Considering the Social Background of Prenatal Tests in Japan

Azumi TSUGE

Introduction

Prenatal tests or diagnoses are available for hundreds of genetic conditions, including chromosome abnormalities, inborn errors of metabolism, neural tube impairments, and single gene disorders (Powell 2000: 47). Ultrasound detects many structural defects (Powell 2000: 47).

Since amniocentesis becomes widespread in the U.S., Rothman, B. K. conducted her fieldwork in New York and drew a detailed portrait of pregnant women's psychological situation regarding their pregnancy and prenatal tests. Women who undertook amniocentesis to detect genetic disorders of the fetus may terminate the pregnancy if the fetus does have genetic disorders. Therefore Rothman pointed out that women who took the test think that the pregnancy is tentative (Rothman [1986]1993). Rothman showed, for an example, that the use of amniocentesis changed the emotional and social experience of quickening. Rapp, R. published on the ethnography of prenatal testing, on how pregnant women made their own decisions about prenatal testing, and how scientists developed the technologies, how medical doctors and genetic counselors inform and deal with the women's difficult decisions in an interwoven milieu of diverse social backgrounds, class, race, ethnicity, and so on (Rapp 1999).

A unique feature related to reproductive technology in Japan can be seen in prenatal tests. The ratio of women undergoing prenatal tests other than ultrasound scanning in Japan is relatively lower than in any other medically advanced countries. According to Sato, who was one of the leading specialists on prenatal testing in Japan in the 1990's, he reported that the incidence of Maternal Serum Screening (hereinafter MSS) conducted in the United States is about 167 times that of Japan, and the frequency of amniocentesis in Germany was ten times that of Japan in 1999 (Sato, 1999: 51-59). Another research report shows that only three percent of all pregnant women received prenatal diagnosis based on maternal serum marker screenings or chromosome analysis (Sasaki et al. 2011: 1007). On the other hand, the fact is that many clinics and hospitals have been practicing ultrasound scanning and abortion procedure in Japan.

Access to an abortion has been allowed since 1948 under several exceptions, although criminal abortion sentences in the penal code basically prohibit abortions. Lately, about 200,000 abortions are performed every year. However, the fetal abnormality is not one of the reasons for allowing abortion in Japan. Therefore, abortions after prenatal diagnoses are conducted under the exception of the pregnant women's health condition[(1)].

There are diverse perspectives on prenatal testing and on terminating pregnancy because of the test results. As Sato pointed out, Japan measured applying these testing involving selective abortion. Many books that discuss prenatal testing has been published in Japan (e.g. Tamai et al. 2014, Sakai 1999, 2013, Toshimitsu 2012). However, some medical doctors intend to promote them for the sake of pregnant women's needs and some women want to undertake them.

A new prenatal test, called the Non-invasive Prenatal Test (on NIPT) was introduced in 2013. NIPT may change women's experiences and their attitude toward the pregnancy and fetus. With such views on prenatal tests, I will explore in this paper the present Japanese situation of prenatal tests and the background of women's choice about prenatal tests.

Firstly, I will present the Japanese situation surrounding prenatal testing, particularly comparing it to other countries and areas, and then point out several related issues. Secondly, I will look into Japanese social history in relation to prenatal testing and having children with a disability. Finally, I will discuss why Japanese women want to choose or not to choose prenatal testing.

1. Prenatal testing in present Japan

In Japan, prenatal screening such as MSS and first-trimester screening are not routinely offered to pregnant women (Nishiyama et al. 2015). There is no official statistic about prenatal testing in Japan. According to Sasaki et al., the number of maternal serum screening tests they calculated is about 18,000 in 2008. The number of amniocentesis test is about 13,000. A nuchal translucency (NT) scan at 11 to 13 weeks of gestation was also rarely performed, although ultrasound examination is usually performed during the first trimester to check the fetal heartbeat and growth in almost all pregnant women in Japan (Sasaki et al. 2011).

Sasaki pointed out that one of the reasons why relatively few pregnant women receive prenatal diagnoses is the lack of information provided by doctors (Sasaki et al. 2011). So I will describe why medical doctors in Japan

do not give information about prenatal tests.

We can see the unique Japanese features surrounding prenatal tests in the government guideline on MSS. The MSS, called triple marker test, was introduced to Japan in 1994, and since then it is used to calculate the probability that a baby is affected with Down syndrome, Edward syndrome or spina bifida. However, there was public controversy from ethical, legal and social points of view.

It is said that insufficient genetic counseling for this test facilitated the anxiety of pregnant women, and induced useless abortion by misunderstanding the result, which was shown as probability. Therefore, in 1999, the Expert Committee of Ministry of Health on Prenatal Diagnoses published the guideline (See Appendix 1). Thereafter, the number of maternal serum screening tests was decreased for a few years.

Appendix 1

Wording of the indicator of maternal serum marker test by the Committee of Ministry of Health issued in 1999

1. A doctor does not need to tell a pregnant woman actively about the prenatal test using mother's body blood. However, when a pregnant woman asks for the explanation about this test, a doctor explains the principle of this test as much as possible, and it requires offering as information that it is possible to receive the test at a registration institution.

2. The doctor should not recommend easily the new genetic prenatal test which used mother's blood to a pregnant woman. Moreover, it is not desirable for a testing company etc. to draw up the document in which this test is recommended, and to distribute to many and unspecified pregnant women.

There is much difference here from the situation of US or UK. For

example, the American College of Ob/gyn in the US states that screening and invasive diagnostic testing for aneuploidy[(2)] should be available to all women before 20 weeks of gestation regardless of maternal age (ACOG 2007, 2012).

Powell shows that in the US, an estimated 63 percent of annual births were screened for Down syndrome using one or more markers (Powell 2000: 47). In UK, the National Health Service (NHS) provides a Fetal Anomaly Screening Program to all pregnant women (NHS 2015). France also has a screening policy of providing prenatal testing to all women (Sakai 2013).

It is pointed out that many women who took the test could not understand the meaning of the result shown as probability in MSS. There are few genetic counsellors and medical doctors whose specialty is in clinical genetics in Japan, so it falls to the Ob/gyn to explain about the test if they intend to provide MSS to women.

In addition, a TV documentary was broadcast about a company that intended to recommend the test in an advertising campaign for their commercial gain. For these reasons, the policy was introduced that medical doctors are not required to actively inform pregnant women on the existence of this test, that doctors are advised not to recommend the test and companies concerned are prevented from distributing information about it.

Center for Disease Control and Prevention (CDC) in the US reported that the ratio of the number of women who undertook amniocentesis to the number of women giving birth in a year has continued to decrease from 3.2 percent in 1989 to 1.7 percent in 2003, which may reflect the growing use of non-invasive screening test, such as measurement of maternal serum marker and ultrasound, may reflect (CDC 2005). Meanwhile, ironically the number of

amniocentesis tests has been increasing in Japan (Sasaki et al. 2011) so that the lower MSS ratio in Japan reflect the higher amniocentesis ratio.

Mansfield, C. et al. reviewed medical papers published from 1980 to 1998, and recalculated the ratio of abortion in several countries to the detection of certain fetus malformations (Mansfield et al. 1999). They conclude that 92 percent were aborted out of 5035 cases with diagnosis as Down syndrome, 64 percent out of 204 cases with diagnoses as spina bifida, and 84 percent out of 365 with diagnosis as anencephalia in UK. Natoli et al. reviewed medical papers published from 1995 to 2011, and recalculated the ratio of abortion in the US. They also pointed out that the ratios of abortion in the US vary from 50 to 85 percent. The factors are pregnant women's age, age of delivery, ethnicity, and race (Natoli et al. 2012). In addition, they conclude the ratio is decreasing. Their result shows differences from the Mansfield's result.

Egan, J. F. et al. estimated that Down syndrome live births declined in the US despite an expected increase caused by delayed or extended childbearing (Egan et al. 2004). In Taiwan, amniocentesis for genetic diagnoses began in the late 1960s and early 1970s as a tertiary procedure reserved for only the highest-risk patients in Taiwan. Amniocentesis is often used with women of an advanced maternal age (age 34 years old and over) and younger women who have undergone maternal blood Down's syndrome screening and the result is more than 1/270 (Chan et al. 2012). Lin SY et al. reported that the live birth rate of infants with Down syndrome, per 100,000 live births decreased from 22.28 in 2001 to 7.79 in 2010. They demonstrate that the screenings may be responsible for the marked decrease in the ratio of live birth to total DS in Taiwan observed between 2001 and 2010. (Lin et

al. 2013)

No similar report about the population movements of children with Down syndrome in Japan can be found. The number of cases and the rate of advanced age pregnancy over 35 years old have gone up in these years and it seems that they have influenced the increase in the number of amniocentesis testing and rate. And since the highly precise ultrasonic machine was introduced at clinic, the abnormalities of the fetus found in an ultrasound test increased. Evidently the increased incidence of abortion for the reason of a fetal disease and malformation was occasioned by the high performance of ultrasound machines in Japan.

The debate on NIPT

In 2011, the new prenatal genetic test by use of cell-free fetal DNA, called NIPT launched in the US. The use of NIPT as a commercially available test began to spread to other countries, such as UK, France and China. Therefore the debate concerning the new prenatal test is arose in Japan in 2012. It is said the clinical validity of the non-invasive prenatal test based on cell-free fetal DNA allows detection of fetal aneuploidies, including trisomy 21 (Down syndrome), 13 and 18, as early as 10 weeks of gestation with sensitivity and specificity of over 99 percent among the advanced age group[3]. Mass-media emphasized that the new prenatal test is non-invasive and the results are reliable, almost definitive. They also expressed their concern that women may access abortion easily if the new prenatal test is introduced.

The presence of fetal DNA in maternal plasma was discovered by D. Lo, chemical pathologist from Hong Kong. His group also developed the non-invasive prenatal diagnoses later. Then a company in the US applied the

technology for the first commercial NIPT of its kind for the detection of a chromosomal anomaly, namely The MaterniT21 test. Lo is an advisor and collaborator of the company. NIPT has been available as a self-paid referral service in the private sectors in Hong Kong since December 2011(Yi et al. 2012). The MaterniT21 test is called as The SafeT21 in Hong Kong. I have not found a reason for the name change between The MaterniT21 and The SafeT21. However, we can interpret an ideology much more in the name of The SafeT21 that advanced medical technology offers your "safety" than MaterniT21.

In responding to the social interest in NIPT, the Japan Society of Ob/gyn (JSOG) published a "policy statement on noninvasive testing of fetal aneuploidy using maternal blood" in 2013. This statement notes that: "The test should not be widely introduced into general obstetric clinical practice in Japan until a system is in place for specialists of obstetrics with knowledge of clinical genetics to provide appropriate genetic counseling to pregnant women who require it. The test should only be carried out in pregnant women with an increased risk for fetal aneuploidy, conducting the test in mass screening of general pregnant women should be strictly prohibited." (Sago et al. 2015: 2) Later, so called clinical study of NIPT started in Japan. The study requests women to undertake the definitive diagnoses, such as amniocentesis with the risk of miscarriage, when the result of NIPT shows abnormality.

Sago et al. described the purpose of introducing NIPT for clinical study as follows:

Against this background, the present results imply that offering

> NIPT for pregnant women who wish to undergo prenatal screening of aneuploidy is a reasonable strategy for reducing the number of invasive procedures (Sago et al. 2015: 5).

After one year, the total number of conducted NIPT for a year in Japan was disclosed. According to Sago et al., of the 7,740 women underwent NIPT from April 2013 to March 2014[4], 142 (1.8%) had positive results, 7,594 (98.1%) had negative results. Of the 142 women who tested positive, 13 cases resulted in intrauterine fetal death, and three cases refused to undergo the invasive procedure. Of the 126 positive women who underwent invasive procedures, chromosomal abnormalities of trisomy 21, 18, and 13 were confirmed in 70, 34, and 9 cases, respectively. Among the cases confirmed to involve fetal aneuploidy (n = 111), 110 women opted to terminate their pregnancy, while one woman opted to continue the pregnancy. And three women who tested positive for trisomy 21 refused to undergo invasive procedures and opted to terminate the pregnancy. (Sago et al. 2015)

This result shows several important things about Japanese situation concerning prenatal testing. We cannot know the total number of pregnant women in a year, but we can estimate it from the total number of deliveries: about 1.02 million. Total number of abortion by any reasons is about 200,000 (0.2 million) in 2013. The 7,740 women among 1.22 million is about 0.6 percent of all pregnant women in a year. The number of abortions following NIPT is 110 cases or 0.05 percent of all abortion cases. Next, we will consider why the NIPT is becoming a big controversial issue in Japan.

2. The Historical Background surrounding the Population Policy and the Abortion law

Here, I consider the reason people in Japan are cautious about or against prenatal tests. I think Japanese stand at the present time at the intersection of three historical lines representing trends that started in Meiji Era the three lines represent population policy in relation to the eugenics and the abortion law, the feminist movement, and disabled people movement.

The Pronatalism and the Criminalization of Abortion from Meiji Era to Showa Era

First, I will explain the abortion law in Japan. Many historians point out that infanticide (*mabiki*) and abortion (*datai*) were common in Edo era (1603-1867) and earlier because of economic reasons regardless the national government and each local government also repeatedly prohibited them (LaFleur 1992) but failed. The Meiji government (1868-1912) criminalized abortion under Japan's first modern penal code in 1880. The article which bans abortion in the penal code, called *datai no tsumi or dataizai*, is similar to the criminal abortion law. It was revised in 1907 to make it more severe. The penal code of 1907 has been effected for a century. They planned to increase the population by implementing the criminal abortion law and later to ban many contraception methods and recommended that Japanese nationals have as many children as possible.

During the prewar birth control movement some family planning advocates, doctors, lawyers, and feminists also called for abortion law reform. The legal precedent that allows for doctors to perform emergency

abortions to save a woman's life had been established in 1923, but criminal prosecutions for abortion still occurred regularly.

Norgren described the history of the first wave of Japanese feminist's action against the criminal abortion law. She explains that the Alliance for Reform of the Anti-Abortion Law (*datai ho kaisei kiseikai*) argued that "it is a woman's right not to bear a child she does not want, and abortion is an exercise of this right", but the Alliance members were also clearly influenced by eugenic, financial, and health considerations. The Alliance advocated that abortion was made legal in cases of inferior heredity or leprosy; when the pregnant woman was poor, on public assistance, of divorced; when pregnancy endangered the woman's health; and in cases where pregnancy was the result of rape (Norgren 2001: 28).

From the National Eugenic Law to the Eugenic Protection Law

The National Eugenics Law which was passed in 1940 was modeled on the Nazi sterilization law named the Prevention of Progeny with Hereditary Diseases Act of 1933. The purpose of the law was to force disabled people's sterilization so as not to have children for various "eugenic" reasons in contrast to encouraging for "ordinary people" to have many children. It was reported publicly that 538 cases of sterilization were conducted based on this law (Ichinokawa et al. 1996). However, this law did not allow sterilization without consent, so that the number of cases was not many as the government expected. A woman who is "healthy" or "fit" should give birth repeatedly; in other words, she cannot have an abortion except in very limited situations. On the contrary, a woman who is "unhealthy" or "unfit" should not give birth.

The doctor Ohta was also a eugenicist and he became a House Representative after the war as a member of the Socialist Party. Then he struggled and succeeded in submitting the Eugenic Protection Bill with other House Representatives Kato Shizue, and Fukuda Masako in 1947. However, the bill was not passed. In post-war confusion, many Ob/gyn were in great demand to perform abortions, but only a few special cases were allowed to be performed officially. It is said that many back alley abortions were performed. Such doctord as Dr. Taniguchi Yasaburo advocated expanding legal abortion under the criminal abortion law (datai-zai). In addition, Taniguchi was very concerned about the necessity for eugenic policy. Thus, one group which demanded birth control for women's health and another group which was supported by an Ob/gyn group submitted the bill of the Eugenic Protection Law together. In 1948, the Eugenic Protection Act was passed and an induced abortion was enabled under several conditions such as the health concerns of pregnant women, eugenic reasons including genetic diseases of the pregnant woman and/or her spouse, and pregnancy due to sexual assault. However, the purpose of the Law clearly characterized it as Eugenic Law. It said that the purpose of the Law is to prevent birth of inferior offspring from the aspect of eugenics and protect the lives and health of mothers.

In 1950, economic conditions were identified as a valid prerequisite for administering the law. Then, in 1953, the procedure for having an abortion became much easier. As a result, over one million induced abortions were conducted and officially reported from 1953 to 1961.

In the late 1960's, the anti-abortion lobbying by the religious organization, Seicho no Ie "the House of Life," tried to make abortion illegal

again. LaFleur described the anti-abortion organization as follows:

> Seicho no Ie "the House of Life," that holds that abortion should again be criminalized. ... In writings of Taniguchi Seicho, the head of the organization, the equality of fetal life with life forms outside the womb is stressed. (LaFleur 1992: 161)

Because the economic reasons clause proposed to allow abortion on demand, the pronatalists, that is Seicho no Ie and some members of the Diet of Liberal Democratic Party (LDP) was demanding the removal of the economic reasons clause and in addition to put advices to Japanese women to give birth to their first child at a "suitable age" in the clause that was submitted by the anti-abortion lobby in 1972 to 1974.

On the contrary, the Japanese Medical Association demanded the insertion of the clause called "the fetus article" adding another prerequisite for abortion related to the new prenatal testing in 1970s. The use of prenatal testing could not be foreseen when the Eugenic Protection Law was enacted and revised before 1970 so that the clause of "the fetus article" of the abortion prerequisite is not included.

However, the revised bill did not pass the Diet because the Disabled movement and women's liberation movement are strongly against it. In addition, pronatalists did not agree to what the Japan Medical Association demanded.

3. The Disabled People Movement and the Anti-abortion Policy

There are several books that mention and discuss the disabled movement and prenatal testing around the world (e.g. Rothenberg and Thomson 1994, Saxton 2000, Parens and Asch 2000).

There is a network of people with CP (cerebral paralysis) or nousei mahi, named Aoi Shiba no Kai in Japan. The organization started as a small group for cultivating friendship among its members then became a network. However, it became famous as a radical organization for people with CP in the 1970s. There are two symbolic protest activities to advocate disabled people's rights.

A mother who was bringing up two handicapped children in Yokohama murdered the 2-year-old child with cerebral paralysis in 1970, and the commutation appeal movement for the mother who was the defendant arose in the process of the trial because of mass media and meetings of parents of handicapped children, etc. On the other hand, the organization of Aoi Shiba no Kai of Kanagawa accused society from the side of the "murdered" disabled children (Yokotsuka 2007: 41).

Hyogo prefecture undertook various measures in the 1960's. One of which is "the movement to prevent the birth of an unhappy child" started in 1966 and established "the office of Fuko na kodomo no umarenai taisakushitu (the office to prevent the birth of unhappy children)" in the local government in 1970. The definition of "an unhappy child" is following: (1) a child who is born and not wanted by anyone, (2) a child who is expected to be born but dies unluckily at a perinatal period, (3) a child who would experience an unhappy situation, (4) a child who is deemed as socially disadvantaged.

In opposition to those developments, the organization of Aoi Shiba no Kai submited against the local policy of "Fuko na kodomo no umarenai taisakushitu" an "open letter" and a "requisition" in 1974 (Matsunaga 2001). The movement asserted that it is a healthy person's way of thinking, to consider disabled persons "pitiable, or to feel sorry for them", and likewise "liking to bear the healthy child, wanting to bear safe and sound", etc. and they pointed out that this is the concrete expression of discrimination against the disabled people. In this way they presented their objection from the disabled people's side. They claimed an amniocentesis test implying intent to kill a fetus with abnormality is a challenge to the disabled people. Consequently they opposed.

These two symbolic examples made the Aoi Shiba no Kai famous as a Radical Disabled Person Movement Organization. Also after this, the Aoi Shiba no Kai criticized severely an induced abortion and especially prenatal testing followed by selective abortion.

The women's movement with disability became visible in 1970, despite the struggle of some women activists, disabled movement activities were mainly performed by men at that time (Nikaido 2011). However, it is unquestionable that the movement of disabled women played an important role in both the disabled movement and the feminist movement.

Recently, DPI Women's Network Japan published a report based on their questionnaire and interview survey (DPI Women's Network Japan 2012). We learn from it what terrible situations women with disability survived in 1960s to 80s. I would like to quote several cases in relation to their reproductive rights from the report.

A woman in her 60's with mentally disablility talked about her

experiences in her teens.

> It was around 1963, I was in my teens when they surgically sterilized me by force. That caused menstrual cramps and dullness. I got married when I was about 20 but divorced. My remarried husband also left me because I could not have a baby (60's. mentally disabled).

Another physically disabled woman in her 40's remembered her experience in her teens.

> I started my period when I was in junior high. My mom then said, "You do not need periods, do you?" She meant that I should take out the uterus. I thought I would not be able to have a baby or get married without one so I disagreed with her. But I felt terrible to just hear her say such a thing. I've heard that uterus removal was common among the elderly disabled women when they were younger. (40's. physically disabled)
>
> (Source of above two cases: DPI Women's Network Japan 2012)

As shown in these cases, sterilization has been performed without consent of the referred person under the Eugenic Protection Law upon a medical doctor's application. The law was made for the stated purpose "to prevent the birth of inferior offspring".

However, a preponderance of disabled women have their children, and some of them also need to have an abortion. From their unique stand point, they insist on the right to have a child as well as not to have children. Now,

the "inconsistency" which serves as our focal argument here today is that the disabled people's movement and the women's movement are developing their claims that they accept an abortion for "the economical reason" including substantially social reasons but they do not accept abortion if the reason lies in a fetus.

In 1996, finally, the Eugenic Protection Law was revised as the Maternal Protection Law, which deals with an induced abortion and sterilization, deleting all clauses that could be interpreted as ideologically eugenic. This can be attributed to the disabled people and the feminist movement, and the change of citizens' views toward the rights of disabled people.

After all, the word of eugenics or "yusei" in Japan has been criticized as discriminating against people with disabilities. The word is not frequently used after the reform of the law named "Eugenic Protection Law (yusei hogo ho)" to "Maternal Body Protection Law" in 1996.

4. Demanding Women's Reproductive Choice from 1970s to 1990s

The Japanese feminists movement in the 1970's, called the "Woman Lib" or the Women's Liberation Movement, was against the tradition that a woman was expected to become a good wife and a wise mother, and thus they asserted that "a woman decides whether she gives birth or not" as their claim to protect the right to have an abortion.

It is the issue of Japanese society that the social background surrounding the disabled children and adults was also made the mothers' and wives' responsibility, thus it was claimed that the situation of women who want to have an abortion should be allowed as their own choice. That

was opposed to the opinion of the Aoi Shiba no Kai which criticizes as women who have an abortion of their fetus with disability even though they insist that they do not criticize the individual but rather society. At the base of the confrontation, there is the Eugenic Protection Law which is based on the Eugenic thought of "not to give birth to an impared descendant", and which is based on discrimination against the disabled people.

I introduced the "Discourse of Woman Lib Movement" activists on an abortion in my previous paper (Tsuge 2010). A discussion by Ogino, Miho, following up on Tanaka, Mitsu, one of the most famous figures of the Japanese women's liberation movement in the 1970's, reflects the peculiar dilemma with which Japanese feminists confronted abortion. In the US, feminists resolve the issues by not recognizing a fetus before the first trimester as human. However, Tanaka said that we cannot and dare not say so readily that abortion is our right (Ogino 2004).

I also introduced the thought of Yonezu, Tomoko, who is a feminist activist with a disability (Tsuge 2010). She fought against the trial deletion of the economic reason clause that allowed abortion under the Eugenic Protection Law in the 1970s and 1980s, and then she also fought to revise the name from the Eugenic Protection Law to Maternal Body Protection Law.

She asserts that selective abortion after prenatal testings should not be deemed as 'woman's reproductive right'. She wrote that the designation of such selection as a woman's "right" to be practiced at her own responsibility actually is a new trend of eugenics, and is nothing but an infringement of women's reproductive rights (Yonezu 2002: 17-18).

Sugano, Setsuko explains feminists' discourse on abortion and prenatal tests that "from a sense of crisis regarding eugenics, selective abortion was

not accepted as self-determination; instead, it was regarded as a singular point within the abortion itself" (Sugano 2013:108). She concludes that "self-determination does not justify either selective abortion or a women's choice to undergo prenatal testing" (Sugano 2013: 108).

Discussion

Under these situations as constituted historically, Japanese women stand in-between an ideology that it is natural for women to give birth to 'normal' children and another ideology that women should not commit prenatal tests and selective abortions. Ivry, T. criticized the Japanese atmosphere concerning prenatal testing, citing that an interviewee of her research in Japan said that she felt guilty to have had the prenatal test even after she gave birth a 'normal' child (Ivry 2010).

Social pressure in the name of medicine against women of advanced age

I will discuss the bio-politics regarding a woman's age, especially so-called "advanced age" in the field of reproduction and prenatal testing. I would like to start with a quote from M. Lock in a criticism of the scientific approach to the menopausal body.

> While it offers an extremely powerful paradigm for assembling knowledge about biology, produces a fragmented and partial picture. It uncovers and reifies, isolates and decontextualizes pieces of information, abstracting them from time and space. A person, however, is clearly not an abstract entity, but a conscious being perpetually in a state of change, whose body is the center of ongoing dynamic interactions

among physical and social surroundings (Lock 1995: 371).

It is easy to spot a political message in a scientific medical paper written about prenatal testing even though they are not setting out to emphasize the risks of advanced age, and even though they try to keep a neutral, objective attitude toward their data. Even a simple neutral description presses women to have a prenatal test with this kind of wording: "With the known age dependency of abnormal karyotype, including clinically significant abnormal karyotype," "more than 95 percent of the subjects of this test were women 35 years of age or older."

We know it is natural for medical scientists to report to each other using this sort of language. However, the phrases "advanced age" or "age of 35 years or older" terrified women who want to have a child. We usually refer to age over 35 years as "kourei" in Japanese, it's actual meaning is 'an old person'. It is a little strange for women in their 30's to say they are old in Japan where the longevity is into the 80's.

Under the policy of encouraging women to have children, not only the government, but also mass media and gynecologists as well, emphasize that women ought to conceive children before "kourei". There are also new words that have become popular recently, "ranshi no rouka". It directly means the aging of your eggs in ovaries. Mass media uses this word like you had better have a child earlier before your eggs are aged. It is clearly that Japanese women are under pressure to have children before advanced age.

Misinterpreting information from a medical doctor and a woman's decision making on prenatal testing

There are some doctors who inform about prenatal tests, because of the advanced age of pregnant women, and some doctors explain only when a pregnant woman asks about the test but just hand them a brochure about it. And there are some doctors who don't explain about the test even when a pregnant woman asks a question about the prenatal test.

I discussed in my previous paper that the phenomenon of women saying that they made prenatal decisions is a new dimension of the issue in Japan. "Especially in the case of amniocentesis, many women reported that the reason for them not to have the test was that the doctor did not discuss it with them, and thus they thought the test was not necessary." "They had judged they did not need the tests simply because their doctors did not provide them with information." "Overall. The most frequent explanation for not taking the tests was that it was difficult for them to make a decision based on the tests, so they avoid them." (Tsuge 2010: 122-123)

I will also describe here women's strategies in relation to prenatal tests in Japan. In Japan, some (or many) women tend to avoid difficult decisions. I think this attitude is an important factor for explaining why the ratio of Japanese women undertaking prenatal tests other than ultrasound scanning is relatively low.

On the basis of the results and views above, we confirmed that these roles have strongly affected decision-making on prenatal testing. Women have to make a decision as a wife, a daughter, a daughter in law, an expecting mother, a worker, etc. A good wife and wise mother ideology

exists even now which Ivry also pointed out from her field work in Japan (Ivry 2010).

Previously, when I interviewed a few experts and several women in the early 1990's, women were used to referring prenatal medical decisions to their partners or parents-in-law for fear that they would be blamed for doing the wrong thing, Women prefer to say that their strategy is not to decide it. Recently, however, I found the matter of 'who makes the decision' is changing. Women tend to say that 'they made the decision' when they were asked for informed consent by their doctor now. The expression, 'self-determination' is becoming pervasive in many fields; that is, women are starting to admit to making their own decisions.

Especially in the case of amniocentesis, many women reported that the reason for them not to have the test was that the doctor did not discuss it with them, thus they thought the test was not necessary. But the doctors do not guess that this is their interpretation. This misunderstanding can be explained by referring to paternalism in the Japanese medical system, not just prenatal testing. Although some doctors emphasized that it was the patient's choice to have the test or not, many women expect and rely upon the doctor's paternalistic role.

A typical answer from women who did not undergo the tests and had inadequate information was that they had judged that they did not need to take the tests simply because their doctors did not provide them with information about it. This led them to believe in turn that the baby would not have any problems.

Women in Japan have the strong responsibility (or a burden) for raising children. Indeed, what some of them choose in a strategic way is not to

undertake prenatal tests as well as to do them. It is a choice that some women chose for their peace.

The differences between having an abortion as a woman's choice and an abortion after the result of prenatal testing that shows fetus malformation

We saw the disability movement against eugenic policy is a factor in low rates of taking prenatal tests. Some women and their partners, as well as some doctors, agreed that amniocentesis somewhat discriminates against disabled people. Thus women felt that prenatal test is immoral or unethical and they had difficulty with making a choice. There should be a choice to maintain pregnancy even in case of the unexpected result they have as well as to terminate it.

Another factor in low rates of prenatal tests is the concept of the fetus and view of abortion, as Japanese feminists stated. The Eugenic Protection Law can be interpreted as pushing women to give birth to a healthy baby.

To the contrary of feminist discourse, many women agree that there is a difference between having an abortion as a woman's choice and an abortion after the result of prenatal testing with the fetus malformation. An interviewee who considered abortion described that she must be thought selfish if she has an abortion for her own preference. She continued, however, many people will accept abortion for the reason of fetus malformation in general.

On the other hand, women who undertake the prenatal test have a conflict and then feel guilty not only in the case of abortion but also after giving birth to 'normal' children. They are wondering what they would have done if children had had a chromosomal anomaly. They feel guilty toward

their children because they had tried to select their children.

As I mentioned in introduction, I think that Japanese stand at the crossroads, either promoting prenatal tests or keeping a cautious attitude to prenatal tests. Either way, we face difficult issues. The strategy of "not to choose prenatal tests" may not be valid.

What we seek is a society in which acceptable choices coexist, and many choose not to have prenatal tests but whether a woman undertakes the tests or does not undertake them she would not feel guilty and would not fear being blamed for her choice. Meanwhile people with a disability which could have been detected by prenatal tests live their own lives with dignity. It may be that what we need is not new tests but rather a new society.

Notes

(1) Women's health condition is one of reasons to be allowed having abortions, and it includes the economic reasons after 1950.

(2) Aneuploidy is a medical term meaning that the chromosomal number is abnormal.

(3) The number of 99% is criticized by some experts because of the limited amount of data, for advanced age women.

(4) The samples of this clinical study were sent to Sequenom, Inc. (San Diego, CA, USA) for MaterniT Plus tests, which include molecular analyses of trisomy 21, trisomy18, and trisomy 13. The cost of testing (approximately $2000) was paid for by the pregnant women. The results of the tests were explained at each institution in the genetic counseling sessions. If the results were positive, then either amniocentesis or chorionic villus sampling, in which the cost was included in the initial cost of the testing, was performed for karyotyping, as was previously explained to the women. The karyotype results were also explained in genetic counseling sessions, and continuous genetic counseling with a pediatrics geneticist was also offered. (Sago et al. 2015: 2)

Reference

American College of Obstetricians and Gynecologists (ACOG) (2007). (Reaffirmation 2011).

Screening for Fetal Chromosomal Abnormalities. ACOG practice bulletin; 77.

American College of Obstetricians and Gynecologists (ACOG) (2012). Noninvasive Prenatal Testing for Fetal Aneuploidy: Committee opinion, The American College of Obstetricians and Gynecologists, 545. Retrieved April 17, 2015. (http://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Genetics/Noninvasive-Prenatal-Testing-for-Fetal-Aneuploidy).

Center for Disease Control and Prevention (CDC) (2005). National Vital Statistics Reports; 54(2). Retrieved April 17, 2015. (http://www.cdc.gov/nchs/data/nvsr/nvsr54/nvsr54_02.pdf).

Chang, CF. (2003). Taiwan ni okeru Seishokugijutu heno Taiou(1) （Correspondence to New Reproductive Technology in Taiwan (1), *CLSS Etudes*, 1: 1-92.

Chang, YW. et al. (2012). "An Overview of a 30-year Experience with Amniocentesis in a Single Tertiary Medical Center in Taiwan", *Taiwanese Journal of Obstetrics & Gynecology,* 51; 206-211.

DPI Women's Network Japan (2012). "A Survey on Living Difficulties of Women with Disabilities." In *A Call for Provisions on Women with Disabilities in a Law to Prohibit Discrimination Based on Disability: A Survey on Living Difficulties of Women with Disabilities*. Retrieved April 1, 2015 (http://dpiwomennet.choumusubi.com/english.pdf).

Egan, J. F. et al. (2004). "Down syndrome births in the United States from 1989 to 2001." *American Journal of Obstetrics and Gynecology* 191: 1044–1048.

Eugenic Protection Statistical Report. *The Ministry of Health and Welfare & The Ministry of Health, Labor and Welfare* (All the issued editions).

Ichinokawa, Y., S. Kato, and A. Tsuge (1996). "Yuseihogohou wo meguru saikin no doko (The Recent Movement on the Eugenic Protection Law.)." in Ehara, Y. ed., *Seishoku Gijutu to Gender* (New Reproductive Technology and Gender), 375-390. Tokyo; Keisou Shobo.

Ivry, T. (2010). *Embodying Culture: pregnancy in Japan and Israel*, New Jersey; Rutgers University Press.

Kato, M. (2005). *Women's Rights? Social Movements, Abortion and Eugenics in Modern Japan*, Ph.D. dissertation at Leiden University, Leiden.

LaFleur, W. R. (1992). *Liquid Life: Abortion and Buddhism in Japan*, Princeton and Oxford; Princeton University Press.

Lin SY. et al. (2013). "The Impact of Down Syndrome Screening on Taiwanese Down Syndrome Births: A Nationwide Retrospective Study and a Screening Result from a

Single Medical Centre", PLOS ONE, 8 (9): e75428, Retrieved April 17, 2015 (http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0075428&representation=PDF).

Lock, M. (1995). *Encounters with Aging: Mythologies of menopause in Japan and North America*, Berkeley; University of California Press.

Mansfield C., S. Hopfer, T.M. Marteau, and European Concerted Action: DADA (Decision-making After the Diagnosis of a fetal Abnormality) (1999). "Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter Syndromes: a Systematic Literature Review", *Prenatal Diagnosis* 19: 808–812.

Matsubara, Y. (2002). "Botai Hogohou no Rekishiteki Haikei", in Y. Saito ed., *Botaihogoho to Watashitati*., 35-48. Tokyo; Akashi Shoten.

Matsunaga, M. (2001). "Hyogoken Fukona Kodomono Umarenai Undo to Shougaisha no Sei". *Osaka Jinken Hakubutsukan Kiyou*, 5: 109-126.

National Health Service (NHS) (2015). *Fetal anomaly screening*, retrieved June 10, 2015 (http://fetalanomaly.screening.nhs.uk/) .

Natoli, J. L. et al. (2012). "Prenatal Diagnosis of Down Syndrome: a Systematic Review of Termination Rates (1995–2011)", *Prenatal Diagnosis*, 32: 142–153.

Nikaido, Y. (2011). "The Transformation in Awareness among Disabled Women during the Disabled Persons' Movement of the 1970s: Focus on Fujin-bu (Women's Division) of Kanagawa Joint Association of Aoi-shiba", *Journal of Women's Studies Association of Japan*, 19: 89-107.

Nishiyama, M. et al. (2015). "Chromosome Abnormalities Diagnosed in Utero: a Japanese Study of 28983 Amniotic Fluid Specimens Collected before 22 weeks Gestations", *Journal of Human Genetics* 60: 133–137.

Norgren, T. (2001). *Abortion Before Birth Control; The Politics of Reproduction in Postwar Japan*. Princeton and Oxford; Princeton University Press.

Ogino, M. (2004). "Reproductive Technologies and the Feminist Dilemma in Japan", paper presented at the conference, "Going Too Far: Rationalizing unethical Medical Research in Japan, Germany, and the United States" at the University of Pennsylvania, Philadelphia, April 29.

Parens, E. and E. Asch eds. (2000). *Prenatal Testing and Disability Rights*. Washington D.C.; George Town University Press.

Powell, C. (2000). "The Current State of Prenatal Genetic Testing in the United State", In E. Parens and E. Asch eds. *Prenatal Testing and Disability Rights*., 44-63,

Washington D.C.; George Town University Press.

Rapp, R. (1999). *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York; Routledge.

Rothenberg, K. H. and E. J. Thomson eds. (1994). *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus; Ohio State University Press.

Rothman, B. K. ([1986]1993). *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*. London; W. W. Norton & Company.

Sago, H., T. Okuyama, and H. Kawame (2002). "Shusanki Iden Counseling System Kouchiku ni kansuru Kenkyu: Sanka Iryo niokeru Iden Counseling". (A Study for Establishing Perinatal Counselling System: A Genetic Counselling in Gynaecology.) in J. Furuyama (ed.) Iden Counseling Taisei no Kouchiku nikansuru Kenkyu. Kousei-roudou Kagaku Kenkyu (Research-in-aid by Minister Health and Labor), 629-641. Tokyo: Kousei-roudou sho (Ministry of Health, Welfare and Labor).

Sago, H., A. Sekizawa, and Japan NIPT Consortium (2015). "Nationwide Demonstration Project of Next-generation Sequencing of Cell-free DNA in Maternal Plasma in Japan: 1-year Experience, *Prenatal Diagnosis*, 35: 1–6.

Sakai, R. (1999). *Reportage Shusshouzen Shindan-Seimei Tanjou no Genba ni Naniga Okiteirunoka* (Reportage Prenatal Diagnosis). Tokyo; NHK Shuppan.

Sakai, R. (2013). *Inochi wo erabu Shakai: Shusshoumae Kensa no Ima* (The Society Selects Life: The Present Situation of Prenatal Testing). Tokyo; NHK Shuppan.

Sasaki, A. et al. (2011). "Low Prevalence of Geneti Prenatal Diagnosis in Japan", *Prenatal Diagnosis*. 31: 1007–1009.

Sato, K. (1999). *Shusseizen Shindan: Inochi no Hinshitsu Kanri eno Keisho*. Tokyo; Yuhikaku.

Saxton, M. (2000). "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion" in E. Parens and A. Asch eds. *Prenatal Testing and Disability Rights*. 147-168. Washinton D.C.; George Town University Press.

Sugano, S. (2013). "Sentakuteki Chuzetu to Feminism no Isou"(The Phase of Selective Abortion and Feminism), *Japanese Siciological Review*, 64(1): 91-108.

Tamai M., and M. Watanabe eds. (2014). *Shuseizen Shindan to Watashitati: Shingata Shuseizen Kensa (NIPT) ga Toikakeru mon*. Tokyo: Seikatsu Shobo.

Tanaka, M. (1973). "Matamata Yuseihogoho Kaiaku nanoda!: Shogaisha Mondai wo Chushin ni". *Lib News* 3: 1-4.

Toshimitsu, K. (2012). Juseiran Shindan to Shuseizen: Sono Donyu womeguru Arasoi no Gendaishi. Tokyo: Seikatsu Shoin.

Tsuge, A. (2010). "How Japanese Women Describe Their Experiences of Prenatal Testing", In Sleeboom-Faulkner, M., *Frameworks of Choice: Predictive and Genetic Testing in Asia*. 109-123. Amsterdam; Amsterdam University Press.

Tsuge, A., S. Sugano, and M. Ishiguro (2009). *Ninshin to Shushozen Kensa no Keiken: 375 nin no Koe kara* (Women's Experiences on Pregnancy and Prenatal Testing). Kyoto: Rakuhoku Shuppan.

Yi, H. et al. (2013). "Motivations for Undertaking DNA Sequencing-Based Non-Invasive Prenatal Testing for Fetal Aneuploidy: A Qualitative Study with Early Adopter Patients in Hong Kong", PLOS ONE, 8 (11), e81794, 1-12. Retrieved April 1, 2015 (http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0081794).

Yokotsuka, K. (2007). *Haha yo korosuna!* (Mother, Don't kill your child.). with comment by Tateiwa S. Tokyo: Seikatsu Shobo.

Yonezu, T. (2002). "Shogaisha to Josei: Renndo-shi Hokan-shiau Sabetsu soshite Kaiho". *SOSHIREN News*, 204: 10-21.

Acknowledgement

This study is supported by the Grant-in-Aid for Scientific Research by the Japan Society for the Promotion of Sciences (Class B), 2013-2015, No. 25283017. Tsuge, A. et al. Choices on Medical Technologies and Gender: Research concerning Pregnancy and Prenatal Testing. I also thank Ms Barbare Turner for her thoughtful comments.