

Chapter 9

Summary & Samenvatting

SUMMARY

Chapter 1 *Introduction*

In the Netherlands, the prenatal anomaly test program consists of both screening and diagnostic tests. The prenatal screening program includes the combined test, a first trimester risk assessment for trisomy 21, 18 and 13, and the fetal anomaly scan, a second trimester ultrasound to detect structural anomalies such as neural tube defects. The prenatal diagnosis program includes amniocentesis or chorionic villus sampling to detect chromosomal anomalies and an advanced ultrasound scan. Parents have to decide whether they want to be informed about these tests and once informed whether they want to have the tests. Parents do not always find these choices easy. They might struggle with questions such as ‘what do I feel is a serious anomaly?’; ‘what will I do if an anomaly is found in my unborn child?’; and ‘how will my family and friends judge my choices?’.

Counseling is offered to facilitate parents’ decision about prenatal anomaly screening. In about 80% of the Dutch pregnancies, primary care midwives offer this counseling for prenatal anomaly screening to their clients. The aim of prenatal counseling is to *inform clients* about prenatal anomaly testing, e.g. to provide information about the target anomalies and test characteristics, and to *facilitate clients’ informed decision-making* whether to opt for prenatal anomaly tests or not e.g. to explore together with clients their values regarding raising a disabled child. Most research on counseling for prenatal anomaly screening has focused on the assessment of the quality of clients’ risk perception accuracy, recall of information provided, decision related outcomes, psychological adjustment and communication style of the counselor. Little is known about parental preferences for counseling or about their experience of being counseled for prenatal anomaly screening. Furthermore, relatively little is known about counselors’ views on appropriate counseling and how they counsel in daily practice.

The aim of this thesis was to examine prenatal counseling from the perspectives of clients and midwives and to examine client-midwife communication during counseling in daily, midwifery led-care practice. The research conducted consists of six studies.

Chapter 2 *Prenatal counseling for congenital anomaly tests: parental preferences and perceptions of midwife performance.*

Counseling for prenatal anomaly tests is largely based on the theoretical concept that counseling should comprise both *health education* and *decision-making support*. To our knowledge, little is known about how clients value and experience this theoretical concept in practice. An evidence-based instrument to evaluate the preferences and experiences of future parents regarding prenatal counseling is currently lacking. Therefore, we adapted the existing QUOTE (quality of care through the patients eyes) questionnaire into the QUOTE^{prenatal}, a client centered questionnaire to measure clients’ pre-counseling preferences and post-counseling experiences, and assessed its validity.

In seventeen Dutch midwifery practices, 941 pregnant women and their partners completed the QUOTE ^{prenatal} pre- and post-counseling. The QUOTE ^{prenatal} appeared to consist of three components, which show sufficient reliability: *health education*, *decision-making support* and building a good *client-midwife relation*. Building a good *client-midwife relation (CMR)* to enable the two prenatal counseling functions *health education (HE)* and *decision-making support (DMS)* in practice appeared to be relevant. We proposed to add this function as an important component of prenatal counseling.

The QUOTE ^{prenatal} questionnaire is a reliable instrument to measure client preferences and experiences regarding *CMR*, *HE* and *DMS*. Most clients consider the *client-midwife relation* and *health education* to be (very) important for prenatal counseling. More than one third of the clients consider *decision-making support* to be important. More nulliparous women had preferences for *health education* and *decision-making support* compared to multiparae. Furthermore, the results of our study suggest that overall pregnant women and their partners have comparable needs regarding prenatal counseling for anomaly screening. As a consequence, our findings suggest that counselees are likely to benefit from paired prenatal counseling. That way each of their individual counseling needs can be met and couples can benefit from both receiving the same information and support in making their decisions towards prenatal anomaly tests.

Post-counseling, clients perceived that their midwives performed well in building the *client-midwife relation* and in giving *health education*. About one third of the clients indicated that they preferred more *decision-making support* than they received, indicating that improvement is needed in *decision-making support*.

Chapter 3 *Midwives' views on appropriate prenatal counseling for congenital anomaly tests: do they match clients' preferences?*

The data for this study were collected in November 2010. We aimed to provide insight into midwives' views on appropriate counseling for prenatal anomaly tests, and determine whether these views were concordant with clients' preferences regarding prenatal counseling. Therefore, we mirrored the QUOTE ^{prenatal} so that it could be used to assess midwives' views on appropriate counseling. 1416 Dutch midwives completed the questionnaire. Data of midwives were compared to the 941 QUOTE ^{prenatal} questionnaire-data of clients. Like clients, most midwives value a good *client-midwife relation* and *health education* as important or very important for counseling for prenatal anomaly tests. A more detailed look into *health education* items showed several items that were perceived important by most midwives but not by most clients and vice versa.

Preferably, counseling for prenatal anomaly tests should be consistent with the prenatal counseling model that includes *health education*, *decision-making support* and building a good *client-midwife relation*, but should also be tailored to clients' individual preferences.

Our findings show that only half of the midwives participating in this study seem to subscribe to the *decision-making support* function of prenatal counseling. This might result in prenatal counseling which does not meet the aims of the counseling or the perceived needs of clients. We therefore recommended that midwives reflect upon their views on prenatal counseling. Furthermore, midwives need to bridge the differences between their views on appropriate prenatal counseling and client preferences in daily practice.

Chapter 4 *Introducing video recording in primary care midwifery for research purposes: procedure, dataset, and use.*

Research to support evidence for the actual introduction and enrolment of video-recording studies has been limited. In this chapter we describe how we introduced and used a nationwide video-recording research project of health care provider (HCP)-client interactions in primary midwifery-led care for research purposes. The video-recording study provided data for three of the other papers included in this thesis: Chapter 5, Chapter 6 and chapter 7. Following an invitation to participate, midwives from six practices across the Netherlands volunteered to videotape 15-20 intake consultations. We measured the number of valid recordings and missing recordings; reasons not to participate, non-response analyses, and the inter-rater reliability of the coded videotapes. Video recordings were supplemented by questionnaires for midwives and clients. We used the Roter Interaction Analysis System (RIAS) for coding as well as a newly developed obstetric topics scale. The introduction, complexity of the study and intrusiveness of the study were discussed within the research group. At the introduction of the study, more initial hesitation in cooperation was found among the midwives than among their clients. The intrusive nature of the recording on the interaction was perceived to be minimal. The complex nature of the study affected recruitment, data collection and combining the dataset with the questionnaires and medical records of clients. Although challenging to obtain, video recording of midwife-client interaction proved to provide a unique dataset. Data could be used to answer a wide range of research questions, for instance about lifestyle communication, pregnancy related health education and prenatal counseling for anomaly screening. Researchers planning to use a video recording research approach will benefit from a tight design, vigilant monitoring during the data collection, and a study-design that is as simple as possible.

Chapter 5 *Prenatal counseling for congenital anomaly tests: an exploratory video-observational study about client-midwife communication.*

This study focusses on how the counseling functions *health education*, *decision-making support* and building a good *client-counselor relation* were performed in daily, midwifery practice. The data for this exploratory video-observational study were collected between June 2010 and May 2011. Pregnant women, and if present their partners, were included if

they were new to prenatal counseling for the current pregnancy, aged 18 years or older, and able to read Dutch or English. 269 videotapes on counseling for prenatal anomaly screening provided by 20 midwives within 6 Dutch primary midwifery-led care practices were used to code the client-midwife communication with the RIAS.

Midwives tended to focus their counseling on *HE* compared to *DMS*. The relatively low contribution of clients during the *decision-making support* conversation might indicate poor *DMS* given by midwives. Counseling of multiparae was shorter than counseling of nulliparous women; multiparae received less *HE* as well as *DMS* compared to nulliparous women. This might be appropriate in the light of their personal experiences during an earlier pregnancy, but might also indicate that multiparous women do not get what they need, given their experiences that their needs seem to be unfulfilled after about a quarter of the prenatal counseling consultations. Since in 28% of the cases partners were not present during prenatal counseling, it remains unclear to what extent they contributed to the counseling conversation.

Chapter 6 *Midwives' perceptions of communication during videotaped counseling for prenatal anomaly tests: how do they relate to clients' perceptions and independent observations?*

Chapter 6 describes how Dutch midwives evaluate their own counseling for prenatal anomaly screening in real life practice and how these evaluations relate to clients' experiences and observed performance. 240 of the videos of 20 midwives could be included in this study. Post-counseling the QUOTE^{prenatal} questionnaire was completed by both midwives and clients. Observers coded a selection of the QUOTE^{prenatal} items using the adapted version of the RIAS video-coding system.

We found that in all 240 cases midwives perceived that they performed well on building a good *client-midwife relation*. During 80% of the prenatal counseling, midwives perceived that they provided appropriate *health education*. *Decision-making support* was evaluated as provided by midwives in 17% of the cases. Experiences of clients and observations were highly congruent with those of midwives with regards to the *HE* functions of counseling. Regarding *DMS* congruence of assessments was higher between midwives and observers (80%) compared to midwives and clients (62%).

Our results indicate that *DMS* is more difficult to assess compared to *HE*. An interesting incongruence on item level was found on the item 'provided advice whether to opt for prenatal anomaly screening'; clients perceived to have gotten advice in 40% of the cases while midwives and observers assessed giving advice in about 6% of the cases.

Chapter 7 *Clients' psychosocial communication during prenatal counseling for anomaly screening: how is it related to midwives' communication and client-directed gaze?*

Chapter 7 describes an exploratory study of 184 videotaped prenatal counseling consultations by 20 midwives. We aimed to assess the facilitation of clients' psychosocial communication, known to be especially important for facilitating decision-making, during prenatal counseling for fetal anomaly screening. We assumed that midwives' psychosocial and affective communication, client-directed gaze and counseling duration were positively related to clients' psychosocial communication. We rated the duration of client-directed gaze and used the RIAS to code the client-midwife communication.

Our results indicate that initiating discussion about psychosocial topics does not come easily; clients need to be invited by, for instance, psychosocial questions. We also found that midwives' affective behavior and counseling duration is likely to encourage client's psychosocial communication. Psychosocial communication of clients was, in contrast with our expectations, not related to midwives' client-directed gaze.

Chapter 8 *General Discussion*

Active involvement in counseling for prenatal anomaly screening is important for expectant parents as it facilitates their decision-making process. Clients, meaning both pregnant women and their partners, prefer their counselors to build a good client-midwife relation and to provide *health education*. *Decision-making support* was considered to be important to a less substantial group of participants in our study. The views of midwives are largely in line with the preferences of clients. It is not entirely in line with the theoretical prenatal counseling model, which indicates that the aim of counseling is only accomplished when both *health education* as well as *decision-making support* are provided. Furthermore, several relevant differences between midwives' views on appropriate counseling and clients' preferences exist. Therefore, to realize appropriate counseling for prenatal anomaly screening, midwives need to find a way to overcome the differences between their own views about appropriate prenatal counseling, the theoretical functions of counseling and client preferences.

The video-recording project provided a unique, multi-useful research dataset of prenatal intake consultations and prenatal counseling by midwives. The complementary use of the QUOTE ^{prenatal} questionnaire, for clients and midwives, delivered three different foci to look at counseling for prenatal anomaly screening in practice. This methodological triangulation provided valuable information, such as, how to interpret the findings of each separate focus e.g. observations of the client-midwife communication, experiences of clients and self-evaluations of midwives.

The ongoing developments in prenatal anomaly screening, e.g. the Non Invasive Prenatal Test, stress the importance for such developments in counseling practice, since medical

progress might result in complex choices if an anomaly is indicated in the unborn child. To do so in line with client preferences, further research could be focused on the preferences and needs of clients with low literacy and how they might benefit from the use of value-clarification- or decision aids.

Overall, we concluded that counseling for prenatal anomaly screening by midwives, seemed to be in line with communication during counseling of other health care providers since it was focused on the provision of *health education*. We therefore recommended that prenatal counselors improve the provision of *decision-making support* and thus encourage clients to share their deliberations whether to opt for anomaly screening or not during prenatal counseling for anomaly screening. Doing so, counselors may benefit from the Shared Decision Making approach as a practical guideline to optimize both the *health education* and *decision-making support* functions of prenatal counseling.