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9. "Something is Not Quite Right" – Two Cinematic Narratives about Decision-Making after Prenatal Diagnosis

Christoph Rehmann-Sutter, Christina Schües

The choice of the two films we discuss in this chapter – both released in 2016 – was first motivated by the striking similarity of their titles: *Week 23* and *24 Wochen* (24 weeks). Both refer to the number of weeks of pregnancy, which in both films was linked to a controversial and difficult experience because of prenatal diagnosis and the resulting prognosis. Both films show the moral complexity of the experience, including moral stress, ambivalence towards "medical knowledge", and familial tensions over the outcome and prospect of bringing a "disabled child" into the world. However, the two films differ from each other in many other important respects. *Week 23* is a documentary produced by Ohad Milstein in Israel, shot in Israel and Switzerland and addressing international viewers, while *24 Wochen* is fiction, a drama directed by Anne Zohra Berrached, produced in Germany and addressing a German-speaking audience.

The two films end in opposite ways. In her 23rd week of pregnancy Rahel, the protagonist of the Israeli film *Week 23*, who is carrying twins, learns that one of the foetuses has died in utero. She then has to decide what to do about the surviving foetus – and against the recommendation of her physicians, decides against abortion. As we learn at the end of the film, the child goes on to be born and can be seen toddling around. In the other film, the number 24 refers to the timepoint of a rather tragic late abortion of a foetus with Down syndrome and a severe heart defect. The unborn foetus lives for 24 weeks, and the film ends with an induced stillbirth. Wanting to break a taboo, the protagonist Astrid is going public with her decision to abort.

If we look below the surface and the storyline of the films, any comparison between these two narratives is not straightforward. They do not show

similar situations of prenatal diagnosis, or illustrate how it is understood and handled differently in Israel and Germany. Both films intend to raise questions about the medicalisation of pregnancy and the roles of decision-makers. However, the Israeli film is organised around a biographical narrative of an event that actually happened in the film director's own family. Rachel is his partner; the child is their real child, and the story contains the rather unlikely and unforeseeable plots and twists that often characterise real-life stories. Although a constructed narrative, the other film is a story that could perhaps happen similarly to many couples. It aims to show the moral complexity of the practice of prenatal diagnosis as it is commonly experienced in Germany, and contains many realistic elements, even to the point of including real physicians and real psychologists who play themselves (Berrached 2016). The entertaining yet improbable element of the fictional film is that the character Astrid is a well-known comedian who publicly announces her pregnancy and subsequently her decision to terminate it: all of which is a narrative tool. As a person in public life, Astrid legitimises the voyeuristic gaze of the viewer who peers into the intimate relational life of this family.

Two experiences of pregnancy and familial relationships

The plot of both films is structured by the embodied temporalities of a pregnancy, the ambivalent intuitions of the individuals, and the complex consequences for familial and social relationships.

The story of *Week 23* starts with intimate images showing the love between Rahel and Ohad. It then leads us through expansive fields of hope and anticipation in the first months of pregnancy. The physicians have discovered that Rahel is pregnant with identical twins. There are actually two "little peanuts", as Rahel calls them, writing in her diary. "I didn't know where it would lead, and then we found out we had identical twins," says Ohad. "I come from a background of art as well as film, and the idea of identical twins sounded like a good concept for making art" (Ahituv 2016). However, soon afterwards, in week 23, a shock diagnosis changes everything: one of the twins has died in utero. Physicians tell the couple that the other twin carries a high risk of being severely disabled as a result of being together with the dead foetus. Doctors say that in the rare cases when the second foetus does not die immediately, it is almost certain to be born with severe brain damage and other disabilities. They are unanimous in recommending that the couple should terminate the pregnancy, because the risk

of allowing the child to be born is too high. This places the couple in a critical dilemma. Rahel resists the physician's recommendation; her feelings are very clear. The journey that started with such hope turns into an emotional roller-coaster with no rescue in sight.

Still from Week 23 (2016) שבוע. © Ohad Milstein

Should they end the pregnancy by aborting the surviving foetus? Beyond her maternal instincts and her faith, she has – or so it seems to her, and within this social context – no rational argument for refusing an abortion. In the background of the two families there is however a conflict between different views on the morality of terminating the pregnancy. The families are rooted in two different cultural contexts in two different countries. Rahel's parents live in the German-speaking part of Switzerland, where she grew up in a protected environment, imbued with religion. Her father is a bishop. In their view, all life should be cherished: it comes from God and therefore has a right to be. We should not interfere in divine plans. Rahel's parents believe that even a child with disabilities is a child of God and should have a chance to live. They are very concerned about the pressure Rahel feels as a result of the medical counselling that she has received. Ohad's mother, on the other hand, lives in Israel, and cannot understand Rahel's reluctance to terminate in this situation. Her view

is that if Rahel waits too long, it will be too late. It is self-evident that she should abort, since the child would be disabled for its whole life, and would suffer. This is not a question for her. In her earlier life, as she explains in the film, she has had abortions herself, has lived through the pain and probably also the moral quandaries accompanying them. Her own subjective strategy of normalisation is not to worry too much about abortions. The film shows the visits of Rahel's parents to Israel, and of Ohad's mother to Switzerland. The parents respectfully explain their ideas and thoughts to each other. Caught between different sides, Rahel is torn. She knows that Ohad wants a child with whom he can go swimming and diving, and that by keeping a child with disability she is likely to destroy this dream and burden the family. At the same time, she is acutely aware of her parents' position. In the end, it seems that she is not so much evaluating positions or the value of life, but rather has the strong intuition that her "little peanut" is actually fine. But does such intuition count?

The turning point comes when both Rahel and Ohad start to resist the power of measurements, tests and the physicians, and define the terms of the pregnancy for themselves. They resist medicalisation and take back control over their situation. The medical system is overwhelmingly powerful, and therefore resistance is very difficult, until Ohad discovers a significant mistake. Repeatedly scrutinising the medical papers they have received from the physicians, he checks the calculations. He discovers inconsistencies that can be explained only if numbers have been swapped. This discovery proves to Ohad and Rahel that the medical system is not perfect, or at least not as perfect as their self-confident physicians believed it to be. It promises to perfect procreation by identifying imperfection before birth, but the system itself is not perfect. Humans and human-made practices, including the work of physicians, are prone to fallibility and error.

In this situation, Ohad's mother too changed her mind. She concedes that it is now too late for an abortion. Rahel brings the child to term. The story ends in relief: a healthy baby is born.

24 Wochen is about Astrid's second pregnancy (see Absalon 2020; Institut für Kino und Filmkultur, no date). Astrid is a successful professional comedian, a person in public life. In sketches in front of large audiences, she laughs about her big belly. She is a bright, spirited person, and so is the atmosphere of the film. This does not change after a test reveals that the baby will be a boy – and he will have Down syndrome. She immediately obtains the information that there can be very mild forms of Down syndrome, and also that a late abortion is legally possible.

Sometime later in the pregnancy, and still in a state of uncertainty, Astrid and her partner Markus, together with their daughter Nele, go to a concert where the performers are young people with Down syndrome. The soft chant of the choir is contrasted with a hard, loud beat in a disco where Astrid goes the following night. Astrid and Markus decide to have their child, and also to announce it to everybody: "We want it!" ("*Wir wollen es!*") The response from family members and friends is mostly embarrassed silence. But Astrid's mother, Nele's grandmother, offers to help the young family in this difficult time, and moves into Markus and Astrid's house. But the situation is tense; the grandmother is too intrusive, and she later moves out again. Everybody around the couple seems to have an opinion. But then a second examination shows that the child will be born with a serious heart defect (two holes, no septum, one shared heart valve) that will require immediate surgery after birth and major open-heart surgery later on when the ventricles are large enough. This throws the world of the still-resilient parents out of equilibrium. During a visit to a neonatology ward, Astrid sees tiny premature babies in incubators and wonders whether it might be better for her child not to be. Two mothers recognise the famous comedian Astrid, whom they had heard on radio saying she wanted to keep her baby despite the disability, and praise her for this. But Astrid, who now knows about the heart defect and the future surgeries, is no longer sure. Her determination to keep the baby is dwindling and she decides to have a late abortion. In an emotional scene on the balcony, she confirms her decision by smoking a cigarette, something she had avoided during her pregnancy in order to protect the foetus. Then she screams out her emotion.

A midwife prepares her for the operation by graphically describing all the important details (injection of potassium chloride into the heart). It will be an ordeal for her. In the expectation of losing her child, she knows that it will be difficult to say goodbye to it. In a carefully worded dialogue Astrid asks the midwife what she would have decided in her situation. The midwife answers: "You can only make such a decision if you have to. No one can take it away from you, and no one is allowed to judge it."[1] Astrid says: "I would have liked to have made a different decision. – But I couldn't, I just can't. Maybe because I'm not strong enough, or too scared."[2] She hopes that her decision is the right one –

1 "So eine Entscheidung, die kann man nur treffen, wenn man sie treffen muss. Das kann einem keiner abnehmen und da darf auch keiner drüber urteilen."

2 "Ich hätte mich so gern anders entschieden. – Aber es ging, es geht einfach nicht. Vielleicht weil ich nicht stark genug bin, oder zu viel Angst hab."

for the child and for the family. The film ends with a second broadcast radio interview, and Astrid saying: "I don't know if it was right or wrong. I aborted my child in the seventh month."[3]

One of the most striking scenes in *24 Wochen* is the moment when Markus realises that Astrid already has decided – against their previous agreement – to end the pregnancy. "Is it your decision or ours?" he asks. Astrid replies: "It's mine."[4] That is the only moment in the whole film where Markus loses his temper, smashing objects from a bookshelf. He feels excluded from what he had believed to be a family project. For Astrid, at the end of the day her pregnancy is hers alone. – This resonates with the end of the film, where the uniqueness of a woman's decision is emphasised. The midwife's words ("You can only make such a decision if you have to. No one can take it away from you, and no one is allowed to judge it.") echoes a societal attitude towards "medically" motivated abortions and to prenatal diagnosis in general: it is the woman's sole responsibility. She is in a highly personal conflict and resolves this conflict through the means of prenatal diagnosis and possible termination. The respect granted to the woman, the recognition of her right to autonomy, has a flipside: she is on her own, and others refuse to share responsibility. It is her decision and she has only herself to blame. Nobody else is allowed to judge it, not even her partner or other family members.

In contrast, the family in *Week 23* is highly judgemental. Through their Christian faith, Rahel's Swiss parents know the right thing to do. Terminating a pregnancy because the child is expected to have a disability is not, and never can be, a justified option for them. Ohad's mother, on the other hand, is very clear about her belief that under these circumstances, the pregnancy should be terminated. Her later agreement with the decision to keep the child – because she also thinks that it is now too late – is important for the couple. Harmony in the family is re-established. The ordeal that Rahel goes through is compassionately shared by Ohad, even though he follows his mother's opinion, at least at first. But soon he ardently contributes to the process of decision-making. He is the one who checks and rechecks the physicians' measurement protocols and discovers the mistake that stirs distrust in the medical prognosis.

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3 "Ich weiss nicht, ob es richtig oder falsch war. Ich habe im siebten Monat mein Kind abgetrieben."

4 "Es ist deine oder unsere Entscheidung?" – "Es ist meine. "

Still from 24 Wochen. © Friede Clausz / zero one film 2016.

While the morality of decision-making in *24 Wochen* tends to rest on the woman's shoulders alone, but is shared within the family in *Week 23*, it is the German family that is presented as open and blatantly scrutinised in the public eye. Astrid is a public figure, tells her audiences about her pregnancy, gives radio interviews about her decision, and never claims to be right or justified. The story of *Week 23* stays within the space of the family, and of the future parents' relationship. The family – both Swiss and Israeli – remains existentially important for the lives of Rachel and Ohad. Of course this family is also related to the two different socio-cultural contexts, but the feature film keeps it implicit, whereas in the documentary *24 Wochen* this context is made excessively overt. The comedy show is a family enterprise, and so the family is an enterprise, and its moral intimacy is presented to the public. Yet this German family seems less integral to the overall process of how to decide.

Interrogating prenatal sociality

The two films could not provide a greater contrast in how they raise questions about anticipated familial relationships with the unborn. *24 Wochen* is an exemplary story of a model family, with a woman who takes a solitary decision that should not be judged by anybody; *Week 23* is an intimate story of a unique set of events, which does not in any way claim to be representative other than being real and authentic. But questions of fundamental human significance are present in both films.

Prenatal diagnosis is an advance attempt to get to know the child who is to be born. In this attempt to become capable of making a decision about continuing the pregnancy, the unforeseeable reappears. However medically informed (or as in Rahel and Ohad's case *mis*informed), the diagnosis is still only a guess at the chances of the surviving foetus. And it is not foreseeable how heart surgery will cause a child to suffer; the maternal compassion that leads to her decision not to inflict this suffering on her child by avoiding its live birth is not a reliable indicator of actual child suffering. The deal made between parents and fate under the promise of knowledge includes making hard decisions in conditions of uncertainty. Milstein's film *Week 23* does not simply investigate a difficult process of decision making but is, as the film-maker says in an interview, even more strongly about a disconnect between "parents' gut feelings and female intuition, on the one hand, and medical procedures that don't leave room for this. Moreover, Israeli society is wary of outliers. If you have an unborn child who may not be 100 per cent okay and you want to have it anyway, that's considered off the charts. Being weak and imperfect is shameful in Israel" (Ahituv 2016). Thus the film's themes are manifold: the disconnect between personal body experience and the medical apparatus, on the one hand, and on the other a society that tends to support selecting out a foetus with genetic aberrations or possible severe health problems. Within this context, a self-determined decision to keep a child with the prospect of disability goes virtually unsupported by family or society. This conflict is presented through the different attitudes of the family members. It is interesting and somewhat touching to see that Ohad's mother, who strongly supported an early abortion, relents in a practical but not unsupportive manner when she realises that the pregnancy will continue. "You should pursue the pregnancy, it's too late for an abortion."

The Israeli film, with its background of liberal policies towards prenatal diagnosis and termination if a condition has been detected in the foetus, focuses

on the renunciation of a medically recommended termination; while the German film, with its background of restrictive policies towards prenatal diagnosis and termination if a condition has been detected in the foetus, highlights the pregnant woman's burdened – but in the end also confident – choice. The two films take no sides, nor can they be placed into categories of pro-choice or pro-life films about abortion (Köhne 2018).

Neither *Week 23* nor *24 Wochen* is a sober documentary about typical problems in pregnancy; both films demonstrate how extreme situations and difficult questions are embedded in familial and social relationships. The films show how a situation provoked by prenatal diagnosis may bring out special characteristics of people, shake up relationships, and insidiously influence our view of the world. The emotional shake-up is intensified by the familial and social context. In both films the pregnant woman is faced with a range of opinions about what to do. In *24 Wochen* the focus is strongly on how the couple makes their decision. Even though people in their close circle have opposing or supporting positions, the film rests on the couple's relationship, its conflicts and strengths. The observer in the film follows Astrid and Markus on their path of dealing with medical information, and having sudden insights into the opinions and attitudes of family members and friends towards disability. These are insights and expressed opinions we have not previously asked for, and which are mostly seen as taboo: for example, the outrage of the nanny of the existing daughter Nele, who suddenly quits her job because she finds the prospect of caring for a child with Down syndrome revolting. In the course of the film, the viewer learns quite a bit about the apparatus of medicine, the upsides and downsides of prenatal testing, and the possibilities of neonatological intensive care. Even though genetic disability can be tested for and may no longer be regarded as pure fate, it cannot be shut out of society or be isolated from family discussions. The film is therefore not just about late abortion, but even more about the conflicts between questions of prenatal genetic testing, what to hope for in future life, and how to count on family relationships. The issue of what to hope for in future life and in the family becomes apparent in both films. Yet how the individual opinions, intuitions and hopes are generated is rather different. In the film *Week 23*, it seems that the family is existentially involved in spite of all their differences, whereas in *24 Wochen* the family fundamentally provides the context. Both films depict the way that the pregnant women are caught between their personal intuition and the medical system. Whatever is decided in the end, the medical information that there is "something wrong" with the foetus is never innocuous and always concerns more than one being.

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