

# VIRTUOUS INDECISIVENESS: Structural Moral Ambivalence and the Tentative Implementation of Non-Invasive Prenatal Testing in Japan

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Professor Rin,<sup>1</sup> the head of a maternity department in a regional hospital in northern Japan, specializes in reproductive genetics. The first author (Ivry) met him in the winter of 2014, a year after the Japanese Society of Obstetrics and Gynecology (JSOG) issued guidelines for a clinical trial of a new non-invasive prenatal test (NIPT) that analyzes free-floating fetal DNA in maternal blood, indicating the probability that the fetus has one of three chromosomal anomalies (21,18,13). This new maternal blood test, undertaken during the first trimester, does not endanger the pregnancy but might yield indications of chromosomal anomalies, and thus, might lead to further invasive testing and questions regarding termination. Rin's hospital was one of thirty-four institutions authorized by JSOG in 2013 to provide NIPT.<sup>2</sup>

Reflecting on his encounters with couples coming for the genetic counseling mandatory for those opting for NIPT, Rin said: "Japanese are not good at

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decision-making."<sup>3</sup> He explained that couples have difficulty deciding whether to undergo NIPT and, if they do, how to proceed when receiving the results. Ivry was perplexed by Rin's seemingly negative appraisal of the Japanese as decision-makers and skeptical about his generalization. The pregnant women and couples she had met did not seem particularly hesitant about undergoing a blood test early in the pregnancy; rather, it was the genetic counselors who repeatedly confessed a "lack of confidence" about how to advise their clients. Then, in 2014, she did not yet suspect that she was missing a culturally distinctive nuance in Rin's statement.

Five stints of fieldwork (2014–2019), a close exploration of the NIPT experiences of pregnant women, their partners, and genetic counselors, and much dialogue with her Japanese co-authors, an ob-gyn and a genetic counselor, made Ivry realize that, despite her literal understanding of Rin's words, she had misunderstood their meaning. Explicit and implicit statements by medical professionals about the inappropriateness of quick, unequivocal decisions made her comprehend that rather than complaining about his patients' ineptness, Rin was pleased that reproductive decisions, both pre- and post-diagnostic, did not come easily to them. Ivry had missed the value that Rin associated with ethical ambivalence. In Rin's ethical scheme, indecisiveness—as both an indication and a manifestation of ambivalence—carries no negative connotations. Indeed, for Rin, the genetic counselors, the midwives, and the nurses interviewed, vacillation about undergoing a test that might lead to a termination decision and ambivalence when facing what they called "choices of life" (命の選択, *inochi no sentaku*), i.e., whether or not to give birth, is virtuous. $^4$  Importantly, we do not claim here that Japanese couples always experience initial difficulty when deciding whether to undergo a blood test in early pregnancy, nor that they are discouraged from making decisions. Rather, our findings suggest that both institutionally and individually structured guidelines are established in the mandatory genetic counseling sessions and beyond to ensure that no decision is taken lightly.

This explicit concern with evaluations of the quality of deliberations permeating the arena of NIPT genetic counseling speaks to current anthropological efforts to understand how people endeavor to live a moral life within their glocal moral worlds. Underlying the vibrant anthropological debates and disagreements about how to approach the ethical effectively is an understanding of people not as good or bad per se, but as having notions of good and bad according to which they evaluate themselves and others (Laidlaw 2013). Yet while practices and mechanisms of evaluation have been germane to these debates, the question of how

people evaluate the quality of ethical deliberations in particular social settings remains under-researched.

In the Japanese arena of NIPT counseling, where such evaluations are explicit, it seems that ambivalence—both its absence or presence and its depth—is regarded as a key principle with which to evaluate decision-making. We call this principle "structural ambivalence," where ambivalence stands for a respected ethical stance, rather than the inability to decide, and structural conveys the sway ambivalence holds throughout macro and micro social scales of meaning-making. In this article we trace its working across scales. Maternal blood tests, such as NIPT, that do not endanger the pregnancy and give indications of fetal anomalies have become normalized in many parts of the world. In Japan, under the auspices of structural ambivalence, such tests prompt ethicalization processes, namely, the rephrasing and reframing of social practices into ethical quandaries that demand ethical deliberations that take place across multiple scales of social practice (Ong 2010).

The valorization of indecisiveness notwithstanding, Japanese medical professionals expect prospective parents, like their counterparts in Europe and the United States, to reach decisions about undergoing NIPT and other prenatal tests, to sign consent forms, and to decide about how to proceed after receiving the results. Thus the valorization of indecisiveness is about promoting the quality of decision-making processes, rather than about discouraging decisions. Medical professionals' concerns, however, go beyond autonomy. The Japanese moral world is a "moral assemblage" (Ong 2010; Ong and Collier 2008; Zigon 2010) of religious and ethical traditions that includes layers of Shintoism, Japanese versions of Buddhism and Confucianism, and Western ethical traditions (e.g., Sleeboom-Faulkner 2014; Wargo 1990). The notion of "autonomous decisions" (自己決定, jiko kettei) immigrated to Japan during the 1980s as part of a broader effort to translate bioethical literature from English (Robertson 2010) and became a formal prerequisite in Japanese medical interventions (Akabayashi and Slingsby 2003). This leads to questions about how decisions are made in a social setting that values indecisiveness as a mark of appropriate ethical consideration and about the long-term personal and social consequences of decision-making processes for the deciders' moral subjectivities.

This article addresses these questions while drawing on an ethnography of NIPT genetic counseling in Japanese hospitals contextualized within the moral ambivalence toward reproductive technologies traceable across social scales. We analyze ethical deliberation processes surrounding the provision and uptake of NIPT, tracing their development within the moral assemblage of Japanese maternity care.

The Japanese configuration of NIPT raises questions about the paradoxical role of ethicalization in the implementation of contested technologies in Japanese society and beyond. Our explorations are informed by and contribute to cross-disciplinary conversations at the intersections between the anthropology of reproduction and the anthropology of ethics and moralities about the meaning and purpose of bioethical praxis and, particularly, of moral ambivalence, as configured within glocal reproductive politics (Ginsburg and Rapp 1991).

## REPRODUCTIVE TECHNOLOGICAL CHALLENGES TO SOCIAL ORDER

At the turn of the twenty-first century, as ethnographers started focusing on the increasing involvement of biotechnologies in conception, pregnancy, and birth, they came to understand the making of kin as a terrain of social transformation. Rather than emphasize cultural continuity, as their predecessors had done, contemporary anthropologists identified the range of emerging reproductive technologies—contraceptives, assisted conception and donor technologies, prenatal and preimplantation diagnostic technologies, and the like—as transforming notions of life/death, nature/culture, and relationality, as well as, importantly, challenging the moral order in many societies around the globe (e.g., Franklin 2003; Lock 1998; Strathern 1992).

The range of prenatal diagnostic technologies (PND) to detect fetal anomalies that became available during the second half of the twentieth century has raised many ethical anxieties. Alongside the prospect of the post-diagnostic termination of anomalous fetuses, PND were identified as part of a neo-eugenic apparatus of selective reproduction, leading to ethical public debates in Europe and the United States among health-care providers, disability rights activists, bioethicists, philosophers, feminists, and religious scholars (Gammeltoft and Wahlberg 2014). Questions regarding when life begins and what makes a life worth living were among those perceived as key to understanding local sociocultural configurations of PND (Gammeltoft and Wahlberg 2014). Though in many contexts PND were introduced as tools enhancing women's knowledge and choices, critics voiced concerns that these so-called choices would rapidly become a compulsion to choose the socially endorsed alternative (Strathern 1992).

Indeed, these concerns foretold the normalization of PND in much of the developed world. Nevertheless, the ethical negotiations of non-invasive and invasive tests are configured quite differently. The former signifies interventions not known to carry any risk of miscarriage: for example, blood tests analyzing fetal

proteins and obstetrical ultrasound measurements, both of which give probabilities indicative of fetal anomalies but yielding considerable false positives. Such tests were introduced in the United States as part of an "assurance ritual," a means of affirming that "everything is OK with the baby" (Press and Browner 1994, 212-13), or even, in the case of obstetrical ultrasound, as a bonding device (Taylor 2008). Applicants were rarely invited to reflect on the tests' ethical implications. Invasive tests, on the other hand, such as amniocentesis and chorionic villus sampling (CVS), analyze fetal cells directly and yield definitive results, but they carry the risk of miscarriage. Fetal diagnosis constitutes the explicit purpose of this testing, which invites applicants to weigh diagnosis against the risk of miscarriage. In her seminal exploration of pregnant women's dilemmas about amniocentesis, Rayna Rapp (1999, 3) described how American women feel "forced" to make "concrete and embodied decisions about the standards for entry into the human community." She referred to her informants as "moral pioneers" (Rapp 1999, 307) and showed how genetic counselors offered them a "translation" of genetic knowledge but avoided interfering with their ethical decisions as part of a professional commitment to "non-directiveness," expecting them to use professional knowledge to make decisions on their own.

Ethnographers of PND working outside Euro-American settings identified local ways to handle moral pioneering—that is, mechanisms to share the burden of autonomous reproductive decisions—while engaging in burgeoning scholarship on ethics and moralities (Zigon 2007, 2010). The moment when a pregnant woman is faced with an indication or diagnosis of fetal anomaly was identified, using Jarrett Zigon's (2007) idiom, as a "moral breakdown" (Gammeltoft 2014; Ivry and Teman 2019): a "moment of crisis" (Gammeltoft 2014, 196) when the existentially comfortable moral world breaks down, forcing the pregnant women to "consciously reflect upon the appropriate ethical response" (Zigon 2010, 5). Zigon (2009, 269) calls such reflections "ethical work," seeing them as a response to an "ethical demand" (Zigon 2007, 139) and a tactic to recover "nonconsciously acceptable ways of living in the world." Zigon clarifies: "I do not intend the notion of acceptable to be equivalent to obligatory. Rather, it is much more about being existentially comfortable in one's world. . . . ethics in my terms is the process that is aimed not at the good but rather aimed at cultivating this existential comfort in and between the ranges of influence of . . . various moralities" (Zigon 2010, 5).

It should be emphasized that NIPT does not endanger the pregnancy. Yielding probabilistic but highly accurate results with low false positives (2.5 for Down Syndrome),<sup>6</sup> it blurs the distinction between non-invasive, safe-yet-inaccurate tests

and invasive, risky-yet-accurate tests. Thus, while in many countries NIPT requires no prior counseling, in Japan, genetic counseling is mandatory, with a mass of medical information that seems to equal that given in pre-amniocentesis counseling documented in the United States (Rapp 1999). Moreover, Japanese NIPT applicants are required to show evidence of serious ethical labor, similarly reminiscent of American amniocentesis applicants (Rapp 1999).

Our analysis of the ethical labor surrounding NIPT in Japan draws on various concepts emerging from the above ethnographies of moral pioneering and the anthropological theorization of moral breakdowns. However, it departs from them in two ways. First, rather than focusing on the drama following the actual diagnosis of a fetal anomaly, we concentrate on the introduction of tentative ethical dilemmas, namely, the processes of ethicalization concerning NIPT's potential to introduce a future moral breakdown, as insinuated in pre-NIPT genetic counseling. Second, we question the developmental trajectory of Zigon's (2007) "moral breakdown" alongside the tactical purposes he designates to ethics. The case of pre-NIPT counseling in Japan invites a reconsideration of the notion of ethical labor as a tactic to recover comfortable moral everydayness; it is discomfort—with technologically assisted selective reproduction—that pre-NIPT counseling cultivates in Japanese consultees. Our findings call, instead, for Michael Lambek's (2010, 2015) and Michael Lempert's (2014) notion of ethics as a performative action that holds value in and of itself. Furthermore, we are inspired by Lambek's (2015, 45) emphasis on ethics as a quality of action and action's spirit and by Lambek's  $(2015,\,8)$ and Arthur Kleinman's (2007) insights on virtue as an important entry point to understanding what matters to people. Our analysis is further informed by notions of bioethics as a symptom of social transitions (Rosenberg 1999) and a product of ambivalence toward progress (Lock 1998; Stevens 2003) and, more specifically, by ethnographic explorations of the emergence of affect in institutional ethics (e.g., Addison 2022). We explore what happens when ethical labor is enacted within a local moral assemblage informed by, among others, institutional respect for ethical ambivalence and a recent history of eugenic state policies.

#### RENOUNCING JAPANESE EUGENIC STATE POLICIES

Terminations of pregnancy and infanticide, euphemistically called *mabiki* (間引き) after the culling of seedlings in rice cultivation, are documented throughout Japan's pre-modern history. They were used as forms of fertility control, particularly in times of crisis (Lock 1998; Norgren 2001). Within the multilayered moral assemblage of Shintoism, Japanese Confucianism, and Buddhism, terminations did

not make for objects of condemnation before the mid-nineteenth century. Indeed, Buddhism and Shintoism never developed notions of singular divine rules, and it was not in the traditions of Shinto priests or Buddhist monks and nuns to challenge complicated moral issues (LaFleur 1992; Wargo 1990); Buddhism, in particular, has always been a venue for rituals to console the spirits of aborted fetuses (LaFleur 1992; see also Hardacre 1997).

The criminalization of abortions soon after the promulgation of the constitution in 1889 marked a new nationalist regime bent on population growth to facilitate Japan's military efforts and become a compatible player in Western colonialism. During the first half of the twentieth century, eugenics became a state ideology that implemented both "positive" and "negative" eugenic practices. At the height of World War II, Japan issued the National Eugenic Protection Law, legalizing the eugenic sterilization of citizens with a "hereditary  $\ldots$  bodily disease or  $\ldots$ . mental disease" (for the full list of conditions, see Kato 2009, 244). After Japan's defeat in 1945, Japanese scientists disassociated themselves from scientific policies and practices influenced by ultra-nationalism (Robertson 2010, 430). However, despite protests, eugenic sterilizations continued until the abolishment of the National Eugenic Protection Law in 1995 following international pressure by disability rights advocates (Kato 2009; Matsubara 2002; Robertson 2010; Tsuge 2021). The Maternal Body Protection Law of 1996 declared its purpose as protecting the health of mothers and babies and had no article listing hereditary diseases that qualify termination.

Public debates, which had started with the introduction of amniocentesis in Japan in the 1960s (Tsuge 2021) and continued after 1996, questioned the ethicality of new technologies to diagnose fetal disabilities. Neither the state nor JSOG endorsed PND, instead signifying them as the revival of the dangerous eugenics ideology. Indeed, while local governments subsidize maternity checkups, PND are not covered. At the turn of the twenty-first century, PND were practiced cautiously, and doctors neither offered or recommended them (Ivry 2009). Post-diagnostic terminations were performed "backstage" in accordance with the legal article about the fear of serious damage to maternal health caused by pregnancy or delivery (Kato 2009, 258). Rather than discussing technologies facilitating selective reproduction, ob-gyns highlighted the importance of maternal nutrition, moderate weight gain, and maternal relaxation to fetal health. The Japanese "mother and baby health notebook" (母子健康手帳, boshikenkotecho), which monitors gestation, birth, and the baby's health until the age of five, conceptualizes pregnant women as fully fledged mothers whose babies happen to dwell in utero (Ivry 2009).



Figures 1 and 2: Different designs of the medical record of maternity checkups.

The drafting of NIPT guidelines in 2013 was the first time that JSOG took explicit responsibility for PND amid unrelenting ethical debates. Deciphering the repercussions of these debates in maternity clinics and genetic counseling sessions invites Aihwa Ong's (2010, 13) anthropology of ethics, which entails "locating ethical practices, that is, tracking ethical configurations where 'ethicalizing' processes and decisions take place." According to Ong (2010, 13), "situated ethics happen at the intersection of competing logics. . . . [Namely,] overlaps and tensions between multiple ethical regimes." In our case, these might be summarized as the tensions between the (American-style) regime of autonomous decision-making, which necessitates the provision of scientific information in an ethically neutral way, and the (Japanese-style) regime of structural ambivalence, which (as we shall see) renders ethical labor an intersubjective endeavor requiring support. Following Ong's lead, this research was designed to trace the processes of ethicalization surrounding NIPT across scales of social practice and their different social agents.

#### METHODS OF TRACING ETHICALIZATION

During ten months of ethnographic fieldwork between 2014 and 2019, Ivry documented formal and informal conversations about NIPT with ob-gyns, genetic counselors, midwives, pregnant women, and their partners. The ob-gyns, genetic counselors, and midwives interviewed came from hospitals throughout Honshu. Most of the interviews with pregnant women and their partners were conducted in a major metropolitan hospital in Tohoku. All interviews were conducted in Japanese by Ivry and transcribed verbatim by a research assistant. Ivry then analyzed the interviews and translated selected parts into English. Questions aimed to elicit

the experiences of either providing or undergoing NIPT within the broader context of the interviewees' lifeworlds.

The initial analysis revealed three interconnected phenomena. First, a range of practices emerged that health-care professionals use for marking NIPT as a problem. Second, evaluation practices set in motion by this problematization were noted. Third, a master narrative evoked by both health-care providers and pregnant couples about their change of mind over time was identified. Routes of enactment of ethical deliberation as they develop through time, beyond cultural notions of the beginning of life or a life worth living, proved powerful entry points to understanding: first, what it takes to make reproductive decisions within a regime that values ethical ambivalence; and second, what the consequences of ethicalization processes are for individuals, the members of their close network, and society as a whole.

We now analyze the findings at the level of PND policymaking as these deliberations frame the conditions for the provision and consumption of NIPT.

## HOW NIPT IS MARKED AS AN ETHICAL PROBLEM BY REPRODUCTIVE HEALTH POLICYMAKERS

JSOG's issuing of guidelines for NIPT in March 2013 seemed to designate a turning point in the governance of reproductive technologies in Japan. Prior to 2013, Japan did not have a state-authorized system of screening for fetal anomalies. Although the technologies were available in Japanese medical institutions, JSOG avoided formally supporting any form of PND. The most explicit formal statement about a PND technology were guidelines issued by the Ministry of Health, Welfare, and Labor in 1999, exempting ob-gyns from informing pregnant women about Maternal Serum Screening (MSS)—a blood test in the first trimester that had already been used as a screening tool for more than a decade in Europe and the United States (Tsuge 2021). Amid disability rights movements' statements about MSS as a neo-eugenic endeavor, half the JSOG members opposed MSS, citing issues of doctor-patient trust relations (Ivry 2009). Ob-gyns in the early 2000s saw it as irresponsible to offer pregnant women a test that yields probabilistic, that is, indefinite, and often false positive results, thus requiring these women to undergo amniocentesis, an invasive test endangering the pregnancy, if they wanted a definite result. JSOG guidance prior to 2013 thus institutionalized an ambiguous state of affairs in which technologies to diagnose fetal anomalies were available in medical institutions but a formal unwillingness to use them prevailed (Ivry 2009). Moreover, under the Maternal Body Protection Law, terminations can take place until twenty weeks and six days of gestation, but diagnosis of fetal anomaly is not listed as an acceptable reason for termination (Ivry 2009).

A decade later, in 2014, when sharing with Ivry their thoughts on NIPT—a considerably more definitive but still probabilistic test that also requires amniocentesis for a definitive result—the four JSOG members interviewed reported that the professional community was, once again, divided almost evenly. As with MSS, NIPT was, they stated, recognized as a neo-eugenic device and feared for its potential to reinforce discrimination against people with disabilities. However, it was different this time. They referred to the social matrix underlying the politics of reproduction in Japan over the past two decades, which showed lingering economic recession, culminating in the March 2011 triple disaster in northeastern Japan, shrinking fertility rates, <sup>10</sup> and increasing rates of working mothers to have considerably transformed the landscape of reproductive policymaking. <sup>11</sup> They also cited the increasing age of Japanese mothers at the time of a first birth, <sup>12</sup> and its statistical correlation with the occurrence of fetal chromosomal anomalies. They emphasized the high credibility of NIPT for tipping the scales slightly in spite of the ongoing reservations of nearly half of JSOG's members. <sup>13</sup>

The aggregate picture emerging from these four JSOG members was a repeated emphasis on JSOG's ambivalence as a professional association. They recounted the serious disagreements around NIPT within JSOG prior to the issuing of guidelines, the list of requirements—including having a certified genetic counselor employed at the hospital—for enabling medical institutions to provide NIPT, and the limitations on patients' eligibility. Their ultimate message was that the JSOG decision to permit NIPT as a clinical trial had not been taken lightly, that the decision did not resolve the test's ethical problems, and that NIPT had not been nor would be made readily available. In other words, the detailed guidelines regarding NIPT's provision and uptake ensure that it is marked as an ethical problem.

The tentativeness and cautiousness regarding the implementation of NIPT in Japan is distinct when compared to its implementation elsewhere. In Italy, Brazil, the United Kingdom, and China, NIPT was offered privately for several years before formal guidelines were issued and even before clinical trials were organized to measure clinical and psychological consequences (Qiu 2019; Zeng et al. 2016). Thus Japan's simultaneous issuing of formal guidelines, the institutionalization of a clinical trial, and the mandatory regimen of genetic counseling pre- and post-testing stands out. Noteworthy is that the explicit objective of the clinical trial in Japan was not to evaluate NIPT's accuracy (already established in American labs),

but to assess pregnant women's responses to the test so as to structure suitable counseling and support. Yet many medical professionals did not consider it enough that JSOG had marked NIPT as an ethical problem; some of them embarked on further problematization initiatives of their own.

## HOW NIPT BECOMES SEEN AS AN ETHICAL PROBLEM BY HEALTH-CARE PROVIDERS

Forty-six-year-old Sachiko is a midwife in a children's hospital. Soon after the hospital became an authorized provider of NIPT, the head of the maternity ward invited the medical staff to share their thoughts about the new test. In her interview, Sachiko expressed her shock on hearing that her institution, a children's hospital, would now be offering a test that "facilitates the selection of life." She described having to conceal her antagonism when drawing blood samples from the women who came to undergo NIPT.

Sachiko felt that NIPT contradicted her professional commitment to the egalitarian care of unborn babies just as much as to neonates and children: "I thought that a children's hospital is all about treating children as human beings regardless of their chromosomal disabilities. We don't exclude children with Down Syndrome from care, right? So why offer a test that discriminates against them?" For her, NIPT epitomizes the paradox of the expansion of medical interventions to support and enhance the lives of people with disability and the simultaneous expansion of genetic tests to diagnose and eliminate disabilities in utero (Ginsburg and Rapp 2021). She felt particular resentment toward one doctor who pointed out that although free medical care was available to children with disabilities, few medical facilities actually offered them care. She saw his utilitarian ethical reasoning about limited resources as a breach of professional commitment: "What kind of human beings are these doctors?" However, discussions with colleagues made Sachiko realize the diversity of perspectives on a test she thought was unequivocally unethical. She gradually started acknowledging the challenges of disability care for parents: "It's not easy to accept a child with a disability."

When Sachiko herself conceived at the age of 42 (Ivry first met her toward the end of her pregnancy), she decided not to opt for NIPT despite being eligible: "I didn't reach the point where I agreed to decide on whether I would abort a child with a disability." Sachiko's determination not to enter a process of decision-making about NIPT was not only a full-fledged decision but also signified, to her, a higher level of virtue. Significantly, only if Sachiko had "agreed" to enter the process of decision-making would she have entered the phase of indecisiveness and

vacillation. This did not mean that she was oblivious to the prospect of fetal disabilities; in fact, while undergoing a routine obstetrical ultrasound, she wondered (although without asking) whether the doctor was properly checking fetal nuchal translucency, seen as indicative of Down Syndrome.

Sachiko started understanding that "people who undergo NIPT don't do it lightly . . . the doctor makes them think hard; it's a weighty decision." This acknowledgment of the intensity of ethical labor that doctors demand from applicants and their worries indicating ethical strife relieved Sachiko's antagonism, invoking her compassion rather than condemnation. Evidence of the performance of hard ethical labor (regardless of the ensuing decision) thus emerges here as a mechanism of legitimization.

The most ambivalent about NIPT among medical professionals were the genetic counselors who have direct responsibility for facilitating the decision-making process of pregnant couples. These low-paid, usually female, practical mediators of decisions complained in their interviews that they were never sure about "how to speak to clients" or "how best to conduct a genetic counseling session." They confessed a "lack of confidence" when conducting both the compulsory session before NIPT and the subsequent sessions informing couples of the test results or discussing further testing. While some reported their clients' insufficient scientific literacy, the counselors' deep concern was for the ethical aspects of their practice, particularly the correlation between prenatal diagnosis and eugenic motivations. Of the sixteen interviewed, ten expressed explicit worries about the discriminatory implications of PND on people with disabilities.

All the genetic counselors were adamant that couples must take responsibility and make their decisions "as parents," thus echoing the formal (aforementioned) conceptualization of pregnancy as in utero childcare. Unlike U.S. genetic counselors who, according to Rapp (1999), are committed to the idea of non-directive counseling and tend to transfer moral responsibility to the pregnant couple, Japanese genetic counselors feel pushed into moral pioneering. One genetic counselor, Chie, said:

When I speak to clients, I always feel that my humanity is being tested. I feel that many people undergo PND without being aware of how heavy the choice that might await them is. I'm conflicted about how much I should say about a technological option which leads to such a heavy choice. I'm concerned that I'm infringing on the client's right not to know.

Chie feels torn between her professional obligation to make information accessible and her commitment to protect pregnant women's well-being. Her conflict echoes a key question: how can reproductive risk be communicated without exposing pregnant mothers to the risk posed by the information? Chie does not see only the provision of full information as the prerequisite of quality counseling; rather, in her ethical scheme, she is equally committed to minimizing the distressing effects of information and respects the right not to know. When first meeting Chie, she had just been hired by the hospital, and Ivry associated her declared lack of confidence with the novelty of the responsibility entrusted to her. However, this declaration persisted in their encounters over the years.

## HOW NIPT BECOMES AN ETHICAL PROBLEM IN ENCOUNTERS BETWEEN PREGNANT WOMEN AND COUPLES AND MEDICAL COUNSELORS

The pregnant women interviewed recalled first hearing about NIPT in media debates, often long before they conceived. Even before their first genetic counseling session, all of the women except Koko (discussed later) had already decided, sometimes after discussions with their partners and other family members, to undergo NIPT. They found their decisions, however, destabilized by care providers' queries.

Kaori, a thirty-seven-year-old accountant with a three-year-old child, was determined, after discussing the matter with her husband, to undergo NIPT in her second pregnancy (as she had in her first), despite receiving no indication from routine checkups of any fetal anomaly. In her first pregnancy (soon after the issuing of JSOG guidelines) she had planned to undergo amniocentesis if an indication of a chromosomal anomaly had surfaced and explained that she was ready to "give up" (諦める, akirameru), that is, to terminate the pregnancy, had the results been positive. Unlike "having an abortion" (中絶する, chuuzetsu suru), a phrase signifying the endpoint action of termination, the frequently used akirameru insinuates a process preceding the decision and even regret for being pushed by the circumstances to end the pregnancy.

In her second pregnancy, when Ivry met her, Kaori held to her decision to undergo NIPT; however, she had now changed her mind and was determined she would give birth to her child regardless of any fetal anomaly diagnosis. "My husband respects my wishes," she reported. This time, she renounced selective reproduction yet opted for NIPT, reframing its purpose. With tears in her eyes, she reported answering her ob-gyn's question about why she would undergo NIPT if

she had no intention of terminating: "If medical progress offers a way of knowing beforehand, I want to know." It is worth noting that the ob-gyn framed NIPT explicitly as an obvious means of selective reproduction, while conflating the decision about whether to undergo NIPT with a tentative decision about whether to terminate upon diagnosis of a trisomy. Kaori explained the importance of prior knowledge as a way of "preparing her heart" and organizing her work and family life to accommodate a child with special needs, thus reframing NIPT as a tool of care rather than of selective reproduction. Her approach, in fact, conforms with the consent signed at the end of pre-NIPT genetic counseling sessions: Article 8 states that the purpose of prenatal testing is to prepare the optimum environment for the fetus after the birth, while Article 9 clarifies that fetal anomaly alone is not a legal reason for termination.<sup>14</sup>

Kaori talked about her change of mind between her first and second pregnancies, both of which were spontaneously conceived and wanted pregnancies. At the time of the first pregnancy, "I couldn't imagine what it really means to have a child." However, the experience of nurturing a child had transformed her thinking: "I'm in awe of the life that comes out into the world. . . . The quality of this amazement has nothing to do with whether that life has a disability or not." Kaori managed to choose NIPT while repudiating selective reproduction—a repudiation that reflects Japanese discourses of disability justice and their conjunctive maternal commitments. <sup>15</sup>

#### "ARE YOU REALLY SURE YOU WANT TO UNDERGO NIPT?"

Mako and Satoshi Yoshida received a fetal anomaly indication shortly after their technologically assisted conception. They had first heard about NIPT at the infertility clinic where they had undergone treatment, and then at a pregnancy checkup that revealed an indication of a fetal anomaly. Their ob-gyn noted a "slightly" extended nuchal translucency measurement. He tried to mitigate the information by assuring them that all other indicators were normal. He also explicitly reassured them, saying "you don't need to worry too much," thus invoking his professional commitment to protect pregnant women from any unwanted effects of risk information on their well-being. "There is a one in 10,000 chance of there being a problem . . . . 80 percent that everything is OK," said the ob-gyn. Satoshi, reframing the logic of ensuring maternal peace of mind, thought that it would be "better to minimize the 20 percent and achieve peace of mind." Mako, despite her initial opposition, eventually agreed to undergo NIPT "as a last resort," thus reinforcing that their decision was made after serious deliberation—as a last not a first

resort, but not as a choice. Satoshi said that although they had talked about what they would do if the diagnosis was positive, they had not yet reached a decision. Indecisiveness concerning termination persisted amid the choice to undergo NIPT.

The genetic counselor who met with the Yoshidas asked them several times whether they were really sure about undergoing NIPT: "You might think that the test will easily relieve you of worries, but it is not really about instant relief from uncertainty. Please think hard, as it might lead you to a selection of life . . . ethical quandaries might arise." Such warnings about looming tentative ethical ordeals and explications of the ethical risks lurking beneath NIPT were evident in the accounts of all the pregnant women and all the partners. Whether or not the couples received a prior indication of a fetal anomaly, they were often asked by ob-gyns, nurses, or genetic counselors to explain their decision and to think hard.

The only woman who did not report such intervention by her care providers was Koko, a thirty-seven-year-old who had separated from her fiancé shortly before discovering she was pregnant with their child. She described her pregnancy as deeply disruptive; however, having encountered women her age who were experiencing infertility, she felt lucky to be pregnant and obligated to give birth. Having not sought any health-care information due to her ambivalence, it was, she said, her ex-fiancé who first suggested NIPT; she, herself, was not at all inclined. Recognizing Koko's conflict, the nurse arranged an emergency appointment with a genetic counselor. Whereas the health-care providers in all of the other accounts were reported to have questioned and often frowned on the decision to undergo NIPT, giving their referrals unwillingly, Koko was the only interviewee who received help from a medical professional in making an appointment for NIPT. Her visible struggle seems to have propelled the nurse to help her; in contrast, pregnant couples who showed determination to undergo the test prompted medical professionals to raise questions and demonstrate opposition.

A few reports emerged of medical professionals who went further than just implying tentative ethical dilemmas. Shizue, a forty-two-year-old dancer in her second pregnancy, described her shock when the nurse who introduced NIPT outlined the heaviness of the tentative ethical dilemma. The nurse explained that if the test yielded a positive result and the woman then receives a positive result from amniocentesis and decides to terminate, the termination will take place at a stage when she can already feel fetal movement. The nurse designated NIPT as a road to termination and termination as the killing of a sentient being. Reports of such ominous introductions to NIPT stand in sharp contrast to anthropologists' depictions of medical professionals in other countries recommending NIPT unequivocally or

even prescribing the test without discussion, particularly to pregnant women over thirty-five. In China, women are even expected to provide a compelling reason for refusing (Qiu 2019), while in Germany, the medical system has been reported to routinely schedule women for testing and encourage little prior ethical deliberation (Reinsch, König, and Rehmann-Sutter 2021, 208).

In Japanese hospitals the requirement to think hard about whether to undergo NIPT is sometimes strategically institutionalized in the timeline of counseling and testing (even beyond JSOG's guidelines). In one institution the pregnant woman can only undergo the test one week after the mandatory counseling session. The genetic counselor in charge of NIPT in that institution explained that this requirement was put in place to ensure "serious thinking." Some Japanese doctors seem to believe that even obligating serious thinking proves insufficient. Thirty-nine-year-old Keiko considered herself lucky to even get a referral, as her friend's doctor insisted that NIPT was unnecessary and refused to provide her with a referral. Keiko's own doctor relented only when she expressed deep maternal anxiety, which can, it seems, inspire doctors' compassion.

#### NIPT AS AN "ETHICAL TURN": Post-Diagnostic Evaluations and Moral Breakdowns in the Aftermath of Negative and Positive Results

The potential impact of the ethicization of NIPT can be fully appreciated when examining accounts of receiving a negative result, namely, that the fetus does not appear to carry one of the three trisomies. These accounts were often found to take the form of a post-diagnostic self-evaluation, with pregnant women and couples attempting to justify their decisions and get reassurance of their own moral caliber.

The Yoshidas, whose doctor reported an extended nuchal translucency measurement, explained that "if not for that discovery . . . we wouldn't have thought about NIPT." Likewise, Akira and Momo Suzuki, aged forty-two and forty, respectively, explained that if they had been younger, they wouldn't have considered undergoing NIPT; after all, added Akira, "the Ministry of Health has made this possible." There were those who felt the need to emphasize the (unexpected) merit of undergoing NIPT, beyond just "the relief" of not carrying a baby with a disability. "It was good," said forty-three-year-old Akiko, "the test gave me an opportunity to contemplate the meaning of giving birth and made me realize that a baby is a miracle."

Shizue used the opportunity of informing her husband about the negative result to enact a moral pedagogy aimed at promoting greater commitment to their unborn child. She told him: "There is no guarantee that our child will be born healthy, and even if it is born healthy, the test only indicates three trisomies. There is no guarantee that our child won't be stupid or grow up to be a murderer." So with the three trisomies ruled out, the couple now committed to raising any child born with devotion. Shizue, like Kaori discussed earlier, came to denounce selective reproduction.

In some cases, receiving a negative result led to ethical strife and even a post-diagnostic "moral breakdown." Forty-two-year-old Asuka, a nurse and mother of a four-year-old, burst into tears when recounting the guilt she felt toward the unborn baby on hearing the negative result:

I experienced many hardships of pregnancy but tried not to think "there is life there." I went to the hospital to have an ultrasound and was happy to see the little heart beating; it was a relief, I was glad. But afterwards, I tried not to think about it. When I was pregnant with my first child, he moved from the very beginning, and when my stomach hurt, I said, "let's get through this together." This time, I waited for the results of the NIPT and did not say anything [to the unborn baby]. When the result came back negative, I apologized to the fetus and said, "forgive me . . . for not thinking about you properly."

Asuka experienced a moral breakdown *after* being informed that her baby did not carry one of the three trisomies. She described undergoing a serious pre-NIPT decision-making process with her husband and her doctor, in which they decided to undergo NIPT and terminate in the case of a positive result. These decisions might have pushed her to suspend bonding with her unborn baby, making her pregnancy only "tentatively tentative" (compare Rothman 1986). This did not, however, prevent her from breaking down in the aftermath. Rather than recovering the comfortable moral world, the negative result evoked a moral and emotional breakdown (compare Addison 2022) and a spell of further ethical labor, riddling the taken-forgranted moral assumptions about what constitutes appropriate parental demeanor in the face of tentative disability with tension.<sup>16</sup>

It is against the possibility of post-diagnostic breakdown and the looming disruption of a (supposedly) established maternal—fetal bond that genetic counselors conduct their counseling sessions. Rie, an experienced counselor said:

When I start the genetic counseling session, I make a point of hearing from the mother about her feelings when she discovered she was pregnant. Many women say they were happy. I proceed with the counseling, wanting her to cherish that feeling. [It is important for me to open like that] because even if they choose termination, I think a woman would like to say goodbye [to the fetus], so I want the mother to take the time she spent with her unborn child seriously.

Rather than condemning abortion, Rie's approach is oriented toward enhancing maternal—fetal relations across the life-death divide, partly as a support strategy for bereaved mothers. She works to prevent the mother's disconnection from her fetus.

In Japan, fetal death is acknowledged with a death certificate from as early as twelve weeks of gestation. In the hospital where Ivry conducted field work, the death of a fetus was recognized and commemorated with a structured ritual that Courtney Addison (2022, 268) might identify as an "enchanting turn." The midwives dress the dead baby in a tiny cotton kimono and arrange it in a special box surrounded with origami flowers. The parents, accompanied by the medical staff, carry the box down a side corridor to a quiet circular room with no religious symbols where they light incense and pray silently. While an analysis of such rituals lies beyond the scope of this article, it should be noted that the ritual acknowledges the parent-fetus relationship as human relations, regardless of whether the fetal death was the result of termination, miscarriage, or stillbirth.

This emphasis on human relations helps us understand that the deliberation processes encouraged in genetic counseling sessions sometimes culminate in a change of mind beyond just repenting for the temporary disruption of maternal-fetal relations; indeed, some couples end up regretting their decision to undergo NIPT altogether. Chie, the genetic counselor mentioned earlier, witnessed such fundamental change of mind in her patients. When discussing in 2019 whether she had gained more confidence in her profession in the two years since Ivry first met her, Chie shared an experience that had impressed her deeply.

Usually, when the NIPT result was negative, I would say, "What a relief! It's so good that the result is negative". . . and people usually said they were relieved. But then, recently, there was a couple who said nothing like this. They said, "Yes, OK, thanks." I asked them if . . . they were feeling OK. They said—particularly the man—that after doing the test they came to question





Figure 3: Kimono for a twelve-week-old deceased fetus.
Figure 4: Kimonos for deceased fetuses from twelve to forty weeks.

the reason for doing it and realized that they are prejudiced against children with Down Syndrome. They felt guilty for undergoing a test that might lead to the termination of a person with a disability. Since then, I have become more careful with my words. I want to be able to give counseling in a way that is sensitive to the couples.

Chie, like the pregnant parents, engaged in post-diagnostic self-evaluation. She proceeded to explain the merits of the "lack of confidence" in their professional ability repeatedly referred to by her and other genetic counselors and embarked on a chain of successive tentative scripts of reproductive misfortunes.

If they receive a positive result, undergo amniocentesis, have an anomaly diagnosed, decide to terminate, and then feel bad about that decision, I want to be able to tell them that it was not a bad decision. That I was there with them and witnessed how hard they thought in reaching a decision that was suitable for that moment in time. You see, this is where I don't have confidence. I think it's not necessarily good to have confidence in such matters. I think it might be better to provide counseling while constantly searching for answers and not having confidence.

Thus, Chie explicitly evaluates lack of confidence as a professional virtue. Nonetheless, she told Ivry that she makes sure never to show this to her clients, understanding that for clients to feel comfortable, her "lack of confidence" must never surface during counseling sessions.

## STRUCTURAL AMBIVALENCE, VIRTUOUS INDECISIVENESS, AND THE PARADOXES OF ETHICALIZATION IN JAPAN AND BEYOND

What do positive appraisals of indecisiveness, hesitation, lack of confidence, and other reifications of ethical ambivalence tell us about the meanings, purposes, and consequences of ethicizing biotechnologies in Japan? And what can this ethnography contribute to anthropological explorations of ambivalence and ethicalization beyond Japanese society at its intersection with reproductive technologies? The case study of a maternal blood test early in the pregnancy reminds us that ethics itself can become an object of evaluation and that a focus on how deliberation processes are evaluated can offer a perspective for understanding what is at stake for the different parties in particular sociocultural settings. The main issues in the decisions surrounding NIPT for Japanese policymakers, care providers, pregnant women, and their supporters might differ, but their quandaries boil down to similar questions concerning the ethics of relations: doctor-patient, maternal-fetal, and parent-child. All of these questions respond to an ethical demand to consider and reconsider the multiple aspects of future tentative dilemmas of terminating fetuses diagnosed with one of three trisomies that might be revealed through NIPT.

Under the auspices of structural ambivalence, genetic counseling becomes dedicated to creating space for prospective parents' ethical deliberations no less than providing them with accessible scientific knowledge (compare Addison 2022). Patients must make up their own minds, but counselors are committed to support their pre-diagnostic deliberations in preparation for possible future strife. Counselors are responsible for providing information about NIPT's accuracy and the probability of fetal anomalies according to maternal age. However, they see this information, in and of itself, as a risk factor for maternal well-being and feel obliged to warn their clients about the ethical risks surrounding NIPT. Facing subsequent invasive tests and a termination decision after a positive diagnosis makes for a risky horizon; however, making a two-fold determinant decision, namely, to undergo NIPT and to terminate if a fetal anomaly is diagnosed, proves equally as risky, as Asuka's experience suggests. Determination is risky, but indecisiveness might have provided her with an ethical safety net, particularly if witnessed by a counselor who can attest to the enactment of serious ethical labor in the case of a future moral breakdown following a negative or positive result.

The duration and depth of the indecisiveness can be regarded as criteria for evaluating both individual moral caliber and the seriousness of the deliberation process. This invites anthropologists to acknowledge that in particular sociocultural settings, indecisiveness signifies a potent ethical stance rather than a failure to decide. Indecisiveness can linger under regimes of structural ambivalence; in Japan, public debates over brain death (Akabayashi and Slingsby 2003; Lock 1998) and IVF regulations have continued for three decades.

In the summer of 2019, the Japanese reproductive genetics community was scandalized by media reports about unauthorized clinics providing NIPT for cheaper prices. Competition with authorized facilities notwithstanding, the NIPT consortium members expressed outrage that NIPT was being provided with little counseling: "What happens to a couple if, with no prior preparation, they only realize what this test is all about after receiving a result?" At stake for these reprogenetic experts was the blurring of NIPT's eugenic implications through the erasure of the deliberation process encouraged by counseling. It was the loss of ethical ambivalence that they mourned.

Interestingly, both scholars who insist that ambivalence constitutes an aspect of the Japanese self resulting from the particular trajectory of Japanese modernization (e.g., Ohnuki-Tierney 1990) and those who view it as the inevitable flipside of postmodernity more broadly (e.g., Bauman 1991) theorize ambivalence as a spontaneous, unintentional, and almost unconscious undercurrent in people's lives. This ethnography, however, shows mindful efforts to cultivate ambivalence as a virtuous ethical practice. If there is anything particularly Japanese about the configuration of ambivalence elucidated here, it is perhaps the license ambivalence receives to openly structure private and public ethical deliberations.

Rather than muffling "unexamined neo-eugenic assumptions . . . through organizational routines of signing consent forms," as Faye Ginsburg and Rayna Rapp (2021) described in the United States, NIPT genetic counseling sessions in Japan may become pedagogic procedures to keep prospective parents alert to the eugenic assumptions underlying reprogenetic technologies. Far from being institutional mechanisms to restore a "morally comfortable world of unquestioned action" (Zigon 2009, 269), ethicalization processes at both the level of policymaking and the clinical level of NIPT genetic counseling become forms of what might be called the "exclusionary inclusion" of contested technologies. They are, in short, about having one's cake and eating it, too: in other words, using reprogenetic technologies while, at the same time, cultivating and maintaining unrelenting ethical discomfort about them.

Importantly, the ambivalence cultivated in pre-NIPT genetic counseling sessions should not be confused with ambiguity; it is, in fact, its opposite. Ambivalence is about the elucidation of correlations between social realms of practice. In clinical encounters in Japan it is often made clear that the termination of anomalous fetuses hovers at the horizons of NIPT. Furthermore, ambivalence flourishes on the acknowledgment of the divergent perspectives of different social agents and the internal complexities within each perspective. In short, ambivalence is the cognitive skill of seeing complexity clearly, and indecisiveness is its enactment.

Beyond Japanese genetic counseling, the prospect of making space for complexities seems precisely what makes ambivalence attractive as a vantage point for some contemporary anthropologists (e.g., Jovanović 2016; Kierans and Bell 2017). Rather than the nonjudgmental approach advocated by early cultural relativists, within the current moral economy of anthropology (Stoczkowski 2008), the call to cultivate ambivalence represents a countercurrent to the ethicalization of our discipline, testifying to the efforts required to suspend judgment in the face of pressures to take a stand.

Questions about the quality of ethical deliberations become more pertinent with the ethicalization of the world. Anthropologists engage with such evaluative questions when lamenting the "erosion" (Lambek et al. 2015, 2) of the language of ethics (which accompanies its spread to countless social activities) or noting that talk about ethics may appear "hypocritical" (Lambek et al. 2015, 3) or "hollow" (Das 2015, 55). We suggest that beyond such acknowledgments, if we are to understand how people seek to lead a moral life, it is essential to contemplate the question of how people and their ethnographers evaluate the quality of ethical deliberations.

#### **ABSTRACT**

Anthropological engagement with moralities and ethics assumes that people evaluate themselves and others according to their notions of good and bad; yet little is known about how people evaluate the quality of their deliberations. Such evaluations of the seriousness of ethical deliberations prevail in Japan's genetic counseling for pregnant couples considering NIPT, a maternal blood test early in pregnancy that does not endanger the pregnancy but might lead to termination dilemmas. These deliberations are based on the idea that the ambivalence over whether to provide or undergo a potentially selective test is virtuous. This article examines how Japanese policymakers, medical professionals, genetic counselors, and pregnant couples make decisions within social settings that valorize indecisiveness. Ambivalence emerges as the cognitive skill of seeing complexity clearly. How people and their ethnographers evaluate the quality

of ethical deliberations is essential to contemplate if we are to understand how people seek to lead a moral life. [ethicalization; ambivalence; virtue; prenatal diagnosis; genetic counseling; reproductive decisions; local moralities and ethics; Japan]

#### 摘要

道徳と倫理への人類学的な関与は、人々が善悪の概念に従って自分自身や他人を評価することを前提としている。しかし、人々がその討議の良し悪しをどのように評価しているかについてはほとんど知られていない。このような倫理討議の深刻な評価は、妊娠を危険にさらすことはないが中絶のジレンマにつながる可能性のある妊娠初期の母体血液検査である NIPT を検討している妊娠中のカップルに対する日本の遺伝カウンセリングでは一般的である。これらの討議と躊躇いは、潜在的に選択的なテストを提供したり受けたりすることが道徳にかなっているのかどうかという両価性の考えに基づいている。この論文では、日本の政策立案者、医療専門家、遺伝カウンセラー、および妊娠中のカップルが、決断をためらうことに評価する社会環境の中でどのように決定を下すのかを調べる。両価性は、複雑さを明確に見る認知スキルとして現れる。人々とその民族誌学者が倫理的審理の質をどのように評価するのかは、人々がどのように道徳的な生活を送ろうとしているのかを理解し熟考することが不可欠だ。[倫理化、両価性、美徳、出生前診断、遺伝カウンセリング、生殖決定、地域の道徳と倫理、日本]

#### NOTES

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- The names and selected details of research participants were changed to protect their privacy.
- See https://www.mhlw.go.jp/content/11908000/000754902.pdf. Accessed on 12 March 2023.
- 3. The interviews all occurred in Japanese and were translated into English by Ivry.
- 4. Virtue here is based on Thomas Widlok's (2012) idea of virtue as an observable practice rather than an idealized notion.
- 5. Debates persist about how anthropologists should effectively approach the ethical: as a day-to-day immanence in people's lives (Lambek 2010), an eventual occurrence (Lempert 2014; Zigon 2007) or as a form of reasoning (Sykes 2012), sentiment or sensitivity (Throop 2012), or performative action (Lambek 2010; see also Lempert 2014). How should ethnographers account for individuals' endeavors to constitute themselves as moral subjects while paying heed to the intersubjective and social dimensions of ethical reflections (Jackson 2005)? These questions offer some examples of the vibrant field of inquiries into ethics and moralities in anthropology. For a conclusive review, see Mattingly and Throop 2018.

- See https://www.mhlw.go.jp/content/11908000/000754902.pdf. Accessed on 12 March 2023.
- 7. Pregnant women can choose to undergo checkups (using local government payment coupons) in a range of facilities including general hospitals, maternity hospitals (often run privately by an ob-gyn), or birth centers run by midwives.
- 8. The research was approved by the ethics committees of each of the three authors' institutions. In addition to the interviews, Ivry also conducted participant observations in NIPT genetic counseling sessions in a hospital in northeastern Honshu (Tohoku) in 2019. The authors also collected fifty-two questionnaires about pregnant women's experiences of NIPT, also using them to find pregnant women willing to be interviewed. The second and third authors, who are medical professionals, introduced the research to applicants for pre-NIPT genetic counseling. Women interested in participating were invited to watch a short introductory video recorded in Japanese by Ivry (available by request). Those who consented filled out a questionnaire about their NIPT experience and indicated their readiness to be interviewed by Ivry. The authors also gathered media coverage of the public debates on NIPT, statement papers, formal instructions for conducting NIPT and supplementary explanatory materials, genetic counseling textbooks, and NIPT statistics issued by JSOG and the Japanese Ministry of Health since issuing the guidelines in May 2013.
- 9. At the time of the interview, the women ranged in age between thirty-five and forty-six. Of the total twenty-seven, thirteen were parents of one or two children, thirteen were working mothers, twenty-six were married, and their partners ranged in age between thirty-four and fifty-two. The women lived in various towns around Tohoku, and ten had received an NIPT referral from the maternity clinic in their hometown. Of the interviewees, eleven couples had undergone fertility treatment to conceive. All the interviewees received negative NIPT results; seven were interviewed shortly after receiving the results.
- Fertility rates declined to 1.41 in 2012 (https://www.mhlw.go.jp/toukei/saikin/hw/ jinkou/geppo/nengai12/dl/gaikyou24.pdf; accessed on 12 March 2023).
- 11. Working mother rates were 52.4 percent in 2018 (https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai12/dl/gaikyou24.pdf; accessed on 12 March 2023).
- 12. Average mean age was 30.3 in 2012 (https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai12/dl/gaikyou24.pdf; accessed on 12 March 2023).
- 13. There is a 99.1 percent detection rate for Trisomy 21 according to Sequenome, the U.S. company that developed the test.
- 14. Indeed, while a doctor cannot legally be sued for failing to diagnose a fetal anomaly, in a legal precedent from 1992, parents won a suit against a doctor who was found guilty of infringing their right to make "mental preparations" (精神的準備, seishintekijunbi) for the birth of a child with special needs (Maruyama 2014).
- Elaboration on prospective parents' negotiations with Japanese disability politics lies beyond the scope of this article.
- Eri Takeda and colleagues (2018) reported on post-partum maternal distress in women who underwent NIPT.

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