Chapter 3

Midwives' views on appropriate antenatal counseling for congenital anomaly tests: do they match clients' preferences?

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ABSTRACT

Objective This study aims to provide insight into: a) midwives´ views on appropriate prenatal counseling for congenital anomaly tests, and b) whether these views match clients´ preferences regarding prenatal counseling.

Design A comparative (midwives versus clients) questionnaire survey. Cognitive interviews (N=8) were used to validate the internal validity of the midwifery questionnaire results.

Participants and setting 1416 Dutch midwives (response 62%) completed a questionnaire measuring their views on appropriate prenatal counseling for congenital anomaly tests.

Measurements We used the 58-item midwives' version of the QUOTE ^{prenatal}, an instrument to assess clients' counseling preferences. Descriptive statistics were used to explore midwives' views on appropriate counseling and how these relate to client preferences as measured previously with the clients' version of the QUOTE ^{prenatal}.

Findings Almost all midwives consider the *client-midwife relation* (100%) and *health education* (95%) to be (very) important for appropriate prenatal counseling for congenital anomaly tests. Almost half of the midwives consider *decision-making support* (47%) to be (very) important. These findings are practically congruent with client preferences. Still, clinically relevant differences were found regarding 13 individual items, e.g. more clients than midwives value 'medical information about congenital anomalies' and 'getting advice whether to take prenatal tests or not'.

Key conclusion Like clients, most midwives value a good *client-midwife relation* and *health education* as (very) important for prenatal counseling for congenital anomaly tests. Less than half of them value *decision-making support*. These findings are in contrast with the literature in which *decision-making support* is seen as the most important part of prenatal counseling for congenital anomaly tests.

Implication for practice Preferably, prenatal counseling for congenital anomaly tests should be consistent with the three-function model of prenatal counseling i.e. maintaining a *client-midwife relation,* providing *health education* as well as *decision-making support,* and tailored to clients' individual preferences. Since not all midwives subscribe to these functions, reflection on their views is important. Furthermore, midwives need to bridge their views on appropriate prenatal counseling and client preferences. To do so, midwives may benefit from the Shared Decision Making approach.

INTRODUCTION

Medical and policy developments in prenatal screening and diagnostic testing have led to a rapid increase in the number of congenital anomalies for which testing is available [1,2]. The amount of information about testing that is communicated to clients has increased and seems difficult to manage for both counselors and clients [3,4]. In the Netherlands, prenatal screening for congenital anomalies has been available since 2007. Primary care midwives are the designated counselor in about 80% of the pregnancies [5,6]. They are trained to offer prenatal counseling to help clients understand information about congenital anomaly tests and to help clients in making autonomous, informed decisions [7,8].

Appropriate counseling usually serves the two functions *teaching* and *counseling,* embedded within a non-directive approach [9-11]. In the context of prenatal counseling, these counseling functions are referred to as *health education* and *decision-making support* [12]. An important third function, i.e. maintaining a *patient-provider relationship*, is considered to be a prerequisite for enabling these two counseling functions [13,14].

While providing *health education,* midwives enhance clients' knowledge by giving medical information about topics such as the prenatal tests available and the anomalies that can be diagnosed, but no golden standard exists for the information needed to make an informed decision about participation in prenatal screening [15-18]. During *decision-making support* counselors help clients in making autonomous, informed decisions by for instance discussing diverse scenario's and putting moral issues on the agenda [8,19]. A good *client-counselor relation* can be established by showing empathy and unconditional support regardless of the decision a client makes about taking or refusing a prenatal test or by terminating or continuing a pregnancy [14,20].

Clients differ in the value they attach to the three functions of the prenatal counseling model, including the non-directive approach. Most Dutch clients do value the *client-midwife relation* and *health education* as important functions of prenatal counseling. A relatively smaller group values *decision-making support* as an important function, although more than two third of the clients value one specific aspect of *decision-making support,* i.e. 'getting advice on whether to have prenatal tests or not' [12]. So, for the majority of clients, the three function prenatal counseling model fits well with their preferences, and a significant number of clients indicate that they value a directive approach during *decision-making support* expressed in the need for advice. This suggests that a personalized approach to counseling that takes clients' individual preferences regarding the topics discussed as well as their need for decision-making support (e.g. non-directive versus more directive or Shared Decision Making) into account will be most likely to meet client needs [12]. These findings are consistent with client preferences for personalized health care in general and prenatal care in particular [21-24].

There has been little investigation of the views of counselors regarding the three-function model of prenatal counseling, including the non-directive approach. Roter *et al.* [9] describes some scepticism regarding the desire of genetic counselors to fully address the *decision-making support* function of counseling. The study of Sheets *et al.* [25] illustrates that genetic counselors and parents differ in the importance they attach to different aspects of information (or *health education*) about having a child with Down syndrome. In the context of end of life counseling health care providers seem to be reluctant to offer advice about treatment options even when patients specifically asked for it [26]. Understanding counselors' views on appropriate counseling is important. If counselors do not endorse all three functions of the prenatal counseling model, the provision of appropriate, personalized prenatal counseling may be at risk.

This paper aims to describe midwives' views on appropriate prenatal counseling for congenital anomaly tests focussing on the three functions of the prenatal counseling model, *health education*, *decision-making support* and the *client-midwife relation* and to compare midwives' views to previous findings on clients´ preferences [12]. The following research questions are addressed: a) what are midwives´ views on appropriate prenatal counseling for congenital anomaly tests, and b) do these views match clients´ preferences regarding prenatal counseling?

It was hypothesized that midwives attach more importance to *health education* than to *decision-making support* as a result of the extensive amount of information they are obliged to give according to Dutch educational programs and research [15-18]. Midwives are also most familiar with the role of *health educator* since the role of counselor has been relatively recently (2005) introduced in the midwifery profession as well as in the prenatal screening program in the Netherlands (2007) [6,27] (See for more information about the Dutch prenatal counseling setting Appendix A).

METHODS

This study is part of the DELIVER study, a multi-center national research program to evaluate the quality and provision of primary midwifery care in the Netherlands [28].

The design of the current nation-wide cross-sectional study was approved by the Institutional Review Board and the Medical Ethical Committee of the VU University Medical Centre, Amsterdam, The Netherlands.

Participants

Midwives

All midwives who were members of the Royal Dutch Associations of Midwives (KNOV) were invited to participate in our cross-sectional survey questionnaire in November 2010. 87% of the Dutch, working midwifery population and 98% of the midwives working in primary midwifery care are members of the KNOV [29].

Clients

In the current study we used data from our cross-sectional study about parental preferences and experiences regarding prenatal counseling for congenital anomaly tests by midwives [12] and compared those findings with the results of the midwife questionnaire. In the study of clients, 941 parents from 17 Dutch midwifery practices, including 538 women and 403 partners, participated. The sample of participating women was representative for the Dutch pregnant population except for level of education (the sample was higher educated compared to the pregnant Dutch population) and ethnicity (the sample contained lower percentages of non-Dutch compared to the pregnant Dutch population). Significantly more pregnant women valued the *client-midwife relation* as important or very important compared to partners, 99% versus 96% respectively. Women and their partners placed the same value on the *health education* function; 85% valued this prenatal counseling function as important or very important. *Decision-making support* was valued important or very important by more than one third of the women and their partners [12]. Since the differences between women and partners regarding their valuation of the *client-midwife relation* seem to have no practical relevance, we use the overall results of women and partners in this study.

Measures

Background characteristics

The self-administered questionnaire for midwives contained socio-demographic items such as age, gender, work experience, country of origin and religion.

Midwives'-version QUOTE ^{prenatal} questionnaire

The questionnaire used to measure midwives' views on appropriate prenatal counseling for congenital anomaly tests mirrored the 58-item QUOTE ^{prenatal} questionnaire (**Qu**ality **o**f care **t**hrough the patients' **e**yes), that we developed to assess clients' preferences and experiences regarding this type of prenatal counseling. Used among parents, the QUOTE ^{prenatal} questionnaire showed high levels of internal consistency measured with Cronbach's alpha [12]. We used the same items of the QUOTE ^{prenatal} in this study, but rephrased them in order to change the focus to midwives' views on appropriate prenatal counseling (see tables 3a,3b,3c for the resulting midwives'-version QUOTE ^{prenatal} questionnaire).

The questionnaire contains generic communication items and specific items about prenatal counseling for congenital anomaly tests [12]. The three functions of prenatal counseling were addressed in the three components of the QUOTE ^{prenatal} questionnaire: 15 items covered the *client-midwife relation* (i.e. generic items), 24 items covered *health education* (i.e. specific items) and 16 items concerned *decision-making support* (i.e. specific items) (Table 2 and Tables 3a, 3b, 3c). The remaining 3 items covered statements about organizational aspects of prenatal counseling, such as number of consultations used for pre-test counseling. The items of the questionnaire were formulated as *importance* statements ('As a midwife I perceive as important for prenatal counseling, that…') to be answered on a 4-point scale. Response options were 1, 'not important'; 2, 'fairly important'; 3, 'important'; and 4, 'very important'.
When used in the midwife population, we found good Cronbach's alpha estimates of internal consistencies for the three components of the questionnaire: *client-midwife relation* 0.86, *health education* 0.86 and *decision-making support* 0.82. Item-total correlations (ITCs) were higher than the threshold of 0.30 we used (ranging up to 0.65), except for Q56, Q3 and Q9 [30]. These three items with low ITC scores were not removed when we adapted the questionnaire for use with care providers so that the measurement tool would mirror the results from the client QUOTE ^{prenatal} as much as possible.
We undertook internal validation of the findings of the questionnaire using Cognitive Interviews (CI) (N=8) [31]. During the Cognitive Interviews midwives, who had not yet completed the questionnaire, were asked to complete the questionnaire while thinking aloud, including the indication of their rating for each questionnaire item. Participants were instructed to complete the questionnaire from the perspective of their view on appropriate prenatal counseling for congenital anomaly tests as if there were no practical limitations such as time and rewarding system. The interviews were audio-taped and transcribed verbatim.
Results of the CI show that midwives indeed interpreted and rated most items of the questionnaire focusing on their views of appropriate counseling without letting practical limitations disturb their ratings. Still, 15 items were partially interpreted and answered while taking into account the limitations of daily practice (Tables 3a,b,c items marked with $^{\#}$).

Procedures

Questionnaires were sent to the home address of midwife participants in order to minimize bias due to influences of colleagues. A prepaid and preaddressed return envelope could be used to return the questionnaires. After two weeks, non-responders received a reminder including a new questionnaire and return envelope.

Analyses

If 15% or less of the values were missing on item level of the questionnaire, the missing values were replaced by the mean on the sub-scale. Analyses were carried out using SPSS 17.0.2.

Participants
Descriptive statistics were used to describe the demographic characteristics of participants who completed the questionnaire. We compared characteristics of respondents with characteristics of the National midwifery population to examine the representativeness of our research sample concerning the variables: age, gender and location of vocational education.

Midwives' views on appropriate counseling
In line with our earlier study using the QUOTE ^{prenatal} methodology [12] importance scores on the three components of the questionnaire were used to rate views on aspects of appropriate counseling. Importance scores were calculated as the percentage of midwives who rated individual items as important (score 3) or very important (score 4) or components as important or very important (scores ≥2.50).

Midwives´ views on appropriate prenatal counseling and clients' preferences
Midwives' views on aspects of appropriate prenatal counseling for congenital anomaly tests were compared to clients' preferences regarding prenatal counseling as reported in our previous paper [12]. If both midwives and clients value the same components or items of the components as important or very important, this was considered as congruence between midwives' views and client preferences. If more than 75% of the midwives listed components and/or items as important or very important for appropriate counseling, but less than 75% of the clients or vice versa, with a difference of at least 10%, we considered this as a clinically relevant difference in midwives' views on appropriate counseling and client preferences.

FINDINGS

Participants
Of the 2300 eligible midwives, 1416 (62%) completed and returned the questionnaire. Table 1 shows that 1354 (98%) of the participating midwives were female, 24 (2%) were male. Mean age was 37.9 years, (SD=10.4). Mean years of work experience was 11.9 years (SD=9.3). A comparison with the characteristics of the study population and the Dutch midwifery population showed no differences in percentages of >5%, except for the category 'other' regarding 'place of education'. Five hundred and forty seven (39%) of the respondents were religious and 737 (52%) were non-religious. As missing data per item were ≤5% for each of the items of the questionnaire, missing values were not replaced.

Table 1 Demographic Characteristics of the test Sample Midwives (*N*=1416) and of the Dutch midwifery population.

Characteristics	**Sample of Midwives**	**Dutch midwifery population** [a]
Membership KNOV	N=1416 (100%)	N=2264 (86.7%)
Age		
Mean; SD; missing	37.9 years; 10.4; 41 (2.9%)	
N (%) < 40 years	835 (60.1)	1644 (63)
N (%) > 55 years	95 (6.8)	198 (7.6)
Gender	**N (%)**	**N (%)**
Male	24 (1.7)	43 (1.6)
Female	1354 (95.6)	2569 (98.4)
Missing	38 (2.7)	
Place of graduation		
Amsterdam	383 (27.0)	641 (25)
Groningen	74 (5.2)	147 (6)
Maastricht	373 (26.3)	660 (25)
Rotterdam	356 (25.1)	638 (24)
Other / Abroad	174 (12.3)	523 (20)
Missing	56 (4.1)	3 (0.1)
Religious background		
Religious	547 (38.6)	Not available
Non-religious	737 (52.0)	
Missing	132 (9.4)	
Work experience		
Mean; SD; Missing (%)	11.9 years; 9.3; 44 (3.1)	Not available

[a] Hingstman and Kenens, 2011.

Midwives' views on appropriate counseling

Table 2 shows that two of the three functions of prenatal counseling as measured with the components of the questionnaire, *client-midwife relation* (100%) and *health education* (95%), are perceived as important for appropriate prenatal counseling for congenital anomaly tests by almost all midwives. Forty seven percent of the midwives considered the component *decision-making support* as either important or very important for appropriate counseling.

Table 2 Components of the questionnaire and the content. Column three and four: Midwives and clients rating the three components (very) important for prenatal counseling (scores 3-4).

Component	Content	Midwives N=1416[a] (%)*	Clients[b] N=941 (%)*
Client-midwife relation	Items reflect the client-centered attitude of the midwife during the professional consultation or items that describe conditions for having a client-centered conversation	1293 (99.9)	865 (97.9)
Health education	Medical test information, (test) procedural information, risk information, societal information (e.g. costs of prenatal tests, eligibility for tests)	1154 (95.4)	775 (89.4)
Decision-making support	Exploration of values, social support and pressure on decision-making, discussion about the different options and outcomes of scenarios	581 (47.0)	328 (38.5)

* Valid percentages.
[a] Sample size varies due to missing data. Missing value analyses showed 91% (N = 1283) complete cases for the component *client-midwife relation*, 85% (N = 1198) complete cases for *Health education* and 87% (N = 1226) completed cases for *Decision-making support*.
[b] Clients: pregnant women and partners.

Looking at item level, tables 3a, 3b and 3c show the percentages of midwives who rated the individual items of the three components as important or very important, ranked from high to low. Scores on the 15 individual items, concerning the *client-midwife relation,* ranged from 100% to 76%, with highest scores for the items 'Listen to what the client is trying to ask' (Q6); 'Use clear and comprehensible language' (Q16). The two items with lowest percentages were 'Show empathy (Q10)' and 'Tell the client that she can always contact me about questions she may have (including when the practice is closed)'(Q18).

Percentages of scores on the 24 items concerning *health education* ranged from 98% to 41%. Thirteen of these 24 items were listed as important or very important for appropriate counseling by more than 75% of the participating midwives, with highest percentages for the items 'Explain the usefulness of prenatal screening to the client' (Q31) and 'Tell the client about all the different types of prenatal tests' (Q32) (Table 3b). The two items with lowest percentages were: 'only discuss specific information about follow-up test and possible anomalies with the client if it becomes clear that the client will need them' (Q56) and 'Tell the client about the incidence of birth defects in the Netherlands' (35) (Table 3b).

Furthermore, table 3c shows that percentages of scores on five of the 16 items concerning *decision-making support* reached the 75%, with highest percentages for the two items concerning tailored communication: 'Respond to what the client already knows about prenatal screening' (Q22) and 'Am interested in who the client is' (Q21). The two items with lowest percentages were: 'Ask whether client's family, friends or other people close to her would support her decision about prenatal screening' (Q51) and 'Ask whether client's family,

friends or other people close to her would support her decision to terminate the pregnancy if the child were to have a congenital abnormality' (Q54) (Table 3c).
Regarding organizational items of prenatal counseling none of the items were interpreted as important for appropriate counseling by more than 75% of the participants. Most midwives value asking the client to come together with their partner to the prenatal counseling as important or very important (67%) and scheduling a separate appointment for counseling was least valued (19%).

Table 3a Items of the QUOTE [prenatal] regarding the *client-midwife relation*. Figures show the number and percentage of midwives and clients who rated these items as (very) important (scores 3 or 4).

Number	Item description: For me it is important that I as a midwife…	Midwives N=1416[a] (%)*	Clients[b] N=941 (%)*
	Client – midwife relation		
Q6	Listen to what my client is trying to ask	1347 (100)	(99.7)
Q16	Use clear and comprehensible language	1348 (99.9)	(95.1)
Q1[#&]	Take plenty of time to answer clients questions	1342 (99.6)	(98.3)
Q5[&]	Take clients concerns seriously	1343 (99.5)	(98.9)
Q19	Accept clients' decisions on whether or not to opt for prenatal screening	1321 (98.1)	(87.9)
Q15[&]	Make clear that my client can ask anything she wants to know	1320 (97.8)	(92.5)
Q23[#]	Paint a realistic picture (not just through 'rose-tinted spectacles')	1314 (97.3)	(93.8)
Q4	Put my client at ease	1307 (97.1)	(96.8)
Q7	Am open and honest about every aspect of the pregnancy	1293 (96.1)	(98.3)
Q12	Know what the client is talking about	1291 (96.1)	(80.9)
Q8[#&]	Give the client enough time to explain herself properly	1270 (94.7)	(92.9)
Q17	**Give the client (additional) written information**	**1260 (93.5)**	**(60.0)**
Q24[&]	Give my client the feeling that I am tuning in to her as a person	1254 (92.8)	(82.8)
Q18[#]	Tell the client that she can always contact me with any questions she may have (including when the practice is closed)	1229 (91.2)	(79.8)
Q10	**Show empathy**	**1015 (75.5)**	**(61.7)**

*Valid percentages.
[a] Sample size varies due to missing data. Missing data were found for 25 items of the questionnaire ranging from 5% to 10%.
[b] Clients: pregnant women and partners.
Bold figures contain items which are either important for ≥ 75% of the midwives, but not for ≥ 75% of the clients or vice versa.
[#] Items that were at least partially interpreted and answered in the context of the limitations of daily practice.
[&] Items that were answered in the context of required prenatal counseling, although limitations of daily practice prevented participant from acting accordingly.

Table 3b Items of the QUOTE [prenatal] regarding the *health education*. Figures show the number and percentage of midwives and clients who rated these items as (very) important (scores 3 or 4).

Number	Item description: For me it is important that I as a midwife…	Midwives N=1416[a] (%)*	Clients[b] N=941 (%)*
	Health education		
Q31[&]	Explain the usefulness of prenatal screening (what the client can decide to do eventually)	1320 (98.1)	(90.0)
Q32[#]	Tell the client about all the different types of prenatal tests	1318 (98.0)	(86.8)
Q13	Impart information on prenatal testing	1310 (97.8)	(88.2)
Q26[&]	Explain which anomalies can be identified using prenatal screening	1300 (96.7)	(90.7)
Q58	Make sure that the topics the client consider to be important are discussed at length	1286 (95.9)	(88.8)
Q43	Explain which prenatal tests will be done first and which will be done later, if required and/or necessary	1278 (94.9)	(82.7)
Q45	Explain how long the client may take to decide whether or not to have the prenatal tests	1271 (94.5%)	(81.0)
Q48[#]	Discuss all clients options with regard to prenatal screening and the implications	1206 (90.1)	(82.3)
Q29[&]	Discuss possible negative implications of prenatal screening for the unborn child	1201 (89.8)	(95.2)
Q36	Ask about clients family´s history of birth defects	1206 (89.7)	(77.1)
Q33&	**Tell the client how prenatal screening can affect her emotions and mental wellbeing**	**1181 (87.9)**	**(74.9)**
Q41	Tell the client why she is or is not eligible for certain prenatal tests	1164 (86.7)	(82.4)
Q42	Explain what will happen DURING the prenatal tests	1120 (83.5)	(87.0)
Q27[#]	**Explain which anomalies <u>cannot</u> be identified using prenatal tests**	**985 (73.3)**	**(85.4)**
Q39	**Tell the client about HER chances of having a child with a congenital abnormality during this pregnancy**	**984 (73.3)**	**(83.6)**
Q40	Talk to the client about how HER risk of having a child with a birth defect will affect her	982 (73.2)	(76.3)
Q44	Explain who will give the client the results of the prenatal tests and how (verbally, in writing or by telephone)	982 (73.0)	(68.3)
Q37	Explain how often congenital anomalies occur in pregnant women of clients age	937 (69.6)	(68.4)
Q46	**Explain how long the client may take to decide whether or not to terminate the pregnancy, should the test results show an anomaly**	**933 (69.5)**	**(81.8)**
Q34[&]	Tell the client how much prenatal tests cost	890 (66.1)	(55.9)
Q38[#]	Explain how the chances of a birth defect are calculated for the clients unborn child	843 (62.7)	(72.5)
Q28	**Provide medical information about the anomalies that are being tested for**	**681 (50.6)**	**(76.0)**
Q56[@]	**Only discuss specific information about follow-up tests and possible anomalies with the client if it becomes clear that the client will need this information**	**640 (50.4)**	**(75.1)**
Q35	Tell the client about the incidence of birth defects in the Netherlands	550 (41.0)	(54.4)

*Valid percentages.

[a] Sample size varies due to missing data. Missing data were found for 25 items of the questionnaire ranging from 5% to 10%.

[b] Clients: pregnant women and partners.

Bold figures contain items which are either important for ≥ 75% of the midwives, but not for ≥ 75% of the clients or vice versa.

[#] Items which are at least partially interpreted and answered in the context of the limitations of daily practice.

[&] Items that were answered in the context of required prenatal counseling, although limitations of daily practice prevented participant from acting accordingly.

[@] Items with low Item Total Correlation (≤ .30).

Table 3c Items of the QUOTE [prenatal] regarding the *decision-making support*. Figures show the number and percentage of midwives and clients who rated these items as (very) important (scores 3 or 4).

Number	Item description: For me it is important that I as a midwife…	Midwives N=1416[a] (%)*	Clients[b] N=941 (%)*
	Decision making support		
Q22[&]	**Respond to what the client already knows about prenatal screening**	**1232 (91.3)**	**(65.9)**
Q21	**Am interested in who the client is**	**1186 (88.4)**	**(50.6)**
Q11	**Am understanding about clients ideological background or religion**	**1183 (87.6)**	**(32.3)**
Q20	**Ask the client questions that makes her think**	**1168 (86.6)**	**(65.0)**
Q25	**Encourage the client and her partner to talk together about prenatal screening**	**1151 (85.3)**	**(47.0)**
Q55	Ask how the client thinks she will react to the results of the prenatal tests	821 (61.2)	(49.5)
Q14[#]	Enquire clients' standards, values and views on prenatal screening and diagnostic	738 (54.9)	(45.7)
Q49[#]	Talk to the client about how her family and she would react to a child with a birth defect	727 (54.2)	(61.3)
Q50[#]	Ask the client to explain her decision to take / not to take the prenatal tests	624 (46.5)	(51.7)
Q3[@]	Tell which websites the client can use to find information about prenatal screening and diagnostic	617 (45.9)	(37.0)
Q53	Ask whether test results indicating that clients unborn child has a birth defect would cause problems with her conscience	578 (43.2)	(48.2)
Q30[#]	Tell the client what the Dutch government aims to achieve by providing prenatal tests	434 (32.4)	(42.4)
Q52[#]	Ask the client what for her constitutes a healthy child	294 (21.9)	(45.1)
Q9[@&]	Advise the client about whether or not to take the prenatal tests	214 (16.5)	(69.8)
Q54	Ask whether clients family, friends or other people close to her would support her decision to terminate the pregnancy if the child were to have a congenital abnormality	185 (13.8)	(22.0)
Q51	Asks whether clients family, friends or other people close to her would support her decision about prenatal screening	100 (7.5)	(16.2)
	Organizational items		
Q47[#]	Ask the client and her partner to come to the counseling session on prenatal screening TOGETHER	898 (67.0)	(75.5)
Q59	Plan two appointments to discuss prenatal tests (1 to provide the relevant information and 1 to discuss the decision)	328 (24.7)	(33.4)
Q57[#]	Make a separate appointment for the client to discuss prenatal tests (rather than broaching the subject during the first appointment)	258 (19.3)	(21.8)

*Valid percentages.
[a] Sample size varies due to missing data. Missing data were found for 25 items of the PAC questionnaire ranging from 5% to 10%.
[b] Clients: pregnant women and partners.
Bold figures contain items which are either important for ≥ 75% of the midwives, but not for ≥ 75% of the clients or vice versa.
[#] Items which are at least partially interpreted and answered in the context of the limitations of daily practice.
[&] Items that were answered in the context of required prenatal counseling, although limitations of daily practice prevented participant from acting accordingly.
[@] Items with low Item Total Correlation (≤ 0.30).

Midwives´ views on appropriate prenatal counseling and clients' preferences

Table 2 shows that two of the three components of appropriate counseling can be considered as important for most midwives and clients; the *client-midwife relation* (100%^{midwives} and 98%^{clients}) and *health education* (95%^{midwives} and 89%^{clients}). *Decision-making support* is considered important or very important for appropriate counseling by fewer midwives and fewer clients (47%^{midwives} and 39%^{clients}).

At item level, focussing only on items valued as important or very important by ≥75% of the midwives or clients, Tables 3a, 3b and 3c show incongruence of ≥10% between midwives and clients on 13 of the 58 items of the questionnaire in the valuation of aspects of prenatal counseling. Concerning the *client-midwife relation* items Q10 and Q17 were considered important or very important by most midwives but not by most clients with the biggest divergence found for 'Give the client (additional) written information' (Q17: 94%^{midwives} and 60%^{clients}).

Regarding *health education* five items were considered important by most clients but not by most midwives (Q27, Q28, Q33, Q39, Q46, Q56). The biggest divergence was found for 'only discuss specific information about follow-up tests and possible anomalies with the clients if it becomes clear that the client will need them' (Q56: 50%^{midwives} and 75%^{clients}) and 'provide medical information about the anomalies that are being tested for' (Q28: 51%^{midwives} and 76%^{clients}).

As for *decision-making support* five items (Q11, Q20, Q21, Q22, Q25) were considered (very) important by most midwives but not by most clients. The biggest divergence was found for 'Am understanding about clients ideological background or religion' (Q11: 88%^{midwives} and 32%^{clients}) and 'encourage the client and her partner to talk together about prenatal screening' (Q25: 85%^{midwives} and 47%^{clients}). Furthermore, Table 3c shows that, in particular, most midwives value item Q22 'respond to what the client already knows about prenatal screening' (91%^{midwives} and 66%^{clients}) important, whereas most clients value item Q9 'advise the client about whether or not to take the prenatal tests' (17%^{midwives} and 70%^{clients}) important of this component.

DISCUSSION

The first aim of the study was to explore midwives' views on appropriate prenatal counseling for congenital anomaly tests. The second aim was to evaluate whether these views of midwives match clients' preferences regarding prenatal counseling.

The current questionnaire survey suggests that of the participating midwives, although most consider that appropriate counseling includes building a good *client-midwife relation* and giving *health education,* less than half perceived *decision-making support* as an important or very important function of appropriate counseling. Therefore, our findings suggest that more than half of the midwives do not fully subscribe the three function model of prenatal counseling for congenital anomalies as described in the literature.

Comparisons between midwives' views on appropriate prenatal counseling and client preferences show congruence in the importance they assign to the three counseling functions *client-midwife relation, health education* and *decision-making support*. However, results on item-level suggest clinically relevant differences between midwives' views and clients' preferences regarding prenatal counseling for congenital anomaly tests.

Midwives' views on appropriate prenatal counseling

Amongst the *health education* items regarding prenatal counseling for congenital anomaly tests midwives value as most important items about the content and chronology of the Dutch prenatal screening program. The least valued *health education* items could be characterized as either items with the potential to negatively impact on the experience of pregnancy or as risk communication and procedural aspects of prenatal screening tests. An explanation might be that midwives do not want to disturb the feelings of happiness their clients may have about the pregnancy by addressing – during the first contact they have with their clients – the possible unfortunate outcomes of the pregnancy. In addition, midwives, like other prenatal counselors [4], may have problems addressing all *health education* topics that have to be discussed and therefore prefer not to talk about procedural aspects of prenatal congenital anomaly tests; clients can learn about this after they choose to take a prenatal test. Therefore, it may be that this information is seen as less important for achieving informed decision making in clients and thus consistent with appropriate prenatal counseling for congenital anomaly tests.

Concerning *decision-making support,* midwives in this study perceived 'being interested in who the client is' and 'tailoring their counseling to the individual client' as (very) important, but most of them did not perceive questions about social support or pressure as such. In addition, according to almost all participating midwives 'giving advice' seemed inappropriate in the process of prenatal counseling. This may be due their interpretation of non-directive counseling; an approach that is associated with forbearance of giving advice and anything that comes close to that [8]. Dutch midwives are educated according to this non-directive approach and this study shows that they seem to agree with it [7]. An explanation for the apparent contradiction between the relatively high importance midwives assign to 'asking questions that make the client think' and the relatively low importance they assign to the examples of such questions in our questionnaire, could be found in the results of the Cognitive Interviews (CI). The results of the CI show that at least four of the items that could be used to make clients think more deeply about their decision were answered in the context of the limitations of daily practice; i.e. midwives might find these items important but do not use them in practice due to a lack of time and therefore mark them as not important or fairly important completing the questionnaire. In other words, the results regarding *decision-making support* could be an underestimation of the importance midwives attach

to these items in order to reach appropriate prenatal counseling for congenital anomaly tests. Therefore, midwives might benefit from developing communication skills so that they can better explore their clients' wishes and are subsequently better prepared to help clients make decisions even in the context of the limitations of daily practice.

Midwives' views and clients' preferences

Personalized, appropriate prenatal counseling for congenital anomaly tests is only possible if professionals provide counseling which is consistent with the principles of the gold standard of prenatal counseling and also meets the needs of each individual client. Within the perspective of the three function model of prenatal counseling as reflected in the three components of the questionnaire, this study shows high congruence between midwives' views on appropriate counseling and client preferences, but low congruence to the golden standard which includes *decision-making support* as an important aspect of prenatal counseling. Furthermore, there are some important differences on item level between midwives' views and client preferences.

Regarding the *client-midwife relation,* relatively more midwives than clients value 'giving the client (additional) written information'. Knowing the relatively small amount of information people can recall after a health consultation [33] and the need for clients to make an informed decision, to give written information seems reasonable. However, the most important part is that clients actually read this information. If clients do not value written information, it seems unlikely they will read it unless, during the counseling, they are motivated to do so. It might be useful to test whether more clients would highly value written material that was directly referred to during the counseling visit or material that was provided as 'homework' before the actual counseling, especially if during the counseling this information was tailored to the individual client.

A comparison on item-level of midwives' views on prenatal counseling and client preferences regarding the *health education* component items, shows that more clients prefer to get medical, risk and procedural information than midwives in this study seem to perceive to be important for appropriate prenatal counseling. In literature there is no consensus about what information should be given [15] although some guidelines exist [15-18]. These guidelines, however, only partially account for the perspective and preferences of clients; they are based on expert group opinions [15,18]. Midwives in our study did not fully subscribe to the importance of the items that should be addressed during *health education* according to the current guidelines. This study also detected a discrepancy between what midwives think is relevant information to guarantee informed decision-making and what the bigger group of clients perceive as important to make their personal choice to take or refuse congenital anomaly tests. It seems reasonable that client preferences should be addressed, while midwives have also to make clear why the information they share with clients is important

for them to know in the context of the decision about prenatal congenital anomaly tests. The Shared Decision Making model could facilitate this communication, because it structures the discussion about relevant information exchange and makes clear that the role of expert can shift from professional to client and vice versa [13].

Concerning *decision-making support* items, reflecting a genuine interest in the client and stimulating the client to make an informed, autonomous, personal decision about whether to take the prenatal tests or not, seems to be relevant for almost all midwives. None of these topics seems to be relevant to many clients. Furthermore, the important topic for most clients, 'getting advice whether to take prenatal tests or not' is not seen as important by most midwives. These results seem to reflect that midwives are willing to help their clients in making their decision, using counseling techniques such as asking exploring questions that make clients really think about the decision they face. Clients, conversely, appear to want at least a more clearly focused discussion about what to do. The Shared Decision Making model could serve as a bridge between both midwife and client expectations for *decision-making support*, including the notion that it is the client that has to make the ultimate decision about whether to take or refuse prenatal congenital anomaly tests; at least in Dutch society. Therefore, like other researchers, we emphasize the importance of flexibility in the way prenatal counselors structure the decision-making process so that individual differences in client preferences can be respected while incorporating the goals of prenatal counseling, prenatal testing and who the expert is in the area at hand [8,32,34,35]. As many parents prefer to make their informed choices about prenatal tests together, it is easy to understand why clients value the opportunity for joint counseling. So, although, one third of the midwives do not value having partners invited to attend the prenatal counseling for congenital anomaly tests, we suggest that they should invite them explicitly.

The counseling role is a recent one for Dutch midwives. Counseling for prenatal congenital anomaly tests is one example of the counseling topics midwives have to address in the context of the increasing medicalization of pregnancy and childbearing and the resulting preference sensitive decisions that have to be made [27,36]. From the perspective of the unique history of Dutch midwifery, characterized by a minimal use of medical interventions, the client's views on specific medical advice on these prenatal tests are highly relevant, and might signal a historical shift in expectations of the role of midwives in the more and more medicalised pregnancy and birth process. The shared decision making (SDM) approach could be seen as an answer to this shift towards more clients involvement in decision-making. This approach is recently found to be worthwhile in view of other obstetric decisions such as the decision about birth position [37]. The SDM model would move midwives from a health care provider-centered approach in which the midwife sets the agenda and makes the decisions to a model wherein midwives and clients work together towards personalised care and decision-making. Although the SDM model is being advocated as the solution for strengthening the patient's

role, it remains challenging to accomplish this in every day practice, because of the many other demands good practice make on the provider-patient interaction [38,39]. Nevertheless seems the SDM model promising in addressing clients' expectations for the role of midwives.

Strengths and limitations

To our knowledge, this is the largest nationally representative study of midwives' views on appropriate prenatal counseling for congenital anomaly tests. The response rate of participating midwives was relatively high (62%). Since our sample was heterogeneous in terms of age, years of experience and religious background, the findings can be generalized to the wider population of Dutch midwives. The proportion of midwives younger than 40 years in our population (60%) was similar to this proportion in Dutch midwifery population (63%) and the proportion of male midwives was the same in our population compared to the general midwifery population (1.7% versus 1.6% respectively).

The internal consistency of the midwives'-version QUOTE ^{prenatal} questionnaire was good, based on the Cronbach's alphas we found in this study. ITC of three items were too low (Q3, Q9 and Q56). If we had removed these items from analyses on component level, the overall importance midwives attach to the corresponding prenatal counseling functions (i.e. *health education* and *decision-making support*) would be higher, because midwives address relatively low importance to these aspects of the counseling functions. Consequently, the congruence between midwives' views and the three function model of prenatal counseling as described in literature would have been better than is reflected in the results of this study. Midwives were asked to rate the items of the questionnaire as if working in an ideal world without problems such as a lack of time or knowledge. However, the results of the Cognitive Interviews suggested that although midwives were asked to refer to their ideal practice, daily practice have also been influencing their answers. Therefore, the findings of this study have to be seen in the light of the possibly undesirable impact of clinical midwifery practice on the reported views on appropriate prenatal counseling.

The midwives' version of the QUOTE ^{prenatal} questionnaire could be used in future research, keeping in mind the limitations we mentioned. Further research of our research group will be done to investigate to what extent views on appropriate prenatal counseling for congenital anomaly tests actually influence this counseling in daily practice. Such data will potentially provide insight into aspects that contribute to the performance of counselors in clinical practice.

Key Conclusion

Midwives in our study do not all subscribe fully to the three function model of prenatal counseling for congenital anomaly test. Like clients, almost every midwife looks upon counseling as consisting of building a good *client-midwife relation* and providing *health*

education. Almost half of the participating midwives perceive *decision-making support* as a (very) important function of appropriate prenatal counseling. This focus on giving information may inhibit midwives in daily practice from establishing a real dialogue during prenatal counseling. Consequently, it may cause difficulties in adapting prenatal counseling to individual client preferences- which midwives consider to be important- because engaging in dialogue is required to get to appreciate individual preferences. It may also cause problems in reaching the prenatal counseling goal (informed, autonomous decision making by clients) for which the three functions of prenatal counseling are required.

Implication for practice

Midwives and other professionals who provide prenatal counseling should discuss their attitude towards their role as prenatal counselor with clients in order to ensure that client preferences may be met in conformity with professional standards. Literature based guidelines, professional expertise and client preferences all together determine appropriate, client specific prenatal counseling. The Shared Decision Making model may be useful in establishing a dialogue with clients (women and partners) in order to cope with incongruences between midwives' views on appropriate counseling and client preferences, especially regarding the *health education* and *decision-making support* functions of counseling.

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APPENDIX A Dutch setting

Since 2007 prenatal screening is offered to all Dutch pregnant women using an opt-in approach [16,40,41]. The screening program includes two non-invasive tests: the combined test (CT) a risk assessment for Down-, Patau- and Edwards syndrome (around 12th weeks gestational age), and the Fetal Anomaly ultrasound Scan (FAS) for detecting physical anomalies (around 20th weeks gestational age). The FAS is free for all women, the CT has to be paid for by women younger than 36 years of age [40,41]. Mean uptake of the FAS in the Netherlands in 2011 was around 92% and the uptake for the CT is about 30% for women younger than 30 years of age and 59% for women older than 36 years of age. Invasive tests are offered on indication (e.g. maternal age ≥ 36 years of age, family history) [42].