



## Midwives' perceptions of their role as facilitators of informed choice in antenatal screening<sup>☆</sup>

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### ABSTRACT

**Objective:** to explore midwives' perceptions of their role as facilitators of informed choice in antenatal screening.

**Design:** qualitative.

**Setting:** community midwives, Yorkshire and Humber region, UK.

**Participants:** community midwives offering antenatal screening ( $n=15$ ).

**Method:** semi-structured interviews analysed using Thematic Analysis.

**Findings:** to facilitate informed choice, midwives highlighted both the importance and challenges of engaging in discussion with women, remaining non-directive, within tight timeframes, sometimes with women unable to communicate in English or with complex social needs.

**Conclusion:** midwives varied in the degree to which they believed it was their role to (1) discuss rather than just provide information and (2) to check women's understanding of the information provided. Midwives were concerned about the constraints imposed by first trimester combined screening in terms of the limited time in which they had to facilitate informed choice and the women had to make a decision about screening. To ensure that women understand the options available to them and are able to exercise an informed choice, clinical guidelines are needed that set out *how* midwives can actively facilitate informed screening choices without compromising patient autonomy. This is especially important given the small 'window of opportunity' within which combined first trimester screening is a viable option.

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### Introduction

Prenatal screening is now available in many countries, where patient autonomy is a high priority for policy developers (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2007; EUROCAT Central Registry, 2010; Provincial Health Services Authority, 2010), and informed choice is recognised and accepted as an important aspect of ethical healthcare (World Health Organization, 2006; National Screening Committee, 2011). In the context of antenatal screening, informed choice is characterised as a right to make an uncoerced and informed decision (Beauchamp and Childress, 2001). In practice, and in accordance with guidelines on antenatal screening (NICE, 2010), this means that the role of health professionals is to provide

balanced information in a non-directive way to enable pregnant women to make choices about antenatal screening independently.

The literature suggests that in order to make an informed choice individuals need to deliberate about relevant information by evaluating the 'advantages and disadvantages of all the possible courses of action, in accordance with their beliefs' (Bekker, 2003). It is acknowledged that making independent decisions in this way about antenatal screening can be difficult for women, that they need support to do so (Green et al., 2004; Legare et al., 2006; Ahmed et al., 2012), and that autonomous informed choices can be enhanced by the contribution and active support of well-informed health professionals (Quill and Brody, 1996).

The UK National Screening Committee (NSC) Consent Guidelines for the National Health Service Fetal Anomaly Screening Programme (National Screening Committee, 2011) (NHS FASP) state that 'Facilitating informed choice and obtaining informed consent are essential aspects of the screening process' and 'to do so is a professional obligation'. The guidelines clarify that facilitating the 'choice and consent process' means providing women with up-to-date information developed by the UK NSC and NHS

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FASP, including 'options available along the screening and testing pathway', and discussing 'decisions that might need to be made at each point along the pathway and their consequences', including the 'possible meaning and implication of the test results' (p. 5). The NHS FASP guidelines also state that health professionals are responsible for checking that this information has been understood by the woman and ensuring that they have had time to consider the information before making a decision. They are required to record the offer of screening and the woman's decision in her notes and/or hospital IT system. These latest guidelines are clear on what is required to obtain consent to screening and they also go some way to enabling health professionals to facilitate informed choice, that is, by providing and discussing information and giving women time to make a decision. However, there are no guidelines for health professionals on *how* to facilitate informed choice—*how* to explain the screening pathway, the decision points on this pathway and their consequences, *how* to check that the woman has understood the information, and *how* to help women who experience difficulties in making a decision.

All pregnant women in England and Wales are routinely offered antenatal screening for Down's syndrome. Current NSC policy is to offer the combined test (nuchal translucency measurement plus serum screening of beta-human chorionic gonadotrophin and pregnancy-associated plasma protein-A) between 11 weeks 0 day and 13 weeks 6 days. Women presenting later in pregnancy or declining first trimester screening are offered second trimester serum screening (the quadruple test) between 15 weeks 0 day and 20 weeks 0 day. Previous research shows that women have different expectations about the involvement of health professionals in facilitating 'informed choice'; from being simply providers of information to directing them to which option to choose (Ahmed et al., 2012). While the latter expectation is one that cannot be met within current UK antenatal screening policy, many women say they would still welcome 'advice' at some level. This does not appear to be in conflict with their belief that the final decision is only theirs to make (Ahmed et al., 2012). This desire for advice may present a challenge for midwives who work within a policy framework requiring non-directiveness, and are aware that they should not be influencing women's decision or 'swaying' them in any direction (Williams et al., 2002; Farsides et al., 2004). Nevertheless, research on women's perspectives and antenatal screening guidelines recognise the importance of the active role of health professionals in facilitating informed choices. There is little research on whether and how midwives deal with or negotiate women's needs for advice in practice. Therefore, this study aimed to explore midwives' perceptions of their role as 'facilitators' of informed antenatal screening choices and perceptions of providing advice.

## Method

### Participants

The study included 15 midwives with experience of offering antenatal screening, from midwifery services in the NHS Yorkshire and the Humber region. An email was sent to all midwives in the recruitment area, via the Community Midwifery Team Leader, informing and inviting them to participate in the study. In addition, participants were purposively selected from practices representing a range of socio-economic situations, from deprived through to more affluent areas. We also sought to recruit midwives who worked with caseloads who we considered may have particular difficulties with informed choice, for example, teenage mothers, refugees and asylum seekers, and women with mental health problems. Participants' ages ranged 39–53 years, and the

time in which they had been practicing midwifery ranged 11–31 years; all were British White.

### Procedure

The study was given ethical approval by the Proportionate Review Sub-committee of the Newcastle & North Tyneside Research Ethics Committee. Semi-structured interviews were conducted during July–November 2011 by all three authors at the participants' workplace or home. All interviews were audio recorded and transcribed verbatim by a member of (SA's) administrative support team.

### Analysis

All transcripts were organised and coded using N-Vivo 9 and analysed using Thematic Analysis (Braun and Clarke, 2006). A hierarchical thematic framework was developed and used to classify and organise data according to key themes, concepts and emergent categories. Key themes relating to midwives' perceptions of giving advice, their role in decision-making, and challenges in facilitating informed choice were developed both from the research questions and from the narratives of research participants. Data analysis also involved consistent cross-referencing between the participants for similarities and difference between them. All data were analysed by the same experienced qualitative researcher (SA), who discussed the coding framework and themes with (LDB and PC) to ensure consistency in interpretation of the data. All names used from here on are pseudonyms.

### Findings

#### *Facilitating informed choice through discussion and checking the woman's understandings*

Midwives believed their main role as facilitators of informed choice was to provide information about antenatal screening. Many also believed that it was important to discuss this information:

MW1: Primarily, I see myself as information giver and discussor. ...giving women the opportunity to ask questions, think about which kind of path to take...

These midwives believed that women's choices should be based on an understanding of the different options available and the implications of each of these for them and their families. Therefore, to enable women to think about the antenatal screening information and to draw on their own values, they believed it was important to explain and discuss these options:

MW1: I need to know that they know what the result would mean to them... I try and give them all the options and sort of lay it out, almost like a menu.

MW3: I make them ...consider if it came back high risk, 'What would you do... if you got that information, would you be prepared to go on to the next step?' ...they do then make their own decision.

Nevertheless, midwives discussed the options on the screening pathway with women in different ways. Some midwives took women through the antenatal screening pathway sequentially, while others said they started by asking women about their attitude towards termination of pregnancy:

MW8: ...the question is 'at the end of the day, if you knew for sure that you were having a baby with Down's Syndrome, would you carry on with the pregnancy or not?' ... I give them freedom to not have to explain it to me, but just to recognise that that needs to be part of their thinking.

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