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Midwives' perceptions of their role as facilitators of informed choice in antenatal screening[☆]

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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.

Midwives also believed that it was important not to assume that a woman accepting or declining all available screening tests was making an informed choice:

MW2: ...it's like a tick box to them 'oh we'll just find out everything's okay', and they need to realise what they're entering into.

Midwives said they would engage in discussion about screening with women to ensure that they understood the implication of their choice. These midwives recognised the need for a non-judgemental approach:

MW1: ...when they come in saying 'Yes, I'll have everything', you thinking 'Do you really know what you're taking on'... even the ones who say 'I don't want anything done', I still like to feed a bit more information into that... supportive without trying to sway them one way or the other, but just for my own peace of mind knowing that they know what they're either accepting or turning down.

Midwives also talked about getting the balance right and being sensitive when questioning women about their decision to decline antenatal screening, because too much probing could be perceived by women as directive:

MW8: I would think we were doing them a disservice if we didn't explore reasons for saying 'no'. I just have to be quite sensitive.

MW10: I wouldn't want to make that woman feel pressured... it's just for me to ensure that she has made an informed choice.

While many of the midwives believed it was important to discuss information, others believed that it was important to provide 'the facts' only in the form of information and not to engage in discussion. These midwives believed that an informed choice was one made by women based on information alone and that discussion about the woman's decision could be perceived as directive, particularly when they declined screening:

MW5: I can honestly say I give them the facts and I don't get into any more than that. ...it's up to the individual what they do with (the information). ...If you've made your decision... why would somebody then try to change your mind?

MW12: I'm not there to question their decision-making.

Perceptions of giving advice

Many midwives had experienced women asking them for their advice about antenatal screening, particularly first-time mothers, who were described as often being unaware of the need to make such a decision until the subject was raised by the midwife:

MW3: ...first time mums, some have never even considered Down's syndrome screening so the first time I meet them ...I'm trying to give them the information... and they often say 'what would you do?'

Women from minority ethnic groups were also mentioned, where some women may not be used to being offered choices:

MW4: ...particularly some of the Asian women... They've not had a choice of who they marry, what job they do or education, and then suddenly we expect them to make choices.

Nevertheless, midwives were aware of their influential position and that their own views about screening could influence women's decisions. They acknowledge the need to be non-

directive, refraining from saying what they would do, and the importance of enabling women to make decisions themselves:

MW10: ...(women) are looking at you to steer them one way or the other... the way you word things could have a big influence... I have to say to them 'It isn't my decision to make. It's only you that can make that decision'.

MW14: ...I can't tell them 'yes' or 'no' or what I think they should do ... and I just say 'I'm not you. You have to make your own decision'.

Midwives said that women also asked them what most other women would do and that they avoided responding to this question because it was important for women to make their own decision and not to 'follow the herd':

MW1: ...they still go 'What do most women do?'...it leaves you in an awkward position... just because lots of women have screening, doesn't mean (this woman) should.

Overall, all the midwives in this study agreed that it was important not to give directive advice. Instead they provided information and many also actively enabled women to think about what would be best for them and their family by engaging in discussion.

The challenge of time and technology in facilitating informed choice

Midwives recognised the importance of time in facilitating informed choices. They explained that information about antenatal screening was provided during their first meeting with pregnant women (booking appointment), where women were usually expected to make a decision about whether or not they wanted screening. Many of the midwives said that providing the required information about antenatal screening within a 45 min appointment was challenging:

MW12: ...it could take anywhere from five minutes to half an hour, sometimes longer.

MW3: ...you've got so much information to give them at that first visit, and information gathering from them as well, the risk assessment...

MW4: ...with an interpreter you've got to add at least another ten minutes, if not double the time.

Furthermore, a number of midwives explained that timing had become especially challenging since the advent of combined first trimester screening because they had a 'small window' within which to initiate the nuchal scan in particular. They described the booking appointment as the best opportunity to ensure that combined screening was initiated within the required timeline. However, given that women were provided with information about antenatal screening during the booking appointment, midwives recognised that this gave women little time to make their decision. Given the large amount of information provided to women, some midwives highlighted the importance of giving women time to process and digest information before asking them to make a decision:

MW5: We shouldn't expect women to make choices on the spot

MW1: ...because you need to refer them at that point, you're asking them to make the decision then and they haven't really read it.

Some midwives believed that the booking appointment felt like a one-way information giving session because women had not had the opportunity to read information about antenatal

screening beforehand. Instead, midwives said they gave women a week or two to decide if they were in early pregnancy. However, there was usually time pressure on midwives to refer women to ensure timely combined screening:

MW1: ... ideally it's nice to get them back a couple of weeks later ...but sometimes it's timing, because you've just got that short window of opportunity to have the nuchal done

Given this time pressure, the dilemma for midwives in the case of women undecided about screening was that if they did not instigate combined screening at this stage, then it was not an option available to the woman if she decided later in favour of screening:

MW3: ...we've got to put the tick in the right box otherwise they don't get the screening if they finally decide they want it. ...because once it's sent in it's set in stone, there's no 'Oh sorry, she's changed her mind, she does want a nuchal now'.

Therefore, in cases where women were undecided, midwives explained to women that they would refer them for the combined screening and reassured them that if they decided against screening, then they could decline it when they attended for the nuchal scan and opt for just a dating scan instead:

MW13: ...if they're unsure I will say '... why don't we go ahead with the consent, but you think about it further? ...if by the time you come for your scan and you don't want screening, that's fine you can decline and pull out of it. Just because that is signed to say that you've consented doesn't mean you have to go ahead with it'.

Midwives believed this gave women time to think about screening, where they still had the option of accepting or declining screening. Some midwives tried to ensure that screening was discussed with women when they attended for their scan, and most were confident that women could change their mind if they decided against screening:

MW11: ...we put a little note on front of the notes, 'lady undecided, to discuss again at time of scan'.

MW3: ... at any point between them making a decision or me ticking a box, to them going to the scan, they can change their mind and they're aware of that.

As an alternative for women unsure about antenatal screening, some midwives said that they also offered second trimester quadruple screening. Nevertheless, midwives focused on the offer of combined screening, because this was believed to be more accurate than quadruple screening:

MW11: I don't know why a woman would turn round at 16 weeks and want screening when she could have a more accurate result, as accurate as it can be, at first trimester.

The challenge of preventing litigation: recording the offer of screening

All midwives completed and signed a checklist for combined screening to ensure that women were giving informed consent. This checklist was part of the paperwork to instigate the combined screening process. However, there were no similar procedures for recording discussions and decisions for women who declined screening. Some midwives believed that it was important to record such information, because of concerns about litigation if a woman went on to have an undiagnosed baby with Down's syndrome. Given that these midwives believed that they were responsible for ensuring that the woman had understood the information provided, they also believed that they could be

held responsible for women's lack of understanding of what they were declining:

MW1: ...It was like ripples through the surgery 'Undiagnosed Down's'... the doctors were almost like 'How can this be?'... and I can remember at the time thinking 'What did I talk about' ...I'd written 'Screening discussed, not keen on screening'... but 'Did she really know', 'What did she say?'...it kind of boils down to litigation and would they try and sue you and say 'You never explained that to me properly and now I've got a baby with Down's and ...it's your fault'.

Midwives explained that when they discussed information in-depth, it was difficult to document all the points in a concise and consistent manner. Nevertheless, some explained how they had developed their own systems for keeping a record of their discussion with women to protect themselves from litigation:

MW2: ...it's just us in the room... how do I prove that I've given her that information ...because women will complain if they don't feel that they've had that information... it sounds very defensive... but unfortunately that is the way we're practicing these days... if they do not want to have anything, you'd have to document it.

Using a decision or information aid to facilitate informed choice

Midwives often had to find their own way of explaining the screening pathway and the different options and choices that women could be faced with. Some midwives believed that a diagrammatical representation of the screening pathway with the various decision points along the screening pathway would be a helpful tool in facilitating their discussion with women. This was because they believed it could provide women with a more holistic picture of screening:

MW4: ...seeing things in a diagrammatic form helps people to realise what they're doing. ...They can see the pattern or pathway of where they're going.

Such a tool was also believed to provide midwives with probes for discussing essential points to facilitate informed choice, enable more consistent discussion of information across midwives, and serve as a record of their discussion:

MW8: We're supposed to write down everything that we've discussed ...we all have different styles of explaining things and so I think they can standardise that discussion so that everybody gets a fair explanation.

However, some midwives were unsure about a decision/information aid and believed that it would imply more paperwork or compromise their autonomy:

MW15: It's another piece of paper to fill in...

MW11: ...you'd have to trust that we actually help that woman come to the right decision for her... midwives need to be treated with a little bit more respect and autonomy, that they're doing a good job.

The challenge of facilitating informed choice in women with complex social needs

Some of the midwives explained that facilitating informed choice in a different language was challenging even when using interpreters because there were no words for Down's syndrome in some languages:

MW5: I had a Mandarin interpreter who insisted there was no such thing (as Down's syndrome), because it wasn't in the dictionary.

Midwives explained that they often had to describe the condition instead, but this was challenging because they were unsure of the best way to do this and were concerned about whether or not the interpreter was using non-judgemental, hence non-directive, language:

MW8: ...when I'm using a particular Mandarin interpreter I can hear the word Mongol... words that we wouldn't use.

Some midwives resorted to using photographs in such situations. As there are no photographs of people with Down's syndrome in the current NSC screening information leaflet (National Screening Committee, 2010), midwives found their own sources and gave different justifications for selecting the source and/or images:

MW4: ...I try and have a picture of what a Down's syndrome child looks like, not just in a white context but within their racial colour, because that can make a difference to how the picture looks.

MW7: (I've got) a booklet from a voluntary organisation that works with children with Down's syndrome, but with photographs of children with all different colours to back up what I'm saying.

Midwives described facilitating informed choice with teenagers as challenging. Midwives had difficulties in enabling teenagers to focus on antenatal screening because of their complex social needs, such as, parental/financial support and housing:

MW9: 'Where am I going to live? Is my boyfriend going to leave me? What am I going to do for money?'... it's incredibly hard to help them to understand how important a decision it is, at a time when they're probably coming to terms with the very shock that they're pregnant, it's not planned, they're maybe still at school... I truly don't feel that they've made a fully informed choice.

Discussion

Midwives in this study believed that the decision about antenatal screening was personal to the women and her partner and, therefore, the decision to accept or decline antenatal screening was the woman's. Many of the midwives had experienced women asking for directive advice about antenatal screening, but emphasised that they would not say anything intentionally to influence or sway women's choices in any direction. They were however very aware of the potential for midwives to have an influence on women's screening choices. Midwives explained how they focused on enabling women to make informed choices based on their own understandings of the information, available options and their own values. Overall, midwives were well aware of the requirement to be non-directive facilitators of informed choice (Williams et al., 2002). Nevertheless, the findings highlight a number of areas where facilitation of informed choice could be (unintentionally) compromised. These areas need practical solutions and clinical guidelines, supported by policy, to enable midwives to better facilitate informed choice.

Clinical guidelines for antenatal screening clarify that it is the role of health professionals to facilitate informed choice, and that this includes discussion about decision points on the screening pathway and their possible implications for further testing or termination decisions (NICE, 2010; National Screening Committee, 2011). Similarly, research shows that women want to discuss information with health professionals (Ahmed et al., 2012, in

press). Our findings show that midwives had diverse views about their role in discussing information, varying from giving 'factual' information only to in-depth discussion of information. They also varied in the extent to which they discussed women's decisions to accept or decline antenatal screening due to concerns about influencing women's decisions. These findings suggest the need for clinical guidelines for health professionals on how to discuss information about antenatal screening and the decision points on the screening pathway objectively.

Midwives in this study generally agreed that a more structured, standardised approach such as an information aid may be beneficial. Such an information aid would visually show the screening pathway, the options and different decision points, and could help midwives facilitate informed choice in a flexible but consistent way. Such an aid could not only ensure an evidence based approach to facilitating informed choice, but could also serve as a formal system for recording discussions and decisions, as well as obtaining consent if signed by both parties (Nagle et al., 2008; Raats et al., 2008).

In line with NHS FASP guidelines, midwives believed it was important to record the offer of screening and the woman's decision (National Screening Committee, 2011) and used the formal system for obtaining informed consent for this purpose. However, there was no formal system for recording such information when women declined screening and the fear of litigation in the case of an 'undiagnosed' baby made some midwives resort to personal record taking. These findings suggest the need for developing a record keeping system to enable midwives to record both decision to accept and decline screening. However, midwives asking women to formally record their decline of screening or making women aware that they are doing so may enforce a sense of 'missed opportunity' or responsibility for the consequences of rejecting an offered test. This idea therefore needs careful thought before implementation.

Midwives recognised that facilitating informed choice involved ensuring that the woman 'has sufficient time to make an informed decision' (NICE, 2010; National Screening Committee, 2011). However, they reported having limited time to provide information in the booking appointment (Williams et al., 2002; Legare et al., 2008), and believed women had limited time to digest and discuss the information to make an informed decision about first trimester combined screening. Women also value information recommended by health professionals (Skirton and Barr, 2010) and discussion about their options with health professionals (Ahmed et al., 2012, in press). Therefore, there is a need for clinical guidelines on how to manage the antenatal screening process to allow women sufficient time for making informed choices, where health professionals can engage in information exchange and not just information transfer (Lee and Garvin, 2003). Such guidelines should incorporate second trimester screening as an option for women undecided about or declining first trimester combined screening.

For women undecided about combined screening, some midwives enabled them to have 'more time' to make a decision by instigating the screening process, booking a nuchal scan with their consent, and informing them that they could decline screening at the scan appointment. This procedure was believed to be in the best interest of women who were undecided, so that they did not miss the opportunity of first trimester screening if they later decided in favour of it. However, this in effect leads to an 'opt out' screening service for some women, something which is contra to current screening policy. Furthermore, research suggests that even minor actions, like ticking a box, result in more commitment to that decision than making the same decision by doing nothing (Cioffi and Garner, 1996). This procedure may inadvertently be 'directing' women towards a particular course of action and needs further consideration.

Finally, midwives raised concerns about the reality of informed choice in some specific groups. For example, facilitating informed choice with non-English speaking women was particularly a challenge, even when using interpreters and translated information leaflets, because usually there were no words for the tested-for conditions in their first language. A number of midwives believed that it was important to use photographs to facilitate informed choice in such cases. A recent study in the USA also identified that women consider the inclusion of photographs of people with Down's syndrome from a variety of racial backgrounds as important (Levis et al., 2012). Given that the NHS FASP information for 'Testing for Down's syndrome in pregnancy' no longer contains any images of people with Down's syndrome, midwives selected their own sources of photographs and decide which photographs were most appropriate to use based on women's ethnic origin. The effect of photographs is unknown however, and some research suggests they may make women more concerned about having an affected child (Figueiras et al., 1999). Our findings support the need for research on the use of images of people with Down's syndrome in antenatal screening information. In addition, and in support of other research (Wynter et al., 2011), midwives in this study were concerned about teenagers' ability to make informed choices about antenatal screening, highlighting the need for further research on this topic in this group.

Strengths and limitations

To our knowledge, this is the first study to explore midwives' views about facilitating informed choice. This may be because the views of women have been the main priority for researchers and policy-makers (Tsouroufli, 2011). Future research in this area would benefit from exploration of women's views about the challenges raised by the midwives in our study in facilitating informed choice for first trimester screening. We recognise the exploratory nature of this study, however, we believe this does not detract from the validity of our findings as a robust qualitative methodology was followed throughout.

Conclusion

Midwives in this study demonstrated a clear understanding of the policy requirement to facilitate informed choice. They also highlighted challenges imposed by first trimester combined 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 in a variety of situations 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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