Chapter 8

General discussion

‘Als je het proces ter harte neemt,
dan zorgt het doel wel voor zichzelf’

M.K. Gandhi

General discussion

This thesis investigates the fairly new field of counseling for prenatal anomaly screening by midwives. The overall aim was to investigate clients' and midwives' perspectives about appropriate counseling for prenatal anomaly screening. Additionally, this study aimed to provide knowledge about the client-midwife communication during prenatal counseling in daily practice.

For practitioners, this study provides insight into client preferences and experiences. This can be used for enhancing the quality of prenatal counseling. For researchers, this study provides two research tools: the clients' and midwives' version of the Quality Of care Through the patients Eyes (QUOTE) ^{prenatal} questionnaire, to investigate prenatal counseling from the perspectives of clients, and counselors in a comparable way. In addition, the first time use of video-recordings in midwifery led care, has resulted in information on the introduction of this relatively novel research approach to disciplines unfamiliar with it. Our research, as described by a referee from Patient Education and Counseling: on "the question how the prenatal counseling is perceived by those who practice it, by those who should profit from it […] [and by objective observers] is a rare example of a comparison of three different perceptions on this [counseling for prenatal anomaly screening]".

Study outline

We started by adapting the QUOTE questionnaire to the prenatal counseling context. We used the resulting QUOTE ^{prenatal} to assess client-centeredness of midwives' counseling for prenatal anomaly screening by examining the extent to which clients' pre-counseling preferences were met as reflected in clients' post-counseling assessments. We assumed prenatal counseling consultations to be triadic rather than dyadic in practice: pregnant women's partners may play an important role when it comes to the decision whether to opt for prenatal anomaly screening. Therefore, preferences and experiences of partners were also investigated in this study. In our next study we examined midwives' views on appropriate counseling and to what extent these views reflect the theoretical prenatal counseling functions and match clients' pre-counseling preferences.

We introduced video-recordings as a research tool in midwifery practices to examine counseling for prenatal anomaly screening in practice. We described the process of the introduction and enrolment as well as the resulting dataset. We used video recorded prenatal counseling to explore the client-midwife communication during prenatal counseling for anomaly screening in daily, midwifery practice. We brought the data from midwives, clients and video-observations together, to assess congruence between these three perspectives. Lastly, we assessed midwives' (non) verbal counseling skills in relation to psychosocial communication of clients. Clients' psychosocial communication is known to be especially important during the provision of decision-making support, one of the three aspects of prenatal counseling identified in this study.

Summary of the findings

Perspectives of clients and midwives

Fifty-five of the 58-item QUOTE ^{prenatal} questionnaire appeared to comprise three counseling components which show sufficient reliability: *client-midwife relation, health education* and *decision-making support*. The other three items covered organizational aspects of prenatal counseling for anomaly screening. Pre-counseling, most clients considered the *client–midwife relation* and *health education* to be important or very important for prenatal counseling. More than one third of the clients valued *decision-making support* to be important or very important. More nulliparous women had preferences for *health education* and *decision-making support* than multiparous women. A comparison between partners and pregnant women showed only statistically significant differences regarding building a good *client-midwife relation;* more pregnant women compared to partners valued this function to be important or very important. We argued that in practice, when offering triadic counseling, preferences of pregnant women and their partners can be seen as comparable. Pre-counseling, we found that most clients valued being invited together for prenatal counseling. About one third of the clients valued having an appointment that focused primarily on prenatal anomaly testing rather than broaching the subject during the first visit to the midwife. Post-counseling, clients experienced that their needs concerning the *client-midwife relation* and *health education* were largely met, although significantly less multiparous women perceived that their *health education* needs were met compared to nulliparae. Furthermore, about two-third of the clients experienced that their *decision-making support* needs were addressed [**chapter 2**].

Like clients, most midwives valued a good *client–midwife relation* and *health education* as important or very important for prenatal counseling for anomaly screening. Less than half of the midwives valued *decision-making support* as important.

Clients and midwives assessed 13 individual items of the 58-item questionnaire very differently. For instance, more clients than midwives valued 'receiving medical information about congenital anomalies' and 'getting advice whether to take prenatal tests or not' as important [**chapter 3**].

Communication during counseling

Introducing video-recordings in midwifery practice for research purposes proved to be both feasible and challenging. The result is a set of recommendations for researchers who want to use a video-observational approach and, in addition to our initial aim, a unique dataset of recordings that already have been used for the analyses of the midwife-client interaction regarding other topics than counseling for prenatal anomaly screening [1,2]. In about 65% of the cases partners were present during video-recorded consultations [**chapter 4**]. In line with clients' experiences, in our observational study, we found that during prenatal counseling for anomaly screening by midwives most utterances were related to providing *health education*

compared to *decision-making support*. The relatively low contribution to the conversation of clients during *decision-making support* might indicate room for improvement regarding *decision-making support* given by midwives. Counseling of multiparae was significantly shorter than counseling of nulliparous women; multiparae received less *health education* as well as less *decision-making support* compared to nulliparae. Results seem to indicate that partners add verbally less to the triadic conversation compared to pregnant women [**chapter 5**].

From the perspectives of midwives - midwives' self-evaluation - prenatal counseling for anomaly screening was performed well with regards to building a good *client-midwife relation* and providing *health education.* Midwives perceived that they provided *decision-making support* in relatively few cases. However, we found incongruence between midwives and clients (only pregnant women) about the discussion during *decision-making support*. For instance, almost half of the clients reported that they got advice whether to take prenatal screening or not while most midwives perceived they did not give such advice and almost no explicitly expressed advice was observed. Overall, congruence between midwives' self-evaluation and observed communication was higher compared to midwives' self-evaluation and clients' experiences [**chapter 6**]. In **chapter 7** communication concerning *decision-making support* was further investigated in order to get more insight into midwives' communication aspects that were related to pregnant women's' psychosocial communication. In contrast with our expectations, midwives' client-directed gaze was not related to the amount of psychosocial communication of clients. Video-observations did show that in addition to asking psychosocial questions, midwives' affective behavior and the counseling duration were likely to encourage client's psychosocial communication [**chapter 7**].

General discussion of the findings

The findings and conclusions of the six studies together, covering both the perspectives of clients and midwives on prenatal counseling for anomaly screening as well as the communication during prenatal counseling in practice, will be discussed with reference to four subjects: 1) preferences of clients and consequences for prenatal counseling; 2) perceptions of midwives as counselors and the professional context; 3) client-midwife communication; 4) new developments in the field of prenatal anomaly screening and implications for prenatal counseling.

1. Preferences of clients and consequences for counseling

In the literature a two-function genetic counseling model is described containing both 'teaching' as well as 'counseling' [3-11]. Based on our findings about client preferences, we argued that the model should be extended with a third; building a good *client-counselor relationship*. Furthermore, we reasoned the necessity of a new terminology instead of using

the 'teaching' and 'counseling' terminology. The resulting client-centered prenatal counseling model comprises two, core functions *health education* and *decision-making support* and one conditional function, building a good *client-counselor relationship* [**chapter 2**].
From the literature it is known that practitioners need practical recommendations in a concrete and easy to understand manner, so that they can use them while preparing and reflecting upon their care in daily practice [12,13]. For prenatal counselors, knowing that clients prefer to get *health education* and *decision-making support* while building a good *client-counselor relationship,* might be too vague. We therefore give some suggestions about how important aspects of counseling in the eyes of clients might be addressed in practice.

Client preferences on health education
Our study on client, (i.e. pregnant women and their partners), preferences adds to the knowledge of the *health education* function of counseling what clients perceive as important information to talk about during counseling for anomaly screening. In Appendix A, we listed *health education* items that ≥75% of the clients indicated they would preferred to be discussed. When we compare this topic list to topics found to be important by clients in other research we may conclude that like other clients [14], participants in our study preferred some balance between getting all available test information and getting only information about the prenatal test that is currently relevant (items 6 versus 16, appendix A). Furthermore, clients wanted to know and understand the usefulness of the results of prenatal screening. Also in line with other studies [15,16], participants in our study valued getting information about the anomalies that their unborn child is tested for in case they choose to opt for anomaly screening. Clients indicated, that in case of a positive test result, procedure related aspects of prenatal screening were important in terms of the logistics and procedures of testing and follow-up procedures [**chapter 2**; 17-19].
Our study adds to the *health education* literature regarding topics known to be important to address during prenatal counseling. Clients value clarity about the aim of prenatal anomaly tests; about what anomalies (or group of anomalies) prenatal anomaly tests are designed for; and what anomalies are not within the scope of anomaly tests. Clients value information that they can use to know how likely it is that their unborn child has an anomaly. Lastly, in the eyes of clients, it is important to provide insight into the chronological process of prenatal screening and to identify relevant decision timelines in terms of gestational age. For instance, such information might comprise that the Fetal Anomaly Scan (FAS) is performed between 19 -21 weeks of gestational age, so the decision whether to opt for it has to be made around 16 weeks of gestational age in order to have time to make a suitable appointment (appendix A).

Client preferences on decision-making support

In line with other researchers, we found that 70% of the clients did not want to get information only, but also guidance or even advice whether to opt for prenatal anomaly tests or not [**chapter 2**; 17,20]. It seems important for clients that counselors tailor their counseling activities to clients' knowledge and preferences [**chapter 2**; 20-22]. In line with the findings of Gitsels et al [15] we also found that a substantial proportion of clients valued being asked questions that facilitated sharing their deliberations about whether to opt for prenatal anomaly screening or not. Furthermore, it seems to be relevant to explore the scenario of giving birth to a child with a birth defect and to talk about how, for the client important persons, will react to this scenario [23]. Consistent with prior studies, clients participating in our study seem to value a counselor who is really interested in who they are; they want to be seen, known and understood [**chapter 2**; 24-26].

We found no items that were perceived as important or very important by ≥75% of the clients. However, pre-counseling more than one third of the clients did value *decision-making support* [**chapter 2**]. In order to provide some insight into relevant items for the smaller group of clients who value *decision-making support*, we listed the six *decision-making support* items that were preferred to be discussed by ≥50% of the clients in Appendix B.

Client preferences on client-counselor relation

A good *client-counselor relation* is primarily established by nonverbal behavior, such as eye-contact and showing attention by nodding. (Non)verbal affective behavior, such as showing empathy and asking explicitly if the client has (psychosocial) concerns is another important way to build this relation [27-29]. The clients in our study mentioned the following as the most important aspects of building a good *client-midwife relation*: 'listening to what the client is trying to ask', e.g. listening without interrupting and allowing silences while clients search for words; 'using clear and comprehensible language'; 'taking clients' concerns seriously', e.g. acknowledging and legitimizing feelings; 'openness and honesty', e.g. authenticity; 'painting a realistic picture'; 'taking time for the client'; 'accepting clients' decision about prenatal anomaly screening', e.g. unconditional acceptance; and 'tuning into each individual client', e.g. person-centeredness [**chapter 2**; 20-22,27]. Seemingly in contrast with other studies [20-22], less than 75% of the participants valued the two non-related-items 'empathy' or 'getting additional written information'.

Client-centered recommendations for the provision of prenatal counseling

The above paragraph on client preferences indicates that clients prefer a lot of information as well as information tailored to their specific situation. It seems challenging to find a balance between a one size fits all approach in an attempt to provide all information available and tailoring *health education* to individual preferences of clients. Structuring counseling in line

with the Shared Decision Making (SDM) model might be helpful to integrate *health education* and *decision-making support,* which is one way to deal with the dilemma described. The SDM model is the most widely known and practical communication model in the medical setting to support clients in making preference sensitive choices [13]. The choice of whether to opt for prenatal anomaly screening or not is perceived to be a preference sensitive choice; one course of action is not better compared to another course of action [6]. Furthermore, the SDM model acknowledges that some information is relevant for one client but not for another, and has recently been implemented in midwifery-led care [30,73]. Given this context, and the fact that others have also been advocating the use of the SDM approach in counseling for prenatal anomaly screening [31-33], we recommend using this approach to provide practical, client-centered recommendations about counseling for prenatal anomaly screening. By using the term SDM approach rather than SDM model we try to emphasize the fact that when it comes to decisions about prenatal anomaly tests these decisions remain 'too personal and too important to be made by anyone other than the woman or the couple involved' [31]. Incorporating the partner in prenatal counseling and thus the decision-process, might help the couple to make a decision they are both comfortable with. So, in line with our preliminary results on client preferences regarding decision-making, the decision-making journey might be shared, but the ultimate decision should be the women's or couples only [31,34]. In the Netherlands, from a legal perspective, it is ultimately the woman who decides about whether to opt for prenatal anomaly tests and an eventual termination of the pregnancy [35].

To really improve prenatal counseling however, one needs not only a practical communication *model*, but also an appropriate counseling *context*. In healthcare, what clients need to know and understand has often been underestimated by care providers [25,26]. Assuming this also applies to clients in the prenatal counseling setting, the question is how to best address these needs if counseling is organized at the end of the first visit with the midwife? This intake already lasts on average 30 minutes [**Chapter 4**], contains in general a lot of questions and information and is provided to pregnant women in the first trimester of their pregnancy; a period in which women tend to be tired more quickly [36-38].

Barr et al. [37] concluded in their study on informed decision making about prenatal screening for Down syndrome, that clients experienced a negative interference of information on a wide range of topics in the first trimester; information overload distracted clients from their decision about screening. Following the recommendations of Boer et al [36] would involve a separate consultation to provide counseling for prenatal anomaly screening that might minimize the likelihood of information during the intake consultation. Furthermore, a separate prenatal counseling consultation provides clients also an extra opportunity to ask questions that remain, comparable to patients of general practitioners, after the first prenatal visit [39]. For prenatal counselors such scheduling might be helpful to fulfil individual needs to know and understand as well as clients' need to be known and understood [25,26]. The

latter is seen as essential for facilitating the personal discussion clients need, in order to make the preference sensitive decision about prenatal anomaly screening and thus for counseling for prenatal anomaly screening [23,27,37].

Relevance to practice

How to provide appropriate counseling for prenatal anomaly screening in practice? It seems relevant to start counseling by setting the choice at hand on the agenda. If we follow a healthcare focused line of reasoning, prenatal anomaly tests can be described as 'the method' and detecting congenital anomalies as 'the objective'. However, from a client perspective 'the objective' is more likely to be reassurance that their unborn child does not suffer from an anomaly. Prenatal counselors need to acknowledge this gap [33,40]. Right from the start, one way to do so is by making clear what questions need to be answered in order to make a decision about anomaly screening. Such questions might address: 1) whether clients want to know if their unborn child has an anomaly or not; 2) what anomalies they find important to know about if any at all; and 3) what they might do in case such an anomaly is to be found [41]. Counselors may fear that clients' answers to question 2 might be beyond the scope of prenatal anomaly screening. Nevertheless these answers place the target of prenatal testing, including what anomalies cannot be detected, directly on the agenda, which is in line with clients' preferences [**chapter 2**;15,42].

Furthermore, clients seem to eventually make their decision, whether to opt for prenatal screening or not, based on their moral values regarding for instance disabled life, termination of pregnancy and the procedure related risk of a miscarriage by performing a diagnostic test procedure [33,41,43-45]. These moral topics and considerations will presumably be addressed if counselors start their counseling as suggested and explore the answers of clients to these questions. Note that not only the answers of pregnant women, but also of partners have to be explored in order to know to what extent partners share the values of their pregnant women. Possible consequences of incongruence can be explored. In this way clients' need to know and understand as well as to be known and understood might be addressed in a more balanced way, compared to a counseling approach that is focused on *health education*.

2. Perceptions of midwives as counselors

The role of counselor was relatively new to midwives at the time this study started. Midwives were familiar with building a good client-midwife relation, the role of being a 'medical expert' or 'sender' who provides information, but not so much with the role of 'counselor' or 'listener' [36,46,47]. Adapting to the role of counselor, which includes new communication skills, seems to be complex in general medical practice. For instance because of an apparent lack of valuing the new role and skills [4,48]. This might explain the views of midwives on appropriate counseling for prenatal anomaly screening. More than 75% of the

participating midwives valued all *client-midwife relation* items as important or very important for appropriate prenatal counseling, but this was only the case for fifty percent of the *health education* items and one third of the *decision-making support* items [**chapter 3**]. Elwyn et al. [13] stress the importance of clinicians who agree with "the need to support autonomy by building good relationships, respecting both individual competence and interdependence on others" as prerequisite to implement the SDM model in practice. Given this context, our finding that most midwives subscribe to all *client-midwife relation* items seems promising. Reasons to not value all *health education* items to be important for counseling remain unclear; they are however in line with other studies who found that healthcare providers seem to underestimate their clients' need to know and understand [49].

Midwives' views on appropriate counseling do not entirely compare well with client preferences as found in this study. Regarding *health education* five items were considered important or very important by most clients but not by most midwives. As for *decision-making support* five items were considered important or very important by most midwives but not by most clients [**chapter 2** and **3**]**.** Other studies also found dissimilarity between the value of information and professional behavior between clients and counselors [17,33,50]. This might be problematic for providing client-centered counseling given the knowledge that clients' preferences regarding *decision-making support* were not perceived as addressed by one third of the clients [**chapter 2**].

The recently developed Professional midwifery profile [30] and the guideline for prenatal counseling about the NIPT [51] can be considered as an important step in the implementation of client-centered midwifery care and to client-centered prenatal counseling. Professional guidelines tend to be a good starting point for behavioral changes in practice [52]. The Profile is clear about what midwives should do when providing client-centered care, including counseling for prenatal anomaly screening: *"Each woman makes her own decisions […]. The midwife assists her clients in making an informed choice on the basis of shared decision-making, thereby guarding her professional boundaries and asking permission of the woman for the care she wants to provide […]. The midwife informs the woman objectively and value-free. Furthermore, the midwife confirms her clients that they are indeed able to make pregnancy related choices themselves. However, not every woman wants or can be fully participating in the decision-making process; the midwife anticipates on this diversity at an individual level."* [30]. As to the role of counselor (coach and communicator) the profile states that the midwife: *"**Explores** the reasons, motivations and barriers for the client and her social environment. [She] **builds a professional relationship** with her clients based on trust and mutual understanding, and accompanies her clients throughout the care process where continuity of care is pursued. The midwife takes into account ethical, psychological, social, cultural, organizational and economic aspects. The midwife **supports** the client and her partner / family through **education and counseling** to come to an informed decision."* [30].

We highlighted in bold, parts of the citation to make clear that in essence the description of the role of counselor is compatible with the prenatal counseling functions we focused on in our study. Moreover, the shared decision-making model mentioned as the basis of facilitating informed choice is an explicit shift towards the use of one preferred communication model when it comes to decision-making, even though it is not explicitly linked to counseling for prenatal anomaly screening.

The new Professional profile is important for stimulating midwives to provide prenatal counseling that is tailored to clients' needs, but it might not be enough. In general the implementation of effective clinical communication into everyday practice takes a lot of time and effort [13,48,53,54]. Several interventions have indeed been implemented in order to facilitate midwives in offering appropriate prenatal counseling. Midwives as counselors are trained in the role of prenatal counselor for anomaly screening. Here the topics described in the Professional profile are addressed [55].

For *health education*, some general guidelines, about what to tell the client and what additional information should be used, exist since 2011 [56] (Appendix C). Furthermore, continuing medical education is provided by the prenatal screening centers on a regular basis [57].

With regard to the *decision-making support* function, midwives are trained to adopt a non-directive attitude and communication style [5,41,58,59]. Non-directiveness is also the central recommended approach in the counseling guidelines of the National Institute for Public Health and the Environment (RIVM). Nevertheless, the Professional profile of midwives (2014) [30] seems to offer the clearest description of what to do during non-directive counseling. Interestingly, the website of the Prenatal screening foundation southwestern Netherlands only focuses on the *health education* part of counseling when describing the tasks of the counselor; the topic *decision-making support* is not described [60].

The aforementioned sources of information and training were published after we finished our data collection. So, at the time of our study, midwives had very little information to rely on while implementing counseling for prenatal anomaly screening in practice. This might have influenced the way midwives viewed appropriate counseling for prenatal anomaly screening. For today's practice, it seems problematic that no clear guidelines are available about how to offer counseling for prenatal anomaly screening according to standards based on today's evidence.

In contrast to the apparent lack of congruent information on counseling, there are clear guidelines on the organizational aspects of prenatal counseling. Midwives are recommended to organize the counseling for prenatal anomaly screening into a separate consultation during the early pregnancy and to invite partners as well [36,61]. Furthermore, midwives are the designated counselors to offer counseling for anomaly screening. There is a reimbursement for pre-test counseling and ensuing post-test information provision about the test results and

its consequences [5]. Payment of counseling is based on an average counseling duration of 30 minutes [62]. Since this information was available at the time of our study, one could argue that midwives could have acted accordingly. However, only one of the participating practices offered counseling in a separate consultation. Our results show, that on the one hand only 19% of the midwives value to organize a separate counseling consultation important for appropriate counseling while on the other hand this view might be justifiable since 22% of the clients pre-counseling prefer to have this separate consultation [**chapter 3**]. However, if midwives intend to use the billable time for counseling, a separate consultation would be most appropriate. When added onto the regular intake, this intake will last 60 to 90 minutes depending on the time reserved for the intake. Information overload and inadequate attention seem unavoidable.

3. Client-midwife communication

Our study on introducing video-recordings of midwife-client consultations for research purposes in the Netherlands [**chapter 4**] is one of the few studies in which the introduction of using videotaped real life consultations is described [63]. Our research on midwife-client communication adds to the wide field of communication research and the smaller field in which video-recordings of daily, medical practice encounters are used [4].

We found that midwives, just like counselors in other medical settings, struggle with their role of counselor and that there is room for improvement [**chapter 5**]. Results indicate that midwives primarily focus on providing *health education*. These findings are in line with research findings regarding general practitioners. Here also a focus on providing information and advice was found, although clients feel a need for a doctor who listens, supports and shows respect [4,37,64].

Perceived workload and time issues are well known bottlenecks for improving provider-client communication [65]. For midwives, this might especially be true, because their workload was exceptionally high during the early years of the millennium as a result of a shortage of midwives [66]. This problem has been solved, but it probably takes time to change the habit of working as efficient as possible to provide care to all pregnant women. Although, midwives get dedicated pay for this counseling based on a set amount of time, at least in our study, midwives rarely used this allocated time [**chapter 4** and **5**]. This might inhibit the improvement of midwives' counseling skills over time. Nevertheless, research results are mixed. We as well as other researchers found that taking more time for a consultation may improve communication in practice [**chapter 6** and **7**; 67,68]. Other studies do not support these findings [69,70].

The non-directive counseling approach, where the counselor refrains from giving direction or advice about the uptake of prenatal tests, seemed difficult to establish in practice [**chapter 6**], but seventy percent of all clients preferred advice whether or not to take prenatal tests [**chapter 2**]**.** Almost 50% of clients perceived that they actually got advice, although both midwives and observers acknowledged that very little explicit advice was given [**chapter 2** and **6**]. In fact, our results are in line with other research, that addresses on the one hand the difficulties not giving implicit direction when providing information about anomaly screening, and on the other hand proposes the use of a relational approach of autonomy [31,59,71-74]. Relational autonomy is subject of research in the field of family ethics. Studies showed that, in real life, autonomy seems to be 'relational', embedded in persons' social contexts and the relations they have with others [73,74]. As a result, autonomy does not so lead to pure individual choices. With regards to the prenatal anomaly screening context, Garcia *et al.* (2010) [75] also emphasized the importance of using a new approach of reproductive autonomy. For clients to make choices about prenatal anomaly screening, it is important to freely share their thoughts and feelings about the decision with their partners and other closely related persons [34,75]. The existence of the concept of relational autonomy in prenatal anomaly screening decisions in practice might explain the importance clients attach to the advice of their counselors. Clients seek several opinions of persons relevant to them, for instance to shoulder the decision together with their partner or to get reassured that they made the right decision [75].Therefore, clients' request for advice should be seen as an opportunity to facilitate clients in clarifying their desires, motives, preferences, values and aims regarding the prenatal anomaly screening offer [34,76,77]. This approach helps clients to a personal understanding of the significance of testing within their own moral framework and to feel confident about their decision [78]. Interestingly, an important website to facilitate decision-making in the Netherlands, provides not only information and tools, but also videos of parents who explain why they opted for anomaly screening or not [55]. This development seems to be in line with the new approach of a relational, reproductive autonomy.

Methodological reflections

Three studies reported in this thesis were based on data derived from questionnaire surveys. At the start of this study, it was essential to select the most appropriate questionnaire. We aimed to find an instrument that measured clients' needs and preferences regarding counseling for prenatal anomaly tests that explicitly involved the input of clients; instead of an instrument based on what experts perceived to be important for prenatal counseling. The QUOTE (Quality Of care Through the patients Eyes) scale seemed to be suitable for measuring our research questions. This scale is based on a concept of quality of care, which is defined as 'the degree to which (perceived) performances of health and social care services meet the needs of people with respect to aspects that are important to them' [79]. QUOTE questionnaires

are described as a group of standardized and validated surveys [79-84], modified for various groups of healthcare consumers, such as patients in need for chemotherapy treatment [80], clients confronted with hereditary cancer [79], patients with a chronic liver disease [85] and cataract patients [86]. We modified existing QUOTE questionnaires following the QUOTE procedure [80], which resulted in the QUOTE ^{prenatal}.

We undertook certain steps to measure the validity of the QUOTE ^{prenatal} questionnaire. We aimed to minimize the burden on respondents. Therefore, we shortened the questionnaire and rephrased difficult questions based on our results of Cognitive Interviews with pregnant women and their partners with low educational level. Dimensionality analyses of the QUOTE ^{prenatal} provided a three-factor structure with sufficient reliability of the internal consistency of the factors [**chapter 2**]. With a threshold for item-total correlations (ITC) set on ≥ 0.30 all but one ITC were acceptable to remain the questions in the QUOTE ^{prenatal}. Due to time restraints, we did not investigate the test-retest reliability of the QUOTE ^{prenatal} nor the convergent validity; the same sample of data was used for both validation of the questionnaire and for our survey into client preferences and experiences. In contrast with our expectations, we were not able to measure the content validity of the QUOTE ^{prenatal} by means of a confirmatory factor analysis. These limitations might have resulted in a questionnaire that does not meet the criteria for a good questionnaire entirely [87]. However, the QUOTE ^{prenatal} appeared to be able to detect issues that need improvement to ensure that prenatal counseling is in line with client preferences [**chapter 2**]. As to the midwives' version of the QUOTE ^{prenatal} we limited validation of the questionnaire to Cognitive Interviews and measurement of the internal consistency, which appeared to be satisfactory [**chapter 3**].

The observational studies reported in this thesis were conducted on a unique dataset of videotaped first consultations including counseling for prenatal anomaly screening by midwives in the Netherlands. To our knowledge, there are no other comparable databases of videotaped material available to study midwife-client communication. This dataset enabled us to answer a wide range of research questions about the first visit of clients to their midwives. However, since we encountered difficulties in recruitment of midwives to participate in our video-observational study, resulting in a lower number of participating midwives and clients, we could not fully avoid selection bias on the part of both the participating midwives and clients. Furthermore, although we introduced the video-recording study to be relevant to answer a variety of research questions, midwives and clients were aware of the focus on counseling for prenatal anomaly screening due to the fact that they completed the complementary QUOTE ^{prenatal} questionnaires. Therefore, we can expect a selection bias toward midwives and clients with an interest in prenatal counseling and an effort of midwives to do their very best during videotaped consultations. However, since participating midwives video-taped at least during several months, in most cases whole intake consultations including prenatal counseling, we believe that videotaped material displayed midwives' usual communication during prenatal counseling [**chapter 4**].

In the observational studies, we used the Roter Interaction Analysis System (RIAS) [88]. An advantage of applying the RIAS coding system is its wide use and proven validity and reliability [89]. During the coding, meaningful utterances, usually a sentence or thought of midwives, pregnant women and their partners, were coded and counted. With the adapted version of the RIAS we were able to identify the focus in communication during prenatal counseling, e.g. *health education*, *decision-making support* or building a good *client-midwife relation* and compare the outcomes of the video-observations with the results of the QUOTE ^{prenatal} questionnaire. A possible limitation to our study is that the adapted version of the RIAS was quite extensive, which made coding more difficult and therefore might have negatively influenced inter rater reliability and therefore our results [**chapter 5** and **6**]. However, this was at least partly compensated by reporting most results on counseling function level and not only on item level.

In our studies we used a quantitative approach in which we counted meaningful utterances to study midwife-client communication. The use of state events, which measure the time spent on each utterance, might have given a more realistic and detailed description of the ongoing communication compared to our approach [90]. Due to the extensive amount of variables we used in our study, the mostly triadic nature of counseling and the software we used, we tried but did not manage to use such approach for verbal communication in our study. To measure nonverbal communication, we indeed used state events to code midwives' client-directed gaze [**chapter 7**] and silences.

Qualitative methods combined with our quantitative approach may have provided broader knowledge about the nature of midwife-client communication during counseling for prenatal anomaly screening. For instance, it would have been interesting to learn, how midwives frame their information in those counseling cases where clients felt they have gotten advice, but where the midwife did not feel she had explicitly provided advice [**chapter 6**].

To conclude

In the eyes of pregnant women and their partners, prenatal counseling for anomaly screening provided by midwives meets their needs to a large extent, and midwives' views on appropriate counseling are roughly in line with clients' preferences. But some important differences exist and midwives' should take notice of these differences. Especially for multiparous women. Midwives should provide (medical) information about the target anomalies of prenatal screening and endeavor to tailor their counseling to each individual client's needs. Midwives' prenatal counseling could presumably be improved by adjusting their counseling to clients who value *decision-making support.* The increased use of affective communication as well as using all the allocated time available for counselling are relevant for improving *decision-making support*. Last, introducing video-recording as a research tool in midwifery practice, provided a unique dataset regarding midwives first consultation with their clients and more specifically of prenatal counseling for anomaly screening.

Recommendations

As a result of our findings we propose a set of recommendations for prenatal counselors, educators, policy makers and future research.

Recommendations for counselors

Based on our findings we encourage midwives and other professionals who provide prenatal counseling for anomaly screening to reflect on the way they address the three prenatal counseling functions in practice. We recommend that counselors:

- Realise that counseling for prenatal anomaly screening in practice is a triadic instead of dyadic process in which partners should be explicitly invited to join.
- Use the Shared Decision Making approach as a practical guideline to optimize and integrate the *health education* and *decision-making support* functions of prenatal counseling.
- Improve some aspects of their *health education* by discussing the target anomalies, procedural-, societal- and risk- aspects of prenatal screening and thereby to facilitate an informed choice.
- Improve their *decision-making support.* Counselors need to consider to ask psychosocial questions, use affective communication and take the advised time for counseling.

Recommendations for educators

"Without nurturing, the lessons from research and communication training flounder in the face of pressures from inappropriate modelling and apparent lack of valuing" [48].

Therefore, we recommend to:

- Train the trainers / counselors who act as students' supervisors in practice in the same way students are trained, with the ambition to guarantee appropriate modeling.
- Allocate education time to discuss students' values on appropriate counseling and to reflect upon these values in the light of professional guidelines and supervisors modeling.
- Provide continuing education, including education credits, on prenatal counseling with the focus on communication skills necessary to integrate *health education* and *decision-making support.*

Recommendations for future research

- Future research should study clients from non-Dutch, non-Western origin and of clients with low literacy skills, to assess whether clients' pre-counseling preferences and post-counseling experiences found in this study also represent theirs.

- Nowadays, the Consumer Quality Index (CQ Index), a measurement tool for quality of care, which is based on inter alia the QUOTE-questionnaire, is recommended above the use of QUOTE-questionnaires [91,92]. However, we recommend to use the QUOTE questionnaires, in studies that focus on a particular communication process like prenatal counseling.
- More insight into the decision-making process of pregnant women and their partners/significant others can inform counselors how prenatal counseling could facilitate this process.
- In 10 years, to repeat a video study of the discussion in the consultation room, might provide valuable information about how developments in midwifery care become visible in every day midwifery practice.

Recommendations for policy makers

"Progress in the standard of communication in the real world can be disappointingly slow". Pressures from, for instance, workload and time issues are well known bottlenecks [48].
We, therefore, recommend:

- Monitoring not only the standard of communication of initial and post-initial counseling for prenatal anomaly screening courses [93], but also prenatal counseling in practice.
- Considering an explicit shift from non-directiveness to a Shared Decision Making approach as the leading approach for all preference sensitive choices in pregnancy [30].
- Considering educating some midwives to excel in prenatal counseling so that they can do this task for other midwives, who choose to focus on other midwife responsibilities.

4. Developments in the prenatal anomaly screening offer

The offer of tests in the field of prenatal anomaly screening is increasing, so midwives and other stakeholders need to stay attuned. The Non-Invasive Prenatal Test (NIPT) for common aneuploidies was recently added to the prenatal anomaly screening program in a nationwide study setting; the TRIDENT study (Trial by Dutch laboratories for Evaluation of Non-Invasive Prenatal Testing) [94,95]. A license for the TRIDENT study has been granted for two years (starting April 1, 2014) by the Ministry of Health. The NIPT is offered to women with an increased risk for carrying a child with Down-, Patau- and / or Edwards syndrome based on a positive CT (≥ 1:200) or medical indication such as already having a child with trisomy 13, 18 or 21 or carriers of Robertsonian translocations involving chromosome 21 or 13 [5,94,95,96]. Since 2007, the CT was paid by insurance companies for women ≥ 36 years of age. As of January 2015, a change of policy was made. All pregnant women have to pay approximately

165 euros if they opt for the CT. If women opt for the NIPT, they have to pay the test out of the coinsurance of their health insurance. Depending on the costs of other healthcare consumption, clients may have to pay up to two thirds of the actual costs of the NIPT, ca. 375 euros. Furthermore, women ≥ 36 years of age are no longer directly eligible for invasive prenatal diagnostics, unless they have a family history of birth defects [**chapter 6**;93,97].
Until now, midwives are the designated professionals to inform their clients about eventual positive test-results of the CT [93]. Inevitably, clients who have an increased risk based on the CT and clients who have a medical indication, might ask questions about available prenatal tests. Midwives may give information about diagnostic tests and the NIPT, based on an information guide for professionals [51]. However, counseling for the NIPT is offered in one of the 8 prenatal screening centers [5], usually by trained obstetricians. These gynaecologists could have completed a post-graduate counselling course together with a range of different care-providers, including midwives [93,97]. However, the current restricted eligibility for NIPT seems to result in a subculture. Pregnant women who are not eligible for NIPT in the Netherlands, can opt to have a NIPT in for instance Belgium or Germany. In those cases NIPT might be used as a first screening test for which pregnant women pay themselves. It is unclear to what extent they are counseled and by whom [98].

Consequences for counseling

The above-described developments have several consequences for midwives as counselors. Obviously, the information they provide about the eligibility for the available prenatal tests and costs has to be updated, as it has been over the past decades. In order to deal with the consequences of the restricted eligibility for the NIPT, in the context of a commercial NIPT-offer abroad, midwives need to excel in sophisticated counseling. The positive characteristics of NIPT - accurate, safe and early testing –could enhance undesirable framing of the NIPT as routine prenatal care. To safeguard voluntary participation, based on informed decision-making will therefore be of utmost importance [99,100,101]. And then again, the choices that are really on the counseling agenda: whether one wants to know about eventual anomalies in the unborn child or not and for what purpose, remain unaltered. The same holds for the information about the target anomalies, in case screening by NIPT stays restricted to aneuploidies of chromosomes 13, 18, and 21 [**chapter 7**; 100].
If the NIPT is to be offered as the first prenatal anomaly screening in pregnancy, midwives probably will play a crucial role as counselors. The question is how midwives could be trained to both offer counseling to a low-risk population as well as a high-risk population due to for instance ultrasound abnormalities. The clinical eligibility for NIPT might become increasingly challenging to handle because this eligibility happens to be different in both groups. With regards to the *health education* function of counseling, midwives might need to learn and to discuss with the clients medical indications as well as medical contraindications for the

NIPT. Contraindications for NIPT comprise an increased nuchal translucency, ultrasound abnormalities, vanishing twin, dichorial twins and limited accuracy of the NIPT in overweighted women [102,103]. So, although clients might view the NIPT to be an attractive test, counselors in some cases have to break the news that NIPT might be not desirable while prenatal diagnostics or an array might be appropriate [94]. Training midwives on the meaning of unexpected findings and for instance the *health education* topics described above seems reasonable. Furthermore, training on how to provide *health education* in a personalized way together with the provision of *decision-making support* seems to be necessary giving the ongoing developments in the field of prenatal anomaly screening and the current prenatal counseling in practice described in this thesis.

With our study, we hope to have contributed to the ongoing discussion and debate in healthcare and policy about what constitutes high quality counseling for prenatal anomaly screening. As a client said: "[To me it was important] to get the feeling that she [the midwife] was talking to ME, and… not just rattle off the information".

APPENDIX A Topics relevant to address during *Health Education* according to most clients [**chapter 2**]

1.	Asks about clients' family's history of birth defects
2.	Explains which anomalies can be identified using prenatal screening
3.	Explains which anomalies cannot be identified using prenatal tests
4.	Provides medical information about the anomalies that are being tested for
5.	Explains the usefulness of prenatal screening (what can the client decide to do eventually)
6.	Informs the client about all the different types of prenatal tests
7.	Explains what will happen during the prenatal tests
8.	Discusses possible negative implications of prenatal screening for the unborn child
9.	Informs the client about her chances of having a child with a congenital anomaly during this pregnancy
10.	Explains which prenatal tests will be performed first and which will be performed later, if required and/or necessary
11.	Tells the client why she is / is not eligible for certain prenatal tests
12.	Discusses all clients' options with regard to prenatal screening and the implications
13.	Explains how long the client may take to decide whether or not to terminate the pregnancy, should the test results show an abnormality
14.	Explains how long the client may take to decide whether or not to have the prenatal tests
15.	Talks with the client about how her risk of having a child with a birth defect will affect her
16.	Only discusses specific information about follow-up tests and possible anomalies with the client if it becomes clear that the client will need this information

APPENDIX B Topics relevant to address during Decision-making support according to 50% of the clients [**chapter 2**]

1.	Advise the client about whether or not to take the prenatal tests
2.	Respond to what the client already knows about prenatal screening
3.	Ask the client questions that make her / him think
4.	Talk to the client about how her /his family and the client would react to a child with a birth defect
5.	Ask the client to explain her decision to take / not to take the prenatal tests
6.	Be interested in who the client is

APPENDIX C Content of prenatal counseling for anomaly screening

Counseling

Counseling is the provision of information by the obstetric care provider about the combined test and the Fetal Anomaly Scan. The following aspect should be addressed during counseling:

The right not to know;

- Information about the anomalies that are the target of screening (down-, edwards- and patau syndrome, neural tube defects, and other physical anomalies);
- Information about the natural course of the disease for which screening is performed and the frequency of occurrence;
- The test characteristics of the CT and FAS. Such as the risk of the anomaly tests, explanation about the test-outcome and the risk of false positive and false negative test results;
- The implications of abnormal test results and possibilities for future research;
- The possible costs of research both tangible and intangible.

In addition, the counselor should give the pregnant women the national information leaflets (of the RIVM). These leaflets contain all important information.

Reference: http://www.prenatale-screening.nl/counseling.html

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