

Is advice incompatible with autonomous informed choice? Women's perceptions of advice in the context of antenatal screening: a qualitative study

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Abstract

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Accepted for publication

2 March 2012

Background Patient autonomy in antenatal screening is a high priority for policy developers in many countries.

Objective This paper presents women's understandings of how health professionals should facilitate informed screening choices with an emphasis on their understandings of autonomy and advice.

Design, setting and participants The study was carried out in 2009 in the UK, using a qualitative approach. Ninety-eight participants of African, British White, Caribbean, Chinese and Pakistani origin had semi-structured interviews, which were analysed using framework analysis.

Results Four themes were identified during the analysis: 'Meanings of advice in antenatal screening: the advice continuum', 'Recognition of the role of health professionals in decision making', 'Understandings of advice in the context of autonomous decision making' and 'Reasons given for wanting advice'. Women said they valued advice from health professionals to make decisions about antenatal screening, but their understandings of 'advice' ranged from information giving only to direction about screening choices.

Conclusion Many women wanted health professionals to support the process of making informed choices by engaging in discussion and did not see advice as incompatible with making autonomous choices. However, some women wanted direction about whether to have a screening test or not, something which policy and guidelines explicitly prohibit. This may cause an ethical dilemma for health professionals who are required to both support women's preference for care and adhere to a policy of non-directiveness. Further clarification is needed on how health professionals should support the process of making informed choices when women ask for clear direction on screening choices.

Introduction

Patient autonomy in antenatal screening is a high priority for policy developers in many countries.¹⁻³ National Institute for Health and Clinical Excellence (NICE) guidelines state that in antenatal screening, women should be enabled 'to make autonomous, informed decisions'.⁴ Autonomous decision making requires patients to choose and act intentionally, with understanding and without influences that determine their actions.⁵ In this interpretation of autonomy, individuals' rights and values are perceived as paramount, where individuals are expected to decide on their own, without any coercion,⁶ that is, the use of force or intimidation by health professionals to make a particular decision.

To promote individual autonomy in antenatal- and genetic-screening programmes, informed choice is recognized and accepted as a key objective.⁷⁻⁹ An informed choice is said to be made 'when the relevant information about advantages and disadvantages of all the possible courses of action is evaluated in accordance with the decision makers' beliefs in order to reach a decision'.¹⁰ The role of health professionals in the context of antenatal screening is to enable patients to make informed choices by providing value-neutral information in a non-directive manner. Operationalizing informed choice in this way has come to be associated with non-directiveness,¹¹ an approach where health professionals do not lead individuals to make particular decisions or choices, but enable them 'to make the best decisions for themselves and their families as judged from their own perspectives'.¹² Accordingly, health professionals understand that they should not make recommendations or give advice because this could be interpreted as directive or coercion. This approach to facilitating informed choice is considered appropriate because only patients can know the values and preferences that are essential to making decisions that are right for them and their family^{13,14} and because it minimizes ethical dilemmas faced by health professionals in giving advice on a moral and emotive issue and

possible allegations of coercion or eugenic practice.¹²

Provision of value-neutral information does not preclude the necessity of explaining information, such as, the advantages and disadvantages of screening for women or the implications of their decision to accept or decline screening. Therefore, discussion of the information should be an important part of enabling women to make informed choices.¹⁵ International guidelines for genetic-testing and -screening services suggest that the process of making an informed choice should take the form of a dialogue between the individual considering testing and the health professional facilitating informed choice.⁹ NICE guidelines on antenatal screening also clarify that women should have the opportunity to discuss the information with health professionals and that health professionals should ensure that women understand information to make an informed choice.¹⁶ However, the NICE guidelines acknowledge that giving women information in a way that enables them to make an informed choice is still a challenge for health professionals.¹⁶ This may be due to a number of factors. For example, the boundary between discussion and direction is unclear for health professionals in facilitating informed choice; the discussion that should take place is of a sensitive nature; and the content of the discussion has not been clarified for health professionals.^{11,17,18} In addition, there are time constraints on busy health professionals.¹¹

Research suggests that while health professionals are expected to be non-directive, many patients would prefer health professionals to engage in the decision-making process.^{19,20} For example, a systematic review of the research on psychosocial aspects of genetic screening showed that over a third of women studied found it difficult to make choices about antenatal screening and wanted more support to do so.²¹ Furthermore, women left to deliberate on their own may feel abandoned and lose trust in their health professional.^{22,23} Facilitating informed choice is further complicated by evidence from various fields of health care, including antenatal screening, showing that patients from many

other cultures place less emphasis on autonomy^{24–29} and are less likely to be actively engaged in decision making.^{30–32} Recent migrants and individuals born in the UK but raised in a particular cultural setting may not value the Western approach to informed choice.^{24,33} Such differences in the value of informed choice may complicate and potentially interfere with care in cross-cultural health-care encounters.^{34,35}

Overall, it is important to recognize the significance of non-directiveness in facilitating informed choice, but also the importance of dialogue between health professionals and patients. In a study exploring diversity in the value attached to autonomous informed choice in antenatal screening in a multiethnic population,³⁶ we found participants talking about the need for such dialogue. In particular, participants talked about their need for advice from health professionals to facilitate decision making, which may seem to contradict the health professionals' role as non-directive. This paper aims to present women's understandings of what the dialogue between them and health professionals should be about, in particular, their understandings of 'advice' and how this relates to autonomous decision making for antenatal screening. The qualitative data presented in this paper were collected as part of the larger study.³⁶

Method

Participants

During February–December 2009, pregnant women were recruited from five ethnic groups, defined in terms of family origins as African, British White, Caribbean, Chinese and Pakistani. One hundred and twenty-seven pregnant women were recruited to obtain the final sample of 98–29 women declined to participate when contacted postnatally. Efforts were made to obtain diversity within each ethnic groups by education (up to GCSE level and above GCSE level), preferred written language (English, French, Mandarin and Urdu), parity (first or

subsequent child), migration (whether born in the UK) and maternal age. See Table 1 for sample characteristics.

Procedure

The study was approved by the appropriate NHS Local Research Ethics Committees. Participants were recruited via midwives who sought initial consent at routine antenatal appointments from all eligible women who were there then followed up by a researcher who was present at these antenatal clinics. The study was conducted about 6 weeks after delivery in participants' homes in four languages by two researchers (author 1 and author 3). Author 1 is Pakistani and completed the study in Urdu with Pakistani women unable to speak fluent English. Author 3 completed the study with participants from all ethnic groups and used French and Mandarin interpreters for African and Chinese women, respectively, who were unable to speak fluent English. The study used Q methodology.³⁷ All participants were required to rank 41 statements relating to 'making an informed choice' about antenatal screening (see Appendix S1) according to whether or not they agreed with them (see (Ahmed *et al.* 2012) for details of the larger study and how these statements were constructed) and then had an audio-recorded interview where they explained why they had ranked statements in the way that they had. This allowed participants to elaborate on their view of informed choice. This paper draws on these interviews.

Analysis

Author 3 listened to all the interviews and transcribed verbatim any part of the interviews where participants talked about the role of health professionals in the decision-making process for antenatal screening, such as, giving advice, providing guidance or making recommendations. This qualitative data was analysed by an experienced qualitative researcher (Author 1) using Framework analysis³⁸ because this approach allows the researcher to be guided

Table 1 Demographic characteristics of study participants (*n* = 98)

		African <i>n</i> = 18	Caribbean <i>n</i> = 11	Chinese <i>n</i> = 23	British White <i>n</i> = 23	Pakistani <i>n</i> = 23
		<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)
Participants' education	Up to GCSE level	5 (28)	6 (55)	9 (39)	7 (30)	12 (52)
	Above GCSE level	13 (72)	5 (45)	14 (61)	16 (70)	11 (48)
Age (years)	Mean (SD)	26 (4.6)	30 (7.2)	31 (4.2)	32 (4.2)	29 (5.4)
Parity	Primiparous	9	3	10	11	6
	Multiparous	9	8	13	12	17
Religion	None		3 (27)	13 (57)	11 (48)	
	Christian	15 (84)	8 (73)	7 (30)	11 (48)	
	Buddhist			3 (13)		
	Muslim	3 (16)			1 (4)	23 (100)
Place of birth	Africa	18 (100)				
	UK		11 (100)		23 (100)	11 (48)
	China			23 (100)		
	Pakistan					12 (52)
Preferred written language	French	5 (28)				
	Mandarin			15 (65)		
	English	13 (72)		8 (35)	23 (100)	15 (65)
	Urdu					8 (35)
Time in UK (Years) – only asked of participant born outside the UK ¹	Mean (range; SD)	5.1 (1–11; 2.7)		5.9 (1–10; 3.0)		7.3 (1–18; 6.7)

¹Missing for three African, two Chinese and three Pakistani participants.

during analysis by a list of core issues considered important for the scope of the study, without being either too rigid or too immersed in raw data. The initial core issues included women's perceptions of advice, guidance and support and their understandings of the role of midwives in decision making about antenatal screening. Framework analysis also allows the researcher to incorporate new relevant issues emerging from the data and makes the analysis of large amounts of data more manageable. Data analysis involved consistent cross-referencing between the participants for similarities and differences. A hierarchical thematic framework was developed and used to classify and organize data according to key themes, concepts and emergent categories. Following discussions, authors 1 and 2 developed key themes from the narratives of the participants, relating to participants' perceptions of the role of health professionals in antenatal screening, particularly in relation to giving advice when offering antenatal screening.

To protect anonymity, participants' quotes in the results section are followed by their study codes, which include information about their ethnic group (A = African; BW = British White; C = Chinese; Car = Caribbean; P = Pakistani).

Results

This section presents the different ways in which participants talked about advice and their understandings of how advice relates to independent decision making about antenatal screening.

Meanings of advice in antenatal screening: the advice continuum

The word 'advice' meant different things to different participants and these meanings could be organized along a continuum, ranging from 'giving information only' to 'providing direction'.

Giving information only

Participants described advice as 'giving information only', such as, that relating to the process of testing, advantages and disadvantages of testing, why testing is offered and potential subsequent results and decisions. Some participants added that the provision of information alone was not sufficient for them to make decisions and that health professionals should explain the information:

...after giving the information they should also explain more ... I welcome health professionals' advice. I would like them to tell me what these tests are about...what the consequences would be. (C23)

Giving guidance and support

Participants also described advice as 'guidance and support'. They wanted health professionals to guide them by helping them work through the information, believing that this would enable them to come to a decision that would be best for them:

You can't make decisions without any knowledge about it so they help or guide you to what you want to do. (A08)

Many of these participants clarified that during such guidance they wanted professional advice, not personal opinions:

Professional advice is a key thing in health service profession. I don't want any personal opinion on it. (BW14)

The participants were concerned about health professionals imposing their own values on women and equated personal opinions with being directional and even forcing women to make a certain decision:

...they are actually imposing their views then on you rather than letting you make your own decision, they are actually influencing you... (P23)

They should advise me and give me information, and not tell me whether I should do it or I have it and force me into doing it. (A18)

Providing direction

Some participants believed that giving advice was part of health professionals' role as caregivers and expected them to recommend whether they should have testing or not:

...you don't know what to do if someone says 'here is the test you make your mind up'. You need more information, more advice... I would want them to recommend, because they have been doing it for so long...they can't just turn it to a job... 'go and make your mind up'. I want sympathy, I want caring and understanding. I need advice, past experiences, everything... (P19)

A number of participants also wanted health professionals to be directive and to give their opinions about testing:

...it's important they give their opinions and not give information only. (C08)

They should give information and advice. They should say that "we think you should go for these tests" I would value their advice. (P17)

Obviously they should give medical advice.... I think the midwife should say if 'I were you I would do such and such'. (C20)

Recognition of the role of health professionals in decision making

Most participants recognized constraints on health professionals in being directive and understood that it may not be ethical for health professionals to give their opinions or be directive. They also understood that advice construed as opinion or as directive could result in litigation. However, participants stated that they would still value such advice, for example

They [health professionals] don't want to sway you with their professional opinions because you know they probably get scared about being sued or whatever, but it would be just nice to say 'most people have it', it's just reassurance...but they can't say 'well this is something I would have done', it's just today's culture. (BW17)

Understandings of advice in the context of autonomous decision making

Participants appeared to be able to separate advice from decision making. While they wanted direction, they believed they would still be able to make a decision that was right for them:

Whether it is ethical or not, I think sometimes it would be useful if doctors/midwives could give a little bit of their own opinion off the record, rather than just information. It would have been nice of her if she said 'look if I were you I would do this because of x, y, z'. I understand some women would be influenced by that whereas I still make my own decision. (BW04)

Many of the participants did not equate health professionals' advice with health professionals making the decision about testing, hence demonstrating that women could separate advice from decision making:

It's wrong to ask a midwife or a doctor to make the choice, but you need to ask for advice. (P04)

When you ask for their opinion it's not like you are asking them to make a choice for you but you are asking their professional view. (A02)

The more advice you get and the more information you get, it helps you to make your decision better. ... Midwives tell me options and then I make my own decision from there... they just try to help you along. (BW19)

Many participants clarified that while they valued health professionals' advice, they may not agree with it or act on it:

You don't necessarily have to accept midwives' views, because they are also human and they make mistakes. You should be supported depending on what your views are... you don't have to agree with what they say and at the same time you need to be supported. (A02)

Some participants distinguished between directiveness and coercion. They stressed that it was important for them to retain control over the decision about testing. Irrespective of what participants meant by advice, why and how they wanted it, they did not want health professionals to coerce them:

I'm not asking the midwife to make a decision. I think it's important they give you advice and looking at both positive and negative, but I wouldn't want them to force me or to do it... I think it should ultimately be up to me to make that decision. (P22)

While the participants did not want to be coerced, some of the things they said could

clearly be considered as directive and coercive in the light of current policy and practice:

I wouldn't want them to be judgemental and say 'well I think you are wrong not to do that'. But if they say 'personally I did it because of blah, blah, blah' that's absolutely fine, as long as they are not being forceful about it either way. (BW22)

[Health professionals should say] that 'we think it's best to do...', not that 'you must do it'. There is a difference between telling somebody and giving advice on some matter. You shouldn't force somebody if they don't want it. (BW20)

Reasons given for wanting advice

Participants said that they wanted advice because the decision about antenatal screening was difficult to make and because they did not want to make the 'wrong' decision. This did not mean that they believed that there was a right or wrong decision to make from the health professionals' perspective, but from their own perspective, for their own situation:

[Health professionals should] guide you on making the decision...because you might just make the wrong decision. (A08)

I need to ask for advice about their view, how they see it... If I'm struggling to come up with a decision I would ask for advice with my situation and my condition." (A02)

One reason participants believed it was difficult to make a decision was because of their lack of expertise, for example, where they did not understand the NHS system. This was either because it was their first pregnancy and/or because they were new in the UK:

Especially being a first time mum, you put your trust in doctors and midwives... they are experts in that area, therefore you are looking to them for help... So it's important to have their professional opinion. (BW17)

I am quite new to the British NHS system... I don't know the reasons and consequences of the tests... so I need the professional to help me make the decision... What sorts of people should do the tests like that? (C23)

Participants described health professionals as 'trained experts', able to give advice based on their expertise and knowledge. Some participants even suggested that it would be irresponsible to make the decision themselves, without health professionals' advice.

They [health professionals] are trained for several years to get the expertise in that area is one of the reasons why you go to them. You trust what they say unless you have a medical background, it'd be irresponsible to use your judgement. (BW17)

Many participants also talked about their trust in health professionals to give advice and belief in their altruistic motives:

Everything they say it's for the better health of the baby and mother. (P05)

Of all the people you could ask, they are probably the people who've got the most balanced views. (BW12)

Discussion

The findings show that many women valued advice from health professionals for making decisions about antenatal screening, but that 'advice' ranged from 'information only' to 'direction about screening choices'. In addition to the provision of information, many women wanted health professionals to help with the decision-making process by engaging in discussion to help them understand information and weigh up the advantages and disadvantages of the available options in relation to their own values. Women did not see such advice and discussion as incompatible with making autonomous choices, although they clarified that they would want to retain control over the outcome, that is, decision taking about whether or not to opt for screening. Other research has suggested that women who feel supported by their health professionals also feel the most autonomous as compared to those who do not feel supported.³⁹ Given that autonomous choices are usually enhanced rather than undermined by the contribution and support of well-informed health professionals,⁴⁰ it is essential for health professionals to engage in discussion with women during antenatal-screening

decision making. Our findings suggest that women believe that autonomous informed choice can be achieved even if the decision-making process is supported by health professionals. For ethical reasons, this study was conducted with women after the birth of their baby, and the number of women making decisions about antenatal screening based on information alone, without support from their health professionals, is not known. Further research on informed choice could explore the extent to which women believe they are unsupported in decision making about antenatal screening.

Somewhat controversially in the light of policy and guidelines that prohibit directiveness, the findings also show that some women wanted direction in decision making, indicating possible ethical dilemmas faced by health professionals who offer antenatal screening in their daily practice. These findings do not suggest that we abandon non-directiveness, but that there is a need to find a balance between different models of autonomy, where health professionals feel supported to discuss and explore women's values and women feel supported to make autonomous informed choices that reflect their values. For this purpose, there is a need for clarification of the nature of the discussion that should take place between health professionals and women offered antenatal screening, whether or not health professionals should give 'advice', and if so, what is permissible and what is impermissible advice. Crucially, health professionals also need guidelines on what to do when women want them to be directive or cannot decide themselves whether or not to opt for testing. Given the sensitive nature of the discussion that is required to facilitate informed choice, consideration also needs to be given to the training needs of health professionals delivering antenatal screening.

Engaging in dialogue with women poses challenges for health professionals who recognize a number of issues associated with facilitating informed choice, including the influence of their own values on the choices that women make; their own ability to present complex information in a sensitive way and time constraints to explain and discuss screen-

ing.^{11,17,21} However, declining to give advice or engaging in discussion are not appropriate options for health professionals given that this level of non-directiveness can also influence the choices women make.⁴¹ It has been argued that neutrality in the unequal relationship of health professional–patient communication is not possible⁴² and that the offer of antenatal screening during routine antenatal care in itself suggests to women that the test is important. This limits the extent to which women believe they have a genuine choice.^{43–46} Therefore, it is important for health professionals to engage in discussion to ensure that women understand that they have a genuine choice of whether or not to opt for antenatal screening. There is growing evidence on shared decision making within health-care settings, showing that decision support can be given in a way that also facilitates value-consistent individual choice. Staff education and training programmes along with quality monitoring in relation to decision support protocols are already operating in some areas of health care.⁴⁷ Further research is needed on how health professionals should support the process of making informed choices in antenatal screening without influencing the outcome.

The focus on individual choice in the current antenatal-screening practice reflects distancing of such services from past allegations of eugenics¹¹ and a growing culture of consumer choice and autonomy. However, our study findings are consistent with guidelines on antenatal screening, which recognize the importance of discussion between health professionals and women to enable women to make autonomous informed reproductive choices.^{7,16} Similarly, Quill and Brody suggest that the central philosophical point of autonomy in health care is that the patient is respected as a person and that it is not respectful for health professionals to deny advice. Respect requires health professionals to listen to and engage with women to help them make choices that are consistent with their own values: ‘Final choices belong to patients, but these choices gain meaning, richness and accuracy if they are the result of a process of

mutual influence and understanding between physician and patient’.⁴⁰ Overall, health professionals should consider women’s needs and priorities by discussing screening with a view to eliciting their values and concerns and providing advice to help them make their decision.⁴⁸

Conclusion

The findings of this multiethnic study show that most women regarded advice, support and help with exploring options as a necessary part of enabling them to take informed autonomous decisions about antenatal screening. This challenges the view that autonomy can only be supported by declining to give advice when requested. There is a need for research and guidance on how health professionals can support the process of decision making without being directive or coercing women. There has been much focus in policy documents and academic literature on informed choice as an outcome but much less focus on the process and the role of health professionals within this. This study shows that further consideration and clarity are needed on informed choice as a process, particularly the role of health professionals, to enhance the quality and equity of antenatal-screening services.

Acknowledgements

The authors would like to thank the community midwives for supporting the study by facilitating recruitment of pregnant women and members of the Project Advisory Group for their contribution to the study: Mushtaq Ahmed, Carol Chu and Gerald Mason from Leeds University Teaching Hospitals, NHS Trust; Lai Fong Chiu, Jenny Hewison, Janet Hirst, Janet Holt, Anne Kerr and Jennifer Lim from the University of Leeds and Wendy Stainton-Rogers from the Open University.

Funding

This work was supported by the Economic and Social Research Council [grant number RES-061-25-0036].

Conflicts of interests

None to declare.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Statements used in the Q-methodology study.

Please note: Wiley-Blackwell are not responsible for the content or functionality of any supporting materials supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author for the article.

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