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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 (Wiegens 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; Pirezadeh 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.

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