5 Between Uncertainty and Routinization

Accounting for Non-Invasive Prenatal Genetic Testing in Germany

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Introduction

Non-invasive prenatal testing (NIPT) for genetic conditions such as Down syndrome (DS) as early as the 9th week of pregnancy became available in 2012 to German women. In contrast to the current gold standard procedure, amniocentesis, which brings a small procedure-related risk of miscarriage, NIPT is promoted by pharmaceutical companies as a safe alternative requiring "only a blood sample from the mother". The advent of NIPT in Germany presents a special case of the broader issue of how to account for the social dimensions and implications of new biomedical technologies (Franklin and Roberts 2006).

In her book *Imperfect Pregnancies*, the biologist and science historian Ilana Löwy (2017) showed how the search for fetal abnormalities, once reserved for older women and those with a family history of birth defects, has emerged since the 1970s as a routine part of prenatal care in Western health care systems. In a follow-up book, Löwy (2018) pointed out that prenatal testing has become primarily a risk management technology aimed at preventing the birth of children with congenital impairments, ideally through interventive therapies, but in practice mainly through abortion. She had argued that, with the advent of relatively risk-free NIPT, serum testing for DS has become so commonplace that many women equate it with being a "good" mother and therefore consent to it without reflection (Löwy 2017).

Social scientists have highlighted the ambivalent medico-ethical features of such predictive genetic testing (Konrad 2005; Hadolt and Lengauer 2009). Among some recent examples of such ambivalence, Guell (2011) has shown that the emergence of genetic tests predictive for diabetes is creating new biosocialities that are at once exclusionary and emancipatory. Lock (2005) has argued that in the case of Alzheimer's disease, claims of predictability and control are coming to resemble a modernized form of fortune telling. Considering the well-known example of testing adults with a family history for Huntington's Disease, cultural studies scholar Katrin

Solhdju (2018) has argued that predictive genetic tests create a "temptation to know" that is generated by the very existence of the test, and by a need for reassurance. These cases of ambivalence of predictive genetic testing, which both exclude and emancipate, claim predictability and yet distance themselves from those claims, and create uncertainty while promising reassurance, can only exacerbate existing ethical conflicts in the context of pregnancy (Löwy 2017). Some social scientists speculate that NIPT might contribute to a further routinization of screening and genetic testing, thereby disempowering women and further excluding people with disabilities from existence and integration in society (Thomas and Rothman 2016).

"A safe test that may relieve your concerns"

NIPT is based on the detection of fetal cell-free DNA (cfDNA) circulating in the mother's blood. The assay can detect variations in the number of chromosomes (aneuploidy) in the fetus—trisomy 13, 18, and 21 (Patau syndrome, Edwards syndrome and DS, respectively). Some tests also detect sex chromosome aneuploidies and other chromosomal microdeletions and duplications. In Germany and other countries, laboratories already offer tests for monogenetic disorders such as sickle cell disease, Huntington's disease, and cystic fibrosis. Thus, the debate about routinization is poised to assume a broader aspect. However, since most of the controversy surrounding NIPT hitherto centers on the detection of DS, I will focus on this in the present article.

NIPT is a technically simple procedure that requires "just a blood sample"[1] collected from the mother. It is non-invasive and therefore does not carry the risk of miscarriage associated with amniocentesis and chorionic villus sampling (CVS). The amniocentesis approach has a procedure-related pregnancy loss rate that is generally reported as 1/200, but can be as low as 1/1000 when corrected for spontaneous miscarriage and practitioner expertise in the procedure (Salomon et al. 2019).[2] NIPT has varying rates of false-positive and false-negative results, depending on the condition being tested for. However, as a screening test for DS, NIPT is highly accurate, with sensitivity and specificity[3] both exceeding 99 percent, and reaching 100 percent in one industry-sponsored study (Flöck et al. 2017). Taken together, NIPT presents

1 Quote from official information provided by the pharmaceutical company Lifecodexx.

2 Amniocentesis requires puncturing the belly of the mother and passing a needle into the amnionic fluid, which brings inherent risks that are moderated by the degree of expertise of the practitioner. However, in the large meta-analysis by Salomon et al. (2019), which controlled for expertise by only including studies with >1000 cases, the corrected rate for procedure-related loss of pregnancy was 0.12%, or roughly 1/1000.

3 Sensitivity is the proportion of cases detected among the total of those affected, and specificity is the proportion of detected cases that are correctly identified.

three main advantages over previous predictive tests for prenatal screening: it can be used earlier in pregnancy, is less invasive, yet more accurate. There are some caveats to all three aspects, but NIPT is typically pitched to the expectant mother as yet another reassuring tool, providing knowledge that "may help alleviate your concerns and worries about possible health problems in your child".[4]

"Reassuringly routinized" technologies of pregnancy care

Social scientists have repeatedly expressed concerns that the adoption of routinization of NIPT might lead to the disempowerment of patients and the further marginalization of disabled people by yet another biomedical technology (Clarke et al. 2003) and the relentless marketing of health by pharmaceutical companies (Dumit 2012), These authors present the adoption of "routine" as part of a negative power relationship. However, rather than assuming *a priori* that "routinization" is negative, I would like to unpack and discuss its different meanings.

Routinization in the context of prenatal testing has distinct meanings at the level of the health care system—possibly involving public funding—and for the individual. At the level of health systems, the routinization primarily refers to a transition from NIP testing to NIP screening, where the practice becomes routinized as a first-tier method replacing conventional biochemical and genetic screening in the first/second trimester. At the time of this study (2017–2020), the debate in Germany, driven in part by requests for insurance coverage of NIPT, is an example of partial rather than complete routinization. For example, if NIPT were to be covered by German health insurance but still offered only to "high-risk pregnancies", it would constitute routinization at the level of health insurance, but not in regard to population screening.

Routinization can also refer to the private, personal level: that of the pregnant woman who elects to take the test because of its "tempting features", and then participates in an "automatic, routinized" way, perhaps without thorough reflection on its meaning and possible implications. In the ethical and psychosocial literature, routinization at the personal level is considered to negatively affect three areas: informed choice, freedom of choice, and the lives of people with a disability (Kater-Kuipers et al. 2018). First, there is apprehension that broader adoption of NIPT will lead to uninformed choice, meaning that couples may not reflect upon their choice and thus be aware of the possible consequences of testing (Gottfreðsdóttir and Arnason 2011). Second, there are concerns that NIPT could become taken for granted as "just another blood test" (Griffin et al. 2017), which would lead to increased participation, heightened social pressure to test, and proliferating termination of affected

4 Quote from official information provided by the pharmaceutical company Lifecodexx.

pregnancies (de Graaf et al. 2017). Third, the total number of people born with a disability could well decrease, leading to reduced healthcare expertise, but correspondingly increased discrimination against people living with a disability. In turn, declining healthcare requirements for people with DS and/or a negative public image of DS could pressure women to opt for prenatal screening and terminate affected pregnancies (van Schendel et al. 2017; Kater-Kuipers et al. 2018). By negatively affecting informed choice and freedom of choice, "routinization of NIPT" could undermine "procreative autonomy", which is seen by some as the only legitimate aim of prenatal testing (Dondorp et al. 2015).

Social scientists have shown how interactions occur for the various concerns arising under the umbrella term of routinization: the uninformed choice, the lack of deliberation, as well as the social pressure to test and terminate a pregnancy upon discovery of a lifelong disability. In his book *Down's Syndrome Screening and Reproductive Politics*, sociologist Gareth Thomas (2017) argues that the routinization of DS screening is fueled by "downgrading" of the procedure and its framing as "just another test". Drawing on ethnographic research in two UK fertility clinics, he describes how clinicians were able to "downgrade" screening in the clinical hierarchy. Because DS screening was, for many reasons, seen as a routine and "simple" test, responsibility for its implementation was assigned to midwives and sonographers. Thomas argues that framing ultrasound screening to parents as "just another simple test" —either explicitly, such as by describing the screening as a "simple test", or implicitly, such as by leaving open the door of the consultation room—may have led some women to passively opt in.

This consideration takes up a line of argument formulated in the book *The Tentative Pregnancy*, by the sociologist Barbara Katz Rothman (1986), who showed from her interviews with women who had undergone amniocentesis that the risk of miscarriage then gave women a "good" reason to refuse prenatal testing. The risk to the life of the child is a strong and rational argument for a woman inclined to refuse the test, whereas it is much more difficult to articulate emotional concerns about her "temptation to know more" about the unborn child. Over 30 years ago, Rothman (1986: 82) predicted that the eventual availability of a blood test for early pregnancy would strip the issue down to its bare bones and confront us with the essential moral issues: "When the risk is removed, the last completely socially acceptable reason for not wanting to know about fetal defects will be gone".

Prenatal diagnosis (PND), of which NIPT is a part, is presented by health care providers as a simple choice for or against undergoing a test. At the same time, PND is embedded in a complex system of medical diagnosis and pregnancy monitoring. This combination raises concerns about increasing routinization that is described as being at once reassuring and frightening. This view of the dual nature of routinization resonates with what anthropologist Rayna Rapp (2000: 23) wrote in her book *Testing Women, Testing the Fetus*: "The technologies of prenatal diagnosis that preg-

nant women encounter appear reassuringly routinized". Rapp (2000: 40–41) thus reminds us that the development and routinization of prenatal diagnosis in the US depend upon a complex intersection between biomedical scientific research, social policies affecting abortion, social movements influencing the cultural climate, and a specific history of litigation pressuring health care providers to improve standards of care.

In this article, I attempt to unpack the umbrella term routinization by empirically investigating how women pragmatically use and make sense of medical technology (Lock and Kaufert 1998). My central argument is inspired by the sociologist Annemarie Mol's (2008) book *The Logic of Care*, in which she argues that modern health care posits two logics: a "logic of choice" and a "logic of care". The "logic of choice" is based on an understanding of people as rationally acting agents, citizens or customers. Here, the ideal agent is an autonomous, informed patient who uses specifically adapted and predetermined tools for solving a problem. Conversely, in the "logic of care", health care is an evolving practice that is concerned less with decision-making than with "tinkering" and "doctoring" (Mol et al. 2010). In this view, tinkering means "making do with what you have in non-ideal circumstances" and adapting it on the spur of the moment. My aim is to problematize and reconstruct the two logics (care and choice) not as a dichotomy, but as complementary analytical axes that encompass a spectrum of cognitive and behavioral strategies. In explicating this analytical "space" between the two logics, I shall show how women's agency is expressed, and how its degree of freedom is limited by existing or developing attachments to a child, or by the decision to take a test under pressure from pre-existing attachments to a child or family.

Pregnancy care and the debate around NIPT in Germany

Germany is the forefront of modern Western technology, which enshrines a specific set of professional cultures, regulations, and policies regarding reproductive medicine and the safety net for children born with a disability. As distinct from the USA, the source of a considerable body of research on genetic testing during pregnancy, Germany has universal health insurance. While the German Health Care System generally provides good medical coverage, it is also criticized for not meeting the needs of families with disabilities (Blümel et al. 2020). While there is an abundance of early intervention services for people with disabilities in large urban centers, such support has been inadequate in rural areas (Thyen et al. 2003). Better recognition of disability in the first years of life has led to improved financial support in recent years (Pflegestärkungsgesetz 2015). For example, parents of children with DS in Germany receive care allowance which enables them to work fewer hours during the child's infancy. While the situation is improving, a focus on

the whole family system and its social integration is still lacking (Vonneilich et al. 2016). As long as there remains a gap between living conditions for families with and without a child with DS, there will be ongoing discussions about testing and funding.

Preventive care during pregnancy and the perinatal period in Germany is described in detail in the binding *Motherhood Guidelines* published by the Federal Joint Committee, the self-governing body that decides on issues of insurance coverage (G-BA 2023). Coverage by universal health insurance has included prenatal diagnosis (PND) and newborn screening (NBS) since the 1970s. Free PND in Germany includes an ultrasound scan during weeks 6–12 of pregnancy to estimate gestational age and determine the number of fetuses, and a basic ultrasound scan of fetal anatomy in weeks 19–25. In Germany, further ultrasound scans, amniocentesis, chorionic villus sampling and umbilical cord sampling are covered if medically indicated. Medical indications include known genetic abnormalities in the family, suspicious ultrasound findings, but also maternal age over 35, which is considered "high-risk pregnancy" by the *Motherhood Guidelines*. At the time of the interviews for this article, specific tests for disabilities such as DS or spina bifida, including the first-trimester scan (FTS), ultrasound without specific indication, the triple test, and NIPT, are mainly paid out of pocket by patients.

Since its 2012 introduction in Germany, NIPT has become a matter of public controversy, more so than in many other countries (Braun and Könninger 2018), with concerns being raised about its fundamental social and ethical issues (Deutscher Bundestag 2019). This debate intensified in 2016 after the National Association of Statutory Health Insurance Funds, the Association of Statutory Health Insurance Physicians, the impartial Chair person, and other impartial members of the Federal Joint Committee requested the inclusion of NIPT in the *Motherhood Guidelines*, and the reimbursement of test costs. In September 2019, the G-BA decided in favor of the 2016 application, but limited to high-risk pregnancies (G-BA 2019a). From the end of 2020, "NIPT can be used and covered by statutory health insurance if the question of whether a fetal trisomy might be present arises during medical prenatal care and this possibility represents an unacceptable burden for the pregnant woman" (G-BA 2019b: 2, translation by the author). Aspirationally, a negative NIPT result will make amniocentesis unnecessary, such that the new regulation should help to reduce the number of invasive tests and consequent miscarriages.

Some see insurance coverage of NIPT as a necessary step towards comprehensive reproductive justice, since NIPT has had to be paid for out-of-pocket, even though amniocentesis is covered for high-risk pregnancies (Buyx 2019). Others argue that insurance coverage serves those who favor increased NIPT use, particularly pharmaceutical companies (Rüffer 2019), calling it the "beginning of the expansion" of these tests (Achtelik 2019), and warning that NIPT coverage puts pressure on women to use the test. Others characterize the expected effect of introducing NIPT

in terms of an expected significant reduction in miscarriage rates, which has not yet been demonstrated (Malan et al. 2018). There are also concerns that the G-BA's decision will reduce the use of more comprehensive ultrasound screening, which will in turn create a false sense of reassurance among women, insofar as NIPT sensitivity and specificity estimates convey a spuriously higher validity than the test actually possesses for some patient groups (BVNP 2020). In Germany, these debates about the pros and cons of NIPT have occurred in the public sphere, but there has been no systematic investigation of women's lived experiences and views on their decision to use or refuse NIPT. In this exploration of women's experiences and practices of NIPT, I aim to bring a better understanding of the meaning and social implications of this new technology.

Methods

This article derives from the 2017–2020 project "Meanings and Practices of Non-invasive Prenatal Genetic Diagnostics in Germany and Israel (PreGGI)", which combined perspectives from philosophy, sociology and clinical medicine. A selection of the project results is published as a book (Schües 2022). The project included a qualitative study in which narrative interviews were conducted following an interview guide. The interviewees were intentionally selected to capture social groups identified as being relevant (Patton 2001: 238). The project team interviewed 48 people in Germany for the study. The interviewees included 21 women who chose NIPT and 15 who did not, 16 women and men with family members affected by DS or another disability, four health professionals, and eight experts on disability and/or genetic testing, with the total (64) exceeding 48 because some respondents met more than one category. Interviews were audio-taped and fully transcribed; the transcribed interviews were anonymized and analyzed using the method of constant comparison (Corbin and Strauss 2008). A comprehensive report of the entire cohort can be found in a previous publication (Reinsch et al. 2021). Uncertainty and routinization emerged as useful analytical concepts during the process of analysis, and the two narratives that were chosen for this article were exemplary of a central dichotomy emerging from the study.

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The temptation to test and know more about their unborn child, on the one hand, and the concern to decide in advance what to do with the test result, on the other hand, emerged as the core social and moral tension among women who used or refused NIPT in Germany. This ambiguity reflects a dilemma for women in neolib-

eral, techno-scientific societies, where the elimination of risk and the temptation to know are powerful cultural narratives. I aim to disentangle this coexistence of the temptation to know more and the urge to know how to handle the results. Two personal vignettes serve to illustrate broader narratives and the range of choices that women have. The use of personal vignettes allows for a presentation of findings that are embedded in the lifeworld [Lebenswelt] of the informants. I present and juxtapose the selected stories sequentially, illustrating different aspects of the complex negotiations of meanings and practices of NIPT within the whole spectrum of prenatal testing practices. Sabrina's story shows how she urges women to reflect carefully about whether to test, considering that the subsequent situation is not straightforward, but "always different after the test". Sabrina's story is contrasted with that of Dorothee for whom NIPT functions as a specific tool in a routinized "logic of testing" that allows her to take responsibility for her family.

Dealing with uncertainty: "It's always different after the test"

Sabrina is a 42-year-old former police officer. After three previous miscarriages she gave birth to a child with DS. I found out about the child's status indirectly during the interview, and remember that this situation was as revealing to me as the content of our conversation. When she contacted me, Sabrina wrote that she had taken NIPT "because some soft markers were positive". I met her in her flat in the south of Berlin, greeted at the door by Sabrina and her 2-year-old child. She and I sit down in the tidy, spacious, and bright living room, and I am offered a cup of tea. The tea cup, decorated with, as I later learn, the child's name, and my observation of a large gap between the first and second digit of the foot (a medical telltale sign of the condition that has been adopted by DS families) confirms that the child has trisomy 21. This positive affirmation was a nice way to learn the diagnosis. Sabrina's manner is "show, don't tell". During the interview, the child enters the room several times, sits on my knees, and wants to draw. Apart from a specific sign language used by mother and child, nothing would distinguish this child during our interview.

Sabrina remembers having felt very positive when she went for her first trimester screening. She was relieved to have avoided the risk of early spontaneous abortion, and saw herself as a normal, healthy mother-to-be. After all, "what could possibly happen now that I had reached 12 weeks?" When I asked her why prenatal diagnosis had not been an option at that point, she replied, "I wouldn't have known why [that would be necessary]". But when her gynecologist remarked, "Do you want to have the finediagnosis—after all, you are older", the then 39-year-old woman agreed. Looking back, she considers herself "naive to have thought that nothing could go wrong". During the ultrasound scan, the prenatal diagnostician said, "We need to talk", which was her first hint that something might be amiss.

She then received advice about the implications of shortened nasal bone and heart malformation, which she recalled as being "non-directive":

> I was told that I could choose to do nothing or have an amniocentesis, and that the latter carried a risk of miscarriage. At that point, I interrupted the prenatal diagnostician and said, "This is a risk I am not prepared to take".

She had heard about NIPT from a friend and suggested it herself because the test was advertised as being risk-free. Only after getting the result did she learn what the test meant in terms of probabilities and certainties. Before taking the test, she had thought, "whatever the test result is, that's what it will be". She believed that the test would be 100 percent accurate and that she could accept the result. However, until she received the NIPT result, she had "hoped that the prenatal diagnostician was wrong". She vividly remembers receiving the result over the phone:

> The ground beneath my feet disappeared. A Saturday three years ago. The day before Christmas. I ate spinach pizza. I have not been able to eat spinach pizza since. I knew that from that moment forward everything would be different.

The effect of the test result on her pregnancy was a psychological "divorce from the child", until weeks later she felt the child's movements. She did not fully embrace having the child again until it was born. "I remember finding a box of maternity clothes some time ago, all black". Looking back on her pregnancy experience, she wishes she had "never known". Sabine's statement about whether she would recommend NIPT to another woman was therefore very nuanced:

> Not in general. For women who are afraid of amniocentesis and who have an increased likelihood [of genetic abnormalities]. They should think in advance about what they would do, how they would deal with the result. Although, as in my case, it is always different after the test.

Sabrina was somewhat unprepared for the ultrasound scan, because she had not thought herself at risk and in particular need of prenatal diagnostics. When it became clear that she was at risk, she opted for NIPT rather than amniocentesis, which posed a lesser risk to her fetus. However, she was reluctant to accept the logic of prenatal testing, still clinging to hope that the clinicians were wrong. Her strong statement on receiving the result, and her subsequent emotional divorce from the child in utero, the child she had hoped the test would protect, led her to say that she wished she had not known. For her, testing practices such as NIPT have ill-framed assumptions and ponderous consequences:

> I currently know of two women who are pregnant again after having a child with DS, and both chose not to have skin fold translucency measured on ultrasound or a fine diagnosis ultrasound later in pregnancy. I would do the same. A test against [DS like NIPT] would not be possible for us. You can't first decide for and later against. It would also be a sign to him [her child], and that is unthinkable.

Sabrina's way of responding to her urge to know is embedded in a logic of "caring". It is centered on the expectation of an unburdened pregnancy, in which the woman, not the clinician, is the expert. Within this logic, NIPT introduces "one more uncertainty" about what to do with the test result and burdens the pregnancy with negative emotions. Sabrina, again concurring with some of the other women I interviewed, said: "Many might not reflect upon implications of NIPT because it is 'just a blood test', with no direct risk to the baby". By this, Sabrina is suggesting that the pharmaceutical company's slogan, which presents NIPT as "an alternative to amniocentesis without the risk (of miscarriage)"[5], misleads women because it obscures the implications of a result. This shows that while NIPT may present the advantage of being clinically non-invasive, the test had multiple personal, social, and medical consequences, and could thus be considered highly invasive.

Testing against uncertainty: "A safe enough test"

37-year-old Dorothee is in her 15th week of pregnancy at the time of our interview. She undertook NIPT to be extra sure that she would not have a child with DS—this would not have been compatible with her own and her partner's ideas of family life, as informed by her sister-in-law's DS. For Dorothee, the outcome was a relief: "One less problem to look after".

Dorothee is in many respects a modern cosmopolitan German woman. Like most of our highly educated respondents, she has a university degree and lives in a densely populated urban area of Berlin. The interview takes place in the open-plan kitchen of a spacious flat, while her partner works in his home office in the adjacent room. Dorothee had her first child 12 years ago, a girl, followed six years later by separation from her first partner, whereupon she moved into a flat next door with a new partner. The responsibilities for the daughter are shared between the two biological parents. Dorothee emphasizes several times that she has a very close, sharing relationship with her 12-year-old daughter and that she considers herself a very good mother when she is herself happy.

Three months before her current pregnancy, Dorothee had an early spontaneous abortion. "Did the loss change your experience of pregnancy?", I asked. "Yes. Now I try not to be too happy, and worries and thoughts are much more present". After

5 Quote from the official information of the pharmaceutical company Lifecodexx.

the miscarriage, she and her partner had a conversation about disability and what kind of child they wanted. Dorothee remembers that it occurred during an underground train ride to the opera, and that the discussion was relatively brief because they both agreed that disability would not be compatible with their mutual aspirations of family life: "My understanding of family life is a partnership, where you are together—independently, participating and sharing in the life of the other family members". Family and loss are an important theme throughout our conversation. Her own parents lost a severely disabled infant at the age of five days. Her brother had died of cancer 15 years ago and her mother died prematurely ten years ago. Of her biological family, only her father and her own daughter remain.

For Dorothee, it was a "relief" to have this conversation on the underground train and to hear her partner say that he would not want his child to have a life like his sister's. "After all, he might have had reservations because of his sister". Nor would the partner want Dorothee to live the life of his mother, who is the sole carer for his 38-year-old disabled sister. Dorothee explains carefully:

> I've had never been in contact with a person with trisomy 21, like my sister-in-law, and […] it's a pretty severe trisomy 21. She can't communicate and she's 38 years old and she lives in Chile with her mother, and […] yes, that had an enormously big influence, since I've known her the past five years now. Influenced by seeing a life that I wouldn't want for myself, wouldn't want for my child. […] Yes, I think my sister-in-law is quite happy in her world, but her world is not connected to our world. […] Well, she really can't, she can't communicate, she can't go to the toilet by herself, and of course that's an extreme case, but […] my partner and I […] can't imagine having a child with trisomy 21, and we would like to rule that out if it's possible.

Dorothee has a clear idea of "what a family should be like": without disability. She wanted to spare her family the hardship of bringing up a disabled child. She reminds me of the attachment to family that women care the most about when considering whether to take this particular test. I use her example because it helps us to understand that thinking in a "logic of testing" is not about choosing an isolated, specific test, NIPT or any other. Rather, testing is part of an ecology of practices that involves thinking in terms of probabilities, a very specific kind of certainty that one must accept. I am not suggesting that Dorothee is representative of "German" women, although I have noted her way of thinking, and of confronting uncertainty by seeking knowledge many times among German women.

In a different part of the interview, Dorothee also points to the common critique of the insufficient supportive care or "safety net" for families of children born with DS:

> Every time I'm [with my family-in-law] I realize that this is not the life I want. And what I want for my child, and […] so, of course, a child accompanies you for life, but not really like that, not in the way that until the child dies, um, how shall I put it, that you must take care of everything.

This critique was also raised by respondents from rural areas, some of whom had to travel two hours to see a specialist. For people like Sabrina, who takes her child to early intervention four times a week, this would be a full-time job if she lived in a rural area.

Dorothee is an exemplary informant because she has a relative with DS and has previously miscarried. She and her partner knew that they did not want a child with DS long before they found out about NIPT. In this sense, Dorothee meets all of Sabrina's stated requirements for testing. Dorothee found "reassurance" in NIPT because of the negative result, but also because in the event of finding of an abnormality she would have been able to opt for an abortion, thus "sparing" her family "a life of hardship". I think that because of her previous experiences, NIPT functions for Dorothee as a specific tool in a routinized "logic of testing". DS, but not disability in general, was something to be avoided; not because it was a frightening unknown, but because her sense of obligations to her family made DS incompatible with "family life where you are together, independent and sharing each other's lives".

Within the logic of eliminating unpredictability, NIPT offers itself as a medico-technological tool with an understanding that is co-inscribed in the tool and its users. This anticipated interdependence (Prout 1996) can also be seen in Dorothee's case. She wanted to avoid the outcome that the test was designed to reveal, and was prepared to face the consequences, and if necessary, terminating the pregnancy. She saw this from the biomedical perspective, thus it was not problematic for her that the clinicians were the experts. At the antenatal clinic she was told that they would usually order a triple test first, and then, if there was a suspicion, be advised to undergo NIPT for "extra" certainty. However, Dorothee wanted NIPT straight away, to be "extra sure" about DS. She had been told about the residual risk of a false result in NIPT, but thought it was "much more minimal" compared to the triple test. She also thought a 98 percent chance was "safe enough" for her, so there was no need for an even more accurate test like amniocentesis.

Discussion: Ways of caring while facing an uncertain future

I sought to understand how a new predictive genetic test, NIPT, is becoming routinized in prenatal diagnosis, while at the same time introducing uncertainty and the potential for women to gain more agency within the complex relationship between pregnancy, disability, and family life. My aim was to show how, far from being

prey to technology, some women make pragmatic use of NIPT as a resource or tool for gaining knowledge, while others reject the demands and obligations of testing practice by embracing the uncertainty of an unfolding pregnancy as an alternative logic.

I have selected two case narratives that represent distinct ways of responding to the urge to "know what you would do", which are embedded in different logics: First, the story of Sabrina, the mother of a child with DS, describes the complex negotiations of meanings and practices of NIPT within the spectrum of prenatal testing practices. Sabrina invites other woman to "know what you would do if you had a positive result" before deciding to test. Her advice is based on the difficulty of resisting the "temptation to know more" as she moves along the spectrum of PND. These difficulties increase with each successive test, in what is often described as a diagnostic spiral. Sabrina understands NIPT as potentially leading to a decision to abort. Her own experience has led her to urge others to reflect carefully about what it means to abort or to live with a disabled child. When Sabrina asks women to consider the consequences of knowing they are carrying a disabled fetus, which includes the prospect of choosing abortion, she is asking them to be informed consumers. At the same time, the choice and deliberation are, as Sabrina points out, complex and call for being "very, very, very careful", in line with the logic of care.

In contrast, Dorothee has a relative with DS and, like Sabrina, had previously lost a fetus due to miscarriage. She and her partner knew they did not want a child with DS before they found out about NIPT. Dorothee found "reassurance" in NIPT—because of the negative result, but also because she would have been able to undergo an abortion in the event of finding an abnormality, thereby sparing her family "a life of hardship". For Dorothee, NIPT becomes a medical technology that functions as a specific tool in a routinized "logic of testing". In this logic, women seek medical reassurance with the help of clinical experts and the NIPT, which offers itself as a medico-technological tool with an inscribed logic (Prout 1996): that of eliminating unpredictability, which is itself based on a "trust in numbers" (Porter 1995).

Sabrina and Dorothee both used NIPT in search of certainty. They are similar in that they have had previous spontaneous abortions, which led them to embrace NIPT as a safe alternative to riskier amniocentesis. However, they both seek reassurance in different ways. Risk and certainty, safety and security are different from the peace of mind that can be found in not knowing (Schües et al. 2022). Whether the prenatal specialist offers relative certainty or complete certainty does not matter to a woman like Sabine, who is looking for knowing in the body, a knowing that is embodied and cannot be abstracted from the knowing body of women (Mol 2014).

I argue that women like Sabine challenge the imperative to know and act based on probabilistic knowledge, refusing self-management, and the privatization of risk by continuing with testing and, if need be, terminating the pregnancy. Instead, the uncertainty of her unfolding pregnancy occupies center stage. Certainty herein lies

an embodied practice of knowledge. Sabine cannot even speak of testing without referring to her child, who might have been aborted. Women like Sabine have become acutely aware of NIPT as a matter of "testing and avoidance". If the experience of an unburdened pregnancy is at the forefront, NIPT adds the uncertainty of the possible decision to keep or abort a (handicapped) child. There are other narratives of women saying they wanted to know in order to prepare themselves, but the more common view of NIPT as an element in an ecology of testing practices leading to abortion is also based on estimates from experts that nine out of ten fetuses with DS in Germany are indeed aborted (ÄrzteZeitung 2017). In Germany, under certain circumstances, abortion is permitted throughout the pregnancy, and is covered by insurance. Abortion is tolerated in Germany for the sake of the physical and psychological integrity of the pregnant woman, which could be endangered by a disabled child. In other words, disability is used as an indirect justification for abortion.[6]

Within a logic of caring for the ongoing pregnancy, NIPT introduces uncertainty and burdens pregnancy with negative emotions. The finding that highly educated women did not "understand" the "probabilistic" nature of NIPT could be interpreted as reflecting poor counselling. However, drawing such a conclusion would fall short of my aim to understand NIPT in constructivist terms, i.e., to reject scientific claims and understandings as the only rational and objective "truth", whereas all other discourses are based on false "belief". If we treat scientific and experiential claims symmetrically, and seek to understand each claim in the specific context of its actual, concrete practices, we could also argue that women are required to "de-script" (Akrich 1992) the meaning of NIPT, untie it from its intended use, and re-inscribe a new meaning.

By answering "you know what you are going to do", but warning that "it is always different" after receiving the test result, women like Sabrina remind us of the very complex nexus of life plans, ideas and ideals of family life, expectations of a healthy child, of what the parents think is desirable, and what is possible for them in society. Pregnancy, these women remind us, cannot be thought of in isolation, abstracted from the real world in which the test is available. Nor can NIPT be considered in isolation from the world in which the child might live. NIPT and its milieu interfere with each other, obliging practitioners to engage in certain other testing or caring practices.

For Sabrina, having a child with DS obliges her to see NIPT as a test that would deprive her existing child of legitimacy, dignity, and the right to live. Testing prac-

6 In Germany, abortions are formally prohibited without medical indication (§218 SGB). However, they are not punishable and are tolerated under the caveat of compulsory counselling, and if they are carried out within the first 12 weeks of pregnancy, which accounts for 96% of the abortions recorded between 2012 and 2022 (DESTATIS 2023). Abortions on medical grounds are covered by health insurance and are permitted throughout pregnancy.

tices, as I have argued, are not just about actions, but also about values and relationships. Because of the commitment to a child that progressively affirms itself, the timing of testing with NIPT is a matter of concern for Sabrina. Early testing would not allow a child to affirm itself.

Expectant parents must position themselves for a possible future that has not yet been mapped out. Choosing uncertainty does not mean that they deliberate less carefully, but that they have different attachments and obligations than in their previous actions. For Dorothee and Sabrina, the attachment is to an already born child and to their existing family. For both women, NIPT, with its probabilistic certainty and clinical non-invasiveness, forms a different element in their respective ecologies of care. The two women profer different responses to the offer of "knowing more" through NIPT and the routinization of testing during pregnancy. However, if we agree with Mol (2008: 75) that what constitutes "good", "worse", or "better" care does not precede practice but is rather an integral part of it, something to be negotiated within the situation or tinkered with as contingencies arise, then both logics are equally valid ways for women to care for the child to be born and the family into which it is to be born.

In some respects, the test for DS might be seen as more than just "seeing what is about to be born" (Löwy 2018). Parents are required to evaluate NIPT in the context of the world into which their child will be born, which are altogether different for Sabine and Dorothee. In this sense, women are more than just "moral pioneers" (Rapp 2000): they are field testing NIPT—with all its implications and obligations—for a society in which technological advances are continuously outpacing ethical and practical considerations.

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