept voor responsiviteit van het zorgsysteem en (2) om zich te richten op professionalisering van de *culturele competentie* en *transculturele communicatie* van de (kandidaat) verloskundig zorgverleners in Nederland.

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Programma Klaar voor een Kind, Gemeente Rotterdam / Erasmus MC. Januari 2011.

- Evaluatierapportage: ontwikkeling en uitvoering opleiding Voorlichting Perinatale Gezondheid.

Peters IA, van Veen DW, van der Weg EW, Steegers EAP, Denktas S.

Programma Klaar voor een Kind, Gemeente Rotterdam / Erasmus MC. December 2011.

Evaluatierapportage pilot 'Training Geboorte en Kraamtijd bij verschillende culturen'.

Peters IA.

Onderdeel van het Europees gesubsidieerde project 'Een Intercultureel Fundament'. Mei 2013.

Evaluatierapportage pilot workshops 'Geboorte en Kraamtijd bij verschillende culturen'.

Ingebed in het Rotterdamse kraamzorgonderwijs.

Peters IA.

Programma Klaar voor een Kind, Gemeente Rotterdam / Erasmus MC. Mei 2013.

- Evaluatierapportage pilot workshops 'Zwangerschap en Geboorte bij verschillende culturen'.

Ingebed in het Rotterdamse verloskundig onderwijs.

Peters IA.

Programma Klaar voor een Kind, Gemeente Rotterdam / Erasmus MC. Mei 2013.

Books

Geboortezorg bij verschillende culturen Fadua el Bouazzaoui & Ingrid A. Peters Uitgeverij LannooCampus, Houten ISBN 978 94 014 3605 2

Summary:

In the Dutch multi-ethnic society the obstetric caregiver frequently provides care to pregnant women with an immigrant background. Differences in lifestyle habits and rituals concerning the preconceptional, antenatal and postpartum period have increasing influence on the provision of obstetric care within a multi-ethnic patient population. Previous studies show that the Dutch obstetric caregivers experience the provision of obstetric care to especially non-western immigrant women as complex. The handbook 'Geboortezorg bij verschillende culturen' (Obstetric care within different cultures) elaborates on evidence-based medicine background information about cultural and religious differences in obstetric care of six most relevant Dutch immigrant groups. Furthermore, the book guides the obstetric caregiver in how to provide care and inform immigrant women from a context-based medicine and patient perspective.

The book is structured by the following chapters:

Chapter 1 Introduction

Chapter 2 Culture and religion

Chapter 3 Diversity

Chapter 4 Preconception period

Chapter 5 First trimester of pregnancy Chapter 6 Second trimester of pregnancy Chapter 7 Third trimester of pregnancy

Chapter 8 Postpartum period

Published interviews

Geboorte en Kraamtijd in verschillende culturen. Leren omgaan met rituelen en gebruiken.

Nataal, Nieuwsmagazine voor pre- en postnatale dienstverlening. December 2012.

- Geboortezorg bij verschillende culturen. Respecteer de cultuur maar blijf jezelf. Kraamsupport. Nr.6 / 2017.
- Geboortezorg bij verschillende culturen. Met respect en humor de verschillen overbruggen
 - Nataal, Nieuwsmagazine voor pre- en postnatale dienstverlening. December 2017.

PHD PORTFOLIO

Summary of PhD training and teaching

Name PhD student: Ingrid A. Peters

Erasmus MC Department: Obstetrics & Gynaecology

PhD period: 2011 – 2018

Promotores: Prof. dr. Eric A.P. Steegers

Prof. dr. S. Denktaş

1. PhD training

		Year	Workload (Hours/ECTS)
Ge	eneral and specific courses		
-	SPSS Introduction course	2011	2.0
-	Access	2016	2.0
-	Leadership course	2016	3.0
-	Access Databases functioneel verbeteren	2017	1.0
-	Quality assessmentcourse Kerteza	2018	2.0
Se	minars, workshops and (research) meetings		
-	Research meetings of the Department of Obstetrics and Gynaecology, Erasmus MC, Rotterdam the Netherlands (1 oral presentation).	2011-2013	2.0
-	Research meetings of the Ready for a Baby program, Erasmus MC, Rotterdam the Netherlands.	2012	1.2
-	Café Bebé, monthly meetings for participating partners, of the Ready for a Baby programme Rotterdam the Netherlands (1 oral presentation)	2011	0.4
-	Casuïstiekbesprekingen (ultrasound), Foundation Prenatal Screening Southwest Region of the Netherlands (SPSZN) (attending)	2011-2018	3.0
-	Kringsymposium Verloskunde Academie, Rotterdam, the Netherlands (oral presentation / workshop)	2011	1.0
-	Dutch Population Screening Act, Prenatal Screening, RIVM/CvB. Regional meeting colon screening (oral presentation)	2011	0.6
-	European project, Intercultural fundament (EIF) Actiz/VGN. Kick-off meeting & final conference (2 oral presentations)	2011-2012	2.0
-	Diversity Forum, Rotterdam, (participation in discussion board)	2012	0.4
-	CvB Café, jaarlijkse bijeenkomst RIVM/CvB	2016	0.4
-	Regional meeting 'Foundation prenatal screening region Utrecht' (SPSRU).	2016	0.2

Presentations and (inter)national conferences and symposia Attending & organization: Symposia of the Foundation Prenatal Screening Southwest Region 2011-2018 6.0 of the Netherlands (SPSZN) (organization & attending 11 symposia) Nederlands Congres Volkgezondheid, Duurzame Gezondheid 2011 1.0 (attending) Derde conferentie Pre- en Neonatale screeningen, RIVM/CvB 2012 0.4 (attending) Vierde conferentie Pre- en Neonatale screeningen, RIVM/CvB 2015 0.4 (attending) Symposium 'De vervolmaakte mens', Stichting Downsyndroom 2017 0.4 (attending) Presentations: Nationaal Congres Preconceptiezorg 2011 (poster presentation) 2011 0.8 Congres Grootstedelijke Perinatale Gezondheid 2. programma 1.0 2011 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (oral presentation) Symposium, Prenatale Screening anno Foundation Prenatal 2011 1.0 Screening Southwest Region of the Netherlands (SPSZN) (oral presentation) Symposium, Lustrum, 5 jaar SPSZN, Foundation Prenatal 2011, 2012 2.0 Screening Southwest Region of the Netherlands (SPSZN) (2 oral 2012 0.8 presentations) Kennispoort Verloskunde 2012 (poster presentation) 2013 1.0 Eindsymposium programma Klaar voor een Kind, programme 2015 1.0 'Ready for a Baby' Municipality Rotterdam / Erasmus MC MC (oral presentation) Symposium, Nieuwe ontwikkelingen en onderzoek, Foundation 2018 1.0 Prenatal Screening Southwest Region of the Netherlands (SPSZN) (oral presentation) Symposium, Eerste Resultaten Trident 2, Foundation Prenatal 2018 1.0 Screening Southwest Region the Netherlands (SPSZN) (oral presentation) Congres Pre- en Neonatale Screeningen 2018 (2 oral presentations 2018 2.0 / workshops) Symposium Dutch platform for Family Medicine & International 1.0 2018 Health (oral presentation) Najaarssymposium, Foundation Prenatal Screening Southwest 2018 1.0 Region the Netherlands (SPSZN) (oral presentation) Symposium 'Eerder dan verwacht' Medilex (oral presentation) 2018 1.0

			PhD Portfolio
Ot	ther: Grant proposal assistance		
-	Assisted in the writing of a grant proposal for 'ZonMw'. Projecttitle: Zwangerwijzer for low educated and immigrant groups.	2011	2.0
-	Assisted in the writing of a grant proposal for 'Stg. Coolsingel'. Projecttitle: IDM-Intervention study	2014	1.0
Ot	ther: Writing of municipal and other reports		
-	Kwartaalrapportages programma Klaar voor een Kind, programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (coauthor)	2011-2013	1.0
-	Nulmetingrapportage Diversiteit & Interculturalisatie Rotterdamse kraamzorgorganisaties, programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (author)	2011	2.0
-	Nulmetingrapportage Diversiteit & Interculturalisatie Rotterdamse kraamzorgopleidingen, programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (author)	2011	2.0
-	Nulmetingrapportage Diversiteit & Interculturalisatie Verloskunde Academie Rotterdam, Hogeschool Rotterdam, programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (author)	2011	2.0
-	'Reaching disadvantage target groups': a review of the literature' for the World Health Organization (co-author)	2012	1.0
-	Evaluatierapportage werving, selectie en implementatie <i>Voorlichters Perinatale Gezondheid (VPG)</i> , Programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (author)	2013	2.4
-	Eindevaluatie programma Klaar voor een Kind, Programme 'Ready for a Baby' Municipality Rotterdam / Erasmus MC (co-author)	2013	2.0
2	Teaching activities		
	cturing		
-	Training: 'Geboorte en kraamtijd bij verschillende culturen', for maternity caregivers. Part of programme Ready for a Baby. Municipality Rotterdam / Erasmus MC (Development and 13 x training)	2011-2012	4.5
-	Workshop: 'Zwangerschap en geboorte bij verschillende culturen', for Midwifery students. Part of programme 'Ready for a Baby'. Municipality Rotterdam / Erasmus MC (Development and 3 x workshop)	2012	2.0
-	'Multicultural Interventions' for medical students; minor Circle of Life, Erasmus MC, Rotterdam (Lecturing and practicals)	2011	2.0
Su	pervising practicals and excursions, Tutoring		
-	Supervising bachelor students (n=6) of the University of Applied Sciences, Rotterdam. Guided students in focus group research in a multidisciplinary project.	2011	3.0

-	Supervising medical students (n=4) of the Erasmus Medical Center, Rotterdam. Guided students in focus group research in a community project.	2012	1.0
-	Supervising two groups of medical students (n=8) of the Erasmus Medical Center, Rotterdam. Guided students in their community projects (quality assessment and qualitative research).	2013	2.0
-	Supervising midwifery students (n=4) of the University of Applied Sciences, Rotterdam. Guided students to conduct their bachelor thesis.	2012-2017	4.0
-	Supervising midwifery students (n=2), University of Applied Sciences, Rotterdam. Guided students during their minor project.	2012-2013	1.0
-	Supervising Human Health & Life Science students (n=2), VU Amsterdam. Guided students to conduct their bachelor thesis.	2015-2016	3.0
Ot	her		
-	Board of Directors, Foundation Prenatal Screening Southwest Region of the Netherlands, SPSZN (attending)	2011	1.0
-	Advisory committee, Foundation Prenatal Screening Southwest Region of the Netherlands (SPSZN) (organisation, attending and 7 oral presentations)	2011-2018	4.0
-	Committee & workgroups 'Kraamzorg bereik, diversiteit en interculturalisatie'. Part of programme Ready for a Baby. Municipality Rotterdam / Erasmus MC (chairwoman & 5 oral presentations)	2011-2012	8.0
-	Brainstorm session 'Kwaliteit counseling Down/SEO). Dutch Population Screening Act, Prenatal Screening, RIVM/CvB, Utrecht (participant)	2012	0.6
-	Workgroup 'Deskundigheidsbevordering & Voorlichting'. Dutch Population Screening Act, Prenatal Screening, RIVM/CvB, Bilthoven (invitee or deputy participant, 2 oral presentations).	2011-2018	3.0
-	Brainstorm session 'Verbetering counseling over prenatale screening'. Dutch Population Screening Act, Prenatal Screening, RIVM/CvB, Bilthoven (participant)	2017	1.0
-	Project group 'Ontwikkeling nieuwe landelijke toetsingsmethode counseling'. Dutch Population Screening Act, Prenatal Screening, RIVM/CvB, Bilthoven (participant)	2017-2018	2.0
-	Board of Directors, Foundation Prenatal Screening Southwest Region of the Netherlands, SPSZN (oral presentation)	2017	1.0
-	Media communications: radio broadcast; BNR Beter, BNR Spits, VPRO podcast Trees and writing press; Nataal and Kraamsupport (4 interviews)	2012-2018	2.0

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ABOUT THE AUTHOR

Ingrid Andrea Peters, the youngest child of A.L.M. Peters and B.M.T. Peters-Romeyn, was born in Papendrecht on the 2nd October 1980. During the quick, early morning homebirth mother was medically assisted by a general practitioner, before he started his consultation hour. During her childhood she lived in Papendrecht and went to primary school in Dordrecht (Dordtse Vrije School). From her early years on Ingrid has been passionate about music, dance and books. She spent lots of time singing, performing ballet and playing several instruments. At the age of 12, this resulted in an admission to follow a pre-conservatorium educational program for



classical singing. She combined this program with high school in Rotterdam (Havo voor Dans en Muziek). It was an inspiring period with classical singing lessons, masterclasses, language and drama education and performances in small concert halls, churches and jazz clubs. In 1997 she left Papendrecht to live in Rotterdam and here she graduated from high school. In 2000 she decided to leave the conservatorium and started a study Social Work and Services on the University of Applied Science in Rotterdam. During her study (2000-2004) she discovered her fascination for ethnic and cultural diversity in relation to societal issues from a public administration perspective while doing an internship as guardian for unaccompanied minor asylum seekers and volunteer work in the deprived neighborhoods of Rotterdam. This motivated her to finish her masters Policy and Politics at the Erasmus University of Rotterdam in 2006. Commissioned by the Ministry of Education, Culture and Science she wrote her master thesis focusing on 'Governance relationship with knowledge institutes' (e.g. TNO).In 2007 she started at the Erasmus Medical Center as coordinating staff advisor at the Foundation Prenatal Screening Southwest region of the Netherlands (SPSZN). She co-founded and professionalized the SPSZN. Currently, she still fulfills her function at the SPSZN and during this period she also functioned from 2008 until 2012 as a co-author of several policy reports like for example the 'Actionplan perinatal mortality' (Aanvalsplan Perinatale Sterfte) and as a 'Project leader interculturalization' within the Rotterdam governmental program 'Ready for a Baby'. In January 2011 she started her PhD research, which resulted in this thesis. Ingrid is married to Gosling J. Putto and together they have three children; Veerle (2010), Irfan (2014) and Julie (2015).

DANKWOORD

Allereerst gaat mijn grote dank uit naar alle (zwangere) vrouwen, deelnemers aan gezondheidsvoorlichting, verloskundigen, verpleegkundigen, gynaecologen, echoscopisten, verloskundige praktijken, echocentra en ziekenhuizen, Stichting Voorlichters Gezondheid, Stichting Prenatale Screening Zuidwest Nederland, Rotterdamse onderwijsinstellingen en maatschappelijke organisaties die een bijdrage aan de onderzoeken in dit proefschrift hebben geleverd.

Het proces van het doen van onderzoek, het schrijven van manuscripten, deze publiceren en het op basis hiervan samenstellen van mijn proefschrift is allerminst solistisch. In belangrijke mate werd dit proces bepaald door de professionele inbreng, steun, advies en wijze lessen van mensen uit het verleden en heden.

Allereerst wil ik mijn promotoren **prof dr. E.A.P. Steegers** en **prof. dr. S. Denktaş** bedanken voor hun persoonlijke en professionele inbreng tijdens mijn promotietraject. **Eric**, ik wil je bedanken voor de mogelijkheid die je mij, als 'vreemde eend in de bijt', hebt geboden om in 2011 te starten met mijn promotieonderzoek. Op essentiële momenten tijdens mijn zeven jaar durende promotietraject vervulde je je rol als mijn promotor. Bijzonder veel dank hiervoor Eric! **Semiha**, jij was het die mij, ondanks mijn aanvankelijke scepsis, aanspoorde te gaan promoveren. Je gaf mij het vertrouwen, de autonomie en ook zo nu en dan het intellectuele 'pak op mijn donder' wat ik nodig had. Semiha, bedankt voor je professionele en menselijke betrokkenheid en bovenal dank voor het zijn van een voorbeeld.

Lieve collega's bij de Stichting Prenatale Screening Zuidwest Nederland (SPSZN) wat heb ik veel aan jullie gehad de voorbije jaren. Allereerst gewoonweg omdat mijn gevarieerde, soms veeleisende functie bij de SPSZN de drukte en mogelijke zorgen omtrent mijn promotietraject relativeerde. Voornamelijk mijn band met jullie is een waardevolle steun voor mij geweest. Jacqueline, ik waardeer het enorm dat je vanaf je aantreden als directeur, en inmiddels bestuurder van de SPSZN, mij in de vorm van flexibele werkindeling faciliteerde in het kunnen combineren van mijn functie voor de stichting en mijn promotie. Maarten, je bent directeur bestuurder van de SPSZN en tevens coauteur van drie artikelen van dit proefschrift waardoor we niet alleen vanuit de SPSZN collega's zijn, maar ook konden sparren over het onderzoek. Mieke, ondanks dat je inmiddels elders werkt mijn dank voor al je inhoudelijke vragen over de onderzoeken, waardoor je mij in staat stelde te oefenen met het geven van een korte en heldere toelichting in plaats van een redevoering;-). Ook de door jou herhaalde malen uitgesproken 'trots' dat ik er in slaagde mijn partner- en moederschap, functie bij de SPSZN en mijn promotie te combineren raakte mij. Nicolette, je bent voor mij tijdens mijn promotietraject een ware kameleon geweest. Je schoot moeiteloos van je rol als mijn collega bij de SPSZN, naar je rol als coauteur van drie van de onderzoeken in dit 'boekje', maar functioneerde ook regelmatig als onofficiële copromotor als tijdens mijn promotietraject strategische keuzes moesten worden gemaakt. Ook in de afrondde fase gaf je nuttig advies en tips omtrent de opmaak en druk van het boekje maar ook over culinaire zaken tijdens de promotiedag. Waarvoor mijn dank, Nicolette! **Edith** en **Tulin**, ik benoem mijn dank voor jullie inbreng tegelijk, omdat ik voor de realisatie van de 'IDM-Intervention study' nauw met jullie heb samengewerkt. Ook kon ik bij jullie op de kamer tussen de werkzaamheden door altijd even mijn verhaal doen als bijvoorbeeld het proces van submitten tijdrovend was of als ik moe was van avonden doorwerken in combinatie met de gebroken nachten als gevolg van een jong gezin. Edith, speciale dank voor je inzichten over enkele figuren in mijn proefschrift en Tulin dank voor je verfrissend realistische uitspraken omtrent de academische wereld.

Beste **Hajo**, samen hebben we de SPSZN in de beginjaren vormgegeven en in het kader van het regionale en landelijke prenatale screening programma veel neergezet. Je gaf mij de autonomie om mijn bestuurskundige en onderzoek competenties te ontwikkelen en aan te wenden voor de stichting en het programma Klaar voor een Kind. Ik waardeer het zeer dat vanaf je directeurschap bij de SPSZN tot op de dag van vandaag er tussen ons een goed contact bestaat. Met jou is altijd een goed gesprek te voeren over thema's zoals etnisch-culturele diversiteit in de geboortezorg, het schrijverschap, reizen en de kinderen. Bedankt!

Voor de realisatie een promotie zijn niet alleen mensen van belang maar ook meer promovendi specifieke randvoorwaarden zoals bijvoorbeeld muziek van belang. In dit kader gaat mijn dank uit naar de Italiaanse radiozender Venice Classic Radio Italia en componist J.S. Bach. Deze muziek gaf mij zeven jaar lang de concentratie tijdens ontelbare analyse- en schrijfuren. Ook wil ik kunstenares Júlia dos Santos-Baptista bedanken voor het mogen gebruiken van haar werk 'Ciranda Sophia' (2008) voor de cover van mijn proefschrift. Je levensverhaal en de thematiek van je werk en mijn onderzoeksvraagstuk completeren elkaar.

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deelden we zowel op de centrumlocatie als op de Westzeedijk een kamer alwaar we ondanks veel werk altijd even tijd vrijmaakten voor een fijn gesprekje of een gezellig momentje (je regelmatig meegebrachte dadels waren heerlijk;-)). Toen je eenmaal aan je huisartsenopleiding begon, vervolgens promoveerde en je specialisatie afrondde bleef ons contact via de digitale weg bestaan. Sev, dank voor je niet aflatende betrokkenheid bij zowel mijn persoonlijke leven als bij mijn promotie.

Ook dank aan de voormalig mede-promovendi en collega onderzoekers **Babs**, **Jashvant**, **Sabine**, **Amber**, **Marijana** en **Vera** waarmee ik vele inhoudelijke, praktische en gezellige gesprekken voerde. Jullie bevlogenheid was inspirerend en heeft voor jullie persoonlijk geresulteerd in een opleidingstraject en carrière in de gynaecologie en voor twee van jullie zelfs in een loopbaan in de internationale academische wereld. Prachtig!

Danielle oftewel **Daan**, ooit heb je mij, ongeveer 12 jaar geleden, welkom geheten op mijn eerste dag op de afdeling V&G van het Erasmus MC. Uiteindelijk werden we collega's in het gemeentelijke programma 'Klaar voor een Kind' en werkten we nauw samen in het succesvolle interventieproject 'Voorlichting Perinatale Gezondheid'. Het was een vruchtbaar en uniek samenspel tussen jouw projectcoördinatie en mijn onderzoeksactiviteiten. Mooi dat we de afgelopen jaren ondanks drukte en veranderende functies ons contact hebben behouden. Bedankt Daan.

Fadua, Teslime, Hafida en Hoesnia (Stichting Voorlichters Gezondheid (SVG)) wat hebben we veel met elkaar meegemaakt de afgelopen zeven jaar! Achtereenvolgens jullie diplomering, de pilot Voorlichting Perinatale Gezondheid waarin jullie in een heel korte tijd meer dan 2000 vrouwen en mannen bereikten, onze tour langs kraamzorginstellingen, kraamzorgopleidingen en de verloskunde opleiding voor het geven van diversiteitstrainingen, ontelbare duo-presentaties op congressen en symposia, schrijvende pers en radio interviews en zelfs een gezamenlijk auteurschap van het boek 'Geboortezorg bij verschillende culturen'. En er volgt nog meer.... Lieve dames, ontzettend veel dank voor alle gezellige autoritjes, heerlijke maaltijden, jullie adhoc acties, creativiteit maar bovenal jullie humor! De bevlogenheid, passie en puurheid waarmee jullie het vraagstuk diversiteit in relatie tot de Nederlandse gezondheidszorg vanuit de SVG ter hand nemen is 'best practice' van de hoogste orde.

Ook heeft het contact met een groot aantal professionals werkzaam binnen de 1e, 2e en 3e lijns prenatale zorg, prenatale diagnostiek, klinische genetica en het landelijke prenatale screeningsprogramma bijgedragen aan mijn promotie. Graag wil ik specifiek Foske, Joyce, Titia, Annette, Philip, Jantine, Ton, Anne, Vivian, Heleen, Robert-Jan en Lutgarde bedanken voor jullie interesse voor mijn promotietraject. Tevens wil ik enkele van jullie aanvullend bedanken voor de bouw van een webapplicatie, kundige adviezen en inzichten en het stellen van kritische vragen.

Lieve Laura, Natascha, Marieke, Stephan, Astrid, Lisette en Selma. Ik koester onze vriendschap ontstaan tijdens één van mijn drie studies. Jullie interesse, het filosoferen over onderzoeksvraagstukken, jullie bemoediging en uitgesproken trots was fijn! Laura aan jou in het bijzonder veel dank voor je adhoc 'native speaker check' van enkele van mijn teksten. Zo knap hoe je dit wist te combineren met je drukke agenda als musicus in Duitsland.

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Nicole, vanaf onze eerste ontmoeting wist ik dat onze kinderen bij jou als hun gastouder in goede handen waren wanneer wij werkten. Je gaf onze kinderen tijdens hun baby- en peuterperiode drie dagen per week de onvoorwaardelijke zorg, warmte en ontwikkelingskansen die ze verdienden. Door jouw aanwezigheid in hun prille leven voelde het voor ons goed om het ouderschap met een carrière te combineren. Het is voor ons dierbaar dat de kinderen nog altijd zo aan je gehecht zijn! Natuurlijk wil ik ook gastouder Lieneke bedanken voor de spoed- en zomervakantieopvang. Ook Kikidsz bedankt voor de goede zorgen voor Irfan en Julie vanaf hun tweede en derde levensjaar. Tot slot dank aan Ingeborg, Renée en Lies die het in de afgelopen jaren mogelijk maakten dat wij wanneer de kinderen sliepen er zo nu en dan in de avond op uit konden. Dit was zeer welkom na een drukke week!

An, we hebben de voorbije jaren als schoonmoeder en schoondochter vooral over de (klein)kinderen vele gesprekken gevoerd terwijl mijn promotie maar nauwelijks ter sprake kwam. Zo hoort het ook te gaan, dus dank voor het ontspannen gekeuvel over het moederschap!

Lieve **Jordan**, **Mariëlle** en mijn lieve nichtjes **Jayda** en **Fayline**, in de afgelopen jaren hebben we ondanks ons drukke leven altijd tijd gemaakt voor gezellige momenten met elkaar. Dank voor al jullie geïnteresseerd vragen over de voortgang van het onderzoek en de door jullie uitgesproken bewondering.

Lieve **Papa** en **Mama**, dat dit proefschrift hier nu ligt is een direct gevolg van het voorbeeld dat jullie gaven met hoe jullie je carrière in de scheepsbouw en medische wereld vormgaven. Wanneer je je met visie, overtuiging en met tomeloze doorzettingsvermogen inzet voor je passie kan je veel bereiken. Dit is wat jullie in de puurste vorm voorleefden.

Lieve **Gos**, we zijn al ruim veertien jaar onafscheidelijk. Je unieke kijk op de wereld, je intelligentie, nuchterheid, directheid en je liefde voor en toewijding aan ons en onze kinderen maakt dat ik elke dag dankbaar ben met jou aan mijn zijde. Het kunnen genieten van elkaar en samen met de kinderen, het gezin runnen als een florerend

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Lieve **Veerle, Irfan** en **Julie**, elke dag kijk ik vol bewondering, dankbaarheid en trots naar jullie. Wat een onmetelijke rijkdom dat wij de ouders mogen zijn van zulke mooie, lieve, sprankelende en creatieve mensen. Hoeveel mama ook heeft geleerd van haar promotie jullie zijn haar grootste levensles. Kus van, mama.



