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Title

Decision-making for non-invasive prenatal testing for Down syndrome: Hong Kong Chinese women's preferences for individual versus relational autonomy

Short Running Title

Decision-making for NIPT among Chinese women

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Conflict Of Interest

The authors declare no conflict of interest.

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Decision-making for non-invasive prenatal testing for Down syndrome: Hong Kong Chinese women's preferences for individual versus relational autonomy

Abstract

Individual autonomy in antenatal screening is internationally recognised and supported. Policy and practice guidelines in various countries place emphasis on the woman's right to make her own decision and are related to concepts such as self-determination, independence, and selfsufficiency. In contrast, the dominant perspective in Chinese medical ethics suggests that the family is pivotal in making medical decisions, hence providing support for relational autonomy. This study explored Hong Kong Chinese pregnant women's preferences for individual versus relational autonomy for non-invasive prenatal testing (NIPT) for Down syndrome. A qualitative study carried out using semi-structured interviews with 36 women who had undertaken NIPT in Hong Kong. The findings show that most Hong Kong Chinese women valued aspects of both relational and individual autonomy in decision-making for NIPT. Women expected support from doctors as experts on the topic and wanted to involve their husband in decision-making while retaining control over the outcome. Somewhat surprisingly, the findings do not provide support for the involvement of family members in decision-making for NIPT. The adequacy of current interpretations of autonomy in prenatal testing policies as an individual approach needs discussion, where policy developers need to find a balance between individual and relational approaches.

Introduction

Antenatal screening programmes for Down syndrome (DS) usually entail first trimester screening using a combination of maternal age, fetal ultrasound and maternal serum biomarkers.¹ Women with a high-risk screening result are offered invasive prenatal diagnostic tests (IPD), which carry the risk of miscarriage of 0.5 to 1%.² Advances in prenatal testing have led to the development of non-invasive prenatal testing (NIPT) for DS.³ NIPT utilises cell-free fetal DNA in the maternal plasma, and has an accuracy rate of over 99% for DS, with a false positive rate around 0.1%,⁴ so it is highly accurate, but not a diagnostic test for DS. Therefore, confirmatory IPD is recommended for women following a NIPT result indicating that the fetus has DS.

NIPT is available commercially around the world,⁵ for use as the initial screening test, in addition to or instead of combined screening, or as a test after a high-risk combined screening result (also known as contingent screening). NIPT for DS is not yet offered via public services, although trials are ongoing to explore its implementation within national screening programmes as a contingent screening test.⁶ There is also much literature on the ethical, legal and social implications of NIPT.⁷⁻⁹ In particular, there are calls for careful consideration in implementing NIPT in the public sector to ensure women make autonomous informed decisions.⁷

Patient autonomy in antenatal screening is internationally recognised and supported.^{10,11} Autonomous decision-making requires an understanding of the options presented and intentional action without undue influence from others.¹² An informed decision 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'.¹³ This interpretation of autonomy places emphasis on the individual's right to make his/her own decision and is related to concepts such as self-determination, independence, and selfsufficiency.¹⁴ However, this individual approach to autonomy assumes that provision of information leads to knowledge and understanding, and enables patients to deliberate and make rational decisions independently. It ignores individual differences and does not take into account individual preferences for decision-making.¹⁵

Relational autonomy also emphasises the importance of personal autonomy, but recognises that individuals are socially embedded and that their identities are shaped within the context of social relationships and social determinants¹⁶ and that patients may not view themselves as independent decision-makers.¹⁷ Unlike Western societies, in other cultural contexts, relational autonomy is more acceptable than individual autonomy. For example, in traditional Chinese ethics "a person is relation-based",¹⁸ where family involvement and consideration of family interests can be seen as fundamental in promoting patient autonomy.^{17,19} The family plays a significant role in healthcare decision-making in Chinese populations.²⁰ Accordingly, there is much literature on Chinese patients' preferences for relational autonomy in various fields of medicine.²⁰⁻²² Similarly, in Chinese society and culture, the husband and his family are expected to play a pivotal role in decision-making about the health and wellbeing of the mother and fetus. However, the involvement of family members in decision-making could also impinge on patients' individual autonomy.²³

Chinese traditional values are still deeply rooted in Hong Kong's population.¹⁷ Yet in contrast to the literature that predominantly supports relational autonomy in Chinese populations, guidelines for health professionals on antenatal screening for DS in Hong Kong reflect the Western model of individual autonomy.²⁴ The concepts of 'relational' and 'individual' autonomous decision-making within the context of antenatal screening in Hong Kong are

important to explore to enable health professionals to support the decision-making process in a way that is valued by patients.

Hong Kong has a government funded combined screening programme for DS, plus much antenatal care also operates within the private sector, resulting in overlap between public and private services.²⁵ Health professionals within public sector hospitals informing women of their high-risk combined screening result, are also likely to inform them about the private availability of NIPT. The cost of NIPT at the time of this study was between 6,000-8,000 Hong Kong Dollars (approximately 750-1,000 US Dollars), depending on the test provider. Although this raises a number of ethical issues in itself,²⁶ Hong Kong offers the opportunity to explore women's preferences for autonomous decision-making for NIPT as a contingent screening test. An understanding of such preferences could enable health professionals to support decisionmaking for NIPT according to women's values. Therefore, this study aimed to explore Hong Kong Chinese pregnant women's preferences for individual versus relational autonomy in decision-making about NIPT for DS, through their experiences and preferences for involving other people in the decision-making process.

Materials and Methods

Participants

Purposive sampling was used to recruit pregnant women attending for NIPT which was available privately within the Fetal Medicine Unit of a public hospital. Inclusion criteria included women who had undertaken combined screening and NIPT, and were Hong Kong-Chinese residents. These women had opted for NIPT after receiving a risk result for DS following combined screening. All women were informed about their high-risk result (usually a risk ratio of higher than 1 in 250) and subsequent testing options by a nurse via telephone. Women were recruited by the first author while they waited for their blood test for NIPT, during June to December 2012. Women interested in participating provided their details and were contacted by telephone two weeks later to gain consent for participation, enquire about the NIPT results and arrange an interview. One hundred fifty-five women were approached and 107 (69%, 107/155) initially agreed to participate and provided their contact information. Thirty-two of these women were excluded because they did not have combined screening (n=9) or had received a high risk NIPT result (n=23). When arranging interviews, 11 women were not contactable using the information provided and 28 declined to participate mainly because they had changed their mind. Thirty-six women participated in the study. The sampling strategy ensured diversity in terms of age, educational attainment and household income. At the time of the interviews, all participants were married, pregnant, had received their NIPT results (all showing that the fetus did not have DS) and had decided to continue with their pregnancy without opting for IPD.

Procedures

An interview guide was developed to explore women's approach to decision-making for NIPT, including their perceptions of the role of healthcare providers, their husband, family members and friends. All participants gave written consent to participate. In-depth interviews were conducted by the first author, either at the interviewee's home or at the Chinese University of Hong Kong. All the interviews were conducted face-to-face in Cantonese, lasted approximately 60-90 minutes, and data saturation was achieved. Interviews were audio-recorded, translated into English and transcribed verbatim. The study received approval from the Chinese University of Hong Kong - Hospital Authority Clinical Research Ethics Committee and Survey and Behavioral Research Ethics Committee.

Qualitative analysis

Thematic analysis was used to analyse the transcripts, using an inductive approach.²⁷ The first five interviews were coded independently by the first and second authors, who identified themes relating to women's preferences and experiences of involving other people in decision-making for NIPT, including who they preferred to involve, how and why, and who was excluded and why. They then discussed emerging themes at length and agreed a coding framework for use by the first author to analyse subsequent interview data. These themes were cross-referenced for associations with women's socio-demographic details (age, educational attainment, and household income) to compare responses. On completion of initial analysis, the themes were discussed, refined and finalised by all the authors, ensuring consistency, credibility and reliability in the interpretation of the data. All names used in the findings are pseudonyms.

Results

Sample characteristics

Interviews were conducted with 36 Hong Kong Chinese women, most of who were over 30 years old, with a high household income (Table 1). These 36 women were receiving antenatal care in various hospitals. All of the women from the same public hospital within which NIPT was being conducted had received a high-risk screening result (n=11), and the remaining 26 women were from another public (n=20) or private (n=5) hospital who had received a high-risk (n=19) or low-risk (n=6) screening result. All women with a high-risk screening result had been offered the options of NIPT, IPD or continuation with pregnancy without any further testing. The six women with a low-risk had opted for NIPT because they wanted a test with more accurate results than combined screening. The reproductive history of the women is presented in Table 2.

[Table 1 and 2 Here]

Qualitative findings

Key concerns for women in deciding whether to opt for NIPT or IPD, were the accuracy of the test results and the safety of the test. Women believed that while NIPT was attractive because of its risk-free characteristic, it would provide a result with 99.1% sensitivity hence understood that it was not diagnostic, and while IPD was attractive because of the diagnostic result, it involved taking the risk of miscarriage. The findings show that women needed information and support to decide whether or not NIPT was the best option for them.

Health professionals as expert advisers and decision facilitator

Women valued advice and support in decision-making, particularly from doctors, showing a preference for relational autonomy. Health professionals were seen as experts, with the ability to provide professional advice based on knowledge and experience of various prenatal tests. Women would have valued discussion and doctors' advice about the advantages and disadvantages of NIPT compared to IPD. While some women had received the opportunity to discuss NIPT with a health professional, most of them had not:

...if the accuracy of NIPT was 100%, not 99.1%, I wouldn't even ask my doctor for advice! (Aged 34, high-risk)

My doctor said that I should take NIPT rather than amniocentesis which was risky. ...we thought it's better to ask the doctor. (Aged 34, high-risk)

They're so busy they don't have time to talk to you about it (NIPT). (Aged 41, low-risk) Most women's accounts of information provision suggest lack of advice and pre-test counselling by some health professionals, hence lack of support in decision-making about NIPT. Instead, health professionals directed women to written information about NIPT and informed them that they would need to make sense of the information and decide about the best option themselves: When I asked for more information, my doctor introduced me to the official website and told me to read over it myself. (Aged 35, low-risk)

...*the n*urse on the phone said "I*t's useless asking the doctor*... *you still need to make the* decision yourself!" (Aged 34, high-risk)

On further exploring information about NIPT, some women found that the test would also provide information about Edward (T18) and Patau (T13) syndromes. This led to further confusion for women about NIPT, and them wanting clarification from their doctor. However, some women found that their doctor was unable to provide information about these additional conditions in a way that they could understand, leading to concerns about health professionals' knowledge about NIPT:

The doctor failed to explain what they (T13 and T18) are... telling me that they're about structural tissue...(Aged 43, low-risk)

Interestingly, women also explained that they would go against doctors' advice if this contradicted their values, suggesting that while they valued relational autonomy, they were able to exercise their individual autonomy.

Husband as shared-decision maker and source of emotional and financial support

Most women said that they involved their husband in decision-making about NIPT, providing further evidence for their value of relational autonomy. This was mainly because they believed it was important to make a shared-decision with the father of the baby:

...he's the dad! I thought I'd better ask him and not just decide myself. (Aged 29, high-risk)

The findings on involving their husband also show women's value of individual autonomy. For example, some women had made the decision to opt for NIPT themselves and informed their

husband of their decision. They explained that this ability to take the lead in decision-making was due to the 'risk-free' characteristic of NIPT:

I made the decision and then discussed it with my husband... because a blood test doesn't carry any risk. (Aged 31, high-risk)

Some of the women who received a high-risk screening result explained that they had felt pressure from their husband to opt for IPD. They believed this was mainly because of the higher cost of NIPT and because their husband was likely to believe that IPD would not lead to miscarriage. Nevertheless, these women persuaded their husband to pay for the test and explained that if the couple continued to disagree, as the mother of the baby, they had the right to make the ultimate decision and that they would have still opted for NIPT:

I wanted to see if he'd care more about money than the baby... I'd still go for NIPT even if he said 'no'. (Aged 39,high-risk)

These women did not want to opt for IPD mainly because of the risk of miscarriage. They believed that the 'highly accurate', 'easy' and 'risk-free' characteristics of NIPT gave them more control over their pregnancy and allowed them to reach a compromise with their husband:

In the end he said "This one is 99.1% accurate, so take this one and forget about the needle!" ...we both reached a compromise and I went for NIPT. (Aged 38, low-risk)

Similarly a woman with a twin pregnancy did not want any further testing because she thought that only one baby may have the condition and that IPD could put both babies at risk. For this woman, NIPT was an 'easy' and 'risk-free' alternative, and she believed that the highly accurate (negative) result would enable her to justifiably argue against IPD:

I thought 'why not just leave it? (all further testing)' ... Then I thought, "Why not? It's only a blood test and I could get confirmation!" (Aged 39, high-risk)

A number of women, particularly those with a high-risk screening result, described their husband as a source of emotional support during this challenging time, providing support for relational autonomy. This role involved husbands obtaining and synthesising information about NIPT, reassuring women that NIPT was a safer option than IPD and providing financial support:

My husband was so *rational and even did the calculations*. ...he *said "The probability of getting a normal (NIPT) result, but an abnormal outcome is very, very slim" (Aged 38, high-risk)*

My husband said, "We don't have much money, but if money can buy sense of relief, then it's okay (to have NIPT)! (Aged 35, low-risk)

Family members as unable to support decision-making

In contrast to relational autonomy, most women reported not involving family members in decision-making about NIPT. Women generally referred to their parents/parents-in-law (elders), explaining that there was a generation gap, mainly because elders' lacked experience of current antenatal tests, and had misunderstandings about DS and inheritance:

My mother is from an older generation and wouldn't understand what we've been through... She might think "our family doesn't have any problems"... But, I was told Down's could happen besides heredity! (Aged 37, high-risk)

Another reason women did not involve elders in decision-making was because they would have to share their high-risk screening result, which they thought could be emotionally distressing for their elders. Women said they would have also found it difficult to explain differences between the various tests, including those that they had already taken and subsequent options. Women also believed that their elders could misinterpret a high-risk screening result as their baby having the condition: ...because they (our parents) wouldn't be able to understand it... They didn't even have ultrasound when they had me... They might not even know what Down's syndrome is! (Aged 35 low-risk)

I haven't told my parents yet as they may become more worried! ...they might think or imagine that the baby has DS! (Aged 31, high-risk)

Most of the women also explained that there was no need to involve family members in decisionmaking about NIPT because the test was risk-free:

...there's no risk to the baby, I can just decide for myself without scaring the elders!

(Aged 29, high-risk)

Some women also believed that their elders may have opposing views to theirs, indicating that a discussion with them would have meant having to take their views into consideration, hence providing further evidence against relational autonomy. In line with individual autonomy, these women preferred to remain in control of their pregnancy:

People like my mother-in-*law would come up with a quick solution like abortion... I've* carried this baby for several months already... it's my baby, I feel differently to how they feel! (Aged 38, high-risk)

Some women explained that while they would not involve their elders in decision-making about NIPT, they may inform them out of respect:

They're the grandparents (of the baby)...I've discussed with my mom and said, "I'd still take this test even if you opposed!" (Aged 34, high-risk)

At most, some of the women discussed their situation with their sister(s), but only those who had been pregnant themselves, because they were believed to have experiential knowledge that could be useful for decision-making: I talked to my sister about tests for DS, because she could understand and she knew about my concerns. (Aged 35, high-risk)

Only one woman described involving other family members in decision-making about NIPT. This woman had a low-risk screening result. However, her husband had concerns about the baby having DS, because of his family history of autism, and therefore insisted on IPD. The woman disagreed with her husband's decision and sought the support of her in-laws, who were supportive of her decision to opt for NIPT as a safer option:

Everybody said, "Absolutely no (to IPD)! There's danger! (Aged 38, low-risk) Overall, most women did not involve other family members in decision-making about NIPT.

Other women as a source of experiential information

Friends can provide an important support network. However, again in contrast to relational autonomy, women did not involve their friends in decision-making about NIPT, mainly because the matter was personal. Some women believed that sharing their high-risk screening results with their friends could have long-term adverse consequences, particularly stigmatization:

...once the baby is born, people would be like 'Hey, let me check, does it look like a baby with Down's syndrome!' I don't want them to have such suspicions. (Aged 38, high-risk)

While women did not involve friends in decision-making, some of them discussed their decision to opt for NIPT with friends who already had children to explore their experiences of prenatal tests, particularly friends who had had IPD, or friends who were medically trained. Many women also reported participating in discussion groups on the internet to explore other women's experiences of prenatal tests. In line with individual autonomy, women believed such experiential knowledge enabled them to discuss their concerns openly in a safe environment to think about the best option for themselves. *I've read and asked the mums' opinions online.... They shared their experiences, and the* pros and cons...after hearing from them, I firmly decided to have NIPT (Aged 36, high-risk)

Discussion

Most women valued aspects of both relational and individual autonomy in decision-making for NIPT. In terms of relational autonomy, they expected support from health professionals to enable them to understand their options and the implications of these options for their pregnancy. Next, they placed emphasis on the role of the husband in shared-decision making, acknowledging his rights as the father of the baby and his role in providing emotional support. Some women also referred to the importance of drawing on other women's experiential knowledge of NIPT through internet resources. Women valued and gained input from these various agents in decision-making about NIPT, but they did not perceive this as impeding their individual autonomy because they believed they had ultimate control to opt for their preferred procedure. Somewhat surprisingly, the findings do not provide support for the dominant perspective in Chinese medical ethics for the patient being "inseparable from the family in making medical decisions".²²

Many women explained that they felt vulnerable because of their high-risk screening result for DS, and overwhelmed with the task of analysing complex medical information about NIPT on their own. Similar to other studies, women expected their health professionals to facilitate and guide their decision-making about testing,^{15,28,29} and provide information about the accuracy of NIPT and IPD, the benefits, limitations and risks of NIPT versus IPD, and chances of having a baby with DS following a positive or negative result.³⁰ Such information was available through various sources, however, women would have valued receiving it from their

health professional with an opportunity to discuss their concerns. Instead, as shown in previous research,³¹ women's accounts suggest that some health professionals' approached facilitating individual autonomy as simply providing information.

Research suggests that autonomous choices are enhanced by the support of well-informed health professionals,³² and women who feel most supported by their health professionals are likely to feel the most autonomous as compared to those who do not feel supported.³³ Therefore, women at high-risk of having a child with DS should be offered face-to-face counselling with a trained health professional to support their decision-making about NIPT. Further research is needed on how health professionals could provide such support in a way that facilitates value-consistent individual autonomy. The findings also suggest that health professional education and training to deliver NIPT, hence highlight the need for continuing professional education and training for health professionals to facilitate informed decision-making should take into account the views and needs of service users.^{28,35}

In line with policy, prenatal screening is offered to the woman,³³ and although it is acknowledged that they usually make shared decisions about prenatal screening with their partner,¹⁵ the partner's role in decision-making may be overlooked by health professionals.³⁶ Our findings show that women valued involving their partner in decision-making about NIPT, possibly because they may not want to shoulder all the responsibility for having and caring for a child with the condition or for a procedure-induced miscarriage. Such shared decision-making about NIPT could enable the partner to reduce the burden of decision-making on the woman, and for the couple to adjust and cope after a difficult reproductive decision. Other research also reports that the majority of women make decisions about antenatal testing jointly with their partners.³⁷ Furthermore, Western guidelines refer to counselling for the woman and partner or couple.³⁴ The challenge for health professionals in providing counselling for NIPT is to involve the partner, both as a shared decision-maker and in his own right as a father,³⁶ while ensuring that the woman still has ultimate control over the outcome.

Many women also sought other women's experiences and views about prenatal testing for reassurance and to help them form views about their own values, beliefs and preferences.³⁸ Perhaps the use of internet resources allowed them to sought views in a confidential way, without the fear of stigma. Women's need for experiential information provides support for relational autonomy, but in a way that allows women to form their own views, without any social pressure, hence providing support for independent autonomy. In addition, the finding that women were seeking information via online blogs is concerning because this information may be inaccurate or cause undue anxiety. Furthermore, a recent systematic review of 'websites advertising non-invasive prenatal testing for aneuploidy' found that the information on many of them did not comply with guidelines.³⁹ Therefore, to promote autonomous decision-making there is a need for a balanced web-resource to provide both experiential information in the form of "a balanced account of the lives of people with genetic/developmental conditions and their families" and clinical information about procedures in an accessible format.⁴⁰

Much of the literature on Chinese populations supports relational autonomy in decisionmaking as involving family members,²⁰⁻²² including decisions about childbearing.⁴¹ However, most of the women in our study believed that it was not necessary or appropriate to involve family members in decision-making about NIPT, mainly because of the risk-free characteristic of the test. Instead, they wanted to exercise individual autonomy, and protect their baby from any stigma arising from involving their relative. Some researchers suggest the ease and safety of NIPT raises ethical issues.⁴² However, our findings show that these characteristics within a contingent screening pathway may be valued by women as enhancing individual autonomy because they may no longer feel obliged to inform relatives of their high-risk screening result, discuss invasive diagnostic testing or termination of pregnancy. While women in our study preferred not to involved family members in decision-making, we are not aware of the extent to which their decision-making was influenced by factors reported by others,^{43,44} such as, perceptions of their family's attitudes about the condition, prenatal testing and termination of pregnancy, and their religious beliefs.

This was a qualitative study, with a small sample of pregnant women who had undertaken NIPT privately, which inevitably reduces the confidence with which the findings can be generalised. Nevertheless, to our knowledge, this is the first in-depth study on women's decision-making about NIPT and how this relates to individual and relational autonomy. Also, most participants were well educated and from middle or high income groups, hence more likely to exercise their autonomy independently from their family members. This may explain the limited evidence for relational autonomy in our study. Furthermore, the study was conducted with Hong Kong Chinese women only and differences in regulatory, cultural and healthcare settings mean that the findings may not be generalizable to other countries. Further research is needed to explore the degree to which these views are prevalent in different income and education groups, and in other cultures and/or countries.

Our findings raise questions about the adequacy of the current interpretation of autonomous decision-making in the context of prenatal testing as an individual approach,^{10,11,45} where the focus is (rightly) on women's values, beliefs and preferences,¹² but the support of others in the decision-making process is seen as constraining their individual autonomy. Our

findings suggest a need to find a balance between individual and relational autonomy approaches. The challenge for policy and practice in providing NIPT is to ensure that health professionals are trained and feel supported in engaging women in discussion to facilitate valueconsistent decision-making, partners are included in the decision-making process, and women have ultimate control to exercise their individual autonomy.

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Characteristics	N=36
Age	
25-30	3 (8%)
31-34	16 (44%)
35-40	13 (36%)
41-45	4 (11%)
Education	
Secondary School	9 (25%)
Associate degree*	3 (8%)
Bachelor degree	13 (36%)
Master's degree	11 (31%)
Household income per month**	
HK\$50,000 (US \$6,259)	16 (44%)
HK\$40,000-\$49,999 (US \$5,000 - 6,249)	5 (14%)
HK\$30,000-\$39,999 (US \$3,750 - 4,999)	8 (22%)
HK\$20,000-\$29,999 (US \$2,500 - 3,749)	3 (8%)
HK\$10,000-\$19,999 (US \$1,250 - 2,499)	4 (11%)

Table 1: Demographic characteristics of women

*A post-secondary education programme that runs 2 to 3 years, aiming to prepare students for higher education.

** Median monthly household income in 2014: HK\$23,000

Table 2: Reproductive History of women

Characteristics	N=36
High-risk screening result (n=30)	
1 st pregnancy	16
2 nd pregnancy	10
3 rd pregnancy	4
Low-risk screening result (n=6)	
1 st pregnancy	5
2 nd pregnancy	1