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Moral Adherers: Pregnant Women Undergoing Routine Prenatal Screening in Denmark

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> *Ida*: I'm looking SO much forward to it [becoming a mother again]. It's insane how much I look forward to it. Very, very, very, very, very much. And I'm also really, really ready to become a mother again. I really want it to happen now, it's the perfect timing. Lots of things are perfect. I will go on maternity leave in February, which fits perfectly with Sonja's birthday coming up, I can't wait.
> *Laura*: But still, you've decided to opt for the nuchal translucency scan?
> *Ida*: Yes, and I also know that if we learn the baby has Down's syndrome, we would opt for an abortion. I'm one hundred percent sure of that.

In recent years, feminist medical anthropologists engaged in the study of human reproduction, particularly the medicalization of pregnancy and birth, have shifted attention away from earlier approaches that linked the control of women's bodies to male-dominated structures of medicalization and biopower (Oakley 1984; Petchesky 1987; Jordan and Davis-Floyd

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1993), toward documenting how women themselves actively engage with high-tech reproductive medicine in complex, culturally contingent and contradictory ways (Rapp 2000; Lock and Kaufert 1998). Within this tradition, wanted and unwanted pregnancies have often been explored as two disparate research fields, the first focusing particularly on the experience of assisted reproduction and miscarriage (Tjørnhøj-Thomsen 1999; Franklin 1992; Inhorn 2006; Layne 2003) and the latter on social, economic and gendered structures that lead to abortion and infanticide (Ginsburg 1998; Scheper-Hughes 1993). However, as prenatal screening and diagnostic technologies become routine around the globe, a wished-for-child may become unwanted in the process of the pregnancy, challenging in new and compelling ways the notion of 'intended pregnancy'. As argued by sociologist Barbara Katz Rothman, prenatal testing has rendered pregnancies 'tentative', as women hesitate to attach themselves to a fetus they might not want to keep (Rothman 1986). The line between a wanted and an unwanted child has become blurred amid this change, as the words of Ida, a mother expecting her second child, in this chapter's epigraph exemplify.

In her book about the social impact of amniocentesis (2000), medical anthropologist Rayna Rapp demonstrates the difficult decision-making process that women who are confronted with prenatal diagnosis and selective abortion face. Writing at a time when amniocentesis—an invasive diagnostic technology used to detect chromosomal and genetic anomalies in fetuses—was at the cutting edge of becoming normalized, Rapp argues that

> the construction and routinization of this technology is turning the women to whom it is offered into moral pioneers: Situated on a research frontier of expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community (Rapp 2000: 3).

However, while the notion of 'moral pioneering' captures women's responses to the burdens and benefits created by amniocentesis (ibid: 126), the then new and revolutionary reproductive technologies are today deeply routinized in many parts of the industrialized West and, in some cases, have been replaced by newer non-invasive screening technologies, presented as ‘safe’ means by which women can gain more ‘certainty’ about the health of their fetuses (National Board of Health 2004b).

Denmark constitutes a unique case study for such nation-wide normalization. In Denmark, prenatal screening has been offered to all pregnant women, on a routine basis *and* free of charge, since the introduction of a new screening policy in 2004. Since then, Denmark has topped the statistics as the country with one of the highest uptake rates of both prenatal screening and selective abortion in Europe and North America. It is estimated that the overall current uptake of routine prenatal testing is at least 90% nationally and 98% in the Copenhagen area (Ekelund et al. 2008; Schwennesen 2010: 13). Since the implementation of the new regime of prenatal testing, the number of babies born with Down’s syndrome has dropped by more than 50%, giving Denmark a reputation among its Nordic neighbors as a ‘sorting society’ (Schwennesen and Koch 2009: 70; URL 1 n.d.). How has it come to be that so many pregnant women accept prenatal screening? And why has it become common to reject a fetus with Down’s syndrome? Does the notion of ‘moral pioneering’ capture present-day pregnancy experiences within a Danish context?

The aim of this chapter is to explore how selective reproductive technologies (SRTs), understood here as technologies used to *prevent* the birth of certain kinds of children, have become routinized among pregnant women in Denmark. Starting from Rapp’s work, I will argue that the routinization of prenatal screening has created a situation in which pregnant women have become what I term ‘moral adherers’ of SRTs. Furthermore, it is my argument that the highly institutionalized availability of pregnancy ‘opt-outs’ shapes women’s moral reasoning about termination, compelling them to see selective abortion as an acceptable choice and delegating the moral responsibility for fetal selection to the antenatal healthcare system rather than to pregnant women as individuals. In this moral optic, rather than an individual moral burden, selective reproduction becomes a collective responsibility.

In a study of Danish pregnant smokers, anthropologist Mette Bech Risør (2002, 2003) defines ‘reasoning’ as connected to everyday practice, life experiences and moral deliberations that involve weighing good and bad in an individually configured rather than universal way (Risør 2003: 73). Inspired by Risør, I take reasoning as a concept that captures both the ‘habituated’ and the ‘active’ nature of moral deliberations and actions that are connected to the regime of prenatal testing and the historically shifting and culturally constructed moral landscape of selective reproduction in Denmark. The analysis thus takes as its starting point an understanding of women as agents in shaping their reproductive lives, but it also acknowledges that reproductive decisions, aspirations, fears and actions are enmeshed in and conditioned by social and cultural structures of a society, such as reproductive politics. As Rapp puts it, SRTs have ‘enormous discursive and practical powers to define what it is to be normatively human’ (Rapp 2000: 14). In other words, this chapter examines not only how women reason about prenatal screening but also how the use of these technologies influence the ways in which the pregnant women negotiate boundaries between fetal life and death, and between unwanted and wanted ‘kinds of living’ (Wahlberg 2009). The data on which this chapter is based stem mainly from interviews with 12 women and observations of 28 routine prenatal screening sessions at a hospital-based ultrasound clinic in Copenhagen. These research activities took place during eight months of 2011.

Prenatal Screening and Selective Abortion in a Danish Context

Within anthropology, the impact of new SRTs on the experience of pregnancy is well documented (Rothman 1986; Rapp 2000; Press and Browner 1997; Taylor 1998; Mitchell and Georges 1997; Saetnan et al. 2000; Gammeltoft 2014; Gammeltoft and Wahlberg 2014). However, few ethnographers have explored the social impact of routine prenatal screening in a Danish context.[1] This is rather surprising as Denmark stands out as one of the first countries in the world to roll out routine prenatal screening at a national level through a publicly financed health system (Ekelund et al. 2008; Schwennesen 2010: 116), and in comparison with other European countries with similar prenatal testing offers, Denmark is the country where most pregnant women undergo prenatal screening. For instance, England has a system equivalent to the Danish, however in 2011 only 68% of women accepted the offer (Morris and

Springett 2013), and in the Netherlands, where a national screening program was implemented in 2007, women below the age of 36 have to pay 150 Euros to get tested (Lichtenbelt et al. 2013), but despite the national policy, the overall uptake remains low (Engels et al. 2014).

In Denmark, routine prenatal screening was implemented, backed by the government, when the Danish Board of Health issued new guidelines for prenatal screening and diagnosis in 2004. The guidelines recommended that non-invasive prenatal screening, consisting of a first-trimester prenatal risk assessment (FTPRA) for chromosomal anomalies, such as Down's syndrome,[2] and a second-trimester ultrasound scan for congenital malformations, should be offered to all pregnant women, regardless of age and risk profile (Danish Board of Health 2004a). In the guidelines, the board formulated a new criterion of success for the public health program of prenatal screening: 'informed choice'. This was formulated as a solution to what was considered a problematic past of the previous program, where only women aged 35 or older, or women who had a known increased risk of having a child with chromosomal diseases, were automatically given access to prenatal screening and testing. The Danish Board of Health argued that such a regime could be characterized as belonging to a 'paradigm of prevention' since access to services was organized around a pre-defined high-risk group. Instead, prenatal screening should be offered to all pregnant women, based on an ethics of individual choice, volition and self-determination.[3] Furthermore, in order to prevent the new policy from being conflated with state-mandated eugenics, the Board accentuated that the offer should *not* be organized as a nationwide screening program that aimed to include all pregnant women (Danish Board of Health 2004a: 7). Rather, access to screening and testing services should only be given on the request of pregnant women themselves. Therefore, the national guidelines stipulate, women should not be directly invited to participate but are to be asked by their general practitioner (GP) if they want information about the services offered. If so, they should be provided with non-directive information, on the basis of which they then can decide whether or not to undergo prenatal screening. Thus, through this idiom of self-determination and free choice, the Danish Board of Health explicitly emphasized that the objective of the new policy was to enhance the reproductive autonomy of prospective parents. The Danish Parliament issued the following statement:

> The aim of prenatal testing is—within the juridical framework of Danish law—to assist a pregnant woman, if she wants such assistance, to make her capable of making her own decisions. Neutral and adequate information is a necessary condition to this end […]. The aim of prenatal testing is not to prevent the birth of children with hereditary disease or handicap (Parliamentary Decision on Prenatal Diagnosis, May 15, 2003).

However, in spite of this anti-eugenic rhetoric, 'therapeutic' abortion is inextricably tied to prenatal screening, as it is the only biomedical solution to the conditions that can be prenatally diagnosed. Furthermore, since abortion is legal only until week 12 of pregnancy, second-trimester abortions must be approved by one of the country's three 'abortion commissions' [Abortsamråd] whose members are legal, medical and psychiatric professionals. Thus, when prospective parents learn that their fetus has chromosome abnormalities, they are not alone in deciding whether or not this condition warrants an abortion.

According to the Danish Central Cytogenetic Registry (DCCR), 99% of prospective parents who receive a positive diagnosis for Down's syndrome choose to terminate. In 2011, a total of 385[4] late-term abortions were performed due to chromosomal anomalies, including trisomy 21, 18, 13, sex-chromosome disorders and other rare chromosomal diseases; 147 cases of Down's syndrome were diagnosed prenatally; and 29 babies with Down's syndrome were born. Twenty-four of the 29 babies were diagnosed postnatally, due to either no prenatal screening or non-detection in spite of prenatal screening. Five were born after prenatal diagnosis, out of which two were detected after the legal limit of abortion for fetal anomaly in week 24 of pregnancy. In other words, *only three couples* actively chose to give birth to their baby knowing that it had the syndrome (DCCR 2014).[5] I find the relationship between the emphasis on informed choice in the official guidelines, on one side, and the state-sanctioned institutionalization of selective abortion, on the other, highly puzzling. This prompts me to ask how opting for an abortion seems to have become the conventional response when a fetal anomaly is found, and what role the routinization of prenatal screening and selective abortion plays in pregnant women's moral reasoning about boundaries between fetuses that are regarded as 'rejectable' and those that are not.

Moral Adherers

> We just assumed we would do it. That was just the next test we did. I don't know. It's the way it's presented; it just seemed safe to do and part of the process. And I was interested in seeing the baby, if it was on track.
> (Mille, 26, Architect, 14 weeks along in her first pregnancy)

When a woman becomes pregnant in Denmark, she normally consults her GP, who initiates the woman's pregnancy health record and refers her to a midwife. At this initial consultation, the women is informed of the possibility of undergoing routine prenatal screening (if she wants to be informed![6]) and also told that she has to book a time for the screening herself at the local hospital (Schwennesen et al. 2009: 195). In accordance with the dominant ideal of non-directive counseling that underpins clinical practice in Denmark[7] (Koch and Svendsen 2005; Schwennesen 2010), the logic behind this organizing structure is to secure that women are not coerced into accepting prenatal screening but choose 'freely' whether or not to participate. When I began studying pregnant women who had opted for prenatal screening, I was struck by how little some of them knew about the tests and the conditions that can be diagnosed prenatally, the apparent conformity with which all of them approached prenatal screening, and how rarely they, at the outset, expressed moral ambivalence about undergoing screening. Most of the women defined prenatal screening as driven by a need to see the fetus in order to be reassured that it was alive and well, or to know 'the risk of Down's syndrome' and 'other birth defects'. Generally, they did not describe undertaking prenatal screening in terms of active choosing but rather assumed it to be 'a routine act'.[8] None of the women had been given or had vigorously sought additional information about prenatal screening or the diseases and disabilities that they aimed to detect. Instead, the women radiated profound trust in the biomedical system and the medical judgment of healthcare professionals.[9]

When probed for her level of knowledge of prenatal screening, Randi, a 32-year-old academic and first-time mother, answered:

> Whatever they test for, I find important. I have so much faith in this technology, this screening, so they only screen for things that, I mean, they've only offered me this screening, because they assess it to be useful.

When Rapp began her studies of prenatal diagnosis in the 1980s, amniocentesis was seen as a window of unprecedented opportunities for prospective parents to influence the quality of their own and their children's lives. Women submitted themselves to this new technology to reap its biomedical benefits, but in doing so they had to face the risks of reproduction. Not only did they risk miscarrying due to the invasiveness of amniocentesis, but they were also forced to judge the quality of their fetus in case of 'bad' news. However, subscribing to routine prenatal screening as it is perceived in Denmark does not necessarily imply making explicit the moral quandaries of selective reproduction. Rather, many of the women in this study took prenatal screening for granted as an inherent part of the pregnancy process, hardly considering the next step in case of receiving a high-risk assessment. All of the women stated that they would take things 'as they come' if the fetus turned out to be abnormal. For some of the women, the prospect of potentially learning that their fetus could be anomalous was not even within their mind-set prior to the nuchal translucency scan.[10] For instance, Ida said the following when I met her at nine weeks pregnancy:

> I'm convinced I'm not carrying a child with Down's syndrome. I couldn't imagine that. It's quite far out of my consciousness, you know, the odds of something being wrong. Mostly we are there to have a picture [laughing].

In an anthropological study of first-trimester screening for Down's syndrome in the UK, Williams et al. (2005) argue that women 'reported having thought carefully through their own moral beliefs and values prior to screening', concluding that women enacted 'moral pioneering' in this new setting of non-invasive technology (Williams et al. 2005: 1983). However, my findings suggest that in some social settings we have passed the stage where we can speak of women who accept prenatal screening in terms of pioneering. Instead, I propose to conceptualize them as 'moral adherers'. According to the Free Dictionary, 'adhere' means to stick to like glue, to be in support of something or to carry out a plan or scheme (URL 4 n.d.). The notion of 'moral adhering' designates both an individual and collective level; women submit themselves to prenatal screening to reap its *social* benefits; getting reassurance from seeing a moving fetus on the ultrasound monitor appeal powerfully to pregnant women. But they also submit themselves to prenatal screening because they perceive fetal quality control to be the recommended reproductive path. As Mille, a first-time mother, said: 'I just did what I was told.'

When you have the offer, you take it: Collectivized Responsibility of Selection

Anthropologist Margaret Lock argues that reproductive technologies would be confined to the research laboratory without 'the desire of "consumers" to cooperate' (Lock 1998: 206). Danish women have adopted prenatal screening extensively, but as I see it, the high uptake rates are not indicators of active consumerism. Rather, they convey a habitual adherence to a screening program that is being interpreted as a technological and moral imperative, and has been conflated with and thus naturalized as standard antenatal health care (Browner and Press 1995; Press and Browner 1997: 984). 36-year-old Astrid for instance said: 'It's natural, when you have the offer, you take it.' It could be argued that although the regime of prenatal screening officially has been framed as a free offer, the fact that it is offered at all implicitly sends a message to pregnant women that prenatal information is valuable. Prenatal screening is considered beneficial *because* it is offered by 'the system'.

On a self-critical note, one could argue that because I was not present in the biomedical settings of health professional-client communication, I cannot verify the women's representation of information transfer. As such, there is the possibility that what is practiced in the Danish antenatal healthcare system is a system of directive counseling that disregards the ethos of non-directiveness. If this were the case, my arguments could be said to misrepresent a group of women who ought to be seen as victims of a paternalistic counseling system rather than adherers of a routinized prenatal screening regime.[11] However, anthropological studies[12] have demonstrated that the ways in which counseling is understood and practiced are too complex to be dichotomized into two opposing poles of directiveness versus non-directiveness. For instance, in a study of FTPRA in Denmark, Schwennesen et al. (2009) show that even though sonographers made great efforts to provide couples with non-directive counseling in the wake of a high-risk assessment, the couples had a hard time making sense of the risk figure and therefore experienced a need for more direct advice.[13] My reading of the pregnant women in my study is more in line with Koch and Svendsen (2005), who argue that the concept of non-directiveness does not capture how decisions are actually made. As they argue in the context of genetic counseling, decisions of individual counselees made within a health-promoting medical setting are directed toward disease prevention 'by appeals to familial and social responsibility. This does not mean however that non-directiveness is an illusion but rather that the governmental processes, which take place, also functions by the voluntary choice of the counsellee' (Koch and Svendsen 2005: 828). The women I met told me that prenatal screening was never presented as a choice and many of them had not considered that it was possible to turn down the offer; however, prenatal screening was also never spoken of as coerced. Thus, in my interpretation, the regime is working (so well) precisely because it is perceived to benefit prospective parents, while simultaneously allowing the many women who are placed in low-risk categories to keep the moral and emotional predicaments of selective reproduction at arm's length. In the words of first-time mother Andrea:

> Well, as long as all the tests have been negative, we haven't really been confronted with any ethical conflicts. We've kind of just gone along with it. So we haven't really discussed the pros and cons of all of this, or thought through the consequences.

Williams et al. (2005) describe how the women in their study considered the decision-making of prenatal testing and selective abortion a private process, where they themselves had to take responsibility for their choice. However, when it came to the (hypothetical) question of opting for selective abortion, the women I met mostly framed this as an opportunity *given* to them by the biomedical system, thus essentially the Danish state. In my interpretation, this might explain the certainty with which they defined selective abortion as morally justifiable. The women kept stating: ‘if there’s a way out’ and ‘if I have the choice’ when reasoning about abortion. Charlotte, a woman in her 30s expecting her second child, said: ‘I’m not willing to carry on a child’s life with Down’s syndrome if I have the possibility to opt out. I guess we would survive it, but as I have the choice not to, I would rather not.’ And Marie said: ‘I think it’s brilliant that you have the opportunity to opt out and opt for an abortion. It’s a good service actually.’

Social Imaginaries

Even though the women seemed to perceive selective abortion in terms of ‘available opt-outs’ and outsourced the moral responsibility of rejecting defected fetuses to ‘the system’, this does not mean that they did not have their private reasons for wanting to identify a fetal anomaly. In fact, when pushing the women to explain and elaborate on why they perceived prenatal screening to be reasonable, a variety of social expectations and imaginaries about living with disability arose. These social imaginaries seemed to underpin the women’s take on selective abortion as morally acceptable. What it means then is of methodological importance in the sense that these social imaginaries, in most cases, were not articulated until I began probing for more elaborate explanations. It should be noted though that few of the women phrased their outlook on disability from the onset but most expressed that my probing questions made them reflect on things that they had not considered or put into words before. Susanne, a 36-year-old social worker expecting her first child, framed her intention to abort her fetus had it been diagnosed with Down’s syndrome in terms of care for the unborn child. Susanne had not only conceived with technological aid but she also suffered from pulmonary embolism, making the pregnancy potentially life threatening for both her fetus and herself. Essentially, she had one shot at motherhood. Still, she reasoned that she would choose to abort because:

> So few are born with Down's syndrome today, so a child like that is going to have a hard time getting a social network, whereas 10 or 15 years ago, they had plenty of options […] I'm not doubting whether we as parents would love the child, but we would opt for an abortion out of concern for the social life it would have as Denmark is today. It's not a life I would want to offer. So, in reality, my choice is a consequence of the opportunity of choosing… and the choices made by all the others. So yeah, I cried when we received a good risk figure.

33-year-old Marie also stressed that Denmark is not 'geared for' children with disabilities. Unlike most of the women who had no personal experience with disability, Marie had worked several years with disabled people, having witnessed the predicaments of caring for a handicapped child:

> Society is really not geared for children like that. They are not like normal kids. You can't say the same things to them. You risk losing your child earlier. They often have heart diseases, and you have to fight a lot with the system to get support. Of course there are some who are super cute, because they really are special. But there are also the ones that are really… cumbersome. And you can't know which one you're gonna get. You can't know that with a normal child either, but still, that part, the heavy part, I'm not up for that if I can opt out.

While many of the women framed abortion as a means to prevent suffering, both individually and collectively, a few of the women mostly worried about not having the kind of mother-child relationship they wished for if having a disabled child. Randi, for example, envisioned that a disabled child would not be able to engage in *emotional reciprocity*, leaving her trapped in an eternal state of responsibility for a dependent child:

> I think, if I have a child with a physical or mental disability, I mean, depending on the condition and what kind of impairment we are talking about, but in reality I think it could be a good life for the handicapped child. I don't question that at all. But if I can prevent bringing it into the

> world, I wouldn't hesitate, mostly for my own benefit. Because I think the child is going to have a great life no matter what. So some of the horror scenarios are, you know, that the kind of dependency that I presume an infant has, continues, so that when I am 80 years old, my child is depending on me instead of the other way around. That imagery is not part of the kind of egoistic vision that I've bought in to. I mean, you get children with the anticipation that they will repay your efforts [*på forventet efterbevilling*], that you get a repayment [*afbetaling*] for your children. And if I get a disabled child, then it's not certain that I'm going to get back anything.

Thus, these social imaginaries about what living with an impaired child entails fed into the women's perception of selective abortion as a feasible solution. These imaginaries were far from embedded in real-life worlds, as few of them had personal experience with what living with disease and disability actually implies. They reasoned mostly in a 'social vacuum', to paraphrase Rapp (Rapp 2000: 131). However, they did draw on other real-life experiences when reflecting on disabilities and selective abortion. For example, Ida spoke about the hardship of caring for a normal child as the backdrop against which the decision to terminate her pregnancy seemed morally just:

> After having my daughter, I've kind of experienced my limit… for what I can cope with. I had a long birth, was diagnosed with preeclampsia during birth, and then my body just went into shock. My life was actually hanging in a thread, and it took three months before my body was normal again. And Sonja had colic, and I was not allowed to walk around much, and she just cried and cried, so it was just SO hard.

What all the women shared was the ways in which their thought processes circulated not around social and moral judgments regarding fetal life but rather around the prospective of good *quality of life* for the unborn baby and themselves as mothers. It was within the space of 'available opt-outs' and social imaginaries about a hoped-for future free of disease and disability that the women negotiated the criteria for wantedness of their potential child; a negotiation that took shape in relation to both the SRTs they were offered and the embodied and temporal process of growing more and more pregnant as the birth came closer.

Negotiating Wantedness

When I met Randi for the first time, she had recently undergone the nuchal translucency scan, receiving a low-risk assessment for chromosomal anomalies. Like most of the other women, she described the scan as marking a first milestone that enabled her pregnancy to progress. However, although she was expecting a highly wanted and planned-for child, the prospect of actually giving birth to this child was still hinging on the results of the malformation scan:

> I look forward to seeing how big it is now, and to see those two legs cycling around. But I'm also like eh, because maybe we'll find out something's wrong, right? That's also one of the reasons why I'm not already buying baby clothes and stuff, because I'm like, it might be we're not having this child, maybe we're not having this child, maybe we'll have another child. […] I want a child, but not at all costs.

Similarly, Marie said:

> Sometimes I think, I've been waiting so long for this child, so shouldn't we just have it no matter what, but I don't think I would choose that. I wouldn't have a child at all costs.

A wanted pregnancy is only wanted *as long as* everything progresses uneventfully. The women awaited a medical 'quality control' of their baby-to-be before it could become *really* wanted (Rapp 2000: 126). Some of the women were quite clear about the preconditions for wantedness, others were more wavering about where to draw the line between wanted and unwanted. Randi and her boyfriend Jakob, who had conceived with the aid of donor sperm, expressed a zero tolerance of disease and disability. They couched this in a language of egotism; they were not having the child 'for the sake of the child, but for their own sake'. The following conversation took place at the hospital, immediately after the second-trimester scan:

> *Randi*: Well, in reality, this malformation scan, and also the nuchal translucency scan, it's like an instrumental milestone of, you know like,

> precluding certain risk factors, and when we're beyond those, yeah, how can I put it, it's like it does something to my process in the sense that it continues. Because if she [the sonographer] had looked at it and said 'uh, clubfoot or cleft lip and palate' and stuff like that, then we weren't gonna have this child
> *Laura*: So if you had learned the baby had cleft lip and palate, then what?
> *Jakob*: Then it would probably have ended in an abortion
> *Laura*: Ok?
> *Randi*: Yeah, because, in reality, if a health professional tells me, it has disease X or condition X, and if they assessed that this is some kind of disease.
> *Jakob*: But a clubfoot is not really…
> *Randi*: No, but it is a condition, right? It's a symptom or syndrome, I don't know what they call it. But I'm not having that child. I want a healthy child.
> *Laura*: But is cleft lip and palate a disease?
> *Jakob*: It's a really huge problem
> *Laura*: Why?
> *Jakob*: Eh, because it's a regular handicap, it's a regular speech disorder you get out of it, as far as I remember.
> *Laura*: Because you'll lisp or what?
> *Jakob*: I'm not sure, it's not certain they can operate it, and children get teased and… it's not just cosmetic.
> *Randi*: No, it's not just cosmetic, things haven't grown properly together. But again, I'm still thinking that if someone told me that something is wrong with my child, and I can do something about it, like as in not having this child, but having another, then I'm going to do that.

This extended quote not only reveals how I as an ethnographer sometimes had difficulties maintaining a neutral stance, it also demonstrates how this particular couple came to agree upon the conditions for the continued wantedness of their unborn child, defined vaguely as 'healthy'. But the excerpt also illustrates another common feature in the women's reasoning about selective abortion: none of the women expressed concern about whether they would get permission to obtain a second-trimester abortion, neither in apparently 'severe' nor 'mild' cases. Randi and Jakob assumed that *they* held the mandate for deciding what kind of a life they wanted to bring into the world. However, as already mentioned, second-trimester abortions must be approved by one of the commissions of legal, medical and psychiatric professionals. While abortion for Down's syndrome is always approved, conditions such as clubfoot and cleft lip and palate are subject to interpretation and handled differently depending on the committee[14] (Politiken 2012). None of the women (and partners) whom I interviewed spoke about these commissions, and only one[15] spoke about the emotional turmoil of possibly having to give birth to the aborted fetus. Whether the lack of reflection over second-trimester abortion procedures is due to a general gap of knowledge or rather reflects women's unease with reasoning about abortion on a more practical level is hard to tell. However, in my interpretation, it does reflect the (perceived) orthodoxy regarding selective abortion in Danish society. It seems to be the general perception that an abortion is granted, if wanted, which—by all means—is not far from the truth.

Negotiating Fetal Living

Ever since Marcel Mauss' pioneering book, *A Category of the Human Mind: The Notion of Person, the Notion of Self* (1985 [1938]), anthropologists have been interested in the social dimensions of personhood. Generally, anthropologists agree that personhood is a social status granted—in varying degrees—to members of society (Morgan and Conklin 1996: 662). For instance, a study conducted in North America has shown how fetuses are ascribed personhood and agency as a result of the visualization of the unborn baby through ultrasound scanning (Mitchell 2001), while studies of prenatal diagnosis and disability have shown how fetal and neonate personhood is called into question[16] (Landsman 1998; Rapp 2000). I knew after a dozen interviews that the women saw screening as an opportunity to prevent disease and disability which they all depicted as threatening the quality of their lives. But I wondered if these imaginaries, and the premises on which the women reasoned about wantedness, were stable through the course of pregnancy? I asked the women to reflect on whether or not the choice of abortion had an expiration date, and if so, when? I met Charlotte when she was nine weeks pregnant. She explained:

> You could say that I am choosing in relation to the prerequisites I want to offer my child *before* life has begun. But when life has begun [after birth], then it's as it is. Then we would just have to take it as it is.

Marie, ten weeks along, put it in similar terms:

> Something could go wrong during birth, or after, you can't guarantee that won't happen. And you could say that if the baby has come out, then you have to be in it. Then you can't return it. You can't do that. But that's the possibility you have now, you could say.

When Charlotte and Marie were in the beginning of their pregnancies, *biological* birth marked a clear dividing line between 'rejectable' and 'non-rejectable' life. The majority of the women shared this understanding. But the women who I had the opportunity to follow through their entire pregnancy loosened the dividing line between pre- and post-birth as the symbolic marker of non-rejectable fetuses. Marie continued to talk of abortion as a possibility; both prior to and after the malformation scan in week 20. However, when we met for the third time when she had entered week 25 of pregnancy, she spoke of abortion in a different way, though not precluding rejecting the child-to-be entirely either:

> *Marie*: In the beginning everything was quite unreal. I was like, let's see what happens. But now as the pregnancy has progressed I'm also growing closer to the child inside of me.
> *Laura*: So I would like to return to the question about your thoughts on abortion?
> *Marie*: Yeah, I don't know really. Of course it would be more and more difficult, because you are getting closer to your child, but still I'm also thinking a lot about what it would do to your child's life and your own life, and I'm also thinking that if I were to give birth to the baby today, well, how much should you help this child to live?
> *Laura*: You mean, if you went into preterm labor?

> *Marie*: Yes. Because I had a lot of Braxton Hicks contractions, and they [the hospital] said I might be in labor, and so I thought to myself that I might choose to opt-out [on the neonate] then. I don't know if I would, but I mean, they are not completed in any sense at this stage, and I've worked with a lot of premature kids, who had lots of problems.

Though I met several of the women at different stages of their pregnancies, the status of the growing child-to-be continued to be open to negotiation. Even when faced with the risk of preterm birth, Marie reasoned, to my surprise, that her potential child possibly could be 'left to die' as she envisioned potential long-term effects of prematurity as causing suffering. While I was not surprised that women spoke about growing more aware of the unborn child as the pregnancy progressed, I was struck by learning that the negotiation of fetal living did not circulate around questions of their personal moral feelings regarding second-trimester abortion. The negotiation happened mainly in response to the (perceived) *availability* of opt-outs. However, even though Marie envisioned having the choice to leave a premature neonate to die, some of the women closed the 'window of opt-outs' earlier. Meeting Cecilie just days before her child was due underscored the temporality of selective abortion in a quite compelling way. Like the other women, Cecilie was sure that she would opt for an abortion in case her unborn child had had Down's syndrome, but the upcoming birth of her son-to-be brought every prior consideration into a new light:

> I wouldn't care if he were a *Mongol* [child with Down's syndrome] now. With him. I would love him no less. I would have eternal love for him […] Just the thought of not having him now, it's unbearable.[17]

Or as expressed by Andrea when she was in the third trimester of her pregnancy:

> It has changed in the direction of 'now we just have to figure things out', whereas there was more selection in the beginning. And it's true that the damages can be even more severe later without ending in an abortion. So

> it's still important to me to have a healthy child, but now I'm so far in the pregnancy that an abortion is no longer an option.

Conclusion: Structural Directiveness in Danish Antenatal Care

In this chapter, I have provided an ethnographic exploration of the ways in which 12 women reasoned about, gave meaning to and acted within the regime of non-invasive routine prenatal screening as it is practiced in contemporary Denmark. I have argued that the women in this study did not make active, informed decisions to opt for prenatal screening, and did not perceive screening to be riddled with moral conflict. Rather, all of the women took the screening for granted as part of standard antenatal health care and, as such, adhered to it—uncritically. Based on this, I argue that even though Rapp's concept of women as moral pioneers has its pertinence in the context of prenatal diagnosis, it is not apt for women undertaking routine prenatal screening in a Danish context today. It has not been my aim to criticize in any normative sense the current offer of routine prenatal screening. Rather, I have set out to problematize, by way of inquiring about pregnant women's experiences and thought processes, some aspects of the prenatal screening program by pointing to some inconsistencies between *principle* and *practice*. The current prenatal screening program became normalized under the banner of informed choice and self-determination. By arguing that prenatal screening aimed only to enhance prospective couple's reproductive choices and autonomy, not to prevent disabled infants from being born, the Danish state has been able to distance itself from a problematic eugenic past—seemingly with great success. However, though the women reasoned about abortion in relation to their individual everyday lives, social relations and imaginaries about family life, thinking about terminating a pregnancy for medical reasons would simply not make sense if selective abortion was not available. The mere fact that the Danish government has sanctioned and institutionalized prenatal screening and selective abortion indirectly encourages pregnant women to regard their child-to-be as a fluid, negotiable and contested entity that is potentially 'rejectable'.

Notes

1. The studies by Schwennesen (2010), Schwennesen et al. (2008, 2009) and Niklasson (2014) are exceptions.
2. FTPRA, consisting of a blood test from the mother, and a nuchal translucency screening of the fetus detect Down's syndrome (trisomy 21), Edward's syndrome (trisomy 18) and Patau's syndrome (trisomy 13); however, Down's syndrome has become the prototypical image of 'serious disease' connected to prenatal screening and diagnosis (Meskus 2009). However, this is perhaps no surprise since the official information pamphlet on prenatal screening, routinely handed out to pregnant women at the GPs' office, only mentions detection of Down's syndrome and 'serious malformations' as its aim (Danish Board of Health 2004b: 3). During the 21 nuchal translucency scans that I observed during fieldwork, all the sonographers only gave information about Down's syndrome. It took several months before I realized that screening also concerns other chromosome aberrations.
3. From a medical point of view, the main advantages of implementing FTPRA into Danish antenatal care was argued to be its higher predictive value compared to the previous regime and an expected reduction of the number of invasive tests carried out and the number of miscarriages caused by invasive testing, which is about 1% (Schwennesen 2010: 13).
4. According to my research, there are great inconsistencies between the statistical data provided by the Danish Board of Health and DCCR, meaning that a precise overview of the total number of abortions due to fetal aberrations is currently non-existing. In the statistical data, which I have collected from the Danish Board of Health, 660 second-trimester abortions were performed in 2011, out of which 290 were performed on social indication and 339 due to fetal aberrations. This contradicts the 385 abortions performed *singlehandedly* on the grounds of chromosomal anomalies, as listed by DCCR. Second, there are 31 abortions that have been performed but with reason unknown (Danish Board of Health, personal communication). Consequently, it is unknown precisely how many abortions are performed due to congenital malformations, such as

neural tube defects and structural malformations. Taking into account how routinized the regime of selective reproduction is in Denmark, I find this lack of follow-up knowledge quite disturbing.

5. One can only speculate, but taking the statistical evidence into consideration, it is not unlikely that the birth rate of children with Down's syndrome will drop even further, when non-invasive prenatal diagnostic technologies are made accessible in the near future. Non-invasive prenatal diagnosis (NIPD) is an early blood test that yields chromosome information on 'conditions' like sex and trisomies within a few weeks of the establishment of a pregnancy. As Rapp notes, this type of test is high likely to make trait selection via early medical abortion easier and more plausible (Rapp 2011: 16). See also Etisk råd [Ethical Council] (2009).
6. As already mentioned, prenatal screening is to be initiated on the basis of 'informed choice', where the women are asked if they want information about the services offered. However, as the initial quotes demonstrate, the impression I got from my informants was that their doctors mostly took for granted that they wanted to take part. No one asked the women if they wanted information, and only few women expressed that their doctor had explicitly verbalized it as an offer they could choose to accept or refuse, as they recalled it.
7. As Schwennesen (2010) describes, non-directiveness is defined by several bioethicists as the ethical gold standard and as a presumption for the realization of a truly autonomous choice in prenatal counseling (Schwennesen 2010: 15) Non-directiveness, defined as providing complete unbiased information and restraining from giving practical advice (Rehmann-Sutter 2009: 235), is thus seen as a tool to avert a potential powerful and authoritarian paternalistic doctor from determining what is right and wrong and dictating subsequent decisions. Questions have been raised in the Danish debate whether or not the policy of autonomous decisions in prenatal testing works as intended and whether pregnant women and their partners are well informed (Dahl et al. 2006a, b; Bangsgaard and Tabor 2007).
8. See also Schwennesen (2010) for similar findings.
9. This is similar to the Finnish experience as described by Meskus (2009). Schwennesen et al. (2008) also experienced that Danish couples reinstalled profound authority in the healthcare professionals when interpreting risk calculations in the context of FTPRA.

10. This point gets support from the study conducted by Schwennesen (2010) on Danish pregnant women's experience with decision-making in the aftermath of a high-risk assessment of Down's syndrome. Many women reported feeling 'unprepared to deal with this knowledge' (Schwennesen et al. 2009: 200).
11. Let me emphasize that I aim to problematize some aspects of the ways in which routine prenatal screening works, but in doing this I do not intend my criticism to reflect negatively on the women who have undergone screening; criticism of the moral and social impacts of the regime of prenatal screening is not criticism of them.
12. See, for example, Williams et al. (2002).
13. In fact, they write: 'The pregnant women and their partners were unwilling to give up the health professionals as the paternalistic expert' (Schwennesen et al. 2009: 201).
14. In an article published by the Danish newspaper, *Politiken*, a story is told about how the committees in some cases have allowed prospective parents to abort due to cleft lip and palate, while in other cases have declined the request (Politiken 2012).
15. The conversation with this woman took place after she had been both to the nuchal translucency scan and the malformations scan, receiving news that her fetus looked healthy (she subsequently gave birth to a healthy boy). She did not speak about the scenario of having to give birth to the aborted fetus until my probing about her thoughts on that issue.
16. Gail Landsman, for example, describes how American mothers of disabled children insist on the personhood of their children in spite of society's devaluation of impaired children as 'defected merchandise' (Landsman 1998). Anthropologist Elaine Gale Gerber argues that pregnancy must be understood as a 'reproductive continuum' that transcends a binary understanding of pregnancy as present or non-present (Gerber 2002). Gerber shows how French women in early, unwanted pregnancies depict the life growing inside of them as 'eggs', not fetuses. On the other end of the continuum, Danish anthropologist Tine Tjørnhøj-Thomsen has shown how infertile childless women personified unfertilized eggs as 'potential babies' even though they were far from an actual pregnancy in biological terms (Tjørnhøj-Thomsen 1999).
17. On the language used in Denmark to denote disability, see Kulick and Rydström (2015).

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