

What Do Women Want to Choose in Prenatal Testing in Japan?

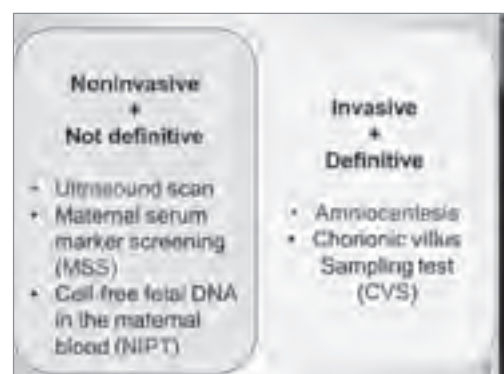
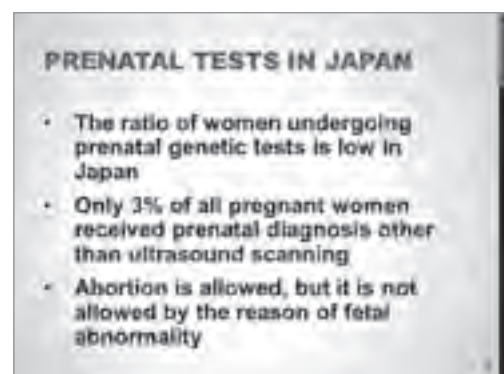
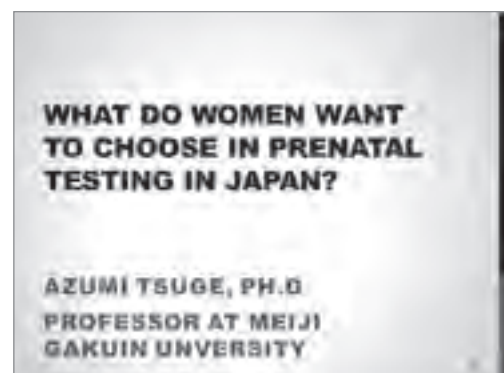


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I am a medical anthropologist. I mainly study interrelation New Reproductive Technologies and Society. Today I will give you information on prenatal testing in Japan, and I would like to show the social background that is relevant to Japanese unique history with regard to prenatal testing.

Japanese Situation Regarding Prenatal Testing

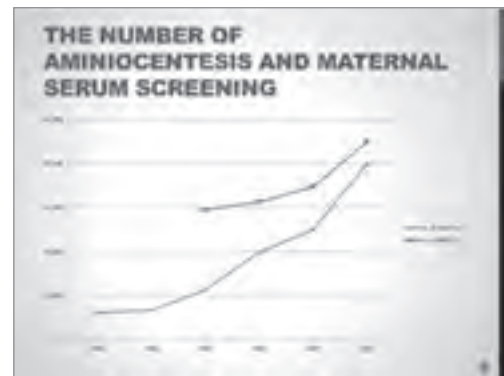
The ratio of women undergoing prenatal tests other than ultrasound scanning in Japan is relatively lower than in any other medically advanced country. According to Sato, who was one of the leading specialists on prenatal testing in Japan in the 1990s, he reported that the incidence of maternal serum screening conducted in the United States, the US is about 167 times that of Japan, and the frequency of amniocentesis in Germany was 10 times that of Japan in 1999 (Sato 1999). Another research report showed that only 3% of all pregnant females received prenatal diagnosis based upon maternal serum marker screenings or chromosome analysis in Japan (Sasaki 2011). On the other hand, the fact is that many



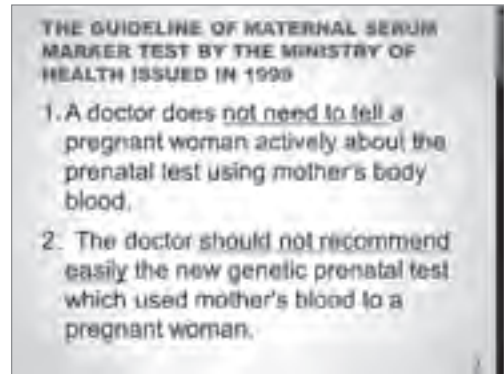
clinics and hospitals have been practicing ultrasound scanning and abortion procedures in Japan. We usually use ultrasound scan, which is not recognized as a prenatal testing is. And maternal serum marker screening and cell-free fetal DNA in the maternal blood are also available though not many pregnant women use them. Cell-free fetal-DNA-based prenatal testing, so called NIPT started in 2013 in Japan. These are said to be non-invasive and are not considered definitive test. Amniocentesis and chorionic villus sampling are said to be invasive tests.

Total numbers of amniocentesis and maternal serum screening in Japan increased between 1987 and 2012. However their total incidence is only 3% of all pregnant women. But in Japan, lately the government has emphasized the declining birth rate. And the number of live births by age group, is shown in this figure. The number of live births is declining. But the subtotal for maternal age over 35 years is increasing.

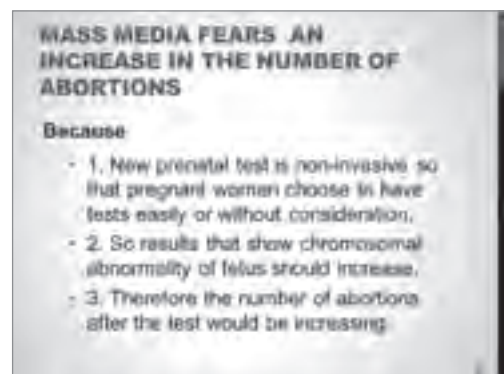
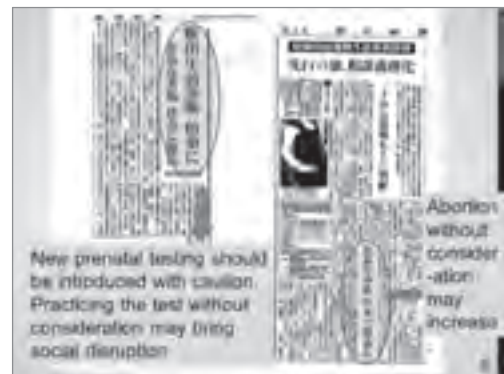
The Japanese Government and the Japan Society of Obstetrics and Gynecology (JSOG-Japanese OB/GYN Association) have emphasized that those are serious issues for Japan because they are related to the increasing the number of infertile women or couples, and may be increasing the ratio of fetus with chromosomal abnormality. The ratio of live birth by women over 35 years old increases from 1950 to 2010. Now you see why the Japanese government and the OB/GYN doctors worry about that from these figures.



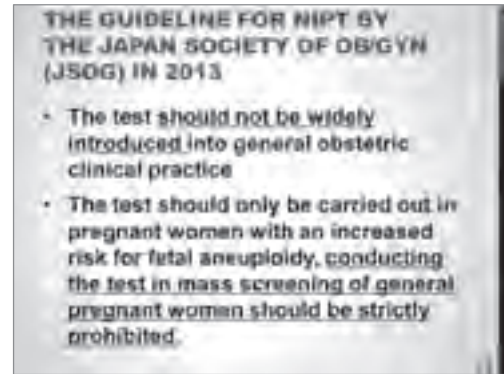
As I already said, Japan has a unique condition and situation regarding prenatal testing. For example, the Expert Committee of Ministry of Health on Prenatal Diagnoses issued the guidelines regarding maternal serum marker test in 1999. It said that a doctor doesn't need to tell a pregnant woman on his own initiative about the prenatal test using mother's body blood. Whenever I show this guideline at a seminar in North America, people always ask me if it is my typo. Then I said, "no, no, no, it's correct. A doctor doesn't need to tell a pregnant woman about the maternal serum marker test."



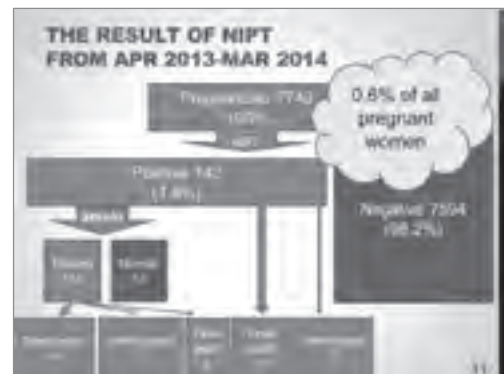
The point of these articles are that introducing NIPT will cause pregnant women to undergo the test easily, therefore the number of abortion after the test would be increasing. I was interviewed by several journalists from the newspaper company in Japan at my office. I asked them if you know how many abortions are conducted in Japan annually before you show the anxiety about abortions by results of prenatal testing. A young journalist said, "I don't know at all." The Japanese total number of abortion – annual abortion number - is about 200,000 a year. But now it's decreasing bit by bit, less than 200,000 abortions. I asked her, "do you know the number of abortions after prenatal testing in Japan?" She said, "I don't know." Then I said her, "you said that the abortion number would be increasing and become problems if we introduce NIPT." Actually, we don't know the precise number of the abortion after prenatal test. The only 3% of pregnant women maybe take it. Among them, maybe 1% or 2% of them would have positive results, then among them, about 90% will abort. It is very few case to have abortion after the result of prenatal testing.



When the NIPT was introduced, JSOG issued guidelines. They stated that the test should not be widely introduced into general obstetric prenatal practice. The test should only be carried out on pregnant women with an increased risk for fetal aneuploidy, and conducting the test in mass screening of pregnant women in general should be strictly prohibited.



Here in Japan, more than 7000 NIPT were undergone from April in 2013 to March, 2014. The result showed that 129 cases among 7,740 pregnancies are trisomy 13, 18 or 21. Most cases were negative through NIPT. It also showed that only 0.6% of all pregnant women were affected by taking the test and about 0.01% of all pregnant women had a positive result.



Japanese History with regard to prenatal tests

And let me show Japanese history regarding prenatal tests. I wonder why Japanese people are cautious about prenatal tests. I think Japanese stand at the intersection of three historical lines. The three lines represent the population policy in relation to eugenics and the legal system of abortion, the feminist movement, and the disabled people movement. I don't have much time, so I just want to point out the important parts. The Meiji Government criminalized abortion under Japan's first modern penal code in 1880. The penal code was revised in 1907 to make abortion a more severe crime. But in 1940 during World War II, National Eugenic Protection Law was passed and it was modeled on the Nazi sterilization law.

1880	Penal Code revised from 1880. It makes abortion a crime.
1902	Birth Control Movement: Margaret Sanger was invited to Japan.
1921	A legal precedent to allow doctors to perform emergency abortion to save a woman's life.
1931	Feminist (first wave) organized Japan Birth Control League and Alliance for Reform of the Anti-Abortion Law. Dr. Oguro Kazuo published his theory for contraception (Oguro Method).
1934	Dr. Ohta Taro invented IUD (Ohta Ring) based on Gitterberg's Ring in Germany in 1930.
1935	IUD and contraceptive methods except for condom were forbidden.
1937	Birth Control Movement was forced to quit. Isheroto-Kaido Shizuo was arrested for Birth Control spreading action.
1940	National Eugenic Protection Law based on the Law of Nazi Eugenic Sterilization.
1948	Eugenic Protection Law legalized abortion under conditions. However penal code of abortion issued in 1907 continues to operate.

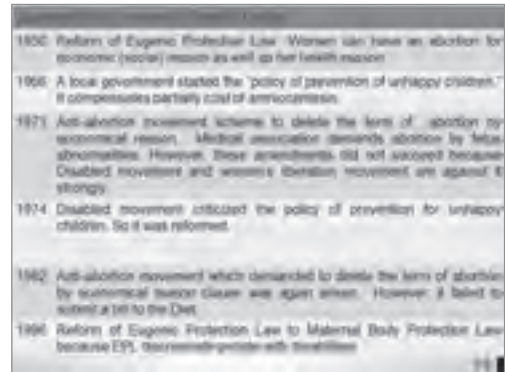
In 1948 after World War II, The Japanese government reformed the National Eugenic Protection Law, and renamed it to Eugenic Protection Act. It legalized abortion under several conditions such as

the health concerns of pregnant women, eugenic reasons including genetic disease of the pregnant woman and/or her spouse, and pregnancy due to sexual assault. However, The penal code of abortion was still valid.

In 1950, Eugenic Protection Act legalized abortion to decrease the birth rate. Then women could have abortions for economic reasons and social reasons. And in 1966 a local government started the policy of prevention of unhappy children. It reimbursed some part of the cost of amniocentesis. In 1973, the anti-abortion movement attempted to delete the term of abortion for economic reason. Medical association demanded abortion based on fetus abnormalities. However, these amendments didn't succeed because the disabled movement and the women's liberation movement are strongly against it.

In 1974, disabled movement criticized the policy of prevention of unhappy children. So it was reformed. In 1996, the Eugenic Protection Act was reformed to Maternal Body Protection Act because Eugenic Protection Act discriminated against disabled people.

In the brochure regarding the policy of unhappy children, it was described that children with disability cannot grow happily, therefore local government introduced the policy to "prevent the birth of unhappy children". The policy in 1970's included paying subsidies for amniocentesis to "prevent the birth of unhappy children". Activists of disabled people rights strongly opposed the policy.

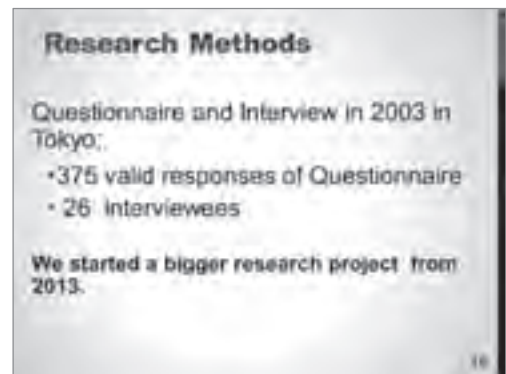


Our research on Prenatal Test

In 2003, we conducted a questionnaire research with open ended questions and we had 375 valid responses to the questionnaire and interviewed 26 women. Now we have launched a bigger research project since 2013.

Conclusion

I would like to conclude here. First, medical doctors emphasize that NIPS is non-invasive, so pregnant women might have a tendency to choose to have that test easily or without consideration. Second, Dr. Mills mentioned about the making decisions or the choice on prenatal test should be free. But many Japanese believe choice is not free. The women stand on intersection of the interrelationship of family and medical doctors. In such a kind of system, some women said that they tried to check the fetus because it was late childbearing and it might be hard for them to take care of a disabled child when they would get old. If they give birth to disabled children, women would feel guilty in the culture. Because Japanese women take the test to have to take responsibility for reproduction. JSOG issued the guidelines that doctors should not actively advise pregnant women on prenatal testing. If women would like to take the test, a medical doctor says, "Oh it's your choice." In other case, many women who didn't take a prenatal test said the reason why they didn't is as follows. Because her doctor didn't explain about prenatal testing directly but giving brief information by printing papers. When we ask in the questionnaire why you didn't take the test, many women responded, "oh, I'm healthy. I'm all right," "my doctor didn't mention about it. I think my doctor would inform me about the test if I had a problem. Many women know what prenatal testing is from the newspaper or the magazine, from the Internet. That's an authentic example of a typical Japanese attitude.



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Her recent publications are as follows:

Mimura K., Kokado M., Hong, H., Chang C., and Tsuge A, 2014. "Patient-Centered Development? Comparing Japanese and Other Gynecological Examination Tables and Practices", *East Asian Science, Technology and Society: An International Journal*, 8(3), pp.323–345

柘植あづみ、2012. 『生殖技術—不妊治療と再生医療は社会に何をもちたらすか』みすず書房

柘植あづみ・二階堂祐子、2014. 諸外国の出生前診断の状況とその背景 『日本医師会雑誌』 143(6),1166-1170 頁