

Difference in attitudes on noninvasive prenatal testing in China and the United States

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BACKGROUND

Non-Invasive Prenatal Genetic Testing (NIPT):

NIPT analyzes cell-free fetal DNA present in maternal serum in order to detect fetal chromosome aneuploidies [1] like Down syndrome (trisomy 21, or 47,+21) or Turner syndrome (45,X). It is more accurate than serum screening or ultrasonography [2] and avoids the physical discomfort of invasive testing methods [3]. However, NIPT is not a diagnostic test; positive results must be confirmed with amniocentesis (amnio) or chorionic villus sampling [4]. Western professional societies currently recommend that NIPT be offered only to women at increased risk of fetal aneuploidy (e.g., advanced maternal age, prior pregnancy with a trisomy) [5].

Commercial market for NIPT:

NIPT was first introduced in Hong Kong in 2011 [6] and was commercially available in the United States soon after [7]. Four companies currently compete for the US prenatal testing market [7]. Two companies offer testing in China [8,9]. In the US, insurance coverage for the cost of the test is variable and arrangements with State subsidies such as Medicaid are inconsistent. In China, the cost of NIPT must be paid for out-of-pocket.

NIPT in the US and China:

First trimester serum screening and invasive, diagnostic procedures are widely available in the US, and are universally accessible in some states, such as California [12]. In China, access to prenatal care is much more prevalent in urban areas and may be dependent on financial capacity, consistent access to health care professionals, and/or patient education [13].

RESULTS

United States

"I was given the option of having an Amniocentesis. The doctor was specialized in this field and had had only 4 losses in the 12 years he had been practicing. Even though that was a bit comforting I was still very hesitant to have it done. It just made me very nervous because of all the results."

"I had [NIPT] done--and it was positive for Trisomy 21, and my doc didn't push for amnio after this test. If amnio is not an option for your family (it was not for us) these tests may be the way to go."

"This is how my doctor presented this test to me: the test is optional. Would the outcome make a difference in whether or not you keep the baby? If not, opt out."

"I literally spent every second researching, googling the subject endlessly to try and find some answers. My doctor & the genetic counsellor I was referred to really provided no comfort or reassurance."

"As far as payment...I just now need to wait for my insurance to deny the bill and then [the NIPT company] will protest...but they likely will still deny it as I believe [my insurance] still wants you to be 35... Once they deny then hopefully [they] will give me the reduced price."

Amnio vs. NIPT

"I recommend amniocentesis, NIPT is just an experiment! Many news outlets all say so! I also did an amniocentesis, without any discomfort!"

"I am doing NIPT today. I am more in favor of doing an amniocentesis, but my husband is afraid of the risk, saying that he isn't willing to take even a risk of 0.1... that it is also dangerous for the baby, in the end we chose non-invasive."

Role of Clinicians

"Today I went to do Down screening and they also let me do NIPT, age does not matter, I did not want to do it, the doctor was not happy, said you had to take the consequence if you don't do it!"

"There was a lot of amniotic fluid so the doctor recommended that I do NIPT, if the results aren't good, I would need to abort"

"They let me directly do NIPT... Once you get in the hospital, you have to do what they say."

Cost and Payment

"If I do amniocentesis I had five thousandths risk of miscarriage...then the doctor recommended non-invasive but it is more than three thousand here, too expensive so I did not do it."

"I personally think that the money spent is wasted, too expensive, and [the doctor] said that is a new technology, they do not know if it's mature or not."

China

OBJECTIVE

To explore the similarities and differences in experiences of women in the US and China who are considering prenatal testing as they make potential choices between serum screening, NIPT, and invasive testing. Anticipated variation stems from the differential access to health care in each country as well as cultural and social attitudes surrounding risk, abortion, and the health care profession.

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FURTHER INFORMATION

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MATERIALS & METHODS

We conducted content analysis of Chinese- and English-language online pregnancy support forums. These forums are generally populated by women who are currently pregnant, although some women who have already given birth and some expectant fathers also participate. Although geographic data is not available, a majority of participants in the Chinese forum confirmed that they resided in Mainland China.

Targeted searches were used to identify posts by forum members that pertained to questions about or shared experiences of using NIPT during 2013. Key words included 'noninvasive prenatal testing' as well as the names of the tests available in each venue. 855 posts were ultimately coded: 520 Chinese posts and 335 English posts.

Chinese results were translated by a bilingual Chinese/English speaker and confirmed by a native Chinese speaker.

Results were coded into themes using qualitative analysis.

CONCLUSIONS

1. NIPT in both China and the United States is generally viewed favorably, however significant concerns exist in both populations on the accuracy and the cost of NIPT. Major factors forum members discussed in choosing between NIPT and traditional prenatal testing were the perception of risk from invasive testing such as amniocentesis, the advice of clinicians, and the cost of testing.

2. In the US, the risk associated with amniocentesis was portrayed as higher, thus suggesting NIPT as a safer alternative. Clinician participation in decision-making in the US was frequently portrayed as largely non-directive, although this was not always portrayed as a positive. Discussions of cost largely centered on issues of insurance reimbursement.

3. In China, risk associated with amniocentesis was generally perceived as lower, although still too high for some women and their families. Clinicians appear to play a larger role in decision-making, and this role is frequently portrayed as directive towards testing. Finally, cost was discussed as a personal expenditure which required women and their families to balance the cost of testing with other family expenses.

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