

Women's decision-making and their experiences in the changing socio-technical system of prenatal testing in Japan, 1980s to 2010s

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This article analyzes the notions of woman's body, reproduction, and choices regarding prenatal testing over the last three decades in Japan from interviews with women about their experiences of pregnancy and prenatal testing. First, the historical background of abortion and prenatal testing in Japan is described focusing on the decriminalization of abortion under the 1948 eugenic policy, subsequent disabled liberation movement against the policy, and how it clashed with women's liberation movement for reproductive choice. Then the article shows how women's attitudes towards prenatal testing have changed over time referring to the interview data, and analyzes factors affecting their decisions regarding whether to take a prenatal test. As the development of testing technology plays a crucial part, and it is important to grasp the interrelationship between technological development, social changes and individual women's attitudes and their families' roles/norms in their decision-making, the analysis regards the complex co-development of technological, political, and cultural factors as a dynamic socio-technical system of prenatal testing in Japan. By doing so, it reveals the implicit politics revolving around the imagery of "mothers giving birth to healthy babies," and the ambivalent positioning of prenatal testing.

Introduction

Since the first report of the use of amniotic fluid for prenatal diagnosis of chromosomal abnormalities in 1966,¹ it has been used worldwide for the diagnoses of hereditary diseases or aneuploidies of fetus (one or more extra or missing chromosomes—i.e. the cause of Down syndrome).² However, decisions surrounding prenatal testing inherently involve ethical questions of "what kind of life is worth living and who is entitled to decide."³ Indeed, a decline in the rate of live births of

1 Steele et al., "Chromosome Analysis," 383-5.

2 The most common fetal aneuploidies associated with an additional chromosome are Down syndrome (trisomy 21), Edwards syndrome (trisomy 18), and Patau syndrome (trisomy 13). (Fundukian, *Gale Encyclopedia*, 310.)

3 Press and Browner, "Why Women Say Yes," 979.

babies with Down syndrome since it began has been reported,⁴ and thus disability rights activists show a clear distrust of such technology while academic discussions have evolved around its eugenic aspects.⁵ This has not, however, eased women's dilemmas about taking the test or their experiences and interpretations of choices they have made.⁶ Women who undergo amniocentesis are reported to be tentative about the test until the results come out.⁷ Hence the impression that women/couples deciding to take the test are "submitted to the discipline of a new reproductive technology in order to reap its biomedical benefits as moral pioneers."⁸

From the viewpoint of social history of technology, historian Ruth Schwartz-Cowan points out the importance of considering prenatal diagnosis as a socio-technical system since "each part of the system has its own scientific history and its own inseparable social history and . . . those separate histories have transpired in many different countries, under many different social, economic, and scientific conditions."⁹ Similarly, feminist medical anthropologist Rayna Rapp states that women's knowledge of prenatal testing is "both individually and socially mediated by differences in class position and scientific literacy and racial-ethnic and religious backgrounds. It is also crosscut by individual, familial, and community histories with reproduction and disability."¹⁰ Medical Anthropologist Margaret Lock describes medicalization of reproductive technology and the new genetics as something that "one must read across cultural domains in any given setting in order to produce a contextualized analysis of reproductive behavior."¹¹

Given these insights, this article will describe the socio-technical system of prenatal testing in Japan, to determine factors which have significant impacts on the decision of whether or not to take a prenatal test and how these have changed over time.¹² To do this, the article begins with a brief history of abortion and prenatal testing in Japan that illustrates the cultural and political contexts of the use of prenatal testing in Japan. Then, using data extracted from interviews conducted between 1991 and 2016, it examines cases of women who actually made decisions

4 Egan et al., "Demographic Differences"; Lin et al., "Impact of Down Syndrome."

5 Parens and Asch, *Prenatal Testing and Disability Rights*.

6 Some Dutch studies show a similar concern about NIPT. For example van Schendel et al., "What do Parents of Children," 525–7.

7 Rothman, *Tentative Pregnancy*.

8 Rapp, *Testing Women*, 306.

9 Cowan, "Women's Roles," 35.

10 Rapp, *Testing Women*, 310.

11 Lock, *Eliminating Stigmatization*, 257.

12 Vassy et al. points out that the sociotechnical settings which vary from country to country affected the interactions during the consultations they observed and thus impacted the decision of whether or not to screen. (Vassy et al., "From policy making," 67.)

about taking the test. This testimony shows the changing narratives of first-hand experiences which are personal, sensitive and often disconcerting. By describing the historical development of the use of this technology based on official records, public debates, and also personal experiences, this article attempts to provide a comprehensive description of a dynamic socio-technical system. In so doing, it reveals numerous factors affecting the decision-making by pregnant women: (1) their will and how that is viewed by society; (2) their level of literacy; (3) family relationships and the norms/values/beliefs embedded in such relationships; (4) the laws and regulations; (5) guidelines and recommendations; (6) the political climate regarding abortion and prenatal testing; (7) cultural and normative perceptions of families, mothers and children, and disabilities; and (8) the rapidly developing technology itself.

A Brief History of Cultural and Political Aspects of Prenatal Testing in Japan

Japan is known as a country that has long allowed abortions to be conducted, but in fact abortion has been illegal there since the late nineteenth century. Japan's first modern penal code (1880) criminalized abortion. This restriction originated from an abortion ban at the end of the Edo period (circa 1603 to 1867), but the notion of criminalization is a clear influence from Europe, in particular, France. Although there was a discussion of the possibility of abandoning the ban on abortion in the late nineteenth century, German influence on Japanese politics became increasingly stronger at the time and the law was made even stricter in 1907 when it was revised.¹³ There was a birth control movement in Japan before the Second World War, but the penal code was further extended to include contraception. Meanwhile, Japan's National Eugenics Law enacted in 1940 enforced the sterilization of disabled people, while encouraging respected citizens to raise healthy children.

In the post-war period, the increasing number of back-alley abortions that caused health damage to women became a serious social issue in Japan. Thus, in 1948, the Eugenic Protection Law was enacted to require abortion in cases of pregnancies with health risks for the mother; pregnancies that gave rise to hereditary and/or mental illnesses in the offspring; and pregnancies that resulted from rape. The law was re-revised in 1949 to address the rapidly growing population: abortions became legal there "if the continuation of pregnancy is likely to seriously harm the mother's health" for not only "physical" but also "economic reasons."¹⁴ As a result, over one million induced abortions under the couples' consent were conducted

13 Nie, "Legal regulation," 95–6.

14 Norgren, *Abortion before Birth Control*; Homei and Matsubara, "Critical approaches."

annually between 1953 and 1961.¹⁵ In the 1950s, an anti-abortion lobbying movement led by a new Shintoist group, *Seicho-no-Ie*, along with several politicians, demanded the removal of the economic conditions clause,¹⁶ but the *Nihon Bosei Hogo Kyokai* (Japan Association of Obstetricians and Gynecology) and *Nihon Ishikai* (Japan Medical Association: JMA), together with women's organizations and various activists protested against this proposal.¹⁷ Similar attempts by pronatalists were repeated in the 1970s and 1980s, but the economic conditions clause remained.

In 1970, JMA requested the insertion of a so-called "fetus clause" which would enable abortions if prenatal testing revealed severe fetal anomalies—so not hereditary or mental illness. As it implied that abortion was a legitimate option for cases of fetal malformations, this proposal was opposed by groups advocating disability rights. To the government, which intended to implement a policy to prevent the births of so-called "unfortunate children"—the children who suffered from severe diseases or disabilities, *Aoi Shiba no Kai*, a self-help group for people with cerebral palsy, asserted that any such policy would discourage people from having children with severe diseases and/or disabilities, and such was an explicit act of discrimination. Subsequently, the policy was implemented but soon suspended.¹⁸

At the time, the second wave feminist movement known as "Woman Lib" was fighting for women's reproductive freedom, but such an assertion clashed with the fundamental allegations made by disability rights advocates. The conflicting claims by the two parties cultivated a rich dialogue regarding reproductive rights and disability rights in Japan, through a painstaking engagement in the controversy, in which the presence of women with disabilities in *Aoi Shiba no Kai* was crucial.¹⁹ They both protested against the Eugenic Protection Law which allowed sterilization without consent upon a physician's application. More than 16,000 people were forcibly sterilized under this law between 1949 and 1996, of which approximately 70 per cent were women.²⁰ As the law's implication was that people with mental/

15 The Japanese Eugenic Protection Law required the husband's consent for abortion of married women, and this remained unchanged when the Law was revised in 1996. In 2021, there is an on-going campaign calling for the deletion of the spousal consent requirement. (Ilgin Yorulmaz, "My body, my choice: Women in Japan all for end to abortion law's 'abusive' male consent requirement," *Number 1 Shimibun* [The Foreign Correspondents' Club of Japan], October 2021; Japanese Minister of Health and Labor, Eugenic Protection Statistical Report, and Maternal Body Protection Statistical Report.

16 LaFleur, *Liquid Life*.

17 Sugano, "Phase of Selective Abortion."

18 Tsuchiya, "Historical analysis."

19 Nikaido, "Transformation in Awareness."

20 Yuseishujutsu-ni Shazai-wo Motomeru-Kai, *Yuseibogoho-ga Okashita Tsumi*.

intellectual disabilities, hereditary or not, must not have children,²¹ women activists with disabilities appealed to their own reproductive choice. “Woman Lib” activists who agreed with them jointly fought in a trial to abolish the law while protesting against the criminalization of abortion.

The demand of these activists was finally realized in 1996 when the law was renamed “the Maternal Protection Law,” with all clauses related to eugenic ideology deleted, and its objectives shifted to the protection of the health of expecting mothers. However, the issue of reproductive rights, or more specifically, the abolition of the Criminal Abortion Law in the Penal Code that activists had been demanding was not acted on.

The introduction of amniocentesis²² for prenatal diagnosis which began in the early 1970s occurred during the above controversies, and perhaps due to this, the conduct rate of prenatal testing in Japan was notably low as compared to countries such as the U.S.A.,²³ the U.K.²⁴ and France.²⁵

In 1994, the use of maternal serum screening (MSS) for testing the likeliness of the fetus having birth defects such as Down syndrome, neural tube defects (NTDs), and trisomy 18, by taking a blood sample from the expecting mother and examining the levels of specific substances (markers) contained in the sample became available in Japan.²⁶ Its use increased gradually till 1998, and although the rate of its conduct was not so significant (up to one per cent of pregnant women), the easiness of taking the test, which implied the possibility of its use as a mass screening test, along with reported confusion by pregnant women due to little information given to them prior to the test gave rise to concerns among the public. Thus the Japan Down Syndrome Society expressed their concern that this method of prenatal testing might eliminate disabled people from society, and mass media criticized its use as “*inochi no senbetsu*” (selection of life).²⁷ These concerns materialized into a view of the government as encouraging discrimination against the

21 DPI Women's Network Japan. “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, May 11, 2012, <http://dpiwomensnet.choumusubi.com/english.pdf>. This issue is now regarded as an infringement of human rights and a partial reparation is made to a number of victims of compulsory sterilization before 1996, but they are requesting the apology by the nation.

22 Toshimitsu, *Juseiran-Shindan to Shusseimae-Shindan*, 68; Hogan, “Set Adrift,” 65–6.

23 Wald et al., “Antenatal Maternal Screening,” 394.

24 National Health Service, “Fatal Anomaly Screening Programme,” accessed in April 10, 2018, <http://fetalanomaly.screening.nhs.uk/>.

25 Vassy, “From a Genetic Innovation.”

26 Sago et al., “Nationwide Demonstration Project,” 1.

27 Sakai, *Reportage Shushhouzen Shindan*.

disabled, thus, the Ministry of Health and Welfare set up the Expert Committee on Prenatal Diagnosis. In 1999, the expert committee presented their “View on Prenatal Marker Screening” that functioned as a guideline for the clinical practice of prenatal testing. It clearly stated that “we must understand that practicing prenatal testing is not only a medical issue but also an ethical, social, and psychological issue. Therefore, we should listen to the opinions and concerns of a variety of parties before we make a conclusion,” which they did, and concluded that obstetricians were not to actively give information about MSS, that doctors should not recommend it to pregnant women, and that companies should not advertise the test for their commercial profit, to avoid further confusion resulting from low literacy of pregnant women and a wider concern about the possibility of mass screening. To reach this decision, the committee needed to consider various complex issues such as the possibility of information provision about prenatal testing leading to the obstetrician being sued for “wrongful birth,” but it came to the decision that its recommendations were fair given that adequate information was provided by the obstetrician upon request by the pregnant woman and that the genetic counseling system was improved. The number of pregnant women taking the MSS dropped immediately after the release of “View on Prenatal Marker Screening” in 1999 but gradually increased and surpassed the initial number.

In 2011, noninvasive prenatal testing (NIPT) for detection of fetal aneuploidies became available, which led to yet another controversy in Japan.²⁸ As NIPT was easier and safer than other tests available, while exhibiting high sensitivity and specificity (enabling a reliable diagnosis—although its results are not definitive), mass media pointed to the danger of women casually taking NIPT and opting easily for termination.²⁹ To respond to such a public concern, the Japan Society of Obstetrics and Gynecology (JSGO) published a guideline for the use of NIPT in 2013.³⁰ It stated that NIPT should not be widely performed in general obstetric clinics until an appropriate system of genetic counseling was established. In addition, the society stipulated that the test “should only be carried out on pregnant women with increased risks for fetal aneuploidy” and its use for mass screening should be strictly prohibited.³¹ Thereupon NIPT was introduced in Japan in 2013, and became available in

28 Sago et al., “Nationwide Demonstration Project,” 5.

29 The Japanese Maternal Body Protection Law permits abortions to protect pregnant women against health problems which include those caused by economic reasons, but not for fetal abnormalities.

30 Japan Society of Obstetrics and Gynecology (JSGO) guideline for NIPT clinical practice, 2013, http://www.jsog.or.jp/news/pdf/guidelineForNIPT_20130309.pdf.

31 JSGO, “Botaiketsu wo mochiita atarashii shusseimae-idengakuteki-kensa ni kansuru shishin” [The guideline for new prenatal genetic test by maternal serum screening], 2013, quoted English translation from Sago et al., “Nationwide Demonstration Project,” 2.

institutions certified by the Japanese Association of Medical Sciences. This kept the rate of prenatal testing low,³² which in 2016 was approximately seven per cent among total pregnant women and 25 per cent among those in advanced maternal ages. The low rate is also attributable to high costs, as the costs of NIPT plus amniocentesis with genetic counseling in the case of a positive result is relatively high and are not covered by the public health insurance. Nevertheless, the rate of testing in Japan doubled since 2008.

Another problem became prominent in 2016: a supposed increase in the conduct of NIPT in non-obstetric clinics, which were not certified and did not provide genetic counseling.³³ Many young couples started to visit such clinics after seeing advertisements online. The clinics offered NIPT, which tells the sex of the baby as well as information about a hundred or so disorders, and without needing to take a course of counseling. Thus, in 2019, the JSOG attempted to update its guidelines. Meanwhile, the Ministry of Health, Welfare and Labor organized an expert committee to discuss the requirements for the appropriate practice of NIPT. Based on the committee's report, a new system for the conduct of NIPT started in 2021, in which a doctor or a genetic counsellor provides information to pregnant women about rearing disabled children and about available social support, along with information about abortion.³⁴

Women's Experiences of Decision-Making Regarding Prenatal Testing

In order to understand transitions in the socio-technical system of prenatal testing in Japan, it is important to refer not just to publicly available sources, but also the narratives of pregnant women. Thus, this section presents interviews of women who went through decision-making about prenatal testing in Japan from 1980s to 2010s. Their narratives are extracted from semi-structured interviews conducted in 1991 (the 1991 study)³⁵, in 2003 and 2004 (the 2003–4 study)³⁶, and in 2013 to 2016 (the

32 Sasaki et al., "Current status."

33 Japanese Ministry of Health, Labor, and Welfare, and Deloitte Touche Tohmatsu LLC, Report of survey on actual situation of prenatal testing, a program of support facilitation for children and childrearing, 2020, <https://www.mhlw.go.jp/content/11908000/000651251.pdf>.

34 For example, they provide information about parent groups and cases of people with Down's syndrome living self-sufficiently in group homes with welfare/salary incomes. There have been laws and regulations to ensure disability rights and social welfare, but the Act on Comprehensive Support for Persons with Disabilities specifically included when revised in 2020, the public supports for self-sufficient lives of people with disabilities.

35 Tsuge, "*Shussboumae Shindan*" [Prenatal diagnosis], 45–78.

36 Tsuge, Sugano, and Ishiguro, *Ninshin* [Pregnancy].

2013–6 study)³⁷. Their narratives supplement the above historical description. The anonymous interviewees were all female with male partners. They were between their late twenties and early forties when they became pregnant, and all completed secondary or higher education. The language used was Japanese.

Interviews in the 1991 Study

This study looked at eight women who considered having genetic counseling or prenatal testing. Four of them were advanced in age but did not take prenatal genetic testing. They all had routine ultrasounds. Three out of four mothers of previous children with genetic/congenital disorders decided to take the test in the late 1980s to 1991. Akemi and Eriko are in this category, and thus can be described as having risks associated with their clinical histories.

The first, Akemi, lives in a suburban city with her husband and two children. In the early 1980s, when she was in her late twenties, she gave birth to her first baby who had minor malformations of fingers and toes. When the doctor told her and her husband that some fingers and toes of the newborn were absent, Akemi related, “I was astounded, I pitied him, and I was sorry that I couldn’t give a proper birth to him. My mother wondered if I had too much coffee or took painkillers. Later I understood why she did so—it was her apology to my husband and his parents. But it hit me the hardest.”³⁸ Although Akemi’s parents-in-law accepted their grandson’s anomalies relatively quickly, her parents had a greater difficulty in doing so. Although their attitudes changed gradually, and Akemi grew better able to deal with prejudice, she became anxious when she was pregnant again in the late 1980s.

Her second pregnancy raised different questions: “I love my [first] son truly and I thank him for being born. . . . But I’m painfully aware of the discrimination against the socially vulnerable. [So, I was] more reluctant to have a baby with disabilities when I was pregnant again.” When she expressed her concerns to the doctor during mid-pregnancy, he conducted a detailed ultrasound scan. It was traumatizing for her as it lasted for two hours, and was in the presence of residents and students as it was a university hospital. The doctor said the test showed no sign of anomalies but mentioned a slow development of the fetus. This made her worry throughout the pregnancy, but the baby had no disabilities when it was born. Looking back on her experience, she felt she grew stronger through the experience of raising children with the help of surrounding people, including her parents, parents-in-law, the older child’s pediatrician, elementary school teachers and a parent group for children with malformation of limbs.

37 Unpublished data.

38 Akemi, interview by author, April 12, 1991, a city in northern Japan, a face-to-face interview.

The second interviewee, Eriko, gave birth to a child with Down's syndrome in the late 1980s, when she was in her late twenties.³⁹ Her parents and the parents-in-law were both supportive. At the time of her interview, she was working with another mother who also had a child with Down's syndrome to start a support group in Tokyo for children like theirs. When she became pregnant again, her child's pediatrician recommended genetic counseling and explained amniocentesis briefly. As Eriko recalls,

The doctor said that the mother was to make the final decision. . . . I [felt] the fetus was alive when I heard the heartbeat of my first baby . . . [Therefore,] I was very scared of a needle in my belly [for amniocentesis] because it might pierce my [second] baby's head. When I told my husband about the genetic counseling, I stressed I couldn't have a termination after listening to the heartbeat. . . . I didn't care if the second child had a problem, and I assured him that it wouldn't. . . . My husband agreed so I didn't visit the hospital.

However, she emphasized: "I think [taking amniocentesis] is really the parent's decision . . . as it is no good if parents . . . can't be positive about raising a [handicapped] child. It would be a pity for the child to be born in such a family. . . . Whether the child lives happily or not depends on the parents."

At the time this study was conducted, the term "fetus diagnosis" had started to appear sporadically in the mass media. In this sense, both Akemi and Eriko were typical examples as their reasons for considering a fetus diagnosis were the clinical histories of genetic/congenital disorders in their previous children. However, their experiences were strikingly different. Akemi's decision was clearly influenced by a typical old norm of a daughter-in-law needing to bear healthy children for the extended family of the husband, which was expressed as Akemi's mother's concern. Having a child with a disability was considered "abnormal" and could potentially stigmatize the parents as well as the extended family.⁴⁰ Also, people had often been explicitly rude towards the visibly disabled, which has become less noticeable in cities but remains in some rural regions.

Levels of literacy were also different in the two cases. Unlike Akemi's case, Eriko received sufficient information about genetic counseling and amniocentesis from the pediatrician of Eriko's child with Down syndrome, which allowed her to make a decision by herself. Eriko's previous experience with a disabled child was positive, and she had found a public health nurse who visited her and advised her about raising a child with disabilities very helpful, and the nurse connected her to

39 Eriko, interview by author, May 24, 1991, a suburban city in Tokyo, a face-to-face interview.

40 Lock, *Eliminating Stigmatization*, 258–61.

another mother in a similar circumstance. Such a supportive environment was not particularly common, however, as, there still were doctors who had prejudiced notions of patients with disabilities.

Interviews in the 2003–4 Study

In this study, twenty-six women were interviewed, of which twenty-one did not have prenatal testing, while all had routine ultrasound.⁴¹ One had the MSS, two had amniocentesis, and two had detailed ultrasound screenings. The cases of three interviewees follow: Fumiyo, who had the MSS, Haruka, who had amniocentesis overseas because she thought her doctor in Japan was reluctant toward prenatal testing, and Jun, who decided to take a detailed ultrasound screening to see if she had a legitimate reason for terminating her pregnancy.

Fumiyo, a fulltime worker in Tokyo, gave birth to her third child when she was thirty-five, around the year 2000.⁴² Her doctor provided information about the MSS test⁴³ because of her age and recommended that she make a decision by discussing the issue with her husband and her parents. However, there was another important consideration for Fumiyo: “We were more worried about our older children because they would have to look after their handicapped sibling for many years to come. . . My mother said it was our choice, but we had to think about our elder sons.” The MSS test showed a lower-than-average probability of the fetus having abnormalities compared to others in her age group, which made her deeply relieved, but she expressed how she continued to be bothered by a question of what she would have done “if the result was a bad one.”

The second interviewee, Haruka is a homemaker and lived overseas due to her husband’s work for several years. While visiting Japan, she realized she was pregnant, so she visited a local Japanese doctor. She was thirty-four years old. She recalled her concerns: “Because it was an advanced-age pregnancy,⁴⁴ I was extremely worried about its risks. So, I told the doctor that I wanted to have amniocentesis. Then he said, ‘but you have decided to give birth, haven’t you?’ which made me realize that he had a negative attitude to the prenatal testing.”⁴⁵ As a result, she had amniocentesis after returning to her country of residence. The result did not indicate

41 For more details, Tsuge, Sugano, and Ishiguro, *Ninshin*, 252–5.

42 Fumiyo, interview by author, July 18, 2003, Tokyo, a face-to-face interview. Ivry reported a similar interview with a Japanese woman (Ivry, *Embodying Culture*).

43 At the time, the triple marker screening test which examined three substances (markers) was offered as an MSS test.

44 In the country she was residing, the cost of prenatal testing was subsidized for those aged 34 or over. In Japan, the advanced-age pregnancy normally refers to pregnancy at the age of 35 or over, and the cost of prenatal testing is not subsidized.

45 Haruka, interview by Sugano and Ishiguro, 4 August 2003, Tokyo metropolitan area.

abnormalities, but if it did, she thought that she might have terminated the pregnancy, as the awareness of an advanced-age pregnancy consumed her badly.

Jun, the third interviewee, was asked to give up her dream of becoming a chef when she was pregnant. Because, as she remarked, some people in Japanese society think that “having an abortion is a better choice than giving birth to a baby with abnormalities,” whereas having an abortion for the mother to achieve her dream is considered “selfish,” she had a test to see if fetal deformity would be detected.⁴⁶ If so, her preference to terminate the pregnancy would be seen socially as somewhat legitimate.

Interviews in the 2013–6 Study

The last study, which ran between 2013 and 2016, included interviewing nine women and a couple, who had or were considering prenatal testing. Two women had had NIPT and three women had had amniocentesis.

Mika lived in the United States with her Asian-American husband and conceived for the first time naturally at the age of forty in the early 2010s. Her doctor discussed ordinary prenatal testing with her, and said it was her choice and suggested that she discuss her options with her partner. She did so and decided not to have the test. However, when she had ultrasound scan during her second trimester, the diagnostic medical sonographer strongly recommended that she have NIPT because of her age, or at least a genetic counseling. As a result, she and her husband had a counseling session, as it was covered by her American health insurance. They thought the fetus was fine at first, but grew less confident after the counseling, as they learned everybody had a chance of having a baby with disabilities. As Mika recalled, “My husband told me that he didn’t have the confidence to raise a child with disabilities. I insisted though that I would give birth even if a chromosomal abnormality was found. . . . But I’m not sure if I really would have. I doubt myself. I don’t think I could make my mind at that time.” Consequently, Mika had NIPT. The result showed nothing alarming.

When Nao was pregnant with her first baby, she was aware of her advanced-age pregnancy and knew a little about prenatal testing, but the doctor provided no information. At the twenty-sixth week, however, trisomy 18 [Edward’s Syndrome] was detected by amniocentesis after detailed ultrasound, but by then termination was no longer a legal option. She continued her pregnancy and had the baby, but it died soon after the delivery. This experience led Nao and her husband to join a self-support group for trisomy 18.⁴⁷ Nao then conceived again in her late thirties through in vitro fertilization. As she recalled, “Couples whose children had trisomy 18 in the

46 Jun, interview by Ishiguro and author, 13 September 2003, a suburban city in Tokyo.

47 They organize photographic exhibitions of children with disabilities to connect families and to promote the understanding of trisomy 18.

group [made me] not mind having a child with a chromosomal malformation. I also thought families of children with incurable diseases didn't look unhappy. So, I become less worried about raising [such] a child."⁴⁸ As she was determined to have the new baby, regardless of its genetic health, she only had a detailed ultrasound scan. She gave birth to a girl when she was forty, and her daughter is growing well.

An Analysis of Study Results

From a brief comparison of above cases, some changes are observable regarding decision-making about taking prenatal testing over time. First, the major reason for taking prenatal tests has shifted from "risks associated with clinical history" of the pregnant woman to "risks associated with maternal age." This agrees with research more generally.⁴⁹ In 1991, four women who were pregnant at an advanced age (35 or over) had a genetic counseling, gathered information about raising children with disabilities, or discussed with the husband and/or parents. However, they did not take a prenatal test. Likewise, in the 2003–4 study, seven out of twenty-six interviewees were aged 35 or over, but only two had prenatal testing. There also were one woman aged 34 at the time of the childbirth who had amniocentesis and another of the same age who had three-dimensional sonography, both of whom had other reasons in addition to their age, for wanting to take a prenatal test. Yet in the same study, Haruka actively chose to have prenatal testing, and data from the 2013–6 study indicate that taking prenatal testing due to advanced age was becoming common. This agrees with available statistical data: in 1971, the "experience of giving birth to a child with chromosomal anomaly or other malformation" was the most common reason to take amniocentesis, but by 1983, it was the "maternal age of thirty-five and over," and this is consistent with the increase in advanced-age pregnancies.⁵⁰

There was also a significant change in information provision about prenatal testing by doctors. In the 1990s, the importance of informed consent was already known, but there still were doctors reluctant to tell patients medical facts directly, believing that it was better for the patient not to have everything disclosed. Also, skills of information provision by the doctors and genetic counselors varied greatly. The Ministry of Health and Welfare's guideline of 1999, made doctors' role in information provision about prenatal testing passive, but how and what information

48 Nao, interview by author, 23 March 2016, a city in California, U.S.A.

49 Suzumori et al., *Genetic Amniocentesis*, 565–7.

50 The average age of mothers having their first child in Japan has increased from 25.7 years old in 1975 to 30.7 years old in 2015 according to the Japanese Ministry of Health and Labor, "The Vital Statistics 2015"; National Institute of Population and Social Security Research, "The Japanese National Fertility Survey," 1990, 2005, and 2015, <http://www.ipss.go.jp/>.

was passed on to pregnant women varied tremendously in the 2003–4 study, from handing out a leaflet to informing in detail to women over certain age. Pregnant women under 35 either knew nothing about the tests or interpreted the absence of information as evidence of “the doctor’s decision that the test was not necessary.”⁵¹ On the contrary, those who received information correctly understood that the doctor was not recommending the test, and they were to make the decision with the partner (and the parents). By the time NIPT became available in 2013, information infrastructure no longer assumed such a traditional doctor–patient relationship, as women/couples got information online and made decisions before they made appointments for the genetic counseling required for NIPT.

Another change is in how the risks of prenatal testing were perceived. In 1991, Eriko explained her reason for not taking the test as the fear of the needle piecing the fetus. The four women who did not take prenatal testing despite their advanced ages also worried about the danger of the test. In the 2003–4 study, too, some interviewees were anxious about possible damages to the fetus or the risk of miscarriage. Therefore, the appearance of NIPT which can be used from the tenth week of pregnancy (earlier than other tests), and which does not harm the fetus, made prenatal testing easier to agree to, despite the need to conduct a definitive diagnosis in the case of a positive result.

Decision-Making regarding Prenatal Testing

Among the women studied here, there were women who were the principal decision-makers themselves,⁵² such as Akemi and Eriko in the 1991 study. These women made the difficult decision by themselves, with some assistance from their husbands. Later, in 2003–4, however, Fumiyo was explicitly advised by the doctor to consult her partner and parents, which indicates the importance of the husband, as well as the couple’s extended families. However, in the 2013–6 study, it was quite typical, as illustrated by Mika and Nao, that the decision was made with the help of their partners and the active pursuit of additional information. Here, the guidelines of NIPT requiring genetic counseling of the wife and the husband may have impacted on the presence of the expecting father in the decision-making. In addition, the style of decision-making seems to have become more varied over time, involving more stakeholders such as the genetic counselor, friends, and self-support groups as in Nao’s case.

The involvement of extended families (often directly) in the decision-making about prenatal testing may be one of the characteristic features of Japanese cases. In

51 Tsuge et al., *Ninshin*, 507–9.

52 Kato, “Women’s Rights?”

addition to the episodes described above, other data from the studies also show that decisions have often been made with direct or indirect inputs of the parents of the couple. This remained unchanged from 1991 to 2003–4, and is consistent with a quantitative survey which indicates that the parents and siblings of the expecting couple are generally also involved in decision-making about prenatal testing.⁵³ Discussing such matters with the couple's parents and siblings is not uncommon in Japan as the decisions inevitably involve the consideration of caregiving expectations within the family from daily care work and mobility assistance, to basic medical care, and even educational/vocational support, such as obtaining appropriate education supplements and choosing appropriate schools. Indeed, as one of the interviewees in the 2003–4 study opined, extended families were involved because “the child being born would affect the people other than the parents.” It is worth noting that such an attitude has not changed and is still observable in the 2010s although the average number of children born to one couple has decreased, and the number of couples living with their parents has decreased also.

Women's Reasons for Prenatal Testing

There was an observable shift in how women described their reasons for having prenatal testing done. In 1991 and in 2003–4, several interviewees explained that the test was for the child to be born, or for the family's older child(ren). Furthermore, in two cases in the 1991 study, the mother's apologies to their children with disabilities were expressed. However, the studies show that the rhetoric of “for the child” was gradually replaced by more direct expressions such as “because we lack confidence in raising children with disabilities.”⁵⁴ In that sense, the decision to terminate pregnancy is recognized as the parents' choice, but it is not always openly accepted, especially if a termination is considered in order for the parents to pursue their desired lives or lifestyles, as shown in the case of Jun in the 2003–4 study.

The intricate and dynamic socio-technical system of prenatal testing in Japan shows changes in women's attitudes, public regulations and medical recommendations, but throughout the notion persists of the family/extended family as the unit of community which is responsible for various care work if a child is born with disabilities. Also unchanged overtime is women's feelings of discomfort or regret for considering to take prenatal testing. As it is a technology that suggests the likelihood of a baby born with abnormalities, it is inevitably linked to the desire to have “healthy” babies. This implication can consume some women badly, like Fumiyo and Mika, but this experience of guilt does not seem to be addressed properly in the current system of prenatal testing.

53 Nakagomi and Yokoo, “Analysis of Decision Making.”

54 Nao, interview.

Conclusion

This paper described the modern history of prenatal testing in Japan, from the 1980's to 2010's, to show the changing technological, political, cultural/familial aspects of decision-making about prenatal testing. It has become clear that from the introduction of amniocentesis in the 1970's, the beginning of prenatal testing in Japan, testing of abnormalities in fetus has been repeatedly criticized by the media and activists. These criticisms resulted in the government working with medical experts to implement careful policies. Unfortunately, their policies were vague and confusing for actual clinical practices, and thus resulted in a variety of interpretations. Meanwhile, pregnant women who obtained information about prenatal testing made decisions, often with their partners and families, based on their medical literacy and their perception of risks, of the tests, the pregnancy (typically advanced-age pregnancy) and those of raising a child with disabilities (such as the impact on their current lifestyle). The combination of these factors, some of which seems local to the East Asia while some appears more universal, gives rise to the current Japanese socio-technical system of prenatal testing, and a careful examination of this system may perhaps lead us to a better understanding of the on-going situation such as the increasing number of women taking NIPT.

The development of different technologies for prenatal testing has enabled parents-to-be to grasp the health status of their fetus at earlier and earlier times, in a much safer and more precise manner. New technology has also enabled users to detect more diseases of the fetus. Overtime, it has become much easier for pregnant women to take the test, and some conditions detected can now be treated, or can now be dealt with at the time of childbirth. However, the options available to pregnant women are either to continue or to terminate the pregnancy. The emphasis in development has been on discovering abnormalities in the fetus at an early enough stage so that the pregnancy can be duly terminated.⁵⁵

NIPT, which had initially been targeting three types of chromosomal abnormalities, can now detect over 100 disorders. Yet, many of these have low incidence rates, and are likely to result in miscarriages/intrauterine fetal deaths naturally, so the early detection does not save these lives. Therefore, some specialists are critical about including these as the target diseases for NIPT. Nonetheless, women/couples visit non-certified clinics and choose to take the test which detects more disorders, at higher prices. The above analysis suggests that perhaps these women/couples have a set of decision-making factors and priorities different from what are considered scientifically/medically correct, and a careful examination of intertwining cultural and technical factors is required before labelling them irrational.

55 Cowan, *Heredity and Hope*, 71-4.

As mentioned, the Japanese Ministry of Health, Welfare and Labor has started a discussion regarding the establishment of a new system of prenatal testing with a focus on NIPT. One of its main topics is the reinforcement of medical/social/psychological support for the continuation of pregnancy even in the case of detection of severe diseases or abnormalities. Yet very few individuals who learn of severe abnormalities of their fetus prepare to give birth. It is reported that 90% of those with definitive diagnoses after NIPT chose to have termination. In such a social climate, it is crucial that the way in which prenatal testing is presented and by whom are critically examined.

According to OECD, in societies with stronger gender biases, including Japan, the percentages of men taking up care-giving roles are lower. Also, the average wages paid to women are much lower compared to men, although the percentage of working women has increased.⁵⁶ These imply that mothers need to work for long hours and may not be able to afford enough time to attend to their children or pay the extra medical fees for children with disabilities/diseases. This may be related to the fact that more women/couples are explicit in wanting to have “healthy” babies.

Surveys about women’s decisions and attitudes about prenatal testing show that women who want to give births without taking a prenatal test, and women who want to take a test to get information about disorders/disabilities of the fetus so that they can ready themselves for the babies to be born are understandably few, as the test results impose hard decisions on them.⁵⁷ Nonetheless, they exist. These women are not against induced abortion or incapable of making decisions by themselves. Rather, data seems to suggest that they are sensitive to how the development of medical technology has marginalized women, diseased and disabled as vulnerable and incapable of making decisions, as they had long been in Japanese society, and somehow wanting to change the situation around by clearly stating what they want. To realize this, I believe substantial changes in prenatal testing that occurred in the last three decades in Japan and what were discussed there should be recorded and remembered. Such a record, I also believe, should provide alternative perspectives to other historical investigations and analyses of socio-technical systems around the world.

Biography

Azumi Tsuge (tsuge@soc.meijigakuin.ac.jp) is a feminist medical anthropologist whose has been engaged in analyses of technologies used in infertility treatment and other medical technologies that exhibit gender biases. She conducts interviews and drawing from the narratives extracted, analyzes the relationship between medical technology, women and society.

56 OECD Database, accessed 12 August 2021, <https://stats.oecd.org/>.

57 Tsuge, “Considering the Social Background.”

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