# 8. What Does Prenatal Testing Mean for Women Who Have Tested?

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Women who use prenatal tests have varied reasons for doing so. It is therefore important to learn from women who have used tests, the reasons why, and for what purposes they have tested. Reasons and corresponding aims of testing constitute what we can call the "meaning" of testing for those who have tested.

One aim of those who test is to be able to decide whether to discontinue (or not) the pregnancy. But we can also ask: why should it be desirable to decide about continuing the pregnancy? What does continuing or terminating a pregnancy mean for those who make that decision in their particular situation? Testing and the information it generates are in some way tools for achieving a desirable outcome. It is therefore not enough to state the obvious: that prenatal tests are tools to find out the likelihood that the child about to be born has a genetic disorder, since this leaves open questions about meanings. Why should this be a good thing to know during pregnancy? One reason could be the perception that a disabled child will suffer and/or cause suffering to the family, for example.

Expecting or knowing a result only in technical terms therefore does not reveal the reasonings of women or couples. The reasons why women take a test are personal and as such do not belong directly to the scientific realm. They give the test a particular significance within the dynamic life context of those who decide. In this chapter we use interviews with women and couples who chose to test for a chromosomal or genetic disorder to better understand what these meanings are, in the lifeworld of those using them, using a comparative analysis of a selection of interviews from Israel and Germany. We will try to identify patterns of meaning-making, and see whether there are significant differences between our Israeli and German interviews. We also discuss the findings in the context of the current bioethical literature on prenatal testing and screening,

https://doi.org/10.14361/9783839459881-013 - am 14.02.2026, 03:33:16. https://www.inlibra.com/de/agb - Open Access -

where two interrelated framings are predominant: that prenatal tests enable women to make "informed decisions", and that prenatal tests are key parts of a practice of "selective reproduction", for which information is meaningful.

Germany and Israel differ in their regulation of the field, the scope of prenatal testing they offer under public funding, and the recommendations of professional associations of obstetrics and gynaecology (OB/GYN) and genetics (see chapter 3 in this volume for details). Israel has a widely implemented prenatal testing scheme, which is publicly funded. However, it does not include NIPT (non-invasive prenatal testing, a test based on analysis of cell-free DNA in maternal blood). Since 2022 Germany has had regulation enabling NIPT to be covered by health insurance, but only if the woman is in a conflict by the lack of knowledge and the risk of psychological harm due to the uncertainty (Rehmann-Sutter/Schües 2020). At the time of the interviews (2017–2019), NIPT had to be paid for privately but its availability was widely known and its uptake common practice. The overall uptake rate of NIPT in Germany has been estimated by Gadsbøll et al. (2020) based on best clinical guesses as < 25 per cent of all pregnant women. In Israel, where the first- and second-trimester screening tests are publicly funded for all women, and where amniocentesis coupled with chromosomal microarray analysis (CMA) is often funded, uptake rates of NIPT were relatively low: in 2019 it was about 4.4 per cent of live births.[1]

Below, the analysis focuses on the meanings attributed to varied types of testing – be they invasive, such as amniocentesis (whether or not coupled with CMA, also known as the "genetic chip"), or non-invasive, such as NIPT and the first-/second-trimester screenings.

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[1] Ami Singer, MD, Head of the Community Genetics Department in the Ministry of Health of Israel, personal communication.

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## Methodology of this analysis

A word is dead, when it is said
Some say –
I say it just begins to live
That day
Emily Dickinson[2]

Analysing the interviews a few years after they had been conducted and transcribed was a special experience for us when writing this chapter. It brought the words of the interviewees back to life in a new way. In the context of analytical questions that we have since generated, selected passages of the interviews made new sense. While speaking, our interviewees could not have been aware of the exact questions that we now had while interpreting the transcripts. Prompted by questions from the interviewer, they essentially told us their stories of testing as part of their life. They explained how testing was important and how it was problematic for them in their particular situation.

In an important sense of the term, interpreting the interviews as we do in this chapter has to do with a "double hermeneutics", as frequently emphasised in interpretative phenomenological analysis (IPA). The analytical process of interviews can be described as a dual interpretation process, because first the participants made meaning of their world, and then second the researcher tried to decode that meaning to make their own sense of the participants' meaning-making (Smith/Osborn 2008). In the first step, the participants' interpretation, there are even more layers involved. Tests are offered to women and couples in the context of meaningful packages that already contain interpretations of what it means to be a responsible parent. Women and couples are well aware of social expectations that restrict the freedom of choice they are constantly assured that they supposedly have. And on the side of the interpreters there are multiple interpretative layers too. We first read the interviews in a narrative fashion, in order to understand "the story" of these women. Then we reread the interviews and asked what the interviewee particularly wanted to get across while telling their story to the interviewer, who they already knew was doing "a study" on prenatal testing. And what we have tried to do in writing this chapter was to set a certain reflective distance between us and the

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[2] Dated 1862; no. 278. In: R.W. Franklin (ed.) (1989): The Poems of Emily Dickinson, Cambridge, MA: Belknap.

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interviewees' full stories, in order to become more attentive to the meanings they attached to the tests. We were looking for typical meaning patterns that show up in the interview dialogues.

Before we say more about what these "typical meaning patterns" can be, we briefly want to explain the procedure of how interviewees were selected, how the interviews were conducted, and how cases were selected for this analysis. The interviews belong to the empirical part of the German-Israeli comparative interdisciplinary study of prenatal testing, which combined social sciences, philosophy and ethics. It was essentially a qualitative interview study in both countries. Before starting to recruit interviewees, ethical approval for the research was obtained from the ethics committees of the University of Lübeck and Ben-Gurion University of the Negev at Be'er Sheva in 2017. The recruiting process differed in each country due to the different contexts of the respective healthcare systems. We invited women who had either taken NIPT or other tests, or declined them. As part of the broader project, we also interviewed healthcare professionals in obstetrics/gynaecology and genetics, policymakers and activists. The interviews with these stakeholders were however not included in the analysis in this chapter. To recruit women in Germany we used a flyer that was distributed through OB/GYN and midwifery practices and pregnancy counselling centres, through online posts, and snowballing. Women who were interested in being interviewed then contacted us. In Israel, recruitment was done through online posts, relevant organizations (e.g., Down syndrome organizations), the authors' social network and snowballing. All participants gave written informed consent for the inclusion of their interview material in this study, and participants were fully anonymised.

An interview guide was initially developed, revised and extended after the first interviews had been transcribed and analysed. The first questions always focused on the women's individual biographies and the histories of and emotions concerning their pregnancies. We then asked how they had learned about prenatal testing and their attitudes toward it, their experience of professional counselling, and their decision-making process regarding the tests. We were also interested in the role of other people and/or sources of information in this process. Subsequently, we asked whether – and if yes, how – the tests changed their experience of pregnancy. Further questions asked their opinions on the financing of the test: whether it should be covered by health insurance or paid for privately. We also asked about their retrospective evaluation of the test, in particular whether they would do things differently or the same if they became pregnant again. To gain a normative insight, we asked what they thought about

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women whose choices about testing or acting upon test results were different. We added specific questions for women whose test results had been positive. We asked how they experienced learning about the positive result, whether they had chosen further invasive confirmatory tests, and whether they had terminated the pregnancy. The interview also focused on the experiences of people with disability, and on their attitude towards life with a disabled child and views on terminating pregnancy.

In Germany, in addition to interviews with professionals of various kinds, we conducted 36 interviews with women and couples who had or had declined NIPT. In six of them, we interviewed both partners together, while in one interview only the partner participated. In 14 of our interviews there was a chromosomal disorder in the (extended) family (more details in Reinsch/König/Rehmann-Sutter 2021). In Israel, in addition to interviews with professionals and activists and with women who declined testing, we interviewed 30 women who had varied types of prenatal tests: first-/second-trimester screens, NIPT, amniocentesis with or without CMA. This number does not include women who had no tests or "only" had ultrasound tests (which in our sample was ultra-orthodox women). Six of the interviewees are mothers of children with Down syndrome.

All respondents received a recruitment letter describing the study and including a disclosure statement. German interviews were conducted in German, face-to-face and in a few cases by telephone. In Israel, interviews were conducted in Hebrew over the phone or via Skype. Israeli interviews were all conducted by Tamar Nov-Klaiman. German interviews were conducted by Anika König or Stefan Reinsch. The guideline-based interviews lasted from 45 to 150 minutes, and in most cases more than an hour. Interviews were audio-recorded, fully transcribed verbatim and pseudonymised following transcription.

For this special analysis we used the 19 German and 30 Israeli interviews with women who *had actually taken* a prenatal genetic test. These women had either received a positive result, and after confirmation by amniocentesis had decided to terminate their pregnancy, or to continue it and have the baby with special needs; or they had received a negative result.

Those sections in the transcripts that contained statements about the meaning of prenatal tests (reasons for testing, aims of testing and related topics) were highlighted and interpreted, considering each interview and its narrative individually. Iterative comparison and abstraction was used to compile a table of distinct, typical meaning patterns. This process was done

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first for each country separately. The categories were then discussed in joint sessions, and meaning patterns adapted by further abstraction to include similar patterns identified in the table of the other country. The result of this process was a joint table of ultimately seven different but interrelated meaning patterns. Many patterns appeared in both German and Israeli interviews, but some were seen more in one country and less in the other.

The procedure was similar to a Weberian ideal-type analysis, which has been formally described by Uta Gerhardt (1994) for qualitative research in particular, and more generally for sociology by Richard Swedberg (2017). In general, the ambition of an ideal-type in sociological theory is to understand and explain a certain cultural phenomenon, i.e. a particular social action that is the focus of our attention. Decisions about prenatal testing can be considered social actions in many important respects. They affect other people beyond the one who makes the decision about testing, and they are also organised actions since they are only possible within social arrangements and using cultural scripts. More explicitly, prenatal testing therefore belongs to what we may call the *pre-partum sociality* of the pregnant woman and couple.[3] While technically looking for features of the foetus, prenatal testing as a social action derives its reasons and aims from within the social relations among the family and in society. It therefore needs to be explained within the social relationships between people.

When we look at the meanings of the prenatal tests, and the reasons and aims that led women to have such tests, we focus on the women's rationales in a specific historical and social context. This could be done very specifically and on a case-by-case basis for each individual. But it is also interesting to see whether we can find some typical patterns in the sense of ideal types. In order to clarify what this notion implies and what ideal types can do (and not do) in theory we now briefly look at this discussion with reference to Weber. As both Gerhardt (1994) and Swedberg (2017) note, Max Weber's work does not give a single authoritative and unequivocal definition of the concept of "ideal type" in his project of *interpretive sociology*. The most comprehensive statement is in his 1904 essay on objectivity. With his idea of ideal types he wanted to explain a specific historical formation (such as "the spirit of capitalism"). Weber strove for

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[3] It is related but not identical to Stefan Hirschauer's concept of "prenatal sociality", i.e. the sociality *of* the unborn, which is socialisation of the unborn during pregnancy (Hirschauer et al. 2014).

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conceptual clarity about a historical formation by means of a synthesis of individual components that he selected in their sharpest, most consistent form. By conceptual clarity he seems to have meant a rational understanding of the meaning of a phenomenon. In chapter 1 of *Wirtschaft und Gesellschaft* there is a second version of the ideal type theory that can be applied to social actions. In Swedberg's reconstruction, this refers to what a hypothetical (or ideal) and typical rational actor can do under certain circumstances. This is a first point to keep in mind: an ideal type explanation assumes, sometimes counterfactually, that the actor is acting rationally, i.e. according to a coherent reasoning. The two criteria Weber then gives for ideal types seem to be (i) that they must be adequate on the level of meaning for what they are intending to explain in reality ("Sinnadäquanz"); and (ii) that they heighten or concentrate the meaning in order to reach a clearer understanding ("gesteigerte Eindeutigkeit"; Weber 2014, Part I, chapter 1, § 1, section 11). This is a second point to keep in mind: claims about ideal types must meet certain criteria. The first is: "What is involved in adequacy on the level of meaning is that the meaning and the action have to fit each other, a bit like the hand in the glove" (Swedberg 2017: 187). This relates to the double hermeneutics, which we have mentioned above: the researchers' interpretation must fit the meanings that actors communicated in the interviews. The heightening or concentration of meaning under the assumption of ideal actors who act rationally and have complete information relates to the explanatory force of an ideal type pattern. We will therefore present ideal meaning patterns with the aim of *adequately representing the meaning* of what women explained and at the same time *heightening and concentrating* this meaning, in order to make it more graspable.

## Findings

### a) German and Israeli interviews

The major difference we found in the interviews is that Israeli women were more likely to seek to maximise detection by testing, even at the cost of risk due to the invasiveness of the procedure, and even in the absence of a medical indication. For example, a notable proportion of Israeli women who were offered NIPT (but no German women in our sample) declined, not because they refused tests in general or because of the costs, but because they wanted to have more comprehensive genetic tests than NIPT, such as amniocentesis combined

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with chromosomal microarray analysis (CMA). This was also found in a subset of our previous interviewees, i.e. parents of children with Down syndrome (Nov-Klaiman et al. 2019, 2022). This difference can be explained in part by the stronger desire of interviewed Israeli women to find out as much as possible about their future children. For a close analysis of the meanings of prenatal testing for women who had the tests, we decided to ignore the particular test chosen, i.e. the meanings given to testing by women who had either performed NIPT or alternative tests, whether invasive (mostly in Israel) or non-invasive, e.g. first-/second-trimester screens.

In this situation it would not make sense to focus exclusively on the features of NIPT that make it unique from the points of view of both providers and women using it. The focus of our analysis shifted from NIPT to multiple variants of (genetic) prenatal tests. Compared to other methods, NIPT is a clinically risk-free testing procedure. In several interviews women said that they would not have had amniocentesis because of the risk it poses to the continuation of the pregnancy. This however appeared among the reasons why they preferred NIPT over other means of prenatal testing, or why they did not go any further with a diagnostic invasive test, even after a positive result. We wanted to know how women and couples understood the meaning of their *act* of testing in the context of a practice that is more extended in time, social distribution and space.

The meanings of testing cannot be sharply distinguished from the reasons that made women decide to have it. These reasons include the physician's recommendation, the expectations of the family, or the perception that a woman had an elevated risk due to her age (> 35). Reasons give one answer to the question of why they tested. But the question has another level of meaning as well: in addition to reasons for consenting to a procedure of prenatal testing, the women and couples referred to what these tests meant in their life situations. The meaning they are referring to is the *intention* of their act of testing: *What did they do it for?* This is an equally central focus of this chapter.

This question is distinct from the medical description of the tests (in terms of probabilities, reliability, or the medical significance of a diagnosis such as trisomy 21), and also distinct from technical descriptions of the tests (in terms of cell-free foetal DNA fragments sequenced), and from the regulatory description of the tests (in terms of permissibility of an abortion under national law, or of claiming reimbursement from health insurance funds). The women often had ideas about what the testing meant to them in their personal situation. But not all of them had; some, especially women in Israel, also said that they

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had the tests just because they are offered and performed as part of medical routine in pregnancy management, and they wanted to do things, as one interviewee put it, "by the book", without giving it much thought. But for those who attached a certain meaning to the test, it was for instance to help prepare themselves for a child with special needs, or to evaluate whether their medical, emotional, social, financial etc. resources would allow them to cope with it. Alternatively, testing was important to allow the termination of a pregnancy if abnormalities were detected, because in their view and personal situation, disability should be avoided. These descriptions of personal meanings of prenatal testing were extremely diverse. They included references to the life situation of the woman or couple in their family and in their country, their previous family history etc. In analysing the interviews and using the "ideal type" approach (explained above), we have been attentive to typical *patterns of meanings* used in these highly personal and diverse explanations.

## b) Patterns found

In the interviews we find multiple and very different subjective descriptions used by the actors to describe this kind of action, "performing prenatal tests". As we have said, in Germany they mostly referred to NIPT whereas in Israel, except for the first-/second-trimester screening tests with their high uptake rates, more extensive tests such as amniocentesis coupled with CMA are commonly preferred over NIPT. These subjective descriptions are embedded in personal narratives and therefore refer to what was personally relevant for the women and couples in their particular situations. These descriptions are heterogeneous, each guided by their special circumstances and previous experiences, their idiosyncratic views on family, pregnancy and disability. So there are probably no two identical descriptions from different people about what it means to do a prenatal test. Similarities and overlaps can nevertheless be found. We started by looking for patterns and then, by dropping more of the particular details, for typical patterns.

To explain this procedure, let us look at an example. Shimrat is an Israeli woman who at the time of the interview had two children after having terminated her first pregnancy following a diagnosis of Down syndrome, which was suspected at the second trimester screen and confirmed by amniocentesis. She said:

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> I'm the one who would need to raise her and I'm not willing to do it – not to myself and not to her. I mean, why? I see no reason why. I didn't hesitate. I don't have a partner. I'm a single mum. But even if I had a partner I wouldn't have kept this pregnancy.
>
> I think, to begin with, all these tests exist for prevention. I see no reason to bring a child into the world when you know in advance that something is wrong. It's not, you know, a missing finger or something like that, which you can live with. It isn't a congenital problem that can be fixed. It's something irreversible. It means condemning her to life that isn't … Not as far as I'm concerned.
>
> In the second pregnancy I was so impatient to have [NIPT] already and get the results and finally breathe. I felt like I couldn't breathe, and I had to breathe.

She explains her situation as a single mother but then quickly goes on to state that this was not the reason why she terminated her pregnancy after receiving confirmation of Down syndrome. But what was it then? There are two main layers of interpretation within her statement. One is about the termination of the first pregnancy, the other about her willingness to have NIPT in her second. On the first level she refers to her understanding of the condition called Down syndrome. In her view, trisomy 21 means that there is more than just missing something, a condition you can live with ("a missing finger"). It will be, as she explains, "something wrong" with the child that cannot "be fixed", and this is something "irreversible". The explanation culminates in a sentence, which however is not spoken to its end: "It means condemning her to life that isn't …" At the left-out end of the phrase she avoids saying what she means about what that life would be for her child. What did she want to say? Or did she use the fragmentary sentence, the unspoken word, on purpose, in order to hint at what cannot be said? The unspoken word(s) must fit the beginning of the sentence: It means "condemning her". From her beginning with *condemning* we hear that she is speaking about a particular life that in her view is highly undesirable. Otherwise she could not have used a word as strong as "condemn".

She was looking back on a difficult decision she had taken quite a while ago in her first pregnancy. She *had* terminated. Now, using the story of her first pregnancy, she explains why in the following pregnancy she *rushed* to get NIPT. She was desperate ("like I couldn't breathe") and needed to ensure the same scenario would not reoccur. Looking more abstractly at the motives of both actions – termination of pregnancy and testing – we can see they are closely linked. She

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saw the testing as a preventive tool, allowing both the child and herself to avoid a life that is deeply undesirable ("willing […] not to myself and not to her").

What is so undesirable as a life that one can say that being condemned to having it? This is something that most generally we call suffering. We therefore decided to use this more abstract term, "suffering" (a term explicitly used by some respondents) to define this meaning pattern: to perform prenatal tests *in order to avoid suffering*. The term suffering covers many concrete visions and fears, some of which may have been in this interviewee's mind. Other people might have different images of what lives or conditions could lead to suffering. But there is one important distinction clearly indicated in this interview statement: the suffering of the child and the suffering of the mother, and perhaps more generally of the family. Based on this consideration we therefore emphasised the two dimensions of this category: testing in order to avoid suffering: not to inflict this suffering on a child, and/or not to inflict suffering on the family and oneself.

After following such an interpretative procedure with all included interviews, we compared the provisional versions of the categories and combined similar interviews into one more general category. Tentatively, we concluded with seven nuanced though interrelated and partially overlapping intentional patterns found in our sample (Table 1):

**Table 1: Typical meaning patterns of prenatal testing**

1) To test in order *to gain knowledge*,
which is in itself an empowerment.
2) To test in order *to be prepared*
for the birth of a child with special needs. This can relate to external aspects: preparation of family and friends, health insurance, housing etc., or to an internal attitude: to get ready to welcome the child, to do the work of grief etc.
3) To test in order to *reduce uncertainty* and to increase certainty.
This provides reassurance for those who believe the pregnancy is developing well, or confirms or disproves the fears of those who have them.
4) To test in order *to find out and to decide*
whether one has the resources and capabilities to have this child, thus whether the pregnancy should be continued.

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5) To test in order *to avoid suffering*  
by avoiding a condition that would inflict harm on the child, and that would also mean suffering for the family and oneself.
6) To test in order to *satisfy the social environment*  
which can be the partner, the parents, or wider family and social milieu.
7) To test in order to *fulfil the physician's recommendation*,  
which can arise from a wish to do everything by the book, or just out of trust in the doctor.

We shall now explain and illustrate all these meaning patterns and provide supporting quotes from both Israel and Germany.[4]

## (1) To test in order to gain knowledge

Tests can be done for the purpose of gaining the knowledge they promise to provide. Knowledge of course has a function: for instance, it should increase certainty or reduce uncertainty and fear. Knowledge can also have a value in itself. It can be an empowerment. It then also empowers people for the task of making the decisions that need making. The rationale is that knowing is always better than ignorance and that knowledge in a way also provides a means of controlling something over the course of events.

For example, Sarah (IL) said:

> [When I receive medical information] it lowers my anxiety, and it empowers me. It gives me the power to make choices. And power in general. In my view, knowledge is power.

She had an amniocentesis with CMA, which she understood to be the most reliable, precise and broad test that there is. Due to her age it was publicly funded in Israel.

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[4] Some of the categories developed in this chapter resonate with descriptions published from the German interviews (Reinsch/König/Rehmann-Sutter 2021).

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## (2) To test in order to be prepared

Tests can be done in order to be prepared for the birth of a child with disability. This can relate to external aspects, such as preparation of family and friends, finding better health insurance, preparing the home. Or it can relate to an internal attitude: getting ready to welcome the child, to do the work of grief by letting go of former expectations etc.

Lisa (GE) is in a same-sex marriage. Both she and her wife had a child from the same sperm donor who was present in the family as the father (however not legally) and cared for the two children each week. When she was pregnant with her son, an ultrasound found an unusually short femur and white spots in the heart. She then had NIPT, not to terminate but to be better prepared:

> The test was a huge gift. I mean, for us, that at the moment when Noah was born, it meant we could just be very happy about this baby. And, um, this mourning process, which there just is, saying goodbye to something that you kind of imagine, whether you want it or not, that runs alongside it, you just don't have it on your radar.

The preparation that she meant was mainly an internal process that included letting go of certain expectations and, as she called it, "mourning" it. Other women said that preparation included external things such as choosing good health insurance for the child.

Ronit (IL) was also sure that she would not terminate:

> But I wanted the test for my own sake, to know and prepare for the situation. Be prepared for what is coming.

This pattern was found in several interviews in both Germany and Israel among people who, for whatever reasons, were sure that they would not choose to terminate but wanted to know in advance what to expect. In Israel, these descriptions came from religious women.

## (3) To test in order to reduce uncertainty and to increase certainty

Some people may have tests to be reassured that the pregnancy is developing well, or in order to confirm or disprove fears if they have them. They either want to be sure of what awaits for the child and themselves, or that the feared disabilities will not be present.

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Sandra (GE), who had two girls in her late 30s, used NIPT because it felt better to know for sure that all was fine:

> Right, because it really was this, this reassurance we were hoping for, that was definitely there.

The test fulfilled the function of confirming her and her partner's hope that all was well. Corinna (GE) said that, in addition to many other considerations, the test was done to confirm the feeling or belief that everything with the baby would be fine:

> But we were still somehow very sure, well, it's just more of a confirmation for us that there's nothing there, I mean, that there's actually no problem.

Anna-Lena (GE) explained the testing in terms of the reassurance that they hoped it would give them, not necessarily in order to hear that there would be no problem with the child, but to know what awaited them. She said:

> Because we were so tortured by uncertainty, because first I thought, "OK, I'll, um, […] we'll just ignore it." I didn't want to do it anyway. […]
> My husband just wanted to be sure, I think, or just know what it was all about, because […]. I think he could handle it better.

Their plan was to continue the pregnancy in any case.

### (4) To test in order to become capable of deciding

This motive, too, is related to the knowledge that a testing procedure can deliver and the power it can provide. But knowledge and the power it gives are not sought for their own sake, but because they open an opportunity to gain the necessary information that makes it possible to see whether this pregnancy should be continued, and whether one has the resources and capabilities to have this child. The levels of disability associated different possible genetic conditions differ enormously, and people may want to know more concretely what they would be dealing with, in order to find out whether they can in fact do it. This then has implications for their decision to continue the pregnancy or not.

After experiencing a spontaneous miscarriage in her first pregnancy, Nurit (IL) received abnormal findings in an ultrasound test in her second pregnancy. She was offered chorionic villus sampling (CVS) – an invasive diagnostic test – and decided to have it, before determining whether to terminate the

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pregnancy. Following a diagnosis of Down syndrome, she terminated the pregnancy. She explained why she had testing in the second pregnancy:

> It was important for me to know what it was, for the future as well. I had already had one pregnancy that failed, and I thought there might be a connection. I wanted to know, to have all the information. It's also a big decision to make – having an abortion. I wanted to be 100 per cent sure that there was a problem, a defect, when we chose to terminate this life.

The decision she was facing was difficult, and in order to make the decision about "this life" she needed maximum information about the existence of a defect.

Gali (IL), whose physician informed the couple of NIPT, explained her attitude toward prenatal testing:

> To reach an informed decision we want to know what there is. If there is something that can be treated – then treat it. And if it's something more dramatic – then I don't reject the option of having an abortion.

Corinna (GE) was looking for information from the test in order to consider whether she would have enough strength to care for this child.

> If it turned out to be trisomy 13 or 18, emm, we said, then we just wouldn't *have the confidence* for it at the moment.

## (5) To test in order to avoid suffering

Testing can be primarily motivated by the intention of preventing suffering. This can mean doing something to avoid a condition that would inflict harm on the child, and it can also mean to avoid suffering for the family and oneself. As our respondents explained, the parents and siblings can suffer because of the physical suffering of the disabled child, but also from the energy and time dedicated to him or her, at the expense of other family members and by exhausting them. The aim of avoiding suffering is close to the aim of avoiding disability but distinct from it, since disability per se does not necessarily entail suffering, and also because the conditions that fall under the rubric of impairment are so different. It is not the disability that is avoided but the severe burden that it may mean for the child, the future mother and the family.

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Dorothee (GE) was very concerned about the burden a disabled child would be for the relatives, and also for their second child. She anticipated a time after she and her husband would no longer be there:

> If my husband and I are no longer there, or something happens, then […] well, […] then who would take care of, well, the responsibility lies with our second child, I would think.

Her caring attitude towards the child in this hypothetical situation meant she did not want this to happen, and therefore she decided to test.

When asked whether financial and social aspects of life with disability were among her considerations about prenatal testing, Orit (IL) explained:

> Aspects concerning the child. If a child is born with a syndrome – the issue of which manifestations the syndrome has. Aspects regarding the family. If a child is born with a syndrome and you know about it in advance – you put your family in a situation that you have a child who's going to consume much more energy from you than your other child, who also needs your time and energy. So you hurt them from all directions. This is the consideration mainly. […] These children suffer. Their families suffer, the other children at home suffer. With all the love and the fact that they are sweet children, they still consume familial energy from their siblings.

Anna (GE) wanted to prevent the severe burden that a disabled child can be for the family and the suffering it can mean. Her aunt was mentally impaired. Her grandmother had to care for her until her death at 95, when the aunt was 75. She said that the experience of this shaped her decision to have a prenatal test at the age of 37:

> And I knew that if I had a child, and especially now so late in life, I couldn't have a handicapped child, because I realise that perhaps I'm already too old [laughs], and because I saw how my grandmother lived, at 95, with this disabled child – my aunt is now 75 – until she died, and I don't believe I'd have had the strength. So it was a very clear, stark decision, simply pro or contra child.

The decision "pro or contra child", as she phrases it, is behind her taking a test. The motivation for testing is to avoid a situation in her future life that she feared she would not have the strength to bear, a child that would overburden her.

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Here are a few more examples from our Israeli sample. Stav (IL), who had NIPT, explained:

> I think disability should be avoided in order to spare the family from suffering, and the child itself. The child, meaning that society would be cruel to him or her.

Ella (IL) had NIPT following abnormal findings in an ultrasound scan. NIPT detected trisomy 18, after which she terminated the pregnancy. She said:

> If there are things I can know in advance and prevent to avoid suffering for myself, for my husband, for my children, of a child with a severe syndrome… Look, people always say that [it should be done] to prevent suffering of the child. The truth is that when there is a severe syndrome, the child is usually so cognitively impaired and so handicapped that they're not able to be aware of their situation and their suffering. That's why I refer more to the horror that the family has to go through.

Hadas (IL) had amniocentesis in her first pregnancy without any medical indication. She had one in her second pregnancy too, due to her age. She explained:

> Certain disabilities are accompanied by a lot of suffering and pain, so this is a very difficult life. For both the child and the family. For the siblings too if there are any.

## (6) To test in order to satisfy the social environment

Tests can also be done to meet expectations of others. It could be the partner who wants a test to be done, it could be the parents or the wider family that builds the social environment. In principle, expectations of the wider society would fall into this category of meanings as well, for instance if one is trying to behave in a manner that would be seen as socially responsible. This is a way to comply with community norms or to enact cultural scripts. In the interviews with those respondents who said that they tested in order to satisfy the social environment, however, we found more references to relevant close others or to the family.

Shani (IL) referred to general social expectations in explaining her choice to have amniocentesis plus CMA:

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> In the end, what won the debate was the idea that you don't want an anomalous child. Anomalous by definition, right? Because all children are exceptional in their own way.

"You don't want" refers to what she assumes to be a generally shared opinion in her society. But Hagit (IL) did it for the sake of her mother, who said she should:

> My mum was mostly the one putting on the pressure. She's the one who eventually funded my NIPT, which isn't publicly funded. I told her I wasn't planning to have it, so she said she would pay and I should have it. Actually, this is why I did. I wouldn't have had it if she weren't pushing.

For Sandra (GE), the decisions behind whether to test or not and which tests to take were difficult. She and her partner quarrelled a lot over it. He absolutely wanted her to have the test in order to be fully secure that nothing was wrong. The fight continued over the interpretation of the test, since NIPT only provided probabilities, not a clear yes or no. She described her partner as pretty much "paranoid" about all this but, in order to move forward in the relationship, she agreed to have the test done, among other things because of potential reproaches from her partner if she refused:

> In the end, I'd be to blame if something was overlooked.

Danit (IL) also told us that her partner desperately wanted her to test. With NIPT, she no longer had any reasons to be scared about testing (as in her previous pregnancies):

> This alternative appeared, of a private blood test instead of amniocentesis. My husband held my hand and told me: "I beg you, do this test. You don't know what disability can do to the family. Please listen. No matter how much we pay. Better to have the test and know than not test at all."

In her partner's considerations we find the concerns that disability means suffering to the family. She saw her own pregnancy as problematic due to her advanced age, and saw that her partner was very stressed because of this:

> I had NIPT and it was considered something that would relax my husband and the environment that my geriatric pregnancy at the age of 35 would be all right. This was my state of mind. I didn't even eagerly anticipate the results. I knew I was doing it for others.

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## (7) To test in order to fulfil the physician's recommendation

Tests in a highly regulated healthcare environment can be chosen out of a wish to do everything right, according to recommendations, to do everything by the book, or just out of trust in the doctor who recommends it.

Sivan (IL) trusted her physician when he recommended she have invasive testing in her situation of being of a more advanced age (over 40):

> He said that in amniocentesis and the added genetic chip most conditions that are tested, or at least a lot of them, are age related. Meaning, at this age there is an advantage for amniocentesis combined with the chip. That's it. At that very moment the decision was made.

Gali (IL) explained that she wanted to do everything right, according to the doctor's recommendation:

> I did everything by the book. Whatever my ObGyn told me. […] When I'm told to do something, I do it. […]
> And then the doctor came [and told us about the test] and we said, "actually we have nothing to lose here. More information. No risk. Let's do it." Without thinking too much about it. Without truly understanding what it means. And we did it.

## A few observations

In Israel, women seemed to take the performance of tests for granted. This could be partially explained by the fact that a wider selection of tests has been implemented in the national healthcare system for a longer time, supported by professional guidelines and practice that recommend their use. It is therefore much more routinised than in Germany.

When Israeli women think about testing, it seems to be more common than in Germany to take for granted that abnormal results will lead to termination of pregnancy, although such instances were also found in the German sample. This could be explained by different interpretations of disability in each culture. In Israel disability is more often directly connected with suffering.

Meaning patterns 1 (pursuit of knowledge), 6 (satisfaction of social environment) and 7 (fulfilment of physician's recommendation) were found mostly in the Israeli sample. This observation should however be read with caution. Given the small size of our samples in both countries, however, the evidence

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it provides can only be anecdotal. It cannot warrant any conclusions for either country beyond indicating a certain tendency that would need to be confirmed by more extensive studies.

More often than in Israel, women in Germany saw the decision to test and the decision to terminate or continue the pregnancy as separate decisions. Most women saw them as being not only independent but also different in content. Even Laura (GE), who chose abortion after a confirmed diagnosis of trisomy 21, insisted that they did not make the decision to terminate beforehand, but as a second and most difficult step only after the amniocentesis. This is seen less often in the Israeli sample. In a minority of cases, Israeli women test in order to know (which is separate from the decision to terminate), i.e. even when they know from the outset that they would not terminate. For some Israeli women, however, testing was also separate in a different sense, i.e. in the sense that testing is done automatically, "by the book". Then, if an abnormality is detected, the decision to terminate is a separate one. But it seems that Israeli women often say: "What is testing for if not to prevent?" – meaning they couple the decision to test with the decision to terminate.

As we expected, women rarely gave a medical description of the tests, even if they said it was a test for certain conditions such as trisomies 21, 13 or 18. But what they were focusing on was the expected lived reality of these conditions. Their predominant concern was the personal existential meaning of testing, which involved themselves as the mother. It was not just their own image of the lived reality of disability that was important to their decision-making rationales, but also the image that society or their family (in their view) addressed to them. An important factor was how they expected the family and society to include and support children with special needs, and how their children would be looked at.

Some women used several different intentional patterns to describe their actions in the same interview. This indicates that the patterns, which we suggest to be ideal types of rationales of testing as a social action, are mutually exclusive only on a theoretical level. In reality, people can combine different patterns in their thinking and in their explanatory discourses, representing different facets of a complex deliberation. Some women however concentrated on one core formulation of the meaning, for which they sometimes used varied wordings.

In some interviews we find patterns from which women wanted to distance themselves. One topic that occurred frequently, mainly in interviews with German participants, was concern about developments in society that they saw

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happening or that they feared would happen in future, which our interviewees saw as problematic if they became dominant in society. For instance, Hanna said that she feared it was becoming more and more "normal" in society to use prenatal tests to check genetic makeup ("um die genetische Ausstattung zu checken"), which would mean society was becoming increasingly ableist ("behindertenfeindliche Gesellschaft"), one in which women would avoid giving birth to children whom society would not welcome ("gesellschaftlich nicht gewünscht"). We have not included these idioms in our list of the typical meaning patterns, since they were not presented as belonging to participants' own actions; and if these idioms have been used in relation to their own actions, then as a negative contrast.

## Discussion

We have focused on women's strategies of sense-making about testing during pregnancy. What did the tests mean to them? Which words did they use when they talked about the tests? How did they frame their decision-making about the test when they explained it in the interview? The question of the nature of the ethical challenge confronting them is closely connected with the meaning pattern they associated with the action of testing. Another related question is how they positioned prenatal testing in the context of their lives and in the society in which they live. This question, as understood by parents (or future parents), also depends on the meaning pattern of how they see testing as a social action.

Our findings give insights into the hermeneutics of testing from the point of view of those who decide about the test and make sense of both the test and its results. That such a hermeneutics of testing from the point of view of women who take the tests is related to but distinct from those rationales provided by geneticists and gynaecologists has long been established, by the classic qualitative interview studies of Rothman (1986), and more recent studies by Gregg (1995), Rapp (1999) and Meskus (2012). In order to understand prenatal diagnosis as a cultural phenomenon it is crucial to consider the women's rationales and their perception of the new kinds of conflicts presented by their supposed genetic responsibility as well.

One of the reasons why we were interested in analysing the interviews under the lens of personal meaning patterns was that in recent bioethical literature there is an increasingly predominant view prenatal tests serve the woman

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or couple either as a tool for decision-making of (we could call this the "autonomy rationale", however demanding this may be in order to enable women to make not just choices but meaningful choices; de Jong / de Wert 2015); or as a legitimate tool to avoid the birth of children with certain conditions, i.e. an instrument in a practice of what has been called "selective reproduction" (Wilkinson 2010; Tarkian 2020). The autonomy rationale found some resonance in our meaning patterns 1 (pursuit of knowledge) and 4 (capability to decide). However, only a few of the women and couples we spoke to used a variant of the autonomy rationale to explain the meaning of their testing. The selective reproduction rationale has been given a scholarly definition by Wilkinson as choosing to have one possible child over another, since "one possible future child is, in some way, more desirable than the alternatives" (Wilkinson 2010: 2). This idiom was rarely explicitly used by women or couples to explain their action in our sample.

However, we did find occasional examples. For instance, Sivan (IL), who was pregnant at the time of the interview, explained that the meanings of raising a disabled child were in the background when deciding about the tests. She said that raising a disabled child is a very difficult and complicated thing. She would therefore prefer to terminate and try again, even at the risk of not succeeding in becoming pregnant.

> We'd rather try again. I mean, have an abortion and try again, even if it's late and even if I'm already 41 or 42. We'd rather try again than be with such a child for life. Try again, even if we might not succeed.

This can be considered a rather explicit expression of "one possible future child is, in some way, more desirable than the alternatives". Similar idioms appeared in a negative way to characterise reasonings people *feared* are becoming predominant in society. The rationale that perhaps comes closest to it is no. 5 (preventing suffering). One may see here an implicit wish to – generally speaking – choose a more desirable child. The desire to prevent suffering is concrete and can be rooted in a caring attitude. This is not the same as parents explaining their action as a choice made from the point of view of "preferences" as to which child should be born instead of another. But from a purely logical point of view, choosing to terminate a diagnosed pregnancy (or testing with the intention of terminating if abnormality is detected) is indeed the manifestation of a preference – that one future child is (for whatever reason) better than an alternative. The meaning therefore remains ambiguous.

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We understand Wilkinson's suggestion to operate on the abstract level of a discussion about the permissibility of certain kinds of reproductive behaviour, such as prenatal testing and conditional termination of the pregnancy. On formal grounds he subsumed prenatal testing within a general category of actions that are said to be practices of selective reproduction. He did so regardless of the actual intentions of women and couples who use prenatal diagnosis.[5] On the basis of our study we should be cautious about accepting such a general categorisation, since it would not do justice to the way women and couples who actually *bear* genetic responsibility in making decisions in their families described their views and decisions.[6] If bioethics should relate to the moral considerations of those who actually are making the decisions about prenatal diagnosis, i.e. the pregnant women and their partners, "personalised ethics" as Meskus (2012) has called it cannot rely on vague or formal assumptions about the "general meaning" of prenatal diagnosis as a social action, which is far distant from the actual thoughts and concerns of those making the decisions.

Further studies are needed to develop a more comprehensive and nuanced picture. One crucial limitation of our study is that we asked women after the fact. Explanations of reasons and corresponding aims can be different, depending on the time they are given. Before having a test, people decide to do the test for particular reasons, which might be remembered retrospectively and reported in terms of their actual situation *after* knowing the result of the test, after having made a decision about termination, or after the child is born.

## Contributions of authors

*Christoph Rehmann-Sutter:* Study design, analysis and interpretation, draft, revision; *Tamar Nov-Klaiman:* Field work (IL), analysis and interpretation, revision; *Yael Hashiloni-Dolev:* Study design; revision of chapter text; *Aviad Raz:* Study design, revision of chapter text; *Anika König:* Field work (GE), revision of chapter text; *Stefan Reinsch:* Field work (GE), revision of chapter text.

We thank Marina Frisman and Vera von Kopylow for thematising transcripts and for supporting us in the interview analysis. We are grateful to Monica Buckland and Jackie Leach Scully for an English revision of the manuscript.

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[5] See the critical discussion of this strategy by Rehmann-Sutter (2021, 2022).

[6] Cf. chapter 2 in this volume.

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