



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

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### 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.

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### 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

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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

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