

Cross-cultural values of 'informed choice' in antenatal screening

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Introduction

- UK NHS antenatal screening policies \Rightarrow informed choices
- Guided by the ethical principle of autonomy
- Other cultures place less emphasis on autonomy^{1, 2} and the family plays a more pivotal role in healthcare decisions³
- Not everyone wants to make healthcare decisions⁴
- Insisting people make decisions \Rightarrow unethical⁵

Do all pregnant women want to make autonomous informed choices about antenatal screening?



Aim of the study

To explore:

- diversity in the value attached to autonomous informed choice in antenatal screening
- similarities and differences in this value in women from different ethnic origins



Method: Design



This study used Q methodology⁶

- a structured approach to the study of subjectivity
- identifies stories that can be told about a topic



Method: Participants

Ninety-eight women
(mothers of newborns):

- 18 African
- 11 Caribbean
- 23 Chinese
- 23 British White
- 23 Pakistani



Method: The Q Set

41 statements about 'informed choice'

one slide - one year!

⇒ Literature review

⇒ 24 interviews... having vs making choice

⇒ Theoretical framework

⇒ Feedback questionnaire



Method: Q Set translation

English

1. It's best to take one step at a time – to have the tests and not worry about what could happen after that.
2. It is important for me to think about the challenge of bringing up a child with the condition.
3. I think that the offer of tests suggests that people with these conditions are worth less than others.
4. I would worry about the child with the condition being treated badly by society.
5. I would look for what my religion says about having such testing.
6. I would not discuss testing with anyone because the decision is mine alone.
7. I would be angry if I was tested without being asked for my permission.
8. Doctors/midwives should give me their professional advice about whether to have testing.
9. I would leave the decision about testing to doctors/midwives.

10. If lots of other people are having testing, then testing would be fine by me.
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.
12. There is no decision for me to make because the tests are just part of good care for pregnant women.
13. It is difficult for me to say 'no' to testing when doctors/midwives offer it.
14. I would take lots of time to make a decision about testing.
15. Having too much information about the tests makes it difficult to make decisions.
16. I find it hard to make a decision about testing because there are too many decisions to make in pregnancy.
17. I would discuss it with my partner/husband but the decision would be mine.
18. I would not want to go against my partner/husband's wishes, so if we disagree, I would do what he wants.

19. Me and my partner
20. I
21. I
22. I
23. I
24. I
25. I
26. I
27. I

Mandarin

1. 最好是一步一步来 – 先做检测而不去担心检测之后的事。
2. 我认为事先考虑清楚抚养一个非正常婴儿的难度是很重要的。
3. 我认为提供这些检测足以说明非正常人群比正常人群低人一等。有这些问题的婴儿比起正常婴儿是一文不值的。
4. 我会担心社会不能正确对待非正常儿童。
5. 我会寻求我的宗教有关这些检测的说法。
6. 关于检测和测试，我不确定。

10. 如果很多其他人都接受这个检测，那么我也接受。
11. 关于这些检测的决定并不比其他的常规孕期检测（比如血压，糖尿病）难做。
12. 我不需要做什么决定，因为这些检测都是呵护孕妇的重要组成部分。
13. 当医生助产士向我提供某个检测时，我觉得很难说“不”。
14. 我会花很长的时间来做出对这些检测的决定。
15. 太多的关于这些检测

19. 我和我的丈夫/爱人应该决定。
20. 参与决定。
21. 兄弟态度。
22. 意见的决。
23. 确定。
24. 决定。

Urdu

- 19- مجھے اور میرے خاندان کو ٹیسٹ کرنے سے باز رکھنا چاہیے۔
- 20- میں اپنے سربراہوں کو ٹیسٹ کے فیصلے میں شامل نہیں کروں گی۔
- 21- میں ٹیسٹ کرنے کے لیے اپنے والدین یا کون بھائیوں سے مشورہ کروں گی۔
- 22- میرے والدین یا کون بھائیوں کے خیالات میرے ٹیسٹ کے بارے میں فیصلے پر اثر انداز ہوں گے۔
- 23- میرے سربراہوں کے خیالات

- 10- اگر بہت سارے لوگ ٹیسٹ کر رہے ہیں تو میرے ٹیسٹ لینے کی ہمت کرنا ہوگی۔
- 11- حمل کے دوران عام صحت کے ٹیسٹوں کے مقابلے میں، بہرہ کے پائے پائے یا جانکے ٹیسٹوں، ان ٹیسٹوں کے بارے میں غلط فہمی زیادہ مشکل نہیں۔
- 12- مجھے فیصلہ کرنے کی ضرورت نہیں ہے کیونکہ یہ ٹیسٹ حمل اور تان کی ایک وجہ والی بات کا ایک حصہ ہیں۔
- 13- جب ڈاکٹر/مڈوائف (ڈی) کے ٹیسٹوں کے بارے میں کسی سے بات کرنا مشکل ہے۔

- 1- میرے لیے یہ کہنا آسان ہے کہ آپ بہت سے لوگ ٹیسٹ کر رہے ہیں اور میں بھی کرنا چاہتی ہوں۔
- کہ میں
- دلنی
- ہائے کی
- تے کتہ
- ہی کی
- نی کرنا

French

1. C'est mieux de prendre chaque chose en son temps : d'avoir les analyses et de ne pas s'inquiéter de ce qui pourrait arriver après ça.
2. C'est important pour moi de penser au challenge d'élever un enfant avec la maladie.
3. Je pense que l'offre d'analyses insinue que les gens qui ont ces maladies sont moins importants que les autres.

9. Je laisserais la décision au sujet des analyses aux médecins/sage-femmes.
10. Si beaucoup de gens avaient les analyses, alors je n'y verrais pas d'inconvénient.
11. La décision à prendre au sujet de ces analyses n'est pas plus difficile que pour les examens de routine durant la grossesse, tels que la pression artérielle de la mère ou le diabète.
12. Il n'y a aucune

17. J'en parlerais avec mon partenaire/mon mari, mais la décision serait la mienne.
18. Je ne voudrais pas agir contre les désirs de mon partenaire/mon mari, donc si nous n'étions pas d'accord, je ferais ce qu'il voudrait.
19. Moi et mon partenaire/mari devrions prendre la décision ensemble au sujet des analyses.
20. Je garderais ma belle-famille hors du

Back-translated into English

7. 我的检测，我
8. 医生助产士应该在是否接受某个检测的问题上向我提供他们的专业建议。
9. 我会把是否接受某个检测的决定留给医生助产士来做。

- 的过程中有太多的决定要做。
17. 我会和我丈夫/爱人商量，但是最终的决策权是我的。
18. 我不会反对我丈夫/爱人的意见。如果我们意见相左，我会遵循他的意见。

26. 测试是分。
27. 产士检测
28. 医生助产士应该在是否接受某个检测的问题上向我提供他们的专业建议。
29. 我会把是否接受某个检测的决定留给医生助产士来做。

- (ڈی) صرف معلومات دینا نہ سکتے کرواٹے چاہیں کہ نہیں، نہ کہ خود۔
- 26- میں سمجھتی ہوں کہ ڈاکٹر/مڈوائف (ڈی) ٹیسٹ کرنے کا نہ کہنے کر، وہ ضروری نہ ہوتے۔
- 28- میں سمجھتی ہوں کہ بہ ٹیسٹ کرنا، ایک ایسی بات ہے کہ ایک حصہ ہیں۔
- 27- میں چاہوں گی کہ ڈاکٹر/مڈوائف (ڈی) مجھے میرے ٹیسٹ کے فیصلے میں مدد کے لیے معلومات دیں۔

- ہوں تو فیصلہ کرنا مشکل ہو جاتا ہے۔
- 16- مجھے ٹیسٹ کے لیے فیصلہ کرنا مشکل لگتا ہے، کیونکہ حمل کے دوران بہت سارے فیصلے کرنے ہوتے ہیں۔
- 17- میں یہ اپنے خاندان کے بات کروں گی لیکن فیصلہ میرا ہوگا۔
- 18- میں اپنے خاندان کی خواہشات کے خلاف نہیں چاہتا ہوں گی، اگر ہم رضامندی نہ ہوتے تو میں وہی کروں گی جو وہ چاہتے گا۔

5. Je chercherais à savoir ce que ma religion dit à propos d'avoir de telles analyses.
6. Je ne discuterai de ces analyses avec personne car la décision est la mienne.
7. Je serais en colère, si on me faisait ces analyses, sans me demander ma permission.
8. Les médecins/sage-femmes devraient me donner leurs conseils professionnels au sujet d'avoir les analyses ou pas.

14. Ça me prendrait beaucoup de temps pour prendre une décision au sujet des analyses.
15. Le fait d'avoir trop d'informations sur les analyses, fait que c'est difficile de prendre des décisions.
16. Je trouve que c'est difficile de prendre une décision au sujet des analyses parce qu'il y a trop de décisions à prendre durant la grossesse.

22. L'opinion de mes parents frères/soeurs influencerait ma décision à propos des analyses.
23. L'opinion de ma belle-famille influencerait ma décision à propos des analyses.
24. Je pense que les médecins/sage-femmes devraient seulement donner des informations, pas des conseils à propos d'avoir les analyses ou pas.
25. Je crois que les médecins/sage-femmes n'offriraient pas les analyses, si ce n'était pas important de les avoir.

Method: Procedure (I)

When offered antenatal screening tests...

Disagree

No strong views

Agree

Sorting the piles

Participants asked to place the statements on a larger grid...

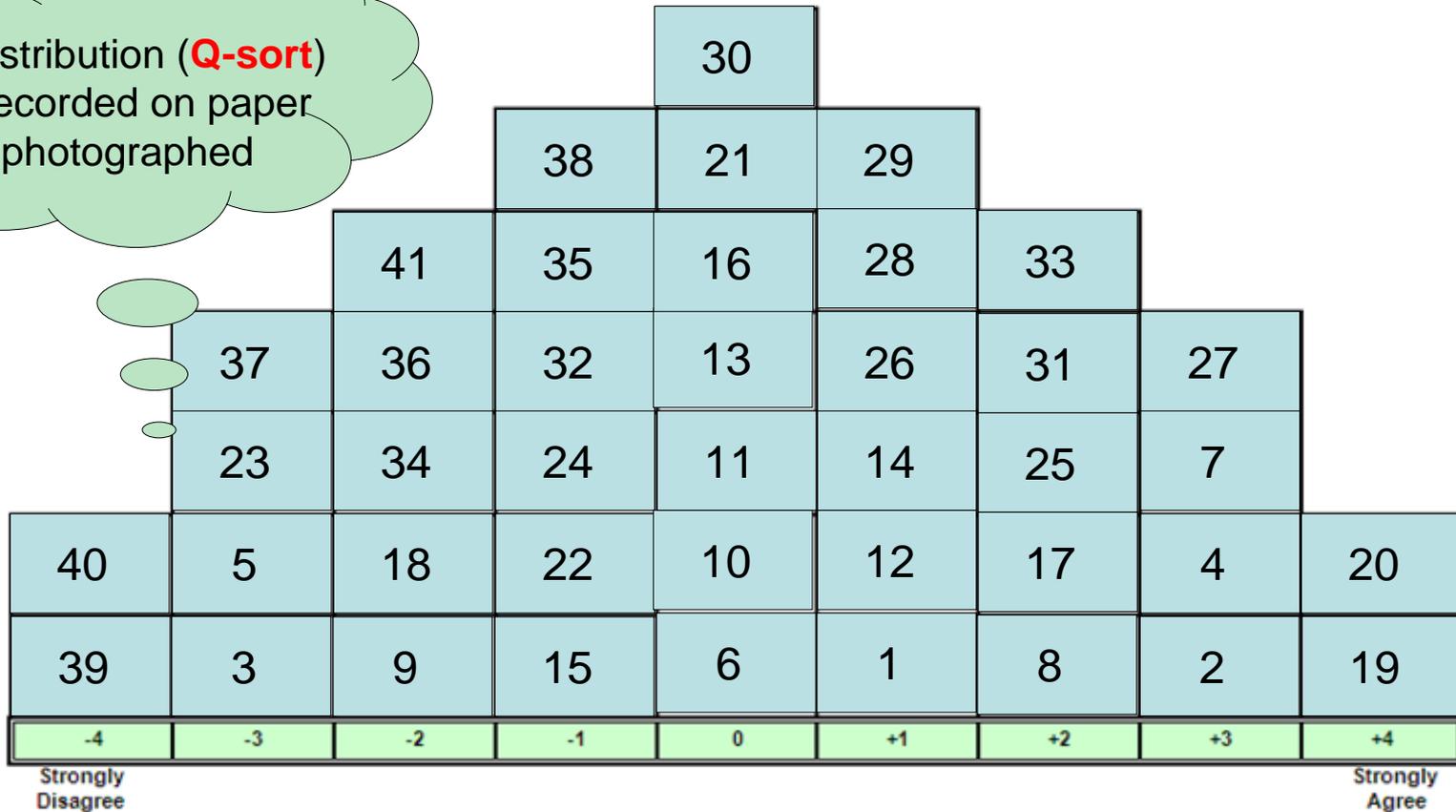
9 I would leave the
d 20 I would keep my
te 12 There is no
d 14 I would take lots
p 40 Doctors should
t n o 8. Doctors/midwives
t t d should give me their
g p p professional advice
t t about whether to
p t have testing.



Method: Procedure (II)

When offered antenatal screening tests...

This distribution (**Q-sort**) was recorded on paper & photographed



Post Q sort interviews: Participants asked why they placed items in two extreme columns (tape recorded)



Analysis

- Used Principle Components Analysis – by person
- Selected five factors (view points) for interpretation
- Identified exemplar Q sorts – best representing factor
- Constructed weighted averages for each factor



Factor Interpretation

Factor 2

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

Distinguishing statements

Consensus statement

+ Post Q-sort interviews

+ Exemplars' demographics

Strongly disagree

Strongly agree



View 1: Choice as an individual right: “My body, my baby, my decision”

26 exemplars: 6 Chinese, 2 Pakistani, 12 British White,
4 African, 2 Caribbean

- **Personal autonomy** – mother’s right to make decision
 - ✓ angry if tested without permission
 - ✓ think about challenges of brining up child with condition/ implications for the mother and other children
 - ✓ take time to make a decision
- **Joint decision with their partner...**
- **Religion and family members opinions** were not important
- **Health professionals** ⇒ information providers only



View 2: Choice informed by religious values: “I accept what God gives”

11 exemplars: 3 African, 4 Pakistani, 2 British White,
1 Chinese, 1 Caribbean

- **Personal autonomy – religious beliefs**

- ✓ accept the child that God gives

- ✓ not have an abortion

- ✓ look to what religion states about having such testing

- ✗ value opportunity to think about termination of an affected child

- Were least concerned about society’s attitudes or being judged as irresponsible and agreed that they would not find it difficult to say ‘no’ to testing

- **Health professionals ⇔ information providers only: HPs**
→ pro-termination → contradictory to religious beliefs



View 3: Choice as a shared responsibility:

“I want midwives to help to me make a decision... don't want to make it on my own”

10 exemplars: 2 African, 6 Pakistani, 1 British White,
1 Chinese

- **Their decision to make with their husband, but:**
 - × decision being theirs alone
 - × being given information only
- **Screening valued as part of antenatal care package**
- **Health professionals ⇒ give advice and help in decision-making**



View 4: Choice advised by health professionals: “I trust the doctor’s opinion”

7 exemplars: 1 African, 1 Pakistani, 5 Chinese women

- **Health professionals only** ⇒ **give advice and help in decision-making**
- Pro-testing and perceived health professionals as ‘wanting the best for the mother and baby’
- Consider themselves ‘fortunate to be offered testing’
- Retain ultimate control of the decision
 - ✓ Angry if tested without permission
 - ✗ Did not want to be *told* what to do



View 5: Choice within the family context: “The decision is not just mine to make”

2 exemplars: Chinese

- **Others informing, influencing and making the decision**
 - ✓ Would be happy for their husband to make the decision
 - ✓ “the doctor should tell me what to do, not ask me to make the decision about testing”
 - ✗ wanting information only
 - ✗ using their own judgement to make a decision
 - ✗ being angry if tested without being asked for their permission



Themes

- **Theme 1 (view 1 and 2):**
women want to make decisions on their own
- **Theme 2 (view 3, 4 and 5):**
women want others to help them make the decision,
particularly health professionals

Do all pregnant women want to make autonomous informed choices about antenatal screening?

No... not on their own



Summary

- Women interpret informed choice' in different ways
⇒ challenge current assumptions that all women want autonomous choices
- Theme 1 ⇒ Women from all five ethnic groups
Theme 2 ⇒ Women from four ethnic groups
Hence, findings not ethnicity specific (education; migration)
- Theme 1 in line with current policy on autonomous informed choices
- Theme 2 suggests women seek and value the 'advice' of health professionals – but retain ultimate control



Implications for policy & practice

- Diversity of views \Rightarrow HP may not need to take different cultural approaches in practice
- UK screening policies require health professionals to provide information and be non-directive
- Variation in women's expectations poses challenges for HP in practice
- Policy needs to revisit 'informed choice' and the challenges and implications for HP, particularly giving 'advice'



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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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