

Chapter 1

General introduction

'Om te zijn moet met eerst en vooral verantwoordelijkheid aanvaarden.
Men moet een taak op zich nemen.'

A. de Saint-Exupéry

“Yes, yes, [counseling should be] really a conversation. Not like hm ... it was a bit uh, too little attention was paid to it. I got that impression a little bit [because the midwife said:] Yes, you can do that, but yes, I do not really know what to tell you about this, we have a leaflet ... and, well read that one.” (A client about her counseling needs).

This thesis is about the conversation between clients and midwives concerning prenatal anomaly screening in early pregnancy. In order to gain knowledge about counseling for prenatal anomaly screening in the Dutch, midwifery-led care context, we focused on two different aspects: 1) the perspectives on counseling of clients and of midwives, and 2) the actual communication between midwives and clients during prenatal counseling. Both aspects are brought together in chapter 6. Before introducing the relevance of investigating midwife prenatal counseling, we first explain the approach to prenatal screening in the Netherlands.

Prenatal anomaly screening

From a positive pregnancy test to considering prenatal anomaly screening

Most expectant parents are happy to discover that they are expecting a baby and probably search the internet for the next step [1]. The client website of the Royal Dutch Association of Midwives (KNOV) recommends that women make an appointment with a midwife for primary, prenatal midwifery led care as soon as they know they are pregnant. The website also recommends women to attend their first appointment together with their partner [2]. Coming together to this intake visit is important for several reasons, including the fact that during the appointment midwives take both clients' and partners' family history regarding inherited birth defects, and provide counseling for prenatal anomaly tests, with the aim to facilitate clients' decision-making regarding whether or not to opt for prenatal anomaly screening [2-6]. For most couples, the decision whether to opt for anomaly screening or not is a decision couples want to make together, which underlines the importance to provide counseling to both of them, to make sure they both have the relevant information and support in making their decision [7,8]. As a result, when it comes to counseling for prenatal anomaly screening, partners are also midwives' clients. In this thesis we consider both pregnant women and their partners as clients; their perspectives regarding counseling for prenatal anomaly screening is our first focus.

Most women and their partners feel excited about their pregnancy but also a bit nervous about the first visit at their midwife [3,9]. At the end of this intake visit, or sometimes in a separate consultation, the midwife introduces the Dutch prenatal anomaly screening program, which aims to detect congenital anomalies in order to provide expectant parents with, if they choose to participate, reproductive choices [4]. Even the offering of the program is cause for parents to confront the fact that although most children are born with no diagnosed anomaly, in

every pregnancy there is a risk that the unborn child has a congenital anomaly [4]. As a result, some expectant parents may struggle to shift from their context of happily expecting a baby to talking about prenatal anomaly screening. The prenatal anomaly screening offer is timed in early pregnancy, because the first test can be completed around 12 weeks of gestation [10]. Because they have a 'right not to know' anything about prenatal anomaly tests, by about 10 weeks gestational age, clients need to make the first decision about prenatal screening: that is to decide whether they want any information about prenatal anomaly tests [11-13].

Dutch prenatal screening offer

If expectant parents accept the information offer about prenatal anomaly screening, the information process starts [14,15]. According to Van Agt *et al.* [16] expectant parents should get information about the available prenatal anomaly tests, the aim of these tests, medical information about the target anomalies and the prevalence of these anomalies. So, at the time of this study (data collection between 2010-2011), clients should have been informed that the Dutch prenatal screening program comprised two tests: 1) the Combined Test (CT) undertaken around 12 weeks gestational age to calculate a pregnancy related risk for Down Syndrome (trisomy 21) [4,10]; and 2) the Fetal Anomaly ultrasound Scan (FAS) done at around 20 weeks gestational age, to detect structural anomalies [4,10]. In January 2011, risk assessments for Edwards- (trisomy 18) and Patau syndrome (trisomy 13) were added to the CT. Since April 2014, the Non-Invasive Prenatal Test (NIPT) is also offered to clients who are identified to be at increased risk on the CT, defined as $\geq 1:200$, or family history [4,17,18]. The NIPT is a blood-screening test for Down-, Edwards- and Patau syndrome [17].

Regarding the target anomalies of the CT and NIPT, clients should be informed that children with Down syndrome have a decreased cognitive function, but that cognition can vary from normal or low intelligence to profoundly impaired. In addition certain complications and risks, such as congenital cardiac defects and ear, nose and throat defects, are higher among individuals with Down syndrome compared to the average population [19]. Clients should hear that children diagnosed with Edwards- and Patau syndrome show much more severe clinical manifestations than trisomy 21; only rarely do affected infants survive to one year of life [10]. Prevalence of Down-, Edwards- and Patau are respectively 1:500, 1:3000, and 1:6000 yearly [10,20].

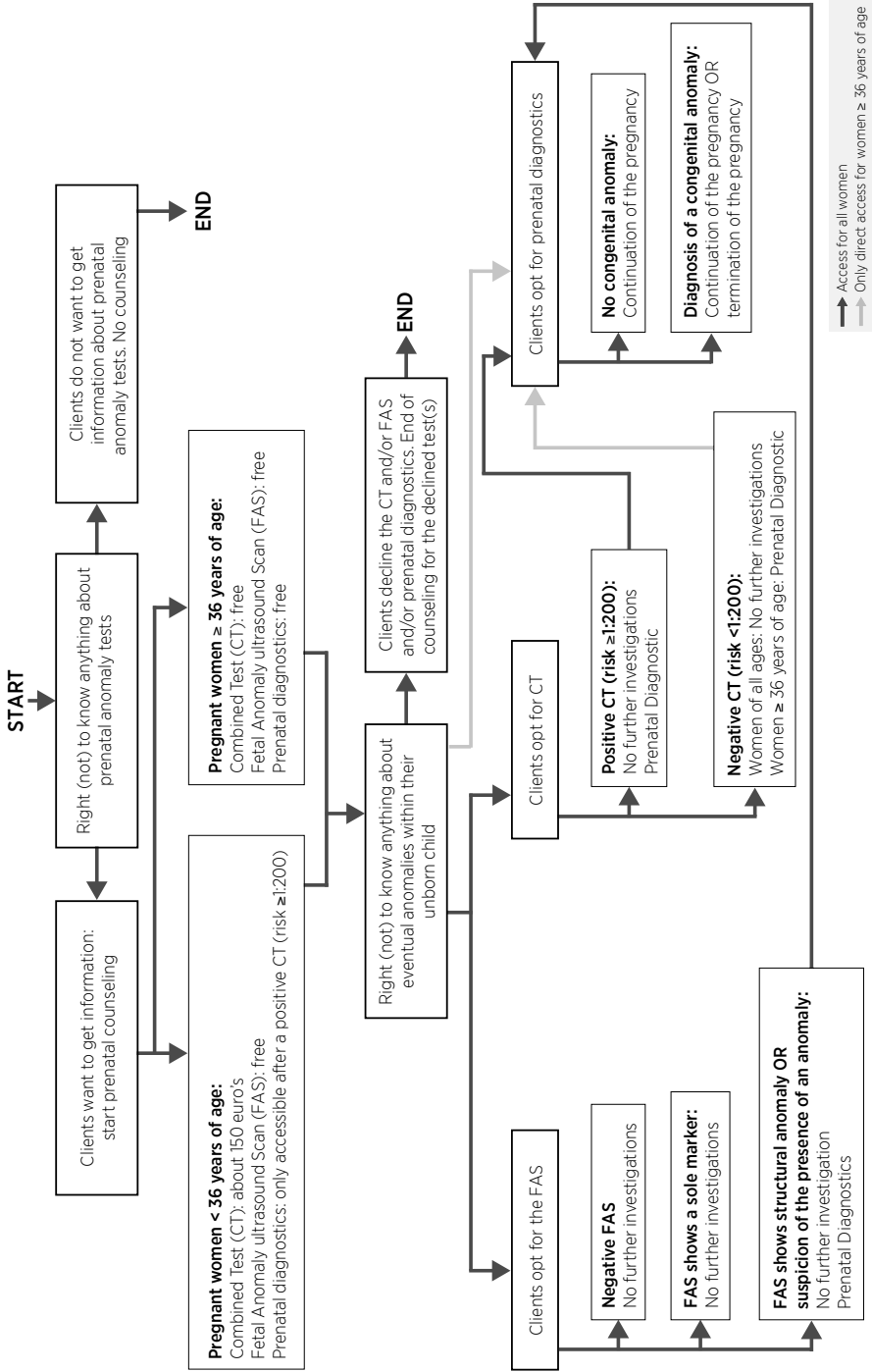
Further, clients should be informed about test procedures, the meaning of test results (screening versus diagnostic), including detection percentages, options after a positive screening outcome and the costs [16]. Thus, clients will be told that the CT comprises a blood test and ultrasound and is, like the FAS, considered harmless for both mother and unborn child [10]. For the client, the CT results indicate personal risk of a trisomy, which will indicate if follow-up prenatal diagnostic is indicated based on a cutoff value $\geq 1:200$ [4]. The test result of the FAS can be divided into three main categories to make clients clear what they can

expect; outcome 1, no anomaly is detected, but clients have to know that, for instance, 25-50% of heart defects are missed; outcome 2, a sole marker is seen that is of no known clinical significance; or outcome 3, a structural anomaly is seen or suspected [10]. When clients receive a positive screening outcome of the CT and/or FAS, and/or NIPT, clients can choose to follow up prenatal anomaly screening by a diagnostic test. Diagnostic, invasive tests are only offered on indication. In addition to positive screens, at the time of this study, maternal age ≥ 36 years of age and family history of birth defects were indications for direct access to diagnostic anomaly tests [12,21]. The FAS and, if indicated, diagnostic tests were free of charge, whereas the CT had to be paid for by women younger than 36 years of age [12,22]. Diagnostic, prenatal anomaly tests comprise an advanced ultrasound, chorion vilus sampling or amniocentesis, aiming to confirm the outcome of screening by providing a diagnosis. Parents should be informed that chorion vilus sampling and amniocentesis are associated with a miscarriage risk of about 0.5%, because the procedures involve the insertion of a needle into the uterus [10,23-25]. Finally, parents ought to be informed about the possibilities for action after diagnostic tests. Such information should comprise the two options continuing or terminating the pregnancy if an unborn child is diagnosed with an anomaly, treatment options and legal terms for termination of the pregnancy [16] (see flowchart Dutch prenatal anomaly test offer).

The right (not) to know

The above information is, in a nutshell, what expectant parents might hear during one of the first visits with their midwife. It is up to the pregnant women and her partner to decide whether to opt for anomaly screening or not and subsequently, whether or not to take a further diagnostic path. In other words: prenatal anomaly screening and diagnosis is offered using an *opt-in* approach; expectant parents have the right (not) to know and are thus encouraged to make their own reproductive choices based on reliable information [3,11,12,14]. To make a personal, reproductive choice is not always perceived as easy by clients [26,27]. The offer of prenatal anomaly screening seems to be an answer to one of clients' main concerns, that is, the wellbeing of their unborn child. At the same time the prenatal screening offer forces clients also to answer moral questions such as 'how welcome are children with an anomaly in my world, my life, my family?' or 'what does this pregnancy mean to me?' or 'how do I feel about the risk of a miscarriage in relation to my wish to know that my child does not suffer from a congenital anomaly?' [27-33]. Ultimately, clients can be confronted with the question whether to continue the pregnancy or to terminate the pregnancy in case of a confirmed, congenital anomaly [4,27,33]. Furthermore, prenatal anomaly screening is becoming better known to the general public. Both to take or decline the offer can be challenging in the resulting context of societal expectations and reactions of family and friends [34,35,36]. Consequently, regardless of whether clients opt for anomaly test or not, the offer of prenatal

Flowchart Dutch prenatal anomaly test offer 2010



anomaly screening alone forces parents to make a difficult choice [26]. Such a difficult choice takes time. Clients might want to (re)read information leaflets, talk to important others, visit advised websites, use a web-based decision-clarification aid, or ask for a second visit to their midwife [4,37].

If expectant parents choose to opt for prenatal screening, the midwife refers them to a provider of prenatal tests. Clients will receive the test result either by the provider of the test or by their midwife; in both cases midwives talk about the test results with the clients [4]. If prenatal anomaly diagnostic tests are to be considered, clients will receive counseling from professionals of one of the eight prenatal screening centers in the Netherlands [4].

Midwives as counselors

A new role

Midwives' perspective on counseling for prenatal anomaly screening is another important focus of this thesis. Midwives provide primary maternity care to approximately 80% of the Dutch pregnant women and are consequently the designated counselors in these pregnancies [4,11,38]. In 2006, midwives provided 202,000 counseling consultations (pre- and post-test counseling) to about 160,000 pregnant women who started prenatal midwifery-led care [38,39]. It is unclear what these figures indicate in terms of the number of counseling sessions per client.

The Dutch midwifery profession has evolved through, among other things, the continuous addition of tasks being added to midwives' responsibilities [39,40]. This was probably especially challenging for midwives between circa 2000 and 2005, when there was a huge shortage of midwives in the Netherlands [41]. At the end of this period, in 2005, the KNOV published a new Professional profile of midwives, with a strong emphasis on client-centered care: "Within daily care, the midwife should find a balance between the expectations, needs, desires and the identity of the individual client and her own professional standards as a midwife" [42]. In order to give midwives more practical guidance, client-centered care was further specified in professional roles and tasks. One of these roles was the role of counselor, which is client-centered by nature [43]: "The midwife as a counselor guides the woman to be her best self (empowerment). She offers the client guidance in gaining insight into her own feelings and behavior and will equip and assist her in making (emotional) decisions. The midwife as a counselor is characterized by her openness, sincerity, respect, listening skills, conversation skills, empathy, and especially her non-directivity" [42].

Although the role of counselor is relevant during conversations about preference sensitive decisions in general, Dutch midwives most often associate counseling with prenatal anomaly tests. This is understandable, since soon after the introduction of the new professional profile, in 2007, the task to provide prenatal counseling for anomaly screening and the role of being

a counselor became part of primary, prenatal midwifery-led care [12]. At the time of this study, the role of counselor was relatively new to midwives. Being a counselor requires the addition of other professional attitudes, associated knowledge and skills than midwives used to have. Midwives were familiar with the provision of information to clients, but not so much with empowering clients to make their own decision. To be oriented to the counselor role, all midwives were required to take a course in prenatal counseling for anomaly screening. This course is a prerequisite for offering prenatal counseling, for all midwives who graduated prior to 2007, at which time counseling became part of the educational requirements [4]. During a course about counseling for prenatal anomaly screening, information about relevant genetics, congenital anomalies, test characteristics and interpretation of test-results was offered as well as information and training regarding risk-communication and the competencies needed to facilitate decision-making in a non-directive, client-centered way while addressing moral and psychosocial issues [4,10]. The course for midwives about prenatal counseling for anomaly tests seem to be constructed in line with the international consensus about how counseling for preference sensitive choices, including prenatal anomaly screening, should be done.

Counseling for prenatal anomaly screening

A counseling model

In a review, Meiser *et al.*, [5] describe two models of genetic counseling, which are used in practice; the 'teaching model' and the 'counseling model'. Within the 'teaching model', counselors focus on information-giving and education, because the information that is transmitted is often seen as very complex, extensive and difficult to understand. For instance, explaining the value of a medical risk assessment, the differences between screening and diagnosis, the variety of the abilities of children with Down syndrome, the huge diversity of anomalies that could be detected with the FAS, the eligibility to screening in the Dutch health care context and recently the introduction of the NIPT, make the information complex and difficult to understand. In the 'teaching model', counselors' main goal is as a medical expert providing information in order to accurately educate their clients.

Within the 'counseling model', the main goal is to promote informed-decisions and to facilitate psychosocial understanding of the personal risks and conditions that could be tested for. Within the 'counseling model', increasing the emotional well-being of clients is also seen as a crucial part of genetic counseling. The 'counseling model' has been described as a psychotherapeutic process in which the counselor listens carefully to the client's story while asking client-centered questions; questions which follow and facilitate the clients' lines of reasoning in giving personal sense to the prenatal screening offer [4,5,6,36,43-48]. In a critical review of empirical studies regarding genetic counseling, Meiser *et al.* [5] suggested a two function counseling model. This model comprises both 'teaching' and 'counseling' in order

to enhance the key goal of genetic counseling; that is the facilitation of clients' autonomous, informed decision-making [4].

A non-directive attitude and client-centered approach

Counselors' guidelines and policy statements have advised counselors to use a non-directive counseling attitude, which means a non-persuasive communication style while facilitating clients' decision-making about prenatal anomaly screening [3,12,22,49,50]. The rationale for the emphasis on a non-directive attitude was to remove the counselors' personal views regarding a particular course of action, because the decision whether to opt for prenatal anomaly screening, or not, is preference sensitive: one course of action is not seen as better than another course of action [14,49,51,52]. Another core concept of genetic counseling is the use of a client-centered approach. Client-centered communication regarding the provision of information, that is the teaching component, focusses on tailoring the information to individuals' preferences, knowledge, interests and concerns [3,53-55]. When client-centered communication is used to facilitate a client's decision-making process, in the counseling function, counselors should follow the client's lead, encourage the client to share their deliberations and help them to make a 'decision-balance', a personal list of pros and cons of prenatal anomaly tests [48,56]. As clients are, in the end, the expert regarding their concerns, values and preferences concerning the decisions at hand, counselors should take the role of an engaged professional guide [37,48].

Recently, more and more authors point to the problems arising in practice from the use of a non-directive counseling approach; provision of information is always framed one way or the other and at least some clients seem interested to hear the opinion of the professional regarding whether they should opt for an anomaly test or not [8,50-52].

Perspectives of clients and midwives

Research on the development of guidelines about counseling for anomaly testing has shown that clients' preferences and counselors' views on appropriate counseling are relevant to incorporate in the ongoing development process of counseling guidelines [57,58]. At the time of this study research into clients' preferences regarding counseling for prenatal anomaly screening and counselors' views on appropriate prenatal counseling was minimal, although the two function counseling model seems to have been adapted within prenatal counseling for anomaly screening.

Clients: pregnant women and their partners

With regard to the 'teaching' function of prenatal counseling for anomaly screening, most clients indicated that some balance between details and brevity was optimal, since the wide

range of options could lead to confusion [59]. However, clients also feel a need for detailed, accurate information about the day-to-day symptoms that result from the anomalies that the unborn child could potentially be tested for, including information on potential suffering, and the potential quality of life for the child and his or her family [60,61]. Additional important aspects are the logistics of testing, follow-up if the test is positive, and options and resources if the child is affected with a disorder [59]. Clients seem to have mixed feelings about information stated with uncertainty and risks assessments, because the usefulness of risk assessments is not always clear to them [62,63]. Regarding the 'teaching' function, research shows that clients prefer information that is adapted to their social, ethnic and cultural background and provided in simple and accessible language, supported by written documents and photos [58,64,65]. During counseling, the client wants to be seen as an equal member of the team; a team in which care-providers know the limits of their knowledge and are willing to refer [58,61].

Research has focused almost exclusively on the 'teaching' function of counseling. Limited attention has been given to clients' preferences regarding the 'counseling' function, despite the fact that most clients do not want to be given 'information only', without guidance. The resulting lack of detailed and systematic insight into clients' 'counseling' preferences is problematic, because within health care, optimizing client empowerment, health decisions, and health behavior requires tailored communication; that is, communication that is adapted to the preferences, interests, and concerns of the individual [3,43,53-66,67]. Furthermore, whereas pregnant women have been included in counseling research, their partners have rarely been. Because of the important role of partners in decisions around prenatal screening for anomalies, we viewed partners to also be midwives' clients. Therefore, both pregnant women's and their partners' preferences regarding prenatal counseling for anomaly screening are investigated within this study.

Midwives' perspectives

Counselors' views on appropriate counseling are important to understand, because these views will reflect the way counseling is carried out in daily practice [6]. From the relatively little available literature it is known that genetic counselors in general, perceive the 'teaching' function as part of their role, but only a minority of counselors view also the 'counseling' function as part of their role [6]. With regard to the 'teaching' function, counselors primarily stressed the importance of informed consent while balancing the information that is given compared to the information that is withheld. Regarding the 'counseling' function, counselors struggle with directiveness versus non-directiveness. Some counselors admitted to provide 'teaching' and 'counseling' based on their own (predictably limited) experience, and gave advice based on the choices they themselves would make. This may lead to a huge variety in counselors' views about appropriate counseling and in daily practice of counseling [61,68,69].

Moreover, several researchers concluded that clients and counselors do have very different perspectives on appropriate counseling and value information and professional behavior, such as non-directiveness, differently [61,70]. These findings and the fact that they were found in a relative small sample of obstetric-, midwife-, nurse- and general genetic counselors underline the relevance to investigate midwives' views on appropriate counseling and clients' preferences in relation to each other.

Communication during counseling

Actual communication during counseling has been investigated in several studies among health care providers with diverse backgrounds, e.g. genetic counselors and cancer genetic counselors [6,71,72]. Studies focus on the provision of the two genetic and/or prenatal counseling functions, 'teaching' and 'counseling' in practice. Counseling has been shown to focus on 'teaching' and that more attention is needed for providing 'counseling' [6,71,73-77]. However, little research has been done to investigate real life communication during prenatal counseling for anomaly screening. Such information is relevant, since it is known that prenatal counseling does not always lead to informed decisions [75,78,79]. As a result, in practice, clients sometimes have to be counseled again once they are already in the room to have the ultrasound of the CT. This is problematic in some cases, when following the receipt of additional information, the clients appreciate the purpose of anomaly screening that they did not grasp earlier and determine just prior to the test being done, that they actually do not want to take the test. It might also indicate that more than one pre-test counseling consultation is needed. For instance, one session to exchange information and another to talk about clients' questions and the decision whether to opt for screening, may be the best approach for some clients. For parents involved in prenatal testing, the today offer of pre- and post-test counseling might be too limited [37].

Study design

This study is embedded in the DELIVER study, a nationwide, multicenter cross-sectional study investigating the organization, accessibility and quality of primary midwifery led care in the Netherlands [80]. Seventeen of the 20 midwifery practices across the country that participated in the DELIVER study, participated in the present study. We studied client and midwife perspectives regarding appropriate prenatal counseling for anomaly screening. Furthermore, we made video recordings of midwife-client interactions during the prenatal intake visit to study prenatal counseling for anomaly screening by midwives in daily practice. The communication process was investigated by means of clients' experiences, midwives' self-evaluations and observations of the video recorded counseling consultations. We used a

mixed methods approach in order to gain knowledge about prenatal counseling by midwives based on multiple perspectives, positions, and standpoints, e.g. the standpoints of qualitative and quantitative research [81].

Perspectives of clients and midwives

At the time of this study there was no measurement tool available to investigate clients' preferences and experiences regarding prenatal counseling for anomaly screening. However, a commonly used measurement tool to measure the perspectives of clients, e.g. their preferences and experiences with care, is the QUOTE (QUality Of care Through the patient's Eyes); a series of questionnaires adapted to a diverse range of healthcare contexts [67,82,83,84]. Each QUOTE-questionnaire consists of two parts. In part one, the pre-counseling questionnaire, clients are asked to what extent they consider aspects, related to the care they are about to receive, as important. In part two, the post-counseling questionnaire, clients are asked to evaluate the consultation regarding the same aspects of care as mentioned in the pre-counseling questionnaire. So, the QUOTE-questionnaires can be used to both investigate clients' perspectives on preferable care and their perspectives on the extent to which these aspects are addressed [83,84]. This focus on clients' perspectives is extremely useful for getting information about clients' preferences, needs, opinions and ideas regarding counseling which can be used to optimize client-centered counseling in practice. We adapted the original QUOTE questionnaire to measure client preferences and experiences regarding prenatal counseling for anomaly screening.

To measure midwives' views on appropriate counseling and their self-evaluation we wanted to use a similar measurement tool that could be compared with clients. We developed a pre-counseling questionnaire to measure midwives' views on appropriate counseling and a post-counseling questionnaire, to measure midwives' self-evaluation of the prenatal counseling they just offered. Both midwifery questionnaires mirrored those of the clients.

Communication during prenatal counseling

In communication research, observational studies are designed to investigate the communication process [5]. In this type of research, recordings of actual health care consultations using audio or video taping are typically used for analyses. Within the Dutch midwifery research context at the time we started our study making audio or video tapes of consultations had never been done. Despite this possible barrier, we felt videotaping was the most effective means to gain a better understanding about what exactly happens during midwives' prenatal counseling. To be able to open the 'black box' and to know more about the coherence between the counseling practice, the prenatal counseling theory, and the perspectives of Dutch clients and midwives on appropriate counseling.

A widely used and valid scheme for coding audio or video taped healthcare encounters is the Roter Interaction Analysis System (RIAS) [6,77,85]. The RIAS focuses on the smallest unit of expression or statement (utterance) to which a meaningful code can be assigned [6,86]. The main focus of the RIAS is verbal behavior. A distinction is made between affective utterances and instrumental utterances, thereby complying clients' most urgent needs: the need to feel known and understood (to be fulfilled by using affective communication) and the need to know and understand (for which instrumental communication is needed) [87,88]. The affective categories include social conversation, such as emotional statements, e.g. empathy. The instrumental categories refer to the communication aspects that primarily focus on solving problems, such as giving information, asking questions and providing counseling [6, 86]. Several studies have adapted the RIAS, to make the coding scheme more suitable and reliable for their coding context [82,89-91]. We adapted the RIAS for coding videotapes of prenatal counseling for anomaly screening by midwives to the items of the QUOTE. We added coding of client-directed gaze to the coding protocol in order to have information about one of the most important forms of nonverbal communication [92-97]. Our adaptation of the RIAS also allowed us to integrate the results of the video recordings with the results of client and midwife questionnaires.

Aims of the thesis

The overall aim of this thesis was to investigate clients' preferences and midwives' views regarding appropriate prenatal counseling for anomaly screening. Furthermore, this study aims to provide knowledge about how prenatal counseling for anomaly screening by midwives is performed in daily practice, from the perspectives of clients, midwives and observers.

Outline of this thesis

The first study of this thesis is about the development and validation of a QUOTE-questionnaire that assesses clients' and their partners' preferences and experiences regarding prenatal counseling for congenital anomaly tests. The resulting questionnaire was used in a cross-sectional study design in primary midwifery care in the Netherlands. Data were used to assess clients' pre-counseling preferences regarding prenatal counseling and clients' experiences. Data of socio-demographic background characteristics of clients were used to determine possible differences between different groups of clients in pre-counseling preferences and post-counseling experiences (**chapter 2**). The final client questionnaire was mirrored for midwives so that it could be used as a pre-counseling instrument for measuring midwives' views on appropriate counseling. All Dutch midwives who were a member of the KNOV were asked to complete this questionnaire. Midwives' views on appropriate prenatal counseling for anomaly tests were compared to clients' preferences and the functions described in the

theoretical prenatal counseling model (**chapter 3**). To examine actual prenatal counseling for anomaly screening in daily practice, we introduced video recording in primary midwifery care. **Chapter 4** describes the introduction procedure, resulting dataset, and use of data for research purposes. In **chapter 5** we used the video recorded prenatal counseling consultations to describe how the functions of prenatal counseling were expressed in daily, midwifery practice. We described the conversational contribution of both clients and midwives during counseling and explored characteristics, which were associated with the performance of midwives' prenatal counseling. After each video recorded counseling consultation midwives completed a post-counseling questionnaire, to evaluate their own counseling. Data of post-counseling client questionnaires, video-observations and midwives' self-evaluations were compared to each other (**chapter 6**). Nonverbal behavior was the topic of the last study within this thesis. In this study we examined if and how the nonverbal behavior 'client-directed gaze' was related to clients' psychosocial communication, which is an important part of the *decision-making support* function of counseling. In addition to midwives' psychosocial questioning, we also examined the relation between verbal affective communication, and clients' psychosocial communication (**chapter 7**).

The thesis ends with a general discussion of the findings including suggestions for further research and practical implications.

REFERENCES

- [1] <http://www.medicinfo.nl>.
- [2] <http://www.deverloskundige.nl>.
- [3] De Boer J, Zeeman K. KNOV-guideline prenatal midwifery led care: recommendation for coaching, interaction and information giving. Utrecht: KNOV, 2008; p.17–46 [In Dutch].
- [4] RIVM. Scenario Prenatal Screening. Down syndrome and fetal anomaly ultrasound scan. Dutch Translation: Draaiboek Prenatale Screening. Downsyndroom en Structureel Echoscopisch Onderzoek. Versie 4.0; 2014. www.rivm.nl [In Dutch].
- [5] Meiser B, Irle J, Lobb E, Barlow-Stewart K. Assessment of the Content and Process of Genetic Counselling: A Critical Review of Empirical Studies. JOGC 2008; 17:434-451.
- [6] Roter D, Ellington L, Hamby Erby L, Larson S, Dudley W. The genetic counselling Video project (GCVp). Am J Med Genet 2006; 142C:209-20.
- [7] Martin L, Van Dulmen S, Spelten E, Hutton E. Prenatal genetic counseling: Future parents prefer to make decisions together, using professional advice. Prenat Diagn 2012; 32(1): 1–128.
- [8] Hillman SC, Skelton J, Quinlan-Jones E, Wilson A, Kilby MD. “If it helps . . .” The Use of Microarray Technology in Prenatal Testing: Patient and Partners Reflections. Am J Med Genetics 2013; 161A(7):1619-27.
- [9] Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. “Patients’ unvoiced agendas in general practice consultations: qualitative study”. BMJ 2000; 320(7244): 1246-50.
- [10] www.prenatalescreening.nl including: Teachers Manual Skills training Prenatal Screening. Developed by: KNOV, SSOV, VAA, VAG, AVM, SROV, NHG, NVOG, VSOP, erfocentrum en VKGN, 2007 [In Dutch].
- [11] Health Council of the Netherlands: Prenatal Screening: Down’s Syndrome, Neural Tube Defects, Routine-Ultrasonography. Dutch Translation: Prenatale Screening op Downsyndroom, Neuraletubisdefecten, Routine-Echoscopie; 2001.2001/11 [In Dutch].
- [12] Health Council of the Netherlands: Population Screening Act: Prenatal Screening: Down’s Syndrome and Neural Tube Defects. Dutch Translation: Wet Bevolkingsonderzoek: Prenatale Screening op Downsyndroom en Neuraletubisdefecten; 2007. 2007/05WBO [In Dutch].
- [13] Ministry of Dutch Civil Code Book 7: Article 449. Medical Treatment Agreements Act. Dutch Translation: Burgerlijk Wetboek 7: Artikel 449. Wet op de Geneeskundige Behandelingsovereenkomst (WGBO) [In Dutch].
- [14] Crombag NM, Vellinga YE, Kluijfhout SA, Bryant LD, Ward PA, Iedema-Kuiper R, Schielen PC, Bensing JM, Visser GH, Tabor A, Hirst J. Explaining variation in Down’s syndrome screening uptake: comparing the Netherlands with England and Denmark using documentary analysis and expert stakeholder interviews. BMC Health Serv Res 2014; 25(14):437-8.
- [15] Engels MAJ. Prenatal Down Syndrome Screening; Screening policies revised. Doctoral thesis. Amsterdam; Vrije Universiteit Amsterdam; 2014.
- [16] Van Agt HME, Schoonen HMJD, Wildschut HJ, De Koning HJ, Elsink-Bot ML. Education about prenatal and neonatal screening programs: Questionnaires for national evaluation of the test-offer procedure. Erasmus MC, Eindrapportage 2007 [In Dutch].
- [17] www.niptconsortium.nl.
- [18] www.meerovernipt.nl.
- [19] <https://pedclerk.bsd.uchicago.edu/page/trisomy-21-down>.
- [20] www.rivm.nl including: Quality requirements Counselor prenatal screening (version 5, set by the Central Organization Prenatal Screening; 03 June 2014). http://www.rivm.nl/dsresource?objectid=rivmp:50878&type=org&disposition=inline&ns_nc=1 [In Dutch].
- [21] Fracheboud J, Van Agt HME, De Koning HJ. Monitoring of reported uptake of the screening program Down syndrome / Fetal Anomaly Scan 2010. Bilthoven, RIVM, Eindrapport Juli 2012 [In Dutch].
- [22] Oepkes P, Wieringa J. The right to know; the 20-weeks ultrasound investigation facilitates a conscious choice. Medisch Contact 2008; 31/32:1296-1297 [In Dutch].
- [23] Feenstra I, Van der Burht I, Voskuilen D. Prenatal diagnostics anno 2011. Bijblijven 2011; 27 (9):34-41 [In Dutch].

- [24] Ekelund CK, Petersen OB, Skibsted L, Kjaergaard S, Vogel I, Tabor A. First-trimester screening for trisomy 21 in Denmark: implications for detection and birth rates of trisomy 18 and trisomy 13. *Ultrasound Obstet Gynecol* 2011; 38:140–4.
- [25] Tabor A, Alfirevic Z. Update on procedure-related risks for prenatal diagnosis techniques. *Fetal Diagn Ther* 2010; 27:1-7.
- [26] Bosk CL. *All God's Mistakes*. Genetic counseling in a pediatric hospital. Chicago and London, The university of Chicago Press, 1995; p. 1-19.
- [27] Gitsels-van der Wal JT, Martin L, Manniën J, Verhoeven P, Hutton EK, Reinders HS. A qualitative study on how Muslim women of Moroccan descent approach antenatal anomaly screening. *Midwifery* 2015. doi: 10.1016/j.midw.2014.12.007.
- [28] Garcia Gonzalez ME. In search of good motherhood. How prenatal screening shapes women's views on their moral duties to their family. Doctoral thesis. Nijmegen, Radboud University; 2011.
- [29] Van Zwieten M. Communication about ethical issues in medical practice. In: *Medical psychology*, Kaptein AA, Prins JB, Collette EH, Hulsman RL (red). 2^e herziene druk. Houten: Bohn Stafleu Van Loghum, 2010; p. 213-224 [In Dutch].
- [30] Williams C, Sandalla J, Lewando-Hundt G, Heymand B, Spencerb K, Grellier R. Women as moral pioneers? Experiences of first trimester antenatal screening. *Soc Sci Med* 2005; 61(9):1983–1992.
- [31] Hunt LM, De Voogd KB, Castañeda H. The routine and the traumatic in prenatal genetic diagnosis: does clinical information inform patient decision-making? *Patient Educ Couns* 2005; 56(3):302–312.
- [32] Van den Berg M. Decision making in prenatal screening. Doctoral thesis, VU medical centre Amsterdam, 2006.
- [33] De Jong A, Dondorp WJ, De Die-Smulders CEM, De Wert GMWR. The dynamics of prenatal screening. *Medisch Contact* 2010; 39:2007-2009 [In Dutch].
- [34] Horstman K. Should we do everything that is possible? *Bijblijven* 2008; 24(6):65-72 [In Dutch].
- [35] Geelen EGM, Horstman K, Widdershoven GAM. Needless worry. Experiences of pregnant women with risk assessments. *Medisch Contact* 2004; 59(45):1770-3 [In Dutch].
- [36] Garcia E, Timmermans DRM, Van Leeuwen E. Rethinking autonomy in the context of prenatal screening decision-making. *Prenat diagn* 2008; 28(2):115-120.
- [37] Van Zwieten M, Willems D, Knecht L, Leschot N. Communication with patients during the prenatal testing procedure: An explorative qualitative study. *Patient Educ Couns* 2006; 63:161–168.
- [38] Wiegers TA. The quality of maternity care services as experienced by women in the Netherlands. *BMC Pregnancy and Childbirth* 2009; 9:18.
- [39] Wiegers TA, Hingstman I. The changing responsibilities of midwives: new figures about time spent on specific tasks. *Tijdschrift voor Verloskundigen* 2008; 33(3):19-24 [In Dutch].
- [40] Verburg MP. The role of primary care midwives in the Netherlands. Evaluation of midwifery care in the Dutch maternity care system: a descriptive study. Doctoral thesis. Amsterdam, AMC-UvA, 2011: H1.
- [41] Wiegers TA, van der Velden LFJ, Hingstman L. Estimated need for midwives 2004 – 2015; Utrecht, NIVEL 2005 [In Dutch].
- [42] Liefhebber S, Van Dam C, Waelput A. Dutch professional profile midwives. Utrecht: Royal Dutch organization of Midwives (KNOV), 2005 [In Dutch].
- [43] Mearns D, Thorne B. *Person-Centered Counselling in Action*. London: Sage Publications, (2nd ed), 1999; p. 5–21.
- [44] Health Council of the Netherlands: Committee Genetic screening. *Genetic Screening*. The Hague: Health Council, 1994; publication no. 1994/22 [In Dutch].
- [45] Resta RG. Defining and redefining the scope and goals of genetic counseling. *Am J Med Genetics* 2006; 142C:269–75.
- [46] Flessel MC, Lorey FW. The California Prenatal Screening Program: “options and choices” not “coercion and eugenics”. *Genetic Medicine* 2011; 13(8):711–3.
- [47] Jakobsen TR, Sogaard K, Tabor A. Implications of a first trimester Down's syndrome screening program on timing of malformation detection. *Acta Obstetrica et Gynecologica Scandinavica*. Nord Fed Society Obstet Gyn 2011; 90:728–36.

- [48] Smith RC, Hoppe RB. The patient's story: integrating the patient- and physician-centered approaches to interviewing. *Ann Intern Med* 1991; 115:470–7.
- [49] O'Connor AM, France Légaré, Dawn Stacey. Risk communication in practice: the contribution of decision aids. *BMJ* 2003; 327:736-740.
- [50] Chieng WS, Chan N, Lee SC. Non-directive genetic counselling-respect for autonomy or unprofessional practice? *Ann Acad Med Singapore* 2011; 40(1):36-42.
- [51] Pennacchini M, Pensieri C. Is non-directive communication in genetic counseling possible? *Clin Ter* 2011; 162:141-144.
- [52] Vanstone M, Kinsella EA, Nisker J. Information-sharing to promote informed choice in prenatal screening in the spirit of the SOGC clinical practice guideline: a proposal for an alternative model. *J Obstet Gynaecol Can* 2012; 34:269-675.
- [53] Durand MA, Stiel M, Boivin J, Elwyn G. Information and decision support needs of parents considering amniocentesis: interviews with pregnant women and health professionals. *Health Expect* 2010; 13(2):125–38.
- [54] Kreuter MW, Strecker VJ, Glassman B. One size does not fit all: the case for tailoring print materials. *Ann Behav Medicine* 1999; 21(4):276–83.
- [55] Todd J, Bohart AC. *Foundations of Clinical and Counseling Psychology*. New York: HarperCollins College Publishers, (3rd ed), 2005; p. 209–39.
- [56] Van Staveren R. Patient centered communication; a guide for medical practice. Utrecht, DeTijdstroom, september 2010 [In Dutch].
- [57] Bernhardt BA, Geller G, Doksum T, Larson SM, Roter D, Holtzman NA. Prenatal Genetic Testing: Content of Discussions Between Obstetric Providers and Pregnant Women. *Obstet Gynecol* 1998; 91:0029-7844.
- [58] Bernhardt BA, Barbara B. Biesecker, Carrie L. Mastromarino. Goals, Benefits, and Outcomes of Genetic Counseling: Client and Genetic Counselor Assessment. *Am J Med Genet* 2000; 94:189–197.
- [59] Ormond KEM, Banuvar I, Minogue SJ, Annas GJ, Elias S. What do Patients Prefer: Informed Consent Models for Genetic Carrier Testing. *J Genet Counsel* 2007; 16:539–550.
- [60] Ahmed S, Hewison J, Green JM, Cuckle HS, Hirst J, Thornton JG. Decisions About Testing and Termination of Pregnancy for Different Fetal Conditions: A Qualitative Study of European White and Pakistani Mothers of Affected Children. *J Genet Counsel* 2008; 17:560–572.
- [61] Wertz D, Gregg R. Genetics services in a social, ethical and policy context: a collaboration between consumers and providers. *J Med Ethics* 2000; 26(4):261–265.
- [62] Shiloh S, Gerad L, Goldman B. Patients' Information Needs and Decision-Making Processes: What Can Be Learned From Genetic Counselors? *Health Psychology* 2006; 25(2):211–219.
- [63] Hsieh Y, Flatley Brennan P. What Are Pregnant Women's Information Needs and Information Seeking Behaviors Prior to Their Prenatal Genetic Counseling? *AMIA 2005 Symposium Proceedings* Page: 355-359.
- [64] Alouini S, Moutel G, Venslauskaite G, Gaillard M, Truc JB, Herve C. Information for patients undergoing a prenatal diagnosis. *Eur J Obstet Gynaecol Reprod Biol* 2007; 134:9–14.
- [65] Browner CH, Preloran HM, Casado MC, Bass HN, Walker AP. Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients. *Soc Sci Med* 2003; 56(9):1933-46.
- [66] Petty R, Cacioppo J. The elaboration likelihood model of persuasion. *Advances Experimental Social Psychology* 1986; 19:123–205.
- [67] Weert van JCM, Jansen J, Bruijn de GJ, Noordman J, van Dulmen S, Bensing JM. QUOTE ^{chemo}: a patient-centered instrument to measure quality of care preceding chemotherapy treatment through the patient's eyes. *Europ J Cancer* 2009; 45(17):2967–76.
- [68] Bramwell R, Carter D. An exploration of midwives' and obstetricians' knowledge of genetic screening in pregnancy and their perception of appropriate counselling. *Midwifery* 2001; 17(2):133-41.
- [69] Veach PM, Bartels DM, LeRoy BS. Ethical and professional challenges posed by patients with genetic concerns: a report of focus group discussions with genetic counselors, physicians, and nurses. *J Genet Couns* 2001; 10(2):97-119.

- [70] Sheets KB, Best RG, Brasington CK, Will MC. Balanced information about Down syndrome: what is essential? *Am J Med Genet A* 2011; 155A(6):1246-57.
- [71] Pieterse A, Van Dulmen S, Ausems M, Schoemaker A, Beemer F, Bensing J. QUOTE-GENE^{ca}: development of a counselee-centered instrument to measure needs and preferences in genetic counselling for hereditary cancer. *Psycho Oncology* 2005; 14:361–75.
- [72] Pieterse AH, Van Dulmen AM, Beemer FA, Ausems MGEM, Bensing JM. Tailoring communication in cancer genetic counselling through individual video-supported feedback: a controlled pretest-posttest design. *Patient Educ Couns* 2006; 60(3):326-335.
- [73] Michie S, Dormandy E, Marteau TM. Informed choice: understanding knowledge in the context of screening uptake. *Patient Educ Couns* 2003; 3:247-53.
- [74] Barr O, Skirton H. Informed decision making regarding antenatal screening for fetal abnormality in the United Kingdom: A qualitative study of parents and professionals. *Nurs Health Sci* 2013; 15:318-25.
- [75] Van den Berg M, Timmermans DRM, Ten Kate LP, Van Vugt JMG, Van der Wal G. Are pregnant women making informed choices about prenatal screening? *Genet Med* 2005; 7:767–76.
- [76] Farrelly E, Cho MK, Erby L, Roter D, Stenzel A, Ormond K. Genetic counseling for prenatal testing: where is the discussion about disability? *J Genet Couns* 2012; 21(6):814-24.
- [77] Ellington L, Kelly KM, Reblin M, Latimer S, Roter D. Communication in genetic counseling: cognitive and emotional processing. *Health Commun* 2011; 26:667–675.
- [78] Fransen MP, Essink-Bot ML, Vogel I, Mackenbach JP, Steegers EA, Wildschut HI. Ethnic differences in informed decision-making about prenatal screening for Down 's syndrome. *J. Epidemiol. Community Health* 2010; 64:262–268.
- [79] Schoonen HM, Essink-Bot ML, Van Agt HM, Wildschut HI, Steegers EA, De Koning HJ. Informed decision-making about the fetal anomaly scan: what knowledge is relevant?. *Ultrasound Obstet. Gynecol* 2011; 37:649–657.
- [80] Manniën J, Klomp T, Wiegers T, Pereboom M, Brug J, De Jonge A, Van der Meijde M, Hutton EK, Schellevis F, Spelten ER. Evaluation of primary care midwifery in the Netherlands: design and rationale of a dynamic cohort study (DELIVER). *BMC Health Serv Res* 2012; 12:69-78.
- [81] Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *J Mix Methods Res* 2007; 1(2):112-133.
- [82] Pieterse AH, Van Dulmen AM, Beemer FA, Bensing JM, Ausems MG. Cancer genetic counseling: communication and counselees' post-visit satisfaction, cognitions, anxiety, and needs fulfillment. *J Genet Couns* 2007; 16(1):85-96.
- [83] Sixma HJ, Van Campen C, Kerssens JJ, Peters L. Quality of care from the patients' perspectives: from theoretical concept to a new measuring instrument. *Health Expect* 1998; 1:82–95.
- [84] Nijkamp MD, Sixma HJ, Afman H, Hiddema F, Koopmans SA, van den Borne B, Hendrikse F, Nuijts RM. Quality of care from the perspective of the cataract patient: the reliability and validity of the QUOTE-cataract. *British J Ophthalmol* 2002; 86:840–2.
- [85] Roter DL, Hall JA, Blanch-Hartigan D, Larson D, Frankel RM. Slicing it thin: New methods for brief sampling analysis using RIAS-coded medical dialogue. *Patient Educ Couns* 2011; 82:410–419.
- [86] Roter DL, Larson SM, Beach MC, Cooper LA. Interactive and evaluative correlates of dialogue sequence: a simulation study applying the RIAS to turn taking structures. *Patient Educ Couns* 2008; 71(1):26-33.
- [87] Engel GL. (1988) How much longer must medicine's science be bound by a seventeenth century world view. In *The Task of Medicine: Dialogue at Wickenburg* (ed. K.White), pp. 113–116. Menlo Park: The Henry Kaiser Foundation.
- [88] Bensing JM. Bridging the gap: the separate worlds of evidence-based medicine and patient-centred medicine. *Patient Educ Couns* 2000; 39(1):17-251.
- [89] Weert JCM, Van Dulmen AM, Spreeuwenberg PMM, Ribbe MW, Bensing JM. Effects of snoezelen, integrated in 24-h dementia care, on nurse-patient communication during morning care. *Patient Educ Couns* 2005; 58(3):312-26.
- [90] Albada A, Ausems MG, Van Dulmen S. Counselee participation in follow-up breast cancer genetic counselling visits and associations with achievement of the preferred role, cognitive outcomes, risk perception alignment and perceived personal control. *Soc Sci Med* 2014; 116:178-86.

- [91] Noordman J, Verhaak P, Van Dulmen S. Web-enabled video-feedback: a method to reflect on the communication skills of experienced physicians. *Patient Educ Couns* 2011; 82:335-340.
- [92] Henry SG, Fuhrel-Forbis A, Rogers MA, Eggly S. Association between nonverbal communication during clinical interactions and outcomes: a systematic review and meta-analysis. *Patient Educ Couns* 2012; 86:297-315.
- [93] Gorawara-Bhat R, Cook MA. Eye contact in patient-centered communication. *Patient Educ Couns* 2011; 82:442–447.
- [94] Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: A literature review. *Psychological Bulletin* 2007; 133:438-463.
- [95] Marcinowicz L, Konstantynowicz J, Godlewski C. Patients' perceptions of GP non-verbal communication: a qualitative study. *Br J Gen Pract* 2010; 60(571):83-7.
- [96] Stepanikova Q, Zhang D, Wieland GP, Eleazer T, Stewart. Non-Verbal Communication Between Primary Care Physicians and Older Patients: How Does Race Matter? *J Gen Intern Med* 2011; 27:576–81.
- [97] Bensing JM, Kerssens JJ, Van der Pasch M. Patient-directed gaze as a tool for discovering and handling psychosocial problems in general practice. *J Nonverbal Behav* 1995; 19(4):223-242.

