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## Midwives' views on appropriate antenatal counselling 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 antenatal counselling for congenital anomaly tests, and (b) whether these views match clients' preferences regarding antenatal counselling.

**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 antenatal counselling for congenital anomaly tests.

**Measurements:** we used the 58-item midwives' version of the QUOTE<sup>prenatal</sup>, an instrument to assess clients' counselling preferences. Descriptive statistics were used to explore midwives' views on appropriate counselling and how these relate to client preferences as measured previously with the clients' version of the QUOTE<sup>prenatal</sup>.

**Findings:** almost all midwives consider the *client–midwife relation* (100%) and *health education* (95%) to be (very) important for appropriate antenatal counselling 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 antenatal counselling 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 antenatal counselling for congenital anomaly tests.

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

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### Introduction

Medical and policy developments in antenatal screening and diagnostic testing have led to a rapid increase in the number of congenital anomalies for which testing is available (Jakobsen et al., 2011; Tischler et al., 2011). The amount of information about testing that is communicated to clients has increased and seems difficult to manage for both counsellors and clients (Shiloh et al., 2006;

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Yu, 2012). In the Netherlands, antenatal screening of congenital anomalies has been available since 2007. Primary care midwives are the designated counsellor in 80% of the pregnancies (Wiegers 2009; National Institute for Public Health and Environment, 2011). They are trained to offer antenatal counselling to help clients understand information about congenital anomaly tests and to help clients in making autonomous, informed decisions (SSOV et al., 2007; van Zwieten, 2008).

Appropriate counselling usually serves the two functions *teaching* and *counselling*, embedded within a non-directive approach (Roter et al., 2006; Pirzadeh et al., 2007; Meiser et al., 2008). In the context of antenatal counselling, these counselling functions are referred to as *health education* and *decision-making support* (Martin et al., 2013). An important third function, i.e. maintaining a *patient-provider relationship*, is considered to be a prerequisite for enabling these two counselling functions (Elwyn, 2004; Smets et al., 2007).

While providing *health education*, midwives enhance clients' knowledge by giving medical information about topics such as the antenatal 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 antenatal screening (van Agt et al., 2007; KNOV, 2010; Schoonen et al., 2011a, 2011b). During *decision-making support* counsellors help clients in making autonomous, informed decisions by for instance discussing diverse scenario's and putting moral issues on the agenda (O'Connor et al., 2003; van Zwieten, 2008). A good *client-counsellor relation* can be established by showing empathy and unconditional support regardless of the decision a client makes about taking or refusing a antenatal test or by terminating or continuing a pregnancy (Mearns and Thorne, 1999; Smets et al., 2007).

Clients differ in the value they attach to the three functions of the antenatal counselling model, including the non-directive approach. Most Dutch clients do value the *client-midwife relation* and *health education* as important functions of antenatal counselling. 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' (Martin et al., 2013). So, for the majority of clients, the three function antenatal counselling 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 personalised approach to counselling 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 (Martin et al., 2013). These findings are consistent with client preferences for personalised health care in general and antenatal care in particular (de Boer and Zeeman, 2008; Kramer, 2011; Rademakers et al., 2011; Mazzi et al., 2012).

There has been little investigation of the views of counsellors regarding the three-function model of antenatal counselling, including the non-directive approach. Roter et al. (2006) describes some scepticism regarding the desire of genetic counsellors to fully address the decision-making support function of counselling. The study of Sheets et al. (2011) illustrates that genetic counsellors and parents differ in the importance they attach to different aspects of information (or health education) about having a child with Down's syndrome. In the context of end of life counselling health care providers seem to be reluctant to offer advice about treatment options even when patients specifically asked for it (Corke et al., 2004). Understanding counsellors' views on appropriate counselling is important. If counsellors do not endorse all three functions of the antenatal counselling model, the provision of appropriate, personalised antenatal counselling may be at risk.

This paper aims to describe midwives' views on appropriate antenatal counselling for congenital anomaly tests focussing on the three functions of the antenatal counselling model, *health education*, *decision-making support* and the *client-midwife relation* and to compare midwives' views to previous findings on clients' preferences (Martin et al., 2013). The following research questions are addressed: (a) what are midwives' views on appropriate antenatal counselling for congenital anomaly tests, and (b) do these views match clients' preferences regarding antenatal counselling?

It was hypothesised 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 (van Agt et al., 2007; KNOV, 2010; Schoonen et al., 2011a, 2011b). Midwives are also most familiar with the role of *health educator* as the role of counsellor has been relatively recently (2005) introduced in the midwifery profession as well as in the antenatal screening program in the Netherlands (2007) (Liefhebber et al., 2005; National Institute for Public Health and Environment, 2011) (For more information about the Dutch setting see Appendix A).

## Methods

This study is part of the DELIVER study, a multi-centre national research program to evaluate the quality and provision of primary midwifery care in the Netherlands (Mannien et al., 2012).

The design of the current cross-sectional cohort 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 (Hingstman and Kenens, 2011).

#### Clients

In the current study we used data from our cross-sectional cohort study about parental preferences and experiences regarding antenatal counselling for congenital anomaly tests by midwives (Martin et al., 2013) 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 antenatal counselling function as important or very important. *Decision-making support* was valued important or very important by one third of the women and their partners (Martin et al., 2013). As 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 <sup>prenatal</sup> questionnaire

The questionnaire used to measure midwives' views on appropriate antenatal counselling for congenital anomaly tests mirrored the 58-item QUOTE <sup>prenatal</sup> questionnaire (Quality of care through the patients' eyes), that we developed to assess clients' preferences and experiences regarding this type of antenatal counselling. Used among parents, the QUOTE <sup>prenatal</sup> questionnaire showed high levels of internal consistency measured with Cronbach's alpha (Martin et al., 2013). We used the same items of the QUOTE <sup>prenatal</sup> in this study, but rephrased them in order to change the focus to midwives' views on appropriate antenatal counselling (see Tables 3a–3c for the resulting midwives'-version QUOTE <sup>prenatal</sup> questionnaire).

The questionnaire contains *generic* communication items and *specific* items about antenatal counselling for congenital anomaly tests (Martin et al., 2013). The three functions of antenatal counselling were addressed in the three components of the QUOTE <sup>prenatal</sup> 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) (Tables 2 and 3a–3c). The remaining three items covered statements about organisational aspects of antenatal counselling, such as number of consultations used for pre-test counselling. The items of the questionnaire were formulated as *importance* statements ('As a midwife I perceive as important for prenatal counselling, 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 client 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 (Field, 2009). 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 <sup>prenatal</sup> as much as possible.

We undertook internal validation of the findings of the questionnaire using Cognitive Interviews (CI) ( $n=8$ ) (Willis, 2005). 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 antenatal counselling 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 counselling without letting practical limitations disturb their ratings. Still, 15 items were partially interpreted and answered while taking into account the limitations of daily practice (Table 3a–3c items marked with ‡).

### Procedures

Questionnaires were sent to the home address of midwife participants in order to minimise 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 counselling

In line with our earlier study using the QUOTE <sup>prenatal</sup> methodology (Martin et al., 2013) importance scores on the three components of the questionnaire were used to rate views on aspects of appropriate counselling. 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  $\geq 2.50$ ).

### Midwives' views on appropriate antenatal counselling and clients' preferences

Midwives' views on aspects of appropriate antenatal counselling for congenital anomaly tests were compared to clients' preferences regarding antenatal counselling as reported in our previous paper (Martin et al., 2013). 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 counselling, 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 counselling 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 11.5 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  $\leq 5\%$  for each of the items of the questionnaire, missing values were not replaced.

### Midwives' views on appropriate counselling

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

**Table 1**  
Demographic characteristics of the test sample midwives ( $n=1416$ ) and of the Dutch midwifery population ( $n=2612$ ).

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

\* Hingstman and Kenens (2011).

**Table 2**  
Components of the questionnaire and the content. Column three and four:  $n$  midwives=1416\* and  $n$  clients (women and partners)=941.

Component	Content of the component	Midwives considering components as (very) important for antenatal counselling (score $\geq 2.5$ )		Clients (women and partners) rating items as (very) important pre-visit (score $\geq 2.5$ ) (%)†
		$n$	(%)†	
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%)	97.9
Health education	Medical test information, (test) procedural information, risk information, societal information (e.g. costs of antenatal tests, eligibility for tests)	1154	(95.4%)	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%)	38.5

\* 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*.

† Valid percentages.

Looking at item level, Tables 3a–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 counselling 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) (Tables 3b and 3c). 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’ (Q35) 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 ‘Be 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 organisational items of antenatal counselling none of the items were interpreted as important for appropriate counselling by more than 75% of the participants. Most midwives value asking the client to come together with their partner to the antenatal counselling as important or very important (67%) and scheduling a separate appointment for counselling was least valued (19%).

#### Midwives’ views on appropriate antenatal counselling and clients’ preferences

Table 2 shows that two of the three components of appropriate counselling can be considered as important for most midwives and

**Table 3a**

Items of the component reflecting the counselling function *client–midwife relation*. Ratings of midwives ( $n=1416$ ) versus ratings of clients (women and partners:  $n=941$ ) on the QUOTE prenatal.

Number	Item description: For me it is important that I as a midwife...	Midwives considering items as important for appropriate counselling (score 3–4)		Clients (women and partners) rating items as (very) important pre-visit (score 3–4) (%) <sup>†</sup>
		n	(%) <sup>†</sup>	
	<i>Client–midwife relation</i>			
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 <sup>‡</sup> –§	Take plenty of time to answer clients questions	1342	(99.6%)	98.3
Q5 <sup>§</sup>	Take clients concerns seriously	1343	(99.5%)	98.9
Q19	Accept clients' decisions on whether or not to agree to antenatal screening	1321	(98.1%)	87.9
Q15 <sup>§</sup>	Make clear that my client can ask anything she wants to know	1320	(97.8%)	92.5
Q23 <sup>‡</sup>	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 <sup>‡</sup> –§	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 <sup>§</sup>	Give my client the feeling that she is tuning in to me as a person	1254	(92.8%)	82.8
Q18 <sup>‡</sup>	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

Grey field contain items which are either important for  $\geq 75\%$  of the midwives, but not for  $\geq 75\%$  of the clients or vice versa.

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

<sup>†</sup> Valid percentages.

<sup>‡</sup> Items that were at least partially interpreted and answered in the context of the limitations of daily practice.

<sup>§</sup> Items that were answered in the context of required antenatal counselling, although limitations of daily practice prevented participant from acting accordingly.

clients: the *client–midwife relation* (100%<sup>midwives</sup> and 98%<sup>clients</sup>) and *health education* (95%<sup>midwives</sup> and 89%<sup>clients</sup>). *Decision-making support* is considered important or very important for appropriate counselling by fewer midwives and fewer clients (47%<sup>midwives</sup> and 39%<sup>clients</sup>).

At item level, focussing only on items valued as important or very important by  $\geq 75\%$  of the midwives or clients, Tables 3a–3c show incongruence of  $\geq 10\%$  between midwives and clients on 13 of the 58 items of the questionnaire in the valuation of aspects of antenatal counselling. 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%<sup>midwives</sup> and 60%<sup>clients</sup>).

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%<sup>midwives</sup> and 75%<sup>clients</sup>) and 'provide medical information about the anomalies that are being tested for' (Q28: 51%<sup>midwives</sup> and 76%<sup>clients</sup>).

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 'Be understanding about clients ideological background or religion' (Q11: 88%<sup>midwives</sup> and 32%<sup>clients</sup>) and 'encourage the client and her partner to talk together about prenatal screening' (Q25: 85%<sup>midwives</sup> and 47%<sup>clients</sup>). Furthermore, Table 3c shows that, in particular, most midwives value item Q22 'respond to what the client already knows about prenatal screening' (91%<sup>midwives</sup> and 66%<sup>clients</sup>) important, whereas most clients value item Q9 'advise the client about whether or not to take the prenatal tests' (17%<sup>midwives</sup> and 70%<sup>clients</sup>) important of this component.

## Discussion

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

The current questionnaire survey suggests that of the participating midwives although most consider that appropriate counselling 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 counselling. Therefore, our findings suggest that more than half of the midwives do not fully subscribe the three function model of antenatal counselling for congenital anomalies as described in the literature.

Comparisons between midwives' views on appropriate antenatal counselling and client preferences show congruence in the importance they assign to the three counselling 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 antenatal counselling for congenital anomaly tests.

### Midwives' views on appropriate antenatal counselling

Amongst the *health education* items regarding antenatal counselling for congenital anomaly tests midwives value as most important items about the content and chronology of the Dutch antenatal screening program. The least valued *health education* items could be characterised as either items with the potential to negatively impact on the experience of pregnancy or as risk communication and procedural aspects of antenatal screening tests. An explanation might be that midwives do not want to disturb the feelings of

**Table 3b**

Items of the component reflecting the counselling function *health education*. Ratings of midwives ( $n=1416^*$ ) versus ratings of clients (women and partners:  $n=941$ ) on the QUOTE prenatal.

Number	Item description: For me it is important that I as a midwife...	Midwives considering items as important for appropriate counselling (score 3–4)		Clients (women and partners) rating items as (very) important pre-visit (score 3–4) (%) <sup>†</sup>
		n	(%) <sup>†</sup>	
<i>Health education</i>				
Q31 <sup>§</sup>	Explain the usefulness of antenatal screening (what the client can decide to do eventually)	1320	(98.1%)	90.0
Q32 <sup>‡</sup>	Tell the client about all the different types of antenatal tests	1318	(98.0%)	86.8
Q13	Impart information on antenatal testing	1310	(97.8%)	88.2
Q26 <sup>§</sup>	Explain which anomalies can be identified using antenatal 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 antenatal 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 antenatal tests	1271	(94.5%)	81.0
Q48 <sup>‡</sup>	Discuss all clients options with regard to antenatal screening and the implications	1206	(90.1%)	82.3
Q29 <sup>§</sup>	Discuss possible negative implications of antenatal 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 <sup>§</sup>	Tell the client how antenatal screening can affect her emotions and mental well-being	1181	(87.9%)	74.9
Q41	Tell the client why she is or is not eligible for certain antenatal tests	1164	(86.7%)	82.4
Q42	Explain what will happen DURING the antenatal tests	1120	(83.5%)	87.0
Q27 <sup>‡</sup>	Explain which anomalies <i>cannot</i> be identified using antenatal 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 antenatal 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 abnormality	933	(69.5%)	81.8
Q34 <sup>§</sup>	Tell the client how much antenatal tests cost	890	(66.1%)	55.9
Q38 <sup>‡</sup>	Explain how the chances of a birth defect are calculated for our 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 <sup>‡</sup>	Only discuss specific information about follow-up tests and possible anomalies with the client if it becomes clear that the client will need them	640	(50.4%)	75.1
Q35	Tell the client about the incidence of birth defects in the Netherlands	550	(41.0%)	54.4

Grey field contain items which are either important for  $\geq 75\%$  of the midwives, but not for  $\geq 75\%$  of the clients or vice versa.

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

<sup>†</sup> Valid percentages.

<sup>‡</sup> Items which are at least partially interpreted and answered in the context of the limitations of daily practice.

<sup>§</sup> Items that were answered in the context of required antenatal counselling, although limitations of daily practice prevented participant from acting accordingly.

<sup>¶</sup> Items with low Item Total Correlation ( $\leq 0.30$ ).

happiness of 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 antenatal counsellors (Yu, 2012), may have problems addressing all *health education* topics that have to be discussed and therefore prefer not to talk about procedural aspects of antenatal congenital anomaly tests; clients can learn about this after they choose to take a antenatal 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 antenatal counselling for congenital anomaly tests.

Concerning *decision-making support*, midwives in this study perceived 'being interested in who the client is' and 'tailoring their counselling 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 antenatal counselling. This may be due their interpretation of non-directive counselling, an approach that is associated with forbearance of giving advice and anything that comes close to that (van Zwieten, 2008). Dutch midwives are educated according to this non-directive approach and this study shows that they seem to

**Table 3c**

Items of the component reflecting the counselling function *decision-making support*. Ratings of midwives ( $n=1416^*$ ) versus ratings of clients (women and partners:  $n=941$ ) on the QUOTE prenatal.

Number	Item description: For me it is important that I as a midwife...	Midwives considering items as important for appropriate counselling (score 3–4)		Clients (women and partners) rating items as (very) important pre-visit (score 3–4) (%) <sup>†</sup>
		n	(%) <sup>†</sup>	
<i>Decision making support</i>				
Q22 <sup>§</sup>	Respond to what the client already knows about antenatal 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 antenatal screening	1151	(85.3%)	47.0
Q55	Ask how the client thinks she will react to the results of the antenatal tests	821	(61.2%)	49.5
Q14 <sup>‡</sup>	Enquire clients' standards, values and views on antenatal screening and diagnostic	738	(54.9%)	45.7
Q49 <sup>‡</sup>	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 <sup>‡</sup>	Ask the client to explain her decision to take/not to take the antenatal tests	624	(46.5%)	51.7
Q3 <sup>¶</sup>	Tell which websites the client can use to find information about antenatal 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 <sup>‡</sup>	Tell the client what the Dutch government aims to achieve by providing antenatal tests	434	(32.4%)	42.4
Q52 <sup>‡</sup>	Ask the client what for her constitutes a healthy child	294	(21.9%)	45.1
Q92; <sup>¶,§</sup>	Advise the client about whether or not to take the antenatal 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 antenatal screening	100	(7.5%)	16.2
<i>Organisational items</i>				
Q47 <sup>‡</sup>	Ask the client and her partner to come to the counselling session on antenatal screening TOGETHER	898	(67.0%)	75.5
Q59	Plan two appointments to discuss antenatal tests (one to provide the relevant information and one to discuss the decision)	328	(24.7%)	33.4
Q57 <sup>‡</sup>	Make a separate appointment for the client to discuss antenatal tests (rather than broaching the subject during my first appointment)	258	(19.3%)	21.8

Grey field contain items which are either important for  $\geq 75\%$  of the midwives, but not for  $\geq 75\%$  of the clients or vice versa.

\* Sample size varies due to missing data. Missing data were found for 25 items of the PAC questionnaire ranging from 5% to 10%.

<sup>†</sup> Valid percentages.

<sup>‡</sup> Items which are at least partially interpreted and answered in the context of the limitations of daily practice.

<sup>§</sup> Items that were answered in the context of required antenatal counselling, although limitations of daily practice prevented participant from acting accordingly.

<sup>¶</sup> Items with low Item Total Correlation ( $\leq 0.30$ ).

agree with it (SSOV et al., 2007). 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 antenatal counselling for congenital anomaly tests. Therefore, midwives need to develop 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*

Personalised, appropriate antenatal counselling for congenital anomaly tests is only possible if professionals provide counselling which is consistent with the principles of the gold standard of antenatal counselling and also meets the needs of each individual

client. Within the perspective of the three function model of antenatal counselling as reflected in the three components of the questionnaire, this study shows high congruence between midwives views on appropriate counselling and client preferences, but low congruence to the golden standard which includes *decision-making support* as an important aspect of antenatal counselling. 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 (Jansen et al., 2008) 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 counselling, 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 counselling visit or material that was provided as 'homework' before the actual counselling, especially if during the counselling this information was tailored to the individual client.

A comparison on item-level of midwives' views on antenatal counselling 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 antenatal counselling. In literature there is no consensus about what information should be given (Schoonen et al., 2011a) although some guidelines exist (van Agt et al., 2007; KNOV, 2010; Schoonen et al., 2011a, 2011b). These guidelines, however, only partially account for the perspective and preferences of clients; they are based on expert group opinions (Schoonen et al. 2011a, 2011b). 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 antenatal 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 (Elwyn, 2004).

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 antenatal 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 counselling 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 antenatal congenital anomaly tests, at least in Dutch society. Therefore, like other researchers, we emphasise the importance of flexibility in the way antenatal counsellors structure

the decision-making process so that individual differences in client preferences can be respected while incorporating the goals of antenatal counselling, antenatal testing and who the expert is in the area at hand (Charles et al., 1999; van Zwieten et al., 2006; van Zwieten, 2008; Durand et al., 2010). As many parents prefer to make their informed choices about antenatal tests together, and also have to live with their choices together, it is easy to understand why clients value the opportunity for joint counselling. So, although, one third of the midwives do not value having partners invited to attend the antenatal counselling for congenital anomaly tests, we suggest that they should invite them explicitly.

The counselling role is a recent one for Dutch midwives. Counselling for antenatal congenital anomaly tests is one example of the counselling topics midwives have to address in the context of the increasing medicalisation of pregnancy and childbearing and the resulting preference sensitive decisions that have to be made (Liefhebber et al., 2005; Christiaens et al., 2013). From the perspective of the unique history of Dutch midwifery, characterised by a minimal use of medical interventions, the client's views on specific medical advice on these antenatal 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 (Nieuwenhuijze et al., 2013). 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 (van den Brink-Muinen et al., 2006; Elwyn et al., 2012). Nevertheless it seems that the SDM model is 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 antenatal counselling for congenital anomaly tests. The response rate of participating midwives was relatively high (62%). As our sample was heterogeneous in terms of age, years of experience and religious background, the findings can be generalised to the wider population of 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<sup>prenatal</sup> 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 antenatal counselling functions (i.e. *health education* and *decision-making support*) would be higher, because midwives address relatively low importance to these aspects of the counselling functions. Consequently, the congruence between midwives views and the three function model of antenatal counselling 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 antenatal counselling.

The midwives' version of the QUOTE<sup>prenatal</sup> 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 antenatal counselling for congenital anomaly tests actually influence this counselling in daily practice. Such data will potentially provide insight into aspects that contribute to the performance of counsellors in clinical practice.

### Key conclusion

Midwives in our study do not all subscribe fully to the three function model of antenatal counselling for congenital anomaly test. Like clients, almost every midwife looks upon counselling 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 antenatal counselling. This focus on giving information may inhibit midwives in daily practice from establishing a real dialogue during antenatal counselling. Consequently, it may cause difficulties in adapting antenatal counselling 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 antenatal counselling goal (informed, autonomous decision making by clients) for which the three functions of antenatal counselling are required.

### Implication for practice

Midwives and other professionals who provide antenatal counselling should discuss their attitude towards their role as antenatal counsellor 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 antenatal counselling. 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 counselling and client preferences, especially regarding the health education and decision-making support functions of counselling.

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### Appendix A

*Dutch Setting:* Since 2007 antenatal screening is offered to all Dutch pregnant women using an opting in approach (van Agt et al., 2007; Health Council, 2007; Oepkes and Wieringa, 2008). The screening program includes two non-invasive tests: the combined test (CT) for determining the possibility of Down (around 12th week

of gestational age) and the second trimester ultrasound (STU) for detecting physical anomalies (around 20th week of gestational age). The STU is free for all women, the CT has to be paid for by women younger than 36 years of age (Health Council, 2007; Oepkes and Wieringa, 2008). Mean uptake of the STU 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  $\geq$  36 years of age, family history) (Fracheboud et al., 2012).

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