
Volume 74
Issue 7
April 2012
ISSN 0277-9536
ELSEVIER
SOCIAL SCIENCE & MEDICINE
an international journal
MOST CITED SOCIAL SCIENCE JOURNAL*
Impact Factor
2.742

Social Science & Medicine 74 (2012) 997–1004

Contents lists available at SciVerse ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Interpretations of informed choice in antenatal screening: A cross-cultural, Q-methodology study

Shenaz Ahmed[a,*], Louise D. Bryant[a], Zahra Tizro[b], Darren Shickle[a]

[a] Leeds Institute of Health Sciences, University of Leeds, Leeds, West Yorkshire LS2 9LJ, UK
[b] Faculty of Health & Life Sciences, York St John University, York, UK

ARTICLE INFO

Article history:
Available online 25 January 2012

Keywords:
U.K.
Informed choice
Antenatal screening
Multiethnic
Cross-cultural
Autonomy

ABSTRACT

Informed choice is internationally recognised and accepted as an important aspect of ethical healthcare. In the UK, NHS antenatal screening policies state that their primary aim is to facilitate reproductive informed choices. These policies, implemented within a multiethnic population, are largely guided by the ethical principle of autonomy. This study was carried out in 2009 in the UK and used Q-methodology to explore diversity in the value attached to autonomous informed choice in antenatal screening for genetic disorders and similarities and differences in this value in women from different ethnic origins. Ninety-eight participants of African, British White, Caribbean, Chinese and Pakistani origin completed a 41-statement Q-sort in English, French, Mandarin or Urdu. Q-Factor analysis produced five statistically independent viewpoints of the value of informed choice: choice as an individual right; choice informed by religious values; choice as a shared responsibility; choice advised by health professionals; and choice within the family context. The findings show that women hold a variety of views on the nature of informed choice, and that, contradictory to policies of autonomous informed choice, many women seek and value the advice of health professionals. The findings have implications for the role of health professionals in facilitating informed choice, quality of care and equity of access.

Introduction

Informed choice is internationally recognised and accepted as an important aspect of ethical healthcare (General Medical Council, 1998; World Health Organization, 2006). In the UK, antenatal screening programme policies, for example for fetal anomaly, and sickle cell and thalassaemia, state that their primary aim is to facilitate reproductive informed choices (NHS FASP, 2010). That is, screening programmes aim to enable people to make *autonomous* choices, based on good quality information, which reflect their personal preferences. In practice, and in accordance with guidelines on antenatal screening (NICE, 2008), health professionals are the ones required to offer screening in a non-directive way to enable pregnant women and their partners to make choices about antenatal screening independently.

Informed choice is important because greater patient involvement in the process of making choices can lead to better decision-making outcomes for patients (O'Connor et al., 2009). The literature suggests that women value the opportunity to make informed choices about antenatal screening. A review of the psychosocial aspects of genetic screening found that many women believe that their choices are informed, however, few women deliberate about the testing information before making their choice (Green, Hewison, Bekker, Bryant, & Cuckle, 2004). The review also found that women vary in the degree to which they make decisions themselves about testing, and that 10–42% of women find it difficult to make these choices and want more support and/or time to do so.

Furthermore, it appears, in relation to healthcare at least, that not everyone wants to make *autonomous* choices (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Robinson & Thomson, 2001), and that patients from some different cultures place less emphasis on autonomy (Bowman & Hui, 2000; Jafarey & Farooqui, 2005). The concept of informed choice itself has been described by some as culturally specific, consisting of a set of Western ideologies that are not valued by people from other cultures (Fagan, 2004; van den Heuvel et al., 2009). Western societies have been characterised as individualistic, where individuals see themselves as independent from their social groups (Hofstede, 1988). In contrast, non-Western, East Asian and South Asian societies are often described as collectivist, where they may value the wishes of the group over their own (Iyengar & Lepper, 1999). Research suggests that in collectivist societies, the family often plays a more active role in healthcare decisions (Cong, 2004; Elliott, 2001; Moazam, 2000). It can be

---

[*] Corresponding author.
E-mail address: s.ahmed@leeds.ac.uk (S. Ahmed).

0277-9536/$ – see front matter © 2012 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2011.12.021

argued therefore, that individuals born in the UK but raised in a particular cultural setting and recent immigrants may not value the Western model of autonomous informed choice (Ahmed, Green, & Hewison, 2005). Although, research suggests that the availability of screening appears to be valued by most women regardless of ethnic group or country of origin, and while the personal acceptability of screening varies within groups, the reasons given for uptake or decline of screening are strikingly similar across groups (Ahmed et al., 2008; Kagu, Abjah, & Ahmed, 2004).

Policy definition and implementation of informed choice in antenatal screening programmes may therefore support the needs of individuals from individualistic societies and may not meet the needs of a multiethnic pregnant population. In order to facilitate the development of coherent strategies through which informed choice could be facilitated in a multiethnic population, it is essential to understand whether and how people from different cultures value the concept (van den Heuvel et al., 2009). While there is much evidence for cultural differences with respect to patient autonomy, this is the first study to explore the value of autonomous informed choice to a multiethnic population within the context of antenatal screening. More specifically, the aims of the study were to explore diversity in the value attached to autonomous informed choice in antenatal screening, and to explore the similarities and differences in this value in women from different ethnic origins.

Method

Q-methodology

This study employed Q-methodology to identify a range of viewpoints about informed choice in antenatal screening. Q-methodology has been widely used to study health related questions, including perceptions of health and illness, quality of life, and understandings of Down's syndrome (Bryant, Green, & Hewison, 2006; Stainton Rogers, 1991; Stenner, Cooper, & Skevington, 2003). Q-methodology is sensitive to cultural variation and has been used successfully in cross-cultural studies (Stenner et al., 2006).

Participants express their viewpoint through their Q-sorts. The Q-sorting procedure requires participants to read propositions (items) related to the research topic and then to rank-order these items from strongly agree to strongly disagree (Brown, 1996). Q-sorting ensures that participants make discriminations between the items and forces them to make choices, therefore making them engage with the research topic (Prasad, 2001). In Q-methodology, each participant's distribution of the statements is known as a ***Q-sort*** and these are the units of analysis in Q-methodology. Factor analysis results in the grouping of expressed opinion profiles based on the similarities and differences in which the statements are arranged by each participant (Brown, 1993). Q-methodology uses factor analytic techniques but correlates people instead of variables, therefore, building typologies and identifying the variety of accounts people construct (Kitzinger, 1987).

Sampling the concourse and deriving the Q-set

The first step in Q-methodology is to collect a sample of statements that is representative of the research topic, known as the concourse (Stainton Rogers, 1995). In this study, the concourse was about things written or said about 'informed choice', both within the context of antenatal screening and health related decisions more generally. Statements for the concourse were generated through a literature review, including journal articles, reports, books, newspapers and magazines. This concourse was supplemented with statements from twenty-four semi-structured interviews with obstetricians; midwives; African, British White, Caribbean, Chinese, and Pakistani mothers of newborns. These interviews were conducted to obtain diverse views about the concept of informed choice for antenatal screening, and analysed using thematic analysis. Quotes relating to diverse preferences for making choices or factors influencing decision-making were added to the concourse. Forty-one statements relating to "making an informed choice" about antenatal screening were selected from the concourse for the final Q-set. This was because people are more consistently positive about the value of having a choice, and have more varied beliefs about making a choice (Barnett, Ogden, & Daniells, 2008). The Q-set also included items on two key aspects of choice behaviour (Deber, Kraetschmer, & Irvine, 1996): 'problem-solving' and 'decision-making'. Problem-solving requires knowledge, hence information, and consideration of the implications of the possible options, and decision-making involves making a choice by considering the trade-offs of the options. An 'informed choice' presumes that the individual has performed adequate problem-solving.

Participants

During February–December 2009, pregnant women were recruited for the Q-study from five ethnic groups: African, British White, Caribbean, Chinese and Pakistani–defined in terms of family origins and chosen because of their religious and cultural differences. Women were initially approached via midwives at antenatal clinics in twenty-one medical practices in a large UK city. These practices were chosen to represent the diversity of pregnant women using maternity services in terms of ethnicity, education and migration. Women were recruited during pregnancy, but complete the Q-sorts about six weeks after delivery. 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 purposive sampling for education (up to GCSE level and above GCSE level – the standard school exit academic qualification at age sixteen), preferred written language (English, French, Mandarin and Urdu), parity (first or subsequent child), migration (whether born in the UK), and maternal age. Participants' self-identified religious affiliation was also recorded. See Table 1 for sample characteristics. All the women had been offered antenatal screening for Down syndrome, sickle cell and thalassaemia, and 67% had undergone antenatal screening for one or more condition.

Materials

The Q-set items were printed onto small cards numbered 1 to 41 for use in the sorting procedure. The Q-set was initially produced in English and then in French, Mandarin and Urdu through a consultative process of back-translation, ensuring that the translated items captured the meaning of the items in English (Birbili, 2000). All participants were provided with a Q-set and a Q-sorting grid (see Fig. 1).

Procedure

The study was approved by the appropriate NHS Local Research Ethics Committees.

Q-sorts were conducted individually at participants' homes, in four languages, by two researchers (S. Ahmed and Z. Tizro). S. Ahmed is Pakistani and completed the study in Urdu with Pakistani women unable to speak fluent English. Z. Tizro completed the study

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

		African $n = 18$ N(%)	Caribbean $n = 11$ N(%)	Chinese $n = 23$ N(%)	British White $n = 23$ N(%)	Pakistani $n = 23$ N(%)
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[a]	Mean (range)	5.1 (1–11)		5.9 (1–10)		7.3 (1–18)

[a] Missing for 3 African, 2 Chinese and 3 Pakistani participants.

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 researchers clarified what was meant by 'antenatal screening tests'. The participants then read the statements and, in a series of steps, ranked them from −4 (strongly disagree) to +4 (strongly agree) in relation to the offer of antenatal screening, physically placing each item into a column on the Q-grid (Fig. 1) according to how they had been ranked relative to each other. This completed distribution of statements on the Q-grid, known as the participant's Q-sort, was recorded for each participant. Each participant had an audio recorded post-sorting interview where they were asked to comment on why they ranked statements as +4, +3, −4 and −3.

Analysis and selection of factors for rotation

Data were input, managed and analysed using PQmethod version 2.11. In Q-methodology, factor analysis is used to correlate participants' Q-sorts to identify which participants' Q-sorts cluster together. Factors were extracted using principal components analysis, which maximises similarities within factors and differences between them. Varimax rotation was used, which rotates factors to ensure that no Q-sort loads significantly at the same level on more than one factor (Watts & Stenner, 2005).

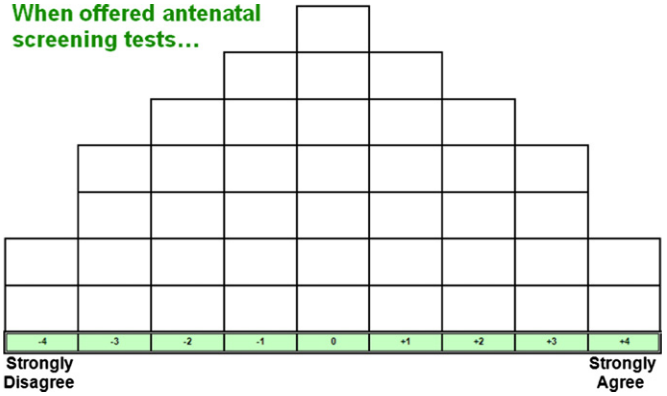

Fig. 1. The Q-sorting grid on to which participants place items from the Q-set to indicate their level of relative agreement or disagreement.

Following rotation, Q-sorts that were exemplars of each factor were identified. Only those Q-sorts with a loading of ±0.04 ($p < 0.01$) on one factor were retained as exemplars (Watts & Stenner, 2005). The identified exemplar Q-sorts were merged to create factor arrays (an average score for each item by factor) using a weighting formula devised by Spearman (Brown, 1980). The factor arrays are idealized Q-sorts for a particular viewpoint or account and are the main output of the statistical analysis that are taken forward for interpretation.

Seven factors were originally extracted, with an eigenvalue of 1.00 or more (Brown, 1980) and at least one exemplar (Stenner et al., 2003). The final selection of a five factor solution was reached after inspection of factors six and seven showed that they did not provide distinct viewpoints that were not captured in the other factors. A factor array was produced for each of the five factors by merging factor exemplars to form a single 'ideal' Q-sort to best represent the factor (see Table 2) (Stenner et al., 2003).

Interpretation

Interpretation of factors involved identifying patterns using the factor arrays and participants' post-Q-sort interviews. Particular attention was given to the placing of 'strongly agree' and 'strongly disagree' items in the factor arrays, and statements identified as statistically distinguishing each factor. S. Ahmed conducted initial interpretation. These were discussed at length with the other authors then refined and discussed again. The qualitative data was used to inform, support or challenge these interpretations at each stage.

Results

Demographic information for the exemplars in the five factors is presented in Table 3. Quotes presented in the results section are followed by participants' codes, which include information about their ethnic group (A = African; BW = British White; C = Chinese; Car = Caribbean; P = Pakistani).

Table 2
Factor arrays: scores against each item by factor.

No.	Statement	F1	F2	F3	F4	F5
1	It's best to take one step at a time – to have the tests and not worry about what could happen after that	+1	0	+2	+1	+2
2	It is important for me to think about the challenge of bringing up a child with the condition	+4	+1	+3	0	+1
3	I think that the offer of tests suggests that people with these conditions are worth less than others	−3	−1	−3	−3	−4
4	I would worry about the child with the condition being treated badly by society	+3	0	0	+3	+1
5	I would look for what my religion says about having such testing	−3	+3	0	+2	0
6	I would not discuss testing with anyone because the decision is mine alone	0	−1	−3	0	−4
7	I would be angry if I was tested without being asked for my permission	+4	+3	+2	+1	−2
8	Doctors/midwives should give me their professional advice about whether to have testing	+2	0	+2	+3	+2
9	I would leave the decision about testing to doctors/midwives	−2	−4	−1	0	0
10	If lots of other people are having testing, then testing would be fine by me	0	−1	+1	+1	0
11	The decision about these tests is no more difficult to make than routine health tests in pregnancy, such as the mother's blood pressure or diabetes	+1	+1	+2	−1	0
12	There is no decision for me to make because the tests are just part of good care for pregnant women	0	+1	+4	+4	−1
13	It is difficult for me to say 'no' to testing when doctors/midwives offer it	0	−2	+1	−2	−1
14	I would take lots of time to make a decision about testing	+1	0	−1	−1	−1
15	Having too much information about the tests makes it difficult to make decisions	−1	−1	0	−1	−2
16	I find it hard to make a decision about testing because there are too many decisions to make in pregnancy	−1	−2	−1	+1	+2
17	I would discuss it with my partner/husband but the decision would be mine	+2	+1	0	+2	−1
18	I would not want to go against my partner/husband's wishes, so if we disagree, I would do what he wants	−3	0	+1	−1	+1
19	Me and my partner/husband should make the decision about testing together	+3	+3	+4	−1	+2
20	I would keep my in-laws out of the process of making the decision about testing	+2	+2	+1	−2	−3
21	I would take advice from my parents or brothers/sisters about having the tests	0	−2	−2	−2	+3
22	My parents' or brothers'/sisters' views would sway my decision about testing	−1	−3	−2	−2	+1
23	My in-laws' views would influence my decision about testing	−2	−3	−2	−3	0
24	I think doctor's/midwife's should give information only, not advice about whether to have testing	−1	+2	−4	0	−3
25	I believe doctors/midwives would not offer the tests if it wasn't important to have them	+3	+2	+3	+2	+1
26	I believe having these tests is just part of being a good mother	+1	0	+3	+4	+2
27	I would want information provided by doctors/midwives to help me make my decision about testing	+3	+2	+3	+2	+4
28	I would consider myself fortunate to be offered these tests free of charge	+1	+1	+1	+3	+1
29	I would worry about what others might think if I decided to terminate a child	0	−1	0	−2	−2
30	I should not be asking the doctor or midwife to make a decision about whether or not I have testing	+1	+2	0	−4	0
31	I value the opportunity to think about termination of a child with a condition	+2	−2	−3	+3	+3
32	If I cannot decide whether to have testing then I should not be tested	0	+1	−2	0	0
33	Decisions about testing should only be made after carefully thinking through all the possible consequences of testing	+2	+3	+1	+2	+3
34	I would worry about people judging me as being irresponsible if I decide not to have testing	−1	−2	+2	−3	−3
35	I would not have an abortion, so there's no point in having testing	−2	+4	−4	−1	−3
36	I would accept the child that God gives me so there is no reason to have testing	−4	+4	−1	+1	−2
37	I want information about the tests but I do not want to make the decision	−3	−3	−1	0	−1
38	I do not want information from doctor's/midwife's – I will use my own judgment	−1	−1	−3	−4	−3
39	My partner/husband should make the decision about testing	−4	−4	−2	−3	+4
40	Doctors should tell me what to do, not ask me to make the decision about testing	−2	−3	0	0	+2
41	I prefer not to make the decision about testing because I am scared of making the wrong decision	−2	0	−1	+1	−2

Factor 1: choice as an individual right: "my body, my baby, my decision"

Q-sorts of 26 participants exemplified this factor: twelve British White, six Chinese, four African, two Pakistani and two Caribbean women. Two Chinese and two African women had been living in the UK for less than five years.

In this account, the emphasis was on personal autonomy, where the mother's right to make the decision was perceived as central. Participants were likely to agree most strongly with being angry if they were tested without their permission. This was because they believed that no-one had the right to do anything with their body without their permission and because they wanted to think about possible subsequent decisions:

> "It's my body. I should decide what to do with it." (A12)
> "It's my right… so that I know what I'm dealing with, rather than just being given some results and then having to deal with it" (BW10)

Consistent with autonomous decision-making, participants agreed with taking time to make a decision, and strongly agreed that it was important to think about the challenges of bringing up a child with the condition. They believed it was important to think about the implications of the condition for the child, mother and her other children:

> "The idea is to think about what that condition means" (BW16)
> "I would consider whether I would be up to the challenge of looking after a child with a severe disability and how that might affect my life" (BW09)
> "It would be silly not to, especially when you have other children, because it would have an impact on them" (BW10)

Participants also strongly agreed with making the decision about testing with their partner, mainly because they believed "the child belongs to both of us" (C07), and also because the father would have a role in subsequent decisions about whether or not to continue with the pregnancy. However, most of the participants strongly disagreed with their partner making the decision about testing. They believed that the decision would be theirs, even if this meant going against their partner's wishes:

> "I would never do exactly what someone else tells me to do when it's to do with my body and my baby. I wouldn't give up the right to choose" (BW09)

Also in line with autonomous decision-making, there appeared to be little interest in involving others in the decision-making process. Participants did not feel strongly either way about advice from their family (parents or siblings) and would keep their in-laws out of the decision-making process. Participants were not worried about people judging them as irresponsible if they decided not to

Table 3
Demographic information for exemplars in the five factors.

		Factor 1 exemplars *n* = 26	Factor 2 exemplars *n* = 11	Factor 3 exemplars *n* = 10	Factor 4 exemplars *n* = 7	Factor 5 exemplars *n* = 18
Participants' education	Up to GCSE level	9	6	4	4	2
	Above GCSE level	17	5	6	3	–
Age (Years)	Mean (range)	30.5 (21–41)	29.8 (20–39)	27.6 (21–37)	30.8 (22–38)	27.5 (27–28)
Parity	Primiparous	10	1	4	3	–
	Multiparous	16	10	6	4	2
Ethnic origin	African	4	3	2	1	–
	Caribbean	2	1	–	–	–
	Chinese	6	1	1	5	2
	British White	12	2	1	–	–
	Pakistan	2	4	6	1	–
Religion	None	13	–	–	2	–
	Christian	8	6	3	3	2
	Buddhist	2	–	1	–	–
	Muslim	3	5	6	2	–
Place of birth	Africa	4	3	2	1	–
	UK	16	–	3	–	–
	China	6	1	1	6	2
	Pakistan	–	2	4	1	–
Language in which Q-sort was completed	French	3	–	1	–	–
	Mandarin	4	–	1	5	2
	English	19	10	3	2	–
	Urdu	–	1	5	–	–
Time in UK (Years)–only asked of participant born outside the UK	Mean (range)	6.6 (2–11)	6.5 (3–18)	6.7 (1–10)	4 (1–8)	4 (3–5)

have testing. Participants also strongly disagreed with accepting the child that God gives and would not look for what their religion says about having testing. This may be because almost half of the group (12/26) did not have a religion, but also because those who said they had a religious affiliation, would not bring this into the decision:

> "Religion has got nothing to do with it. I wouldn't look for what religion says. If you can't cope then you are allowed to abort a child" (P04)

Health professionals were seen as information providers. Participants disagreed with leaving the decision about testing to health professionals, believing that it was a personal decision that that they should make, based partly on what they would do with the results:

> "Testing is all about knowing the results and consequences of what you do with the results. It's not for a doctor or midwife to say 'you can't have a child with a disability' …it's nobody else's choice" (BW10)

Factor 2: choice informed by religious values: "I accept what God gives"

Q-sorts of 11 participants exemplified this factor: four Pakistani, three African, two British White, one Chinese and one Caribbean woman. One Chinese and three African women had been living in the UK for less than five years.

This account of making a choice was similar to factor 1, where participants wanted to make autonomous decisions and had similar views about involving their partner and others in the decision-making process. However, this account was strongly influenced by religious beliefs. Unlike participants in the other accounts, these participants strongly agreed that they would accept the child that God gives and that they would not have an abortion so there was no point in having testing. They disagreed with valuing the opportunity to think about termination of a child with a condition and strongly agreed with looking to what their religion has to say about having such testing:

> "Religion comes first in making decisions" (P08)

Similar to factor 1, health professionals were perceived as information-providers, but for different reasons. Health professionals were perceived as pro-termination of pregnancy, hence as holding views contradictory to participants' religious beliefs, and therefore, professional advice was perceived as intrusive and putting pressure on the woman to opt for testing:

> "I wouldn't feel like they are helping me. I would feel like they are probing into my life" (A05)

Furthermore, this was the only account in which participants agreed that they should not be tested if they could not decide whether to have testing or not. They also strongly agreed that a decision about testing should only be made after carefully thinking through all the possible consequences of testing:

> "You really want to take the test knowing what's in store for you." (A05)

Participants were not concerned about taking lots of time to make a decision about testing or about making the wrong decision, possibly because they already knew what was right for them based on their religious beliefs. While many of these participants were against termination of pregnancy, they were not necessarily against testing. For example, they agreed that it was important to think about the challenge of bringing up a child with the condition and wanted health professionals to provide information so that they could decide whether or not testing was the right option for them.

Overall, unlike factor 1, these participants wanted to make the decision themselves because they felt that health professionals or others who may give advice were unlikely to share or understand their values.

Factor 3: choice as a shared responsibility: "I want midwives to help me make a decision… I don't want to make it on my own"

Q-sorts of 10 participants exemplified this factor: six Pakistani, two African, one Chinese and one British White woman. One Chinese and two Pakistani women had been living in the UK for five years or less.

Similar to the previous factors, participants wanted to make decisions about testing themselves. They agreed that they would be angry if tested without their permission and disagreed with leaving the decision about testing to health professionals. However, unlike factors 1 and 2, participants strongly disagreed with decision being theirs alone and wanted their partner and health professionals to play an active role in the decision-making process. In some cases, participants also wanted to share the responsibility of this decision with health professionals. Participants also most strongly disagreed with health professionals giving information only, not advice about testing, valuing both information and their advice:

> "The health professional's view is important but you should make the decision about testing. I want their help to come to a decision" (P11)
> "They should say that 'we think you should go for these tests'. I would value their advice… I don't want to take on this responsibility on my own." (P17)

Unlike the previous accounts, participants in this account valued antenatal testing as part of an antenatal care package and did not explicitly recognise that they needed to make a choice about testing. For example, participants strongly agreed that there was no decision for them to make because these tests were just part of good care for pregnant women and perceived testing as part of being a good mother. They believed that antenatal testing had been thought through at a professional level and, therefore, it was important to accept testing. Furthermore, this was the only account in which participants disagreed with the statement 'if I cannot decide whether to have testing then I should not be tested':

> "Health professionals have carefully thought this through for our wellbeing, so I completely agree with them [with having testing]… If health professionals think they are important, then I should have them." (P17)
> "Tests are very important. Every mother wants a healthy baby, that's why it's important to do what doctors midwives say." (P05)

Participants also believed that not everyone could decide for themselves whether or not to have testing and, given the importance of testing, health professionals should test women:

> "I think you should still be tested. Some people get really confused. In fact, I think these tests should be compulsory" (P17)

Furthermore, this was also the only account in which participants agreed that it would be difficult for them to say 'no' to testing when health professionals offered it, and that they would worry about people judging them as being irresponsible if they decided not to have testing:

> "If you don't do the test, people might look at you as irresponsible because you don't know the baby might be sick or have a condition." (A13)

While participants in this account could be characterised as pro-testing, most of them said that they would not opt for a termination. Participants strongly disagreed that they valued the opportunity to think about termination of a child with a congenital condition, and disagreed that there was no point in having testing if they would not have an abortion. Instead, participants valued screening because they wanted information about the health of their baby:

> "Testing doesn't mean that you have to have an abortion. It's important to have test to find out about the health of the baby." (P11)

Factor 4: choice advised by health professionals: "I trust the doctor's opinion"

Q-sorts of seven participants exemplified this factor: five Chinese, one African and one Pakistani woman. All except the African woman had been living in the UK for less than five years.

Similar to factor 3, participants valued antenatal testing as part of the antenatal care package, and strongly agreed with considering themselves fortunate to be offered these tests free of charge. They also agreed that they would discuss testing with their partner, but they disagreed with making the decision with their partner. Instead, the health professionals' views were seen as paramount:

> "I should get an opinion from the medical professionals… When the midwife suggests something, I usually agree because I respect their decision" (C16)

Unlike factor 3, the role of the health professionals in facilitating decisions was central to this account. Health professionals were perceived as having an important role in helping women to make decisions about testing by providing professional advice. Of all the accounts, participants most strongly agreed with health professionals giving them advice, and most strongly disagreed that they should not be asking health professionals to make a decision about whether or not they should have testing. Instead, participants placed emphasis on the need for professional advice in order to help them make the right decision for them:

> "I really trust them… their professional opinion would be placed as very strong in helping me to make a decision" (C16)
> "I need and want the doctor or midwife to help me make the decision" (C05)

This was the only account in which participants agreed that they would prefer not to make the decision about testing because they were scared of making the wrong choice:

> "I don't understand some things, so I need help in making the decision… I'm afraid of making the wrong decision" (C05)

Similar to factor 2, this was the only other account in which some participants agreed that they would accept the child that God gives, and would look for what religion says about such testing. However, unlike factor 2, some of these participants would opt for termination of pregnancy and wanted health professionals to play an active role in the decision-making process:

> "If the child is likely to have a serious abnormality, then it is important to have testing. Our religion allows this, if you are likely to have more problems in the future, then you can have an abortion" (P03)

While this account shows that participants highly valued health professionals' help during the decision-making process, participants clarified that they wanted to retain ultimate control of the decision. They agreed that they would be angry if they were tested without their permission and said that they did not want to be *told* what to do:

> "… they're the experts, but then again they can't tell me what to do" (A03)

Factor 5: choice within the family context: "the decision is not just mine to make"

Q-sorts of two Chinese participants exemplified this factor. Both had been living in the UK for five years or less.

This account focuses on significant others informing, influencing, and even making the decision about testing. Participants most strongly disagreed with not discussing testing with anyone because the decision was theirs alone. Unlike any of the other accounts, participants strongly agreed with involving others in the decision-making process, including parents or siblings, and extended family members:

> "Although I'm the one that's pregnant and the baby is mine, in my tummy, I feel that my partner and the family should have a say… we should discuss this among us" (C12)

Participants agreed that they should make the decision about testing with their partner, and that they would not go against their partner's wishes if they did not agree. In contrast to all the other accounts, participants disagreed with 'I would discuss it with my partner but the decision would be mine', and strongly agreed that they would be happy for their husband to make the decision:

> "Whether it's two people or just one making the decision, the decision is his" (C04)

Similar to factors 3 and 4, participants valued antenatal testing and health professionals' opinions. They strongly disagreed with wanting information only from the health professionals, and strongly agreed that 'doctors should tell me what to do, not ask me to make the decision about testing', but clarified that they wanted to retain ultimate control to make the decision about testing:

> "They can provide the information, but I want to have my right to make the decision and not leave it to them." (C12)

Discussion

The findings show that women interpret 'informed choice' in different ways, challenging the current assumption that autonomous choice is what all women want in relation to antenatal screening. While many women valued informed choice as conceptualised by policy, it was not valued as such universally. Women in factor 1 favoured the individualistic approach and the emphasis on autonomy in current policy and practice supported their world-view of control over their own bodies. Women in factor 2 valued a policy of autonomy because it gave them the freedom to act according to their own (religious) values. In these factors, health professionals were perceived as information providers with little role to play in the decision-making process. In factors 3, 4 and 5, women valued screening as part of the antenatal care package and they saw it as a way of obtaining information on the health status of the baby. In contrast to factors 1 and 2, the women in these three factors *wanted* health professionals to be involved in the screening decision-making process by giving advice and helping women to make decisions that are right for them. Irrespective of the degree to which women wanted health professionals to be involved in the decision-making process, all women wanted to retain ultimate control to consent to the test procedure or not (Deber et al., 1996). Furthermore, in factor five women valued decision-making in the family context, and women in four factors agreed that the decision-making process would involve their partner, albeit to different degrees. Therefore, another dilemma for health professionals may be whether and how to include family members and partners in the decision-making processes, while ensuring that women make autonomous choices.

The factors are not ethnicity specific because women from all five ethnic groups were represented in factors 1 and 2, and from four ethnic groups in factors 3 and 4. Nevertheless, factors 3 and 4 were more representative of Chinese and Pakistani women, and factor five of Chinese women only. Also, unlike factors 1 and 2, most of the women in factors 3, 4 and 5 were non-English speakers and had been living in the UK for five years or less, suggesting that different generations of immigrants may have different beliefs. The need for advice about screening tests in these ethnic groups may be related to cultural practices in their country of origin. For example, screening is not presented as a choice in China, instead women are informed that they should undergo the test (Hall et al., 2007). Furthermore, in a survey in Europe and Asia on whether informed choice in prenatal testing is valued universally (van den Heuvel et al., 2009), only a minority of people from Asian countries (China and India) advocated parental choice compared to the majority of people from Northern European countries (Netherlands and the United Kingdom). Overall, our findings show that *some* women from the minority ethnic groups included in this study, particularly those who did not speak English and/or had recently migrated to the UK, wanted advice from health professionals when making informed choices. Women's education was not related to their views. Certain views were more prevalent in some ethnic groups, but the findings are not culturally specific. The diversity of views amongst the women in this study suggests that health professionals may not need to take different cultural approaches in practice, but should be aware of the diversity of views among women in general as well as within ethnic groups.

Our findings also challenge stereotypes about ethnic differences based on religious beliefs. For example, factor 2 focuses on religious values where women did not want health professionals to be involved in the decision-making process. However, factor 4 shows that just because someone is religious and agrees that they would accept the child that God gives does not mean that they would not opt for termination or that they would not want health professionals to play an active role in decision-making. The findings suggest that ethnicity or religion should not be used as a proxy for an individual's values about antenatal screening or their expectations of the health professional's role in making such choices. They emphasise the significance of recognising diversity within different ethnic groups and considering the beliefs and preferences of the individual.

Not all women in the present study wanted to actively use information they were given to make choices about antenatal screening, which raises ethical concerns. For example, in the present study, women's expectations of the role of health professionals in facilitating informed choice ranged from providing information only to providing directive advice and recommendations for antenatal screening. However, health professionals recognise that they should not be giving women advice (Williams, Alderson, & Farsides, 2002) given that UK antenatal screening policies require them to be non-directive. Our findings suggest that the way in which policy currently defines and implements informed choices is culturally specific and as such might meet the needs of some, may be even most women, but it does not meet the needs of *all* women. A significant minority of women attending for antenatal care appear to want guidance and direction in antenatal test decision-making and prefer health professionals to take what may be considered a 'paternalistic' approach (Taylor, 2000). Given that a policy of autonomous informed choice rejects paternalism, it is argued that policy developers and implementers need to revisit the concept of autonomous informed choice and debate what is permissible in terms of advice giving.

The concept of informed choice in relation to antenatal screening is of interest in many countries with a significant multiethnic population, including the UK, Canada, Australia and the Netherlands (EUROCAT Central Registry, 2010; Lawson & Pierson, 2007; Rowe, Fisher, & Quinlivan, 2006). Developers and implementers of policy need to take account of the range of interpretations of informed choice that women might hold, and their expectations of the health professionals' role in informing choices. Policy needs to consider how best to accommodate these while ensuring that parents make decisions that are right for them.

Study strengths and limitations

To our knowledge, this is the first in-depth study into how women value and differentially interpret informed choice in the context of antenatal screening in a multiethnic population. While this study was conducted with women from five ethnic groups in the UK and in four languages, differences in regulatory, cultural and healthcare settings mean the findings cannot be considered generalisable to other countries where the main ethnic minority groups are different. Q-methodology explores diversity of views rather than prevalence of views, where participants are selected purposively. Therefore the claims about ethnic differences in interpreting informed choice presented in this study are considered to be tentative and exploratory (Stenner et al., 2006) and we do not know the degree to which these views are prevalent in the wider UK population.

Conclusion

Despite the acknowledged limitations, this study clearly shows that people have different understandings of what constitutes an "informed choice". This is an issue for health professionals who have the task of facilitating informed choice in multiethnic populations where everyone may not share 'Western' conceptualisations of the concept. As for other aspects of maternity care, a patient centred approach that values patient needs is essential in antenatal screening, so that women feel in control of important decisions which could have consequences for themselves, their families and their babies. We argue that our findings call for developers and implementers of policy to revisit 'informed choice' in antenatal screening, focussing on the role of health professionals as *facilitators* of informed choice beyond the provision of information. In particular, there is a need to consider whether and how health professionals should give advice when women ask for it without relinquishing non-directiveness as a policy goal, and how to ensure that women who feel unable to make a decision on their own are supported to make a choice which feels informed from their point of view and in line with policy from the health professionals' perspective.

Acknowledgements

This work was supported by the Economic and Social Research Council [grant number RES-061-25-0036]. The authors would like to thank the participants, community midwives, and members of the Project Advisory Group: 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.

References

Ahmed, S., Green, J., & Hewison, J. (2005). Antenatal thalassaemia carrier testing: women's perceptions of "information" and "consent". *Journal of Medical Screening, 12*(2), 69–77.

Ahmed, S., Hewison, J., Green, J. M., Cuckle, H. S., Hirst, J., & Thornton, J. G. (2008). Decisions about testing and termination of pregnancy for different fetal conditions: a qualitative study of European White and Pakistani mothers of affected children. *Journal of Genetic Counseling, 17*(6), 560–572.

Barnett, J., Ogden, J., & Daniells, E. (2008). The value of choice: a qualitative study. *British Journal of General Practice, 58*(554), 609–613.

Birbili, M. (2000). Translating from one language to another. *Social Research Update, 31*, 1–7.

Bowman, K. W., & Hui, E. C. (2000). Bioethics for clinicians: 20. Chinese bioethics. *Canadian Medical Association Journal, 163*(11), 1481–1485.

Brown, S. R. (1980). *Political subjectivity: Applications of Q methodology in political science*. New Haven: Yale University Press.

Brown, S. R. (1993). A primer on Q methodology. *Operant Subjectivity, 16*, 91–138.

Brown, S. (1996). Q Methodology and qualitative research. *Qualitative Health Research, 4*, 561–567.

Bryant, L. D., Green, J. M., & Hewison, J. (2006). Understandings of Down's syndrome: a Q methodological investigation. *Social Science & Medicine, 63*(5), 1188–1200.

Cong, Y. (2004). Doctor-family-patient relationship: the Chinese paradigm of informed consent. *Journal of Medicine and Philosophy, 29*(2), 149–178.

Deber, R. B., Kraetschmer, N., & Irvine, J. (1996). What role do patients wish to play in treatment decision making? *Archives of Internal Medicine, 156*, 1414–1420.

Deber, R. B., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2007). Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expectations, 10*(3), 248–258.

Elliott, A. C. (2001). Health care ethics: cultural relativity of autonomy. *Journal of Transcultural Nursing, 12*(4), 326–330.

EUROCAT Central Registry. (2010). EUROCAT special report: prenatal screening policies in Europe 2010. University of Ulster.

Fagan, A. (2004). Challenging the bioethical application of the autonomy principle within multicultural societies. *Journal of Applied Philosophy, 21*(1), 15–31.

General Medical Council. (1998). *Seeking patients' consent: The ethical considerations*. London: GMC.

Green, J. M., Hewison, J., Bekker, H. L., Bryant, L. D., & Cuckle, H. S. (2004). Psychosocial aspects of genetic screening of pregnant women and newborns: a systematic review. *Health Technology Assessment, 8*(33).

Hall, S., Chitty, L., Dormandy, E., Hollywood, A., Wildschut, H. I., Fortuny, A., et al. (2007). Undergoing prenatal screening for Down's syndrome: presentation of choice and information in Europe and Asia. *European Journal of Human Genetics, 15*, 563–569.

van den Heuvel, A., Chitty, L., Dormandy, E., Newson, A., Attwood, S., Ma, R., et al. (2009). Is informed choice in prenatal testing universally valued? A population-based survey in Europe and Asia. *BJOG, 116*(7), 880–885.

Hofstede, G. (1988). *Culture's consequences: International differences in work related values*. Beverly Hills, CA: Sage Publication.

Iyengar, S. S., & Lepper, M. R. (1999). Rethinking the value of choice: a cultural perspective on intrinsic motivation. *Journal of Personality and Social Psychology, 76*(3), 349–366.

Jafarey, A. M., & Farooqui, A. (2005). Informed consent in the Pakistani milieu: the physician's perspective. *Journal of Medical Ethics, 31*(2), 93–96.

Kagu, M. B., Abjah, U. A., & Ahmed, S. G. (2004). Awareness and acceptability of prenatal diagnosis of sickle cell anaemia among health professionals and students in North Eastern Nigeria. *Nigerian Journal of Medicine, 13*(1), 48–51.

Kitzinger, C. (1987). *The social construct of Lesbianism*. Bristol: Sage.

Lawson, K. L., & Pierson, R. A. (2007). Maternal decisions regarding prenatal diagnosis: rational choices or sensible decisions? *Journal of Obstetrics and Gynaecology Canada, 29*(3), 240–246.

Moazam, F. (2000). Families, patients, and physicians in medical decision making: a Pakistani perspective. *Hastings Centre Reports, 30*(6), 28–37.

NHS FASP. (2010). *Fetal Anomaly Screening Programme*.

National Institute for Health and Clinical Excellence [NICE]. (2008). *NICE clinical guideline 62. Antenatal care: Routine care for the healthy pregnant woman*.

O'Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Col, N. F., Eden, K. B., et al. (2009). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Systematic Reviews*, (3), CD001431.

Prasad, R. S. (2001). Development of the HIV/AIDS Q-sort instrument to measure physician attitudes. *Family Medicine, 33*(10), 772–778.

Robinson, A., & Thomson, R. (2001). Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *Quality in Health Care, 10*(Suppl. 1), i34–i38.

Rowe, H. J., Fisher, J. R., & Quinlivan, J. A. (2006). Are pregnant Australian women well informed about prenatal genetic screening? A systematic investigation using the multidimensional measure of informed choice. *Australian New Zealand Journal of Obstetrics and Gynaecology, 46*(5), 433–439.

Stainton Rogers, W. (1991). *Explaining health and illness: An exploration of diversity*. Brighton: Harvester Wheatsheaf.

Stainton Rogers, W. (1995). Q methodology. In J. A. Smith, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 178–192). London: Sage.

Stenner, P. H., Bianchi, G., Popper, M., Supekova, M., Luksik, I., & Pujol, J. (2006). Constructions of sexual relationships: a study of the views of young people in Catalunia, England and Slovakia and their health implications. *Journal of Health Psychology, 11*, 669–684.

Stenner, P. H., Cooper, D., & Skevington, S. M. (2003). Putting the Q into quality of life; the identification of subjective constructions of health-related quality of life using Q methodology. *Social Science & Medicine, 57*(11), 2161–2172.

Taylor, I. (2000). Some patients are happy for doctors to make decisions. *British Medical Journal, 320*, 58.

Watts, S., & Stenner, P. (2005). Doing Q methodology: theory, method, and interpretation. *Qualitative Research in Psychology, 2*, 67–91.

Williams, C., Alderson, P., & Farsides, B. (2002). Is nondirectiveness possible within the context of antenatal screening and testing? *Social Science & Medicine, 54*(3), 339–347.

World Health Organization. (2006). *Medical genetic services in developing countries: The ethical, legal and social implications of genetic testing and screening*.