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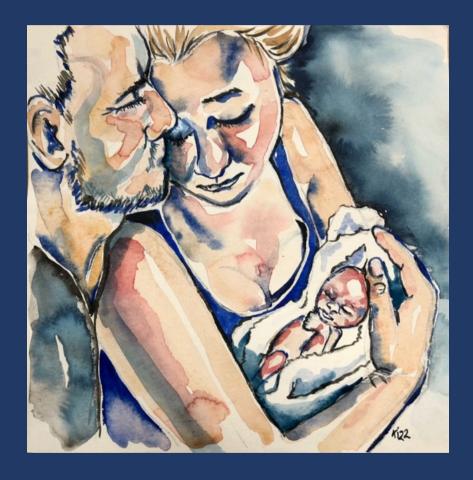
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# THE MORAL LABOR OF MAKING DEATH

An Ethnography of Second-trimester Selective Abortion in Welfare State Denmark

by Laura Louise Heinsen



PhD Dissertation 2022



## THE MORAL LABOR OF MAKING DEATH

# AN ETHNOGRAPHY OF SECOND-TRIMESTER SELECTIVE ABORTION IN WELFARE STATE DENMARK

by

Laura Louise Heinsen



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Front cover: Watercolor painting by artist and midwife, Karen Ingversen; a reworking of a photograph shared by one of my interlocutors, who went through medically induced abortion in gestational week 21 when her unborn child was assessed as having a rare genetic disorder.

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#### **ENGLISH SUMMARY**

In contemporary Denmark, late induced abortions after diagnosis of a fetal anomaly—what I in this dissertation refer to as selective abortion—have grown in number over a relatively short period from being sporadic to a routine part of pregnancy care as a consequence of an increased and more far-reaching implementation of prenatal screening and diagnostics into public antenatal health care in 2004, argued for as promising to increase expectant couples' "informed choice" and "self-determination." However, because most fetal aberrations cannot be diagnosed until *after* the expiration of freely available abortion in the twelfth week of pregnancy, the choice to opt for abortion is not a matter involving solely women and their partners, but a matter administered by the Danish welfare state.

In this article-based dissertation, I investigate how what I conceptualize as "moral labor" shapes how selective abortions are legitimized, practiced and experienced at the nexus of law, biomedicine and everyday lives in the Danish welfare state. I explore this by placing myself in the three realms where legal decisions about selective abortion are made, where care for abortion-seeking couples and the handling of dead and dying fetuses unfolds, and where the decision to abort and the loss of the dead fetus is lived with: in the regional abortion committees, in the public hospitals and in the homes of women and their partners.

Drawing on an approach to morality that takes moral tensions and debates as empirical objects of inquiry rather than as a philosophy that dictates what is good and bad, I ask what moral and emotional challenges arise when death at the beginning of life is actively procured, what forms of justification are brought into play to make selective abortion morally and socially acceptable, and what basic values and norms these practices express.

In order to explore these questions, I carried out 12 months of on-and-off "assemblage-implosion" ethnographic fieldwork between 2020 and 2022, drawing mainly on in-depth interviews with women, men and couples, abortion committee members, Abortion Appeals Board members, gynecologists, fetal medicine doctors, nurses and midwives, as well as on legal documents, medical instructions and guidelines, news stories, drawings, photographs and social media data.

The main finding of the study was that everyone—from abortion committee members, fetal medicine specialists, midwives to couples—involved in the making of death through selective abortion, divided and distributed the moral burden and responsibility between as many hands as possible to minimize the discomfort of

terminating life, and that all generated different discursive and material practices to make selective abortion "routine" and efficient, yet emotionally manageable at the same time.

I propose to categorize these practices as "moral labor," understood as processes that aim to legitimize and stabilize legally, morally and socially ambiguous and unsettling decisions and actions. I argue that placing moral labor at the center of the analysis is a fruitful way of exposing central societal norms and values that shape questions of life, death, normality, disability, belonging and non-belonging in the Danish welfare state. In other words, I argue that moral labor is a productive lens for understanding how citizens are made and what kinds of citizens are wanted and valued in the eyes of the Danish welfare state. Furthermore, I argue that a considerable care gap leaves—on their own—women, couples and agents of the state to manage the moral friction and emotional discomfort associated with selective abortion. The normative position of the dissertation is that as the Danish welfare state intensively invests in prenatal screening and diagnosis to facilitate selective terminations, the state ought to prioritize more highly meeting the care needs that such state-sanctioned-and-effectuated terminations bring about.

#### **DANISH SUMMARY**

I dagens Danmark er sene provokerede aborter efter fund af en fostermisdannelse—hvad jeg refererer til som selektiv abort—over en relativt kort periode vokset fra at være sporadiske til en rutinemæssig del af den danske svangreomsorg som en konsekvens af en øget og mere vidtrækkende implementering af prænatal screening og diagnostik i 2004, der blev indført ud fra devisen om, at det ville øge vordende forældres "informerede valg" og "selvbestemmelse". Fordi de fleste fostermisdannelser først kan diagnosticeres *efter* udløbet af den fri abort i 12. graviditetsuge, er valg af senabort imidlertid ikke et spørgsmål, der udelukkende involverer kvinder og pars, men er et spørgsmål, der administreres af statslige institutioner.

I denne artikelbaserede afhandling undersøger jeg hvordan hvad jeg betegner som "moralsk arbejde" former, hvordan selektive aborter bliver legitimeret, praktiseret og oplevet på tværs af jura, biomedicin og hverdagslivet i den danske velfærdsstat. Det undersøger jeg ved at stille mig i de tre sfærer, hvor juridiske beslutninger om sene aborter træffes, hvor omsorg for abortsøgende par og håndtering af døde og døende fostre folder sig ud, og hvor beslutningen om abort og tabet af det døde foster leves med: I abortsamrådet, på hospitalet og i hjemmet.

Ud fra en tilgang til moralitet, der tager moralske spændinger og debatter som empiriske undersøgelsesobjekter snarere end som en normativ filosofi, der dikterer hvad der er "godt" og "dårligt", spørger jeg hvilke moralske og følelsesmæssige udfordringer, der opstår når døden i begyndelsen af livet skabes, hvilke former for retfærdiggørelse, der bringes i spil for at gøre denne død moralsk og social acceptabel samt hvilke grundlæggende værdier og normer disse praksisser er udtryk for.

For at udforske disse spørgsmål har jeg udført 12 måneders on-and-off "assemblage-implosion" etnografisk feltarbejde i perioden 2020-2022. Feltarbejdet trækker hovedsageligt på dybdeborende interviews med kvinder, mænd og par, abortsamrådsmedlemmer, abortankenævnsmedlemmer, gynækologer, føtalmedicinere, sygeplejersker og jordemødre, men også på juridisk aktindsigtsmateriale, medicinske instrukser og guidelines, nyhedshistorier, tegninger, fotografier og social media data.

Undersøgelsens hovedfund var, at alle – fra samrådsmedlemmer, føtalmedicinere, jordemødre til par - der er involveret i skabelsen af død igennem selektiv abort fordelte og distribuerede det moralske ansvar og byrde imellem så mange hænder som muligt for at minimere ubehaget ved aktivt at skabe døden, samt at alle genererede forskellige diskursive og materielle praksisser for at gøre den selektive abort både "rutinemæssig" og følelsesmæssig håndtérbar på én og samme tid.

Jeg foreslår at kategorisere disse praksisser som "moralsk arbejde", forstået som processer, der har i sigte at legitimere og stabilisere juridisk, moralsk og socialt tvetydige og foruroligende beslutninger og handlinger. Jeg argumenterer for, at det at placere moralsk arbejde i centrum for analysen er en frugtbar måde at åbne for centrale samfundsmæssige normer og værdier, der er formende for spørgsmål om liv, død, normalitet, handicap, tilhørsforhold og ikke-tilhørsforhold i den danske velfærdsstat. Med andre ord argumenterer jeg for at moralsk arbejde er en generativ prisme for at forstå hvordan borgere skabes og hvilke typer af borgere, der i velfærdsstatens øjne er ønskede og værdsatte.

Desuden argumenterer jeg for, at et betydeligt omsorgshul efterlader både par og statsaktører i en situation, hvor de skal håndtere den moralske friktion og det følelsesmæssige ubehag der er forbundet med selektiv abort på egen hånd. Afhandlingens normative position er, at i takt med, at den danske velfærdsstat har investeret intensivt i prænatal screening og diagnosticering for at facilitere beslutninger om selektiv abort, bør staten også prioritere at opfylde de omsorgsbehov, som statssanktioneret-og-statseffektueret abort medfører.

#### **PROLOGUE**

#### Peter and Maj, couple

Sitting under a relentlessly burning sun in the backyard of his suburban terraced house in the Spring of 2020, 36-year-old Peter recounted the moment he received the news that the child he and his wife, Maj, were expecting had been diagnosed as having Down's syndrome. Like most other prospective couples, Peter and Maj took prenatal screening for granted as an integral part of the route to parenthood. As Peter said, "It's something you just do. It's like a health check." The first-trimester nuchal translucency screening did not catch the extra chromosome 21, nor did the following malformation scan in week 20 of pregnancy. Despite having received a risk figure close to the cut-off value demarcating high-risk from low-risk pregnancies, the sonographer reassured them that there was no need to worry. It was only due to Maj's persistent anxiousness that the fetal medicine specialist finally offered them an amniocentesis.

The doctor called Maj on a Friday to break the news. Peter immediately left his job and cycled to the Inner Harbor Bridge in the center of Copenhagen, where he met with Maj. In tears, they hugged each other tightly and both said: "We can't do this. We can't have a child with Down's." Peter explained: "You know, most opt out on a child like that. Because it's extremely difficult. They have a hard life and die early, so it's just like, that's just what you do."

Peter and Maj cycled to Maj's parents to wait for another call from the fetal medicine doctor to get more information about their options and the next step. The doctor said that Maj had to give birth:

We just lost it. We both broke down crying. We asked if Maj couldn't just be sedated to get it over with, but they said that the body has to process it. That it makes it more real. You cannot run from it. You have to face it. And that obviously made it more difficult, but it didn't make us change our minds. We didn't consider keeping it.

On Monday, Peter and Maj met with the doctor to inform her as to what they wanted to do. Peter recalled: "It was very easy to read between the lines that they expected us to opt for abortion. It's the way they speak about things. The papers have been printed before you arrive and before you've informed them about what you've decided."

Maj signed the late term abortion application form. At 3 p.m. the same day, the abortion committee returned with their approval. The same evening, after having dropped off their 3-year-old daughter at Maj's parents' house, Maj swallowed a pill that blocked

her pregnancy hormones. Two days of waiting at home ensued, and on the third day, Maj and Peter were hospitalized. Late in the evening, Maj gave birth to a girl born silent.

As Peter reflected on the decision to terminate, now six months later, he felt that the fact that they had been given permission by the abortion committee "took away some of the guilt." Peter elaborated:

On some level we just applied. Legally speaking, they [the abortion committee] made the decision. They had the final decision. So, when I struggle to come up with convincing arguments for why this was okay, there are some experts in all these ethical aspects that say it's okay. So it gave a kind of comfort to know that people who use a lot of their time on these matters have decided: this is okay to do within the moral and ethics of our society.

But Peter was not only morally conflicted about his motivation for choosing termination, but also with how to think about and reconcile the loss it had caused: "I like the recognition of her if I call myself a father of two, but what's hard about it is that if I acknowledge that, then I've killed my own child."

#### Britta, abortion committee member

On a dark and early morning in November, I logged into Zoom to do an interview with Britta, an elderly doctor who had served as a committee member on one of Denmark's five regional abortion committees alongside her primary job as a psychiatrist. At one point, I asked her if she could recall an application for abortion concerning fetal anomaly that she and her colleagues had decided to decline. The following exchange ensued:

Britta: No, I can't. I can't remember.

Laura: Is that because there aren't any rejections?

Britta: No [laughing], it's not that there aren't any. You can look up the statistics to see how many rejections are given. There aren't many, because they're being counselled. They'll receive counselling in terms of whether there are substantial grounds. A few years back, we had a number of cases in the news concerning whether a clubfoot triggered a rejection, or if the baby was missing a few fingers. And, I can actually remember one case of a missing lower arm which we rejected, where the argument was that these are things that can be compensated. Just as with heart malformations. Many choose to give birth to heart children in spite of the operations the child must undergo. And that's the same with other malformations. We haven't given [approval] on the basis of a cleft lip and palate either. Occasionally, people apply for that, but they don't get it. I've been involved in one case that was authorized [because of cleft lip and palate] but that was because it was part of a syndrome. But, simple cleft lip and palate, you don't give approval. But again, in terms of whether we could compile a positive list, you can't because you

don't know how complicated... it's not certain that the same handicap is the same the next time. So, it's an individual assessment. And, then there is this concern that we might be on a slippery slope, the question of what will happen if more and more diagnoses are added to the "positive list", as we call it. This might be the case, as a consequence of more knowledge. But it might also be that some are taken off [the list] because of increasing possibilities for aid.

#### Monica, nurse

I visited Monica, a middle-aged nurse, in one of Denmark's largest hospitals. Monica greeted me in the lobby with a welcoming smile and a firm handshake and introduced herself as "koordinator af abort og foetus mors" [coordinator of abortion care and pregnancy loss]. While showing me around the ward, at one point we entered a utility room with pink wall-to-wall cabinets. Monica opened one of the cabinets, disclosing its contents. It was stacked with knitted objects, such as beanies, blankets and angel octopuses of all imaginable colors. Amongst the knitted items were also "Moses baskets" knitted in natural colors, the newest addition to the amalgam of hand-made objects that health staff offer to couples who come in for a second-trimester termination or who have suffered an involuntary pregnancy loss. Describing one recent selective abortion she had attended, Monica told me:

I came back with the little one in a Moses basket, and then I had chosen a green blanket with a beanie attached, because he [the fetus] had a huge hematoma on the head, so I had given him a beanie in matching colors. And then I had placed an octopus in matching colors in the basket. And what I find so exciting about this, what's the right word... you know, I just feel a completely different sense of pride when I enter a room showing this. And the look in their eyes. When they approached and saw that he was lying there with the octopus, they just started to cry. You know, the care that we as a hospital, as an institution have the capacity of showing, it's being received really well. It is. [...] I think in the past with the opportunities we had, we weren't particularly sensitive when we had to show it, because it was just placed in a cardboard tray with a tea towel in it. So, the experience for the parents and also for us as responsible nurses, when we have these patients, it's a completely different experience going in and presenting the fetus or the child to the parents with the options we now have.



#### 1. INTRODUCTION

This dissertation is about the moral labor of making and handling death and dving in the form of abortion due to fetal anomaly in the Danish welfare state. During a relatively short period of time, selective abortion has grown from being sporadic to being a routine part of medical care as a direct consequence of the increasing utilization of prenatal risk knowledge in the context of pregnancy (Schwennesen et al., 2008). In 2004, the Danish Board of Health issued new guidelines for prenatal screening and diagnosis, recommending that non-invasive prenatal screening, consisting of a first-trimester prenatal risk assessment for chromosomal anomalies and a second-trimester malformation scan, should be offered to all pregnant women, on a routine basis and free of charge, regardless of age and risk profile (Danish Board of Health, 2004). While prenatal testing technologies were rolled out in the 1970s with the explicit goal of preventing children with disability from being born, most notably Down's syndrome, the expansion of the program in 2004 was justified on the grounds that it would enhance prospective parents' "informed choice" and "self-determination," and conversely that it was not about prevention (Danish Board of Health, 2003a, 2003b). However, from the outset of the new guidelines, uptake rates were high<sup>1</sup>, leading to a decline in the number of children born with Down's syndrome from about 65 before the implementation of the new guidelines to an average of 33 children from 2005 and onwards (Ekelund et al., 2009, 2010). It is estimated that up to 99 percent of prospective couples opt for termination when Down's syndrome is detected in utero (Lou et al., 2018). Thus, most children born with Down's syndrome today result from non-detection or non-use of the offer of prenatal diagnosis rather than a decision to knowingly give birth to it (Spalletta, 2021). To give an example, in 2014, 124 fetuses with Down's syndrome were terminated, and a little over 30 children were born with the syndrome, yet only two of these 30 children had been prenatally diagnosed (Rønsholt, 2017).

In Denmark, pregnant women have a statutory right to first-trimester abortion, after which termination of pregnancy must be approved by a regional abortion committee<sup>2</sup>

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<sup>&</sup>lt;sup>1</sup> According to Danish Board of Health, the overall uptake rate of both tests are approx. 97 percent (Danish Board of Health, 2017: 5)

<sup>&</sup>lt;sup>2</sup> Abortion may be granted based on the following six indications: 1) the pregnancy, birth or care for the child poses a threat to the woman's health, 2) the pregnancy is the result of a crime, 3) there is a risk that the child will be born with a severe physical or mental disability, 4) the woman is unable to take care of a child in a secure way due to her physical or mental illness or limited cognitive abilities, 5) the woman is unable to take care of a child in a secure way at the moment due to young age or immaturity, and 6) the pregnancy, birth or care for a child will cause a serious burden on the woman which is incompatible with the maintenance of the home or the care for other children (Healthcare Act, Consolidated Act LBK nr 210 of 27/01/2022, n.d.).

consisting of a legal representative and two medical doctors. Since the timing of routine prenatal diagnostic tests typically place them *after* the first trimester, whether an affected pregnancy may be terminated is, legally speaking, not just a matter of a woman's informed choice but essentially a question for the committees to decide. Of the approximately 8–900 applications for late term abortion processed by the regional abortion committees, 80 percent concern fetal abnormality and the remaining 20 percent socio-economic indication. Of these 80 percent, between 96 and 99 percent are granted approval (Abortion Appeals Board, 2020; Petersen and Herrmann, 2021), meaning that roughly 600–700 terminations for fetal anomaly are carried out in Denmark each year. At first glance, such decisive numbers reflect the propensity in Denmark for regarding anomalous life as legitimately "expendable," 3 yet, at the same time, they do not provide answers to the questions of: What justificatory logics underwrite them? How is selective abortion managed and grappled with in the maternity wards? Nor to the question: How do these medico-legal domains, in turn, shape intimate experiences of selective abortion?

As a doctoral research student in the larger interdisciplinary and collaborative research project *Technologies of Death and Dying at the Beginning of Life* (henceforth TechnoDeath), I have explored these questions with the aim of generating knowledge about how death through selective abortion is made possible and shaped in the Danish welfare state. I have done so by situating myself ethnographically with those people who enable termination for fetal anomaly to take place on an everyday basis—the abortion committee members, abortion providers and couples. The TechnoDeath project is grounded in the premise that technologies make and remake how death at the beginning of life emerges, is managed, and lived with. Drawing from this overall framework, in this thesis I unearth how lawyers and doctors working in the abortion committees and Abortion Appeals Board arrive at legal decisions, how they grapple with the entrusted responsibility of drawing the line between which fetuses may and may not be terminated in the second trimester, and how they legitimize already established legal practice. I

<sup>&</sup>lt;sup>3</sup> I want to emphasize that while Danish statistics support this tendency to regard anomalous fetuses as "expendable," there is much we do not know for certain. While The Danish Cytogenetic Central Register tracks the annual number of prenatal and postnatal diagnoses of Down's syndrome and other more common chromosomal anomalies, such as Patau's syndrome, Edward's syndrome and sex-chromosome aberrations, there are—despite the normalization of prenatal screening and testing—no accessible data registers surveilling the outcome of prenatal diagnoses of structural and congenital malformations detectable during pregnancy. This leaves a considerable unreported number of the total amount of second-trimester selective abortion. For instance, according to a patient pamphlet made by the Danish Heart Foundation, around 475 children are born with a heart defect each year, the pamphlet noting how: "Many children who would previously have slim chances of survival look toward living a normal life informed very little by illness" (Patient pamphlet, Danish Heart Foundation). Yet I have not been able to find any statistics as to how many prenatally diagnosed heart malformations end in termination. This is also the case concerning brain abnormalities, structural malformations of the major organs, deletion syndromes and other genetic deviances.

examine how clinical care is organized and what care practices midwives and nurses adopt to care well for abortion-seeking couples. Lastly, I explore how women and their partners experience going through late term abortion, and how couples wrestle with what American anthropologist Rayna Rapp has evocatively called a "chosen loss" (Rapp, 1999: 225). In other words, I unravel the moral dimensions of *authorizing*, *effectuating*, and *experiencing* selective abortion in the Danish welfare state.

The choice to give equal attention to the legal practices, abortion provision and the intimate work implicated in selective abortion is not coincidental. These realms configure the welfare state's political construction around access to and management of secondtrimester selective abortion. As the three opening vignettes illustrate, whether you are a couple, an abortion committee member or a healthcare professional, all actors embody and personify the state's different modes of governing death at the beginning of life. When Peter justifies his decision to opt for abortion by mobilizing the abortion committee as co-decision-maker, he situates himself as a responsible citizen belonging to the Danish welfare state, and conforming to the norm of "that's what you do." When Britta refers to the "positive list" as the guiding tool for how to make legal decisions about what fetal conditions trigger a "blueprint" for abortion, she is locating committee work within a larger political framework for drawing the line between which lives can be let into and which can be left out of society. And when Monica pays homage to various knitted objects as positively changing selective abortion care, she too is speaking not only from a personal but also from a welfare state institutional point of view within which hegemonic notions of "good" abortion care prevail.

Termination for fetal anomaly has been described by anthropologists Ayo Wahlberg and Tine Gammeltoft as one amongst several other "selective reproductive technologies" (SRTs) that aim to "prevent or promote the birth of particular kinds of children" (Wahlberg and Gammeltoft, 2017a. Emphasis original). Wahlberg and Gammeltoft argue that SRTs have become "guiding hand" technologies (rather than the "helping hand" technologies of assisted reproduction), directing nature towards socially and culturally desirable ends, such as the production of healthy offspring (ibid.). Selective abortion is conditioned by an ever-expanding range of screening- and diagnostic technologies that enable the establishment of what is so esoterically labeled a "positive diagnosis." Indeed, given that selective abortion is the most frequent solution to "failed" reproduction that biomedicine can provide, the routinization of these tests has prompted several scholars to categorize prenatal diagnostics as a refined version of twentieth century, "back door" (Duster, 2003; Lippman, 2018; Parens and Asch, 2003), "contemporary" (Shakespeare, 1998) or "flexible" eugenics (Taussig et al., 2008).

In the chapters and articles that follow, I build on the notion of selective reproduction as "nature directed." Importantly, my use of the term "selective abortion" is etic, as it was not used by my interlocutors nor was it a term I used during interviews<sup>4</sup>. Recently, scholars have problematized the uncritical use of the term "selection" for political (Adrian, 2020a) and ethical reasons (Rehmann-Sutter, 2021, 2022). For instance, bioethicist Christoph Rehmann-Sutter argues that selective abortion is a "loaded word" that misrepresents the stakes involved for couples by attributing "an overarching selective plan to a woman/couple who may make a decision while feeling deeply troubled and conflicted, and by directly linking such decisions with (negative) eugenics" (Rehmann-Sutter, 2021: 954). Indeed, the term has historic links to the Nazi selection process of the holocaust, referring to the division of persons chosen for forced labor and those sent to gas chambers upon arrival in concentration camps, such as Auschwitz (URL 1). In her study of fertility traveling for donor sperm, feminist STS-scholar Stine Adrian argues that an uncritical adoption of the term "selective reproduction" obscures the political implications of the inclusion and exclusion dynamics at play in selection practices, which perpetuates an understanding of selection as informed by autonomous choice. She shows how a number of material and discursive practices intertwine to make donor sperm selection possible or impossible, and how inclusion and exclusion are bound up with normative notions of, for instance, sexuality, gender and race (Adrian, 2020a). While I agree with Rehmann-Sutter's critique that the imagery of women and couples as being driven by a cynical selective project is flawed, following Adrian's call for attention to the politics of selection, I argue that situating couple's abortion motivations and experiences within a larger framework of contemporary biopolitics and welfare state reproductive governance (Morgan and Roberts, 2012) is as important as taking seriously that choosing to terminate a pregnancy following detection of a fetal anomaly is morally confounding<sup>5</sup>. Furthermore, taking for granted that a decision to terminate due to fetal anomaly constitutes an autonomous decision because medical ethics foregrounds informed choice, as Rehmann-Sutter does, is too simplistic and overlooks the implications for both couples and state actors of being enrolled into a specific ethico-political rationality. Thus, my insistence on the adjective "selective" serves two overall purposes: first, to distinguish

<sup>&</sup>lt;sup>4</sup> In the juridical world, the term consistently used was "fosterskadesager" ["fetal defect cases"]. In the medical care world, the term mostly used was "samrådsaborter" [committee abortions], and the term adopted by couples was mostly "senabort" [late term abortion].

<sup>&</sup>lt;sup>5</sup> In line with Rehmann-Sutter's (2021) point that decisions to end a pregnancy following a fetal diagnosis are bound up with messy and ambiguous emotions, deliberation, experiences and imagined futures, I consistently use the term "late term abortion" when referring to couples' perspectives, both to follow their own terminology and to distinguish clearly the empirical level from my analytical take. To make room for linguistic dynamic, I use "selective abortion", "selective termination", "termination for fetal anomaly" and "disability-selective abortion" interchangeably.

the practice of enabling and performing the termination of anomalous fetuses from other "kinds" of late term abortion, such as those grounded in socio-economic constraints where knowledge about the health of the fetus has typically not been obtained (Scott, 2007: 16); second, to allow for a framework that troubles any notion of policies and practices of reproductive medicine and law as neutral and value-free while taking seriously the profound social shaping of these "choices" that have turned selective abortion into the norm. In other words, my use of the term "selective abortion" should not be understood as something I attach to the individual or couple, but an analytics for understanding modes of governing reproduction in the Danish welfare state where the objective is to prevent the birth of certain kinds of children<sup>6</sup>. As we shall see, amongst my interlocutors as well as in the broader Danish society, most subscribe to the notion that selective abortion serves positive ends.

At the same time, I also want to suggest that fruitful insights can come from empirically exploring selective abortion not merely as a matter of making decisions about whether and how to engage with prenatal technologies but as processes and practices that cut across legal, medical care, and intimate realms. Hence, in the chapters that follow, I show how processes leading to and following termination are in fact about much more than selection: they expose the moral labor of making death in the Danish welfare state.

According to French anthropologist Didier Fassin, when exploring different state institutions, such as the police, courtrooms, welfare services and hospitals, we are offered insights into the "heart" of the state, as our analyses aim "to penetrate the ordinary functioning of public institutions, but also, metaphorically, to examine values and affects underlying policies and practices" (Fassin, 2015: 2). In following this approach, in this dissertation I not only shed light on juridical and medical practices, but also the values and norms underpinning these practices, as well as the moral affects they invoke. As a fetal medicine specialist and member of one regional abortion committee said when he was interviewed for a Danish local newspaper: "When I sit in front of the parents, my eyes often tear up. If they choose abortion, then we're going to kill a fetus. That's very unpleasant and really what the abortion committee is agreeing to" (Bollerup Hansen, 2008).

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<sup>&</sup>lt;sup>6</sup>This is the point that Sarah Franklin and Celia Roberts make in their ethnography of preimplantation genetic diagnosis which relies on the technology of IVF. They write: "the goal of IVF is a child, whereas the goal of PGD is, in a sense, the reverse, in that it is aimed at preventing some kinds of children from being born" (Franklin and Roberts, 2006: 161).

Drawing partly on the methodology of "the implosion" (Dumit, 2014), which rests on an ontological approach where material, discursive, institutional, economic, social and symbolic elements all take part in the making of the world, and partly on what Wahlberg calls "assemblage ethnography" (Wahlberg, 2018, 2022), which is a strategy of following connections from a main site to other locations in order to capture the "system of relations" of a particular socio-technical phenomenon, this dissertation examines how one specific form of death and dying at the beginning of life is shaped at the nexus of biomedicine, law and everyday lives. The construction of this ethnographic "field imaginary" (Marcus, 1998: 3) is guided by the following research questions:

In what ways does moral labor shape how second-trimester selective abortion is legitimated, practiced, and experienced in welfare state Denmark?

- 1. How do abortion committees and the Abortion Appeals Board arrive at legal decisions, and how do they legitimize current legal practice? (Article 1)
- 2. How do publicly financed health staff perform selective abortion care, and what norms and values do these care practices reflect? (Article 2)
- 3. How do women and their partners experience late term abortion following detection of a fetal anomaly, and what are their moral and affective responses to current medico-legal-care practices? (Article 3)

With these questions, I enter ongoing discussions on selective reproduction and the beginnings and endings of life within anthropology and STS-studies (Adrian, 2016, 2017, 2020a; Cromer, 2020; Gammeltoft, 2014; Gammeltoft et al., 2008; Gammeltoft and Wahlberg, 2014; Giraud, 2020; Jensen, 2010, 2011; Kaufman and Morgan, 2005; Mohr and Herrmann, 2022; Navne et al., 2018; Rapp, 1999; Rimon-Zarfaty and Raz, 2009; Risøy, 2009; Schwennesen et al., 2010; Schwennesen and Koch, 2009, 2012; Svendsen, 2015; Wahlberg and Gammeltoft, 2017b), the anthropology of the state (Fassin et al., 2015; Gammeltoft, 2008; Olwig, 2011; Olwig and Pærregaard, 2007; Sharma and Gupta, 2006; Spalletta, 2021; Street, 2012; Vike, 2018), and within a burgeoning body of literature that takes "the moral" as its object of inquiry (Fassin, 2012, 2015; Mattingly 2012; Kuan and Grøn 2017). Following Fassin's approach to studying morality, my aim is not to prescribe whether selective abortion is morally "good" or "bad" but rather to take "moral tensions and debates as... objects of study" (Fassin, 2012: 3). I take as my starting points what my interlocutors experienced as morally difficult and confusing, what they said and did that expressed moral values and norms, and what they said and did to legitimize certain decisions and actions.

By combining this theoretical lineage with a methodological approach that draws from "implosion" (Dumit, 2014) and "assemblage ethnography" (Wahlberg, 2022), I shall suggest a new concept to grasp the work implied in situations where death at the beginning of life is actively procured: the concept of "moral labor." Drawing on Ivry and Teman (2019) and Mesman (2008), I define "moral labor" as processes of legitimizing and stabilizing, however temporarily, legally, morally and socially ambiguous and unsettling decisions and actions of selectively terminating anomalous unborn lives. Across the committees, the maternity wards, and home settings, I show how moral labor captures the stakes for those who are part of making death through selective abortion. The overall argument running through and tying together both my chapters and the scientific papers is as follows: Danes, both lay and professionals, who are actively involved in the state-sanctioned and routinized termination of anomalous lives generate moral labor to turn such life-ending decisions and actions into morally justified, emotionally bearable yet matter-of-course deaths. Moral labor is essential for legal and healthcare professionals to "get the job done" day after day, and it is essential for couples to learn to live with their loss. While I expand on the concept of moral labor in the chapter that follows, some remarks are required on how it emerged as an analytical heuristic (Blumer, 1954) through which I have come to understand the imbrication of selection and death in the Danish welfare state.

#### 1.1. Reading moral labor into selective abortion

My conversations with Peter, Britta and Monica comprise some of the many fieldwork engagements I have undertaken during three years of doctoral research between 2020 and 2022. While my research interests were steered by the overall framework of the TechnoDeath project, going into my doctoral research I brought with me a number of assumptions about what I would encounter. Sporadic news stories and television documentaries reporting on the social impact of the normalization of prenatal screening and diagnostics in Danish society with titles such as "Down's syndrome children are becoming extinct" (Richter, 2011a) and "Death over Down's" (a Danish documentary featured on the national television station DR), coupled with the high uptake of prenatal screening and selective abortion, seemed to me to epitomize a cultural imagery of abortion as "what you choose" when you test positive for a fetal abnormality in Denmark. This assumption about selective abortion as inhabiting a socially accepted norm was, at the same time, also shaped by previous research. In 2011, I followed pregnant women and their partners in a study of motivations for taking up routine prenatal screening. All my informants took prenatal screening for granted as integral to the experience of pregnancy, and should they learn something was wrong with their fetus, all stated without

hesitation that they would opt for abortion. In this context of thinking through what to do in the hypothetical scenario of receiving a positive test result, the women and men I followed back then linked selective abortion directly to the state as a state-sanctioned health recommendation (Heinsen, 2017). Yet, thinking about Peter's judgment of his own conduct as neither really wrong nor really right, his use of the word "killing," and his moral confusion about how to think about the fetus he had "lost by choice" troubled my preconceived expectations of a lack of moral contestation surrounding selective abortion.

As I immersed myself more deeply into the different medico-legal processes and practices that are constitutive of selective abortion, I encountered several abortion committee members who insisted that doing committee work is strictly a matter of legal administration. For example, during an online interview with three representatives from the Abortion Appeals Board, one of them said with emphatic conviction: "We don't manage ethics. We manage the law!" Indeed, I came to understand that legal bureaucracy is key not only to how committees operate, but also to how they legitimize the authorization of almost all selective abortion cases. Yet, when probing committee members about the challenges they faced as part of doing their job, I was alerted to their affective responses (Adrian, 2015). A gynecologist committee member for instance told me that he felt like he was "acting like God," pointing to how the material reality of late abortion infused his work with a sense of emotional and moral discomfort: "The fact that I myself have had it in my hands makes a big impression on me. I've seen it. And performed it [...] When I carry out an ordinary abortion which is 11 weeks and five days, it's never nice, it's never ever been a nice procedure... but it doesn't affect me afterwards at all. But the one lying in the tin bowl gasping does." Echoing this sense of unease invoked by the visual and visceral confrontation with fetal death and dying that is inevitably connected with selective abortion care, several committee members argued that while the abortion committees almost always grant approval in these cases, the committees' existence is still important. As one committee member phrased it:

Occasionally it comes up; what are we really going to do with these committees, because people are given permission anyway? But I also think, especially with those late abortions approaching the age of viability, they also make great demands on the health staff. And I think that for them, the fact that we have an institution, which has given permission, it can take some of the burden off their shoulders that would otherwise be placed on them, because they can say: "Now we're doing this, but I'm not the one who came up with this. It's not me who has given permission.

As I began interviewing gynecologists, midwives, and nurses responsible for carrying out selective abortions, which take place on public maternity and gynecological wards, I encountered a set of what appeared to me to be very firm and fixed ideas about how to

manage care "properly" for abortion-seeking women or couples and their dead or dying fetuses. I met health staff arguing for the benefits of the clinical management of secondtrimester abortion as medically induced birth, not only for medical but for psychological reasons, and I listened to them arguing for the routine practice of nudging couples to see and hold their dead or dying fetus as crucial for the promotion of healing and grief, underpinned by a vast array of, for instance, knitted objects. One midwife told me: "I always assess how the couple is and feels. Some are really in denial, but others are firm in their decision but in a state of shock. Then I ask, 'How do you relate to the child at this stage?' Because I work a lot with attachment to the child. I work with this conscience that even though it's a life that is being terminated, attachment is still really important for the couple to move on in a grieving process." This ideology of attachment was often legitimized in terms of evidence-based practice and "experience"—as many health staff insisted; yet, as I will show later in the dissertation, when I delved further into the literature on these visibility practices, I found differing views on the evidence (or lack thereof) proving the benefit of visibility practices for psychosocial healing (Article 2). This made me wonder: Are these practices driven solely by patient-centered care, or are they perhaps also driven by a need to make the abortion emotionally and morally acceptable for healthcare professionals? Could it be that knitted objects not only transform the personal experience of going through late term abortion following detection of fetal anomaly for women or couples, but also make abortion care provision more bearable for the care providers themselves?

And finally, almost all the couples I interviewed spoke of doctors and abortion committees as co-decision-makers, which took away some of the guilt, as Peter said. Several stated that, although they felt responsible for deciding, they simultaneously enrolled themselves as embedded in a dominant social norm that privileges abortion as a matter of course. As Cecilie, who terminated her first pregnancy due to Down's syndrome, said:

It may well be that I am putting words in the mouth of the Danish healthcare system, but I have felt such an underlying stream of 'this is the obvious choice.' It's going against the flow to choose the other. So that's why I think, of course you have a choice, but there's something about Down's. There's a lot of understanding, and it's a huge loss and stuff like that, but that's just what you do [...] If you were to turn it upside down and say that we had chosen to keep this child, it would've been difficult to get social acceptance. Also, afterwards in circles of friends: there hasn't been anyone talking about it as something we've chosen to kill. People think it's been such a pity for us because there was Down's. It's been the diagnosis that's sort of been the focus.

Parallel to this emphasis on termination for fetal anomaly as a matter of course, bracketed by some of my interlocutors' friends and family as subordinate to the trauma of learning something was wrong with the fetus—as the quotation from Cecilie illustrates—many women and couples also spoke of their experiences in the language of "killing" and "murder." Most expressed, like Peter, a sense of moral confusion about the justifications for abortion, which seemed to intensify immediately after the termination itself, and many struggled with coming to terms with how to live with a sense of self-inflicted loss in socially accepted ways.

Sarah Pink calls the moment in research when you encounter something—a situation or an encounter that deepens what we think we know, or an ethnographictheoretical dialogue—as "the ethnographic hunch" (Pink, 2021: 30). Juxtaposing couples' emphasis on "killing" with committee members' highlighting of committees as helping to shoulder the burden of making fetal death, and in turn, with health staff's accentuation of the value of "facing" one's dead fetus as paramount for good psychosocial healing brought me to the ethnographic hunch that morally loaded practices saturate the medicolegal-intimate world of routinized selective abortion. What is more, reading across the three opening vignettes—Peter's story about what appeared to be an unexpected and bewildering moral confusion emerging in the wake of having done what he himself implicitly categorized as the normatively directive path, namely opting for abortion; Britta's mentioning of an item that is both imbued with negative connotations of eugenics of the past yet, as I learned, vital for the practical accomplishment of legal decisionmaking, namely, the "list"; and Monica's professional pride in delivering not only medically safe abortion care, but abortion care that nurtured and acknowledged a quintessential element of the clinical handling of selective abortion, namely the facilitation of grieving—alerted me to the larger issue at stake in the moral economy of selective abortion: that of the intimately interwoven relationship between the state, abortion-seeking couples, and agents who act as the extended arm of the state.

#### 1.2. Division of moral labor, collective shouldering

The emphasis on "informed choice" as a new ethical principle in the current organization of prenatal services in Denmark epitomizes a proliferating tendency in Western European countries to frame rational choice as an obvious solution to what is considered a problematic eugenic past (Koch, 2004; Schwennesen, 2018; Schwennesen et al., 2008), as well as to frame reproductive matters as inherently personal, underpinned by liberal assumptions about autonomy and individual freedom as natural human desires (Gammeltoft, 2014: 13). Nikolas Rose has characterized a particular technology of government employed increasingly in so-called advanced liberal states as

"responsibilization," referring to how "the problems of problematic persons are reformulated as moral [problems in such a way that] such persons conduct themselves and their existence" (Rose, 2000: 334). Responsibilization is thus essential to forms of "governing at a distance," operating not through coercion or paternalism, but from afar by steering human behavior to cultivate and internalize responsible dispositions through "technologies of freedom." This form of individualization of responsibility has led to what Ilpo Helén calls an "ethical split" in high-tech antenatal medicine, where reproductive healthcare workers solely take *technical responsibility* for identifying and communicating risks and abnormalities, leaving the *ethical responsibility* concerning medical intervention, in particular selective abortion, to the pregnant woman (Helén, 2004).

In contrast, in an ethnographic study of reproductive decision-making amongst orthodox and ultraorthodox Jewish communities in Israel, anthropologists Tsipy Ivry and Elly Teman (2019) propose the concept of "moral labor," referring to "the labor of making conscious efforts to decide on issues for which one is held morally responsible," to account for how Halachic rabbis work to liberate couples, doctors and themselves from the moral burden of making ethical decisions although Israeli prenatal care services follow a formal commitment to nondirective medical counselling. Rabbis giving advice to prospective couples outsource and aggregate medical and religious expertise, dividing moral labor to reach and bear a ruling<sup>7</sup>. Similarly, STS scholar Jessica Mesman (2008) has shown how doctors and nurses working in a Dutch NICU caring for critically ill neonates relocated and distributed decisions on interrupting life-sustaining care to collectively share the responsibility for the decision on life-ending actions. And, Gammeltoft (2014) has ethnographically explored how reproductive decision-making is turned into a collective endeavor in Vietnam, as couples who learn they are carrying a malformed fetus turn to wider family networks of parents, uncles, aunts, sisters and brothers to reach a decision, arguing that couples forged bonds of social belonging by framing their reproductive lives within close relations of kin and community.

Considering the propensity of the language of informed choice in Danish antenatal healthcare, it could be expected that the labor of "making conscious efforts to decide on issues for which one is held morally responsible" is to be found solely amongst women and their partners, in line with Helén's argument about the ethical split. Indeed, as I will show throughout the dissertation, many of the health professionals and couples I have

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<sup>&</sup>lt;sup>7</sup> As an example of this division of labor, they quote one rabbi who told them: "I have never ruled on a difficult Halachic question (like egg donation or abortion) without consulting with a large team of rabbis. Never. So, in cases that are especially difficult for me, I say to myself, OK, but this rabbi allowed it and that rabbi allowed it, and I divide the burden" (Ivry and Teman, 2019: 864).

worked with believe that selective abortion is the outcome of prospective parents' autonomous choices. Women and their partners couched abortion in the language of individual responsibility, guilt and shame, just as legal representatives and doctors echoed this notion of individual volition. One fetal medicine specialist, for instance, emphasized that her task was to help couples "make the decision that is right for them," and one committee member stressed: "It's not the committee forcing them to have an abortion. It's the parents who've decided that this is too much of a burden." Yet my engagements with couples, legal specialists, doctors, nurses and midwives also showed that a complex choreography following the detection of a fetal anomaly divided and distributed moral responsibility, with the effect of collectivizing and to some extent assuaging the sense of moral unease that the making of fetal death instigates. Following Ivry and Teman's notion of a division of moral labor in ethical decision-making, and Mesman's notion of distribution of responsibility in decision-making processes in neonatal intensive care, this dissertation argues that notwithstanding the dominant framing of selective abortion as underpinned by an ethics of individual choice, the moral burden of carrying the responsibility for making death is assumed, refuted and distributed in multiple ways. For instance, abortion committee members distributed responsibility for the legal authorization of selective abortion through the relocation of medical assessment of "seriousness" to non-legal medical experts outside the abortion committees (Article 1). Nurses and midwives accentuated the visual fetal abnormality to women and couples following the birth of the aborted fetus to help legitimize the decision to opt for termination as the "right" decision (Article 2). And women and their partners worked to justify and settle the "rightness" of their decision by couching abortion as an act of love that was morally permissible because it was "blue-stamped" by the state (Article 3). In the words of one fetal medicine specialist: "Often I say to couples when they've told me they want to terminate the pregnancy: 'Most couples in your situation have made the same decision as you.' And it's something I say again and again. Because it's my impression that it matters. Telling them what others have done shows them that choosing abortion is not that uncommon. And that it's the right decision."

On the surface, selective abortion practices in Denmark appear highly routinized and automatized, giving outside observers the impression that anomalous fetuses are being terminated without blinking. Yet when exploring the "heart" of the state, we gain insight into the unsettled waters swum in by those doing the tasks of permitting and performing selective abortion. We learn about their emotional and moral uncertainties and ambiguities, as well as the work done to stabilize and settle this unease in order to "get things done." Importantly, the division of moral labor challenges the notion that reproduction is represented as a collective endeavor only in societies where selective

reproductive technologies are explicitly used as political tools for building healthy nations (Gammeltoft, 2007, 2008, 2014, 2018; Sleeboom-Faulkner, 2010). While the shared shouldering of responsibility tends to circulate around kinship relations in Vietnam, in Denmark—as we will see—it circles more around welfare state bureaucracies.

Ivry and Teman primarily employ the concept of "moral labor" as a means to capture the work of arriving at an ethical decision, and less as a way of comprehending the outcome of decision-making. They note how divisions of moral labor do not always liberate couples and rabbis from the moral burden of selective termination, arguing that "the rabbinic model of shouldering moral responsibility [...] is organized according to a temporal consciousness that sees far beyond the moment of decision-making and accounts for the difficulties lurking in the aftermath of loaded moral decisions. [...] even a successful division of moral labor cannot promise exemption from concomitant moral burdens for either women or their rabbis. Rather, we are reminded that moral breakdowns might not always be recoverable into the mode of ethical unconsciousness, even when outsourced to experts" (Ivry and Teman, 2019: 867). In this dissertation I draw on this insight by proposing that moral labor exceeds those moments of crisis related to decisionmaking. Moral labor, I contend, is both past-, present, and future-oriented, and it is exercised in other spaces than in the clinical encounter between a couple and their doctor, or a couple and their rabbi. As will be shown, it takes place in juridical committees, in maternity wards, and in the private homes of women and their partners as they navigate how to live with their "chosen loss" in relation to their wider social networks and surroundings.

A central premise of this thesis is that in a constantly developing "bio-age" (Bauer and Wahlberg, 2009; Rose, 2004), moral labor has become and is increasingly becoming an inseparable part and consequence of increased biotechnological intervention into life and death across the globe. As selective reproduction plays out at the intersection of the deeply private, the culturally and socially valued and the state-regulated, placing moral labor at the center of analysis is a fruitful way of opening up central societal concerns and normativities underpinning life, death, normality, disability, belonging and non-belonging in the welfare state.

#### 1.3. An assemblage-implosion ethnography

Madden argues that "an ethnographic field is not equivalent to a simple geographic or social space, nor is it a simple mental construct of the ethnographer, but it does require both of these elements" (Madden, 2010: 39). Through active constructing, we shape the production of knowledge and what can possibly be known and said about a given field. I label this dissertation a form of "assemblage ethnography" (Wahlberg, 2018; 2022) that

also draws on the methodology of Implosion (Dumit, 2014). In his work on Chinese sperm banking, Wahlberg (2018) proposes the concept of assemblage ethnography as a "site-multiplying approach" especially apt for studying the routinization of reproductive technologies. Wahlberg tracked and traced a range of connections from his main site, Changsha, to other locations in the country as he investigated how sperm banking came to be located within China's restrictive reproductive complex, consisting of a total set of laws, regulations, family planning institutions, quotas, information campaigns, experts, hospitals, clinics, pharmaceutical companies, premarital counseling sessions, prenatal screening services, sperm donors, and more (Wahlberg, 2018: 10, 19-20). Doing assemblage ethnography includes attention to both "the big complex" circumscribing, in his case, sperm banking, "the daily grind" of fertility clinics and the "experiences" of individuals donating or using sperm for reproductive aims as object of study. Wahlberg writes:

"If ethnographies of lived experience generate insight into the ways in which individuals and communities experience, navigate, negotiate, or relate (for example, to infertility and insemination with donor sperm) and laboratory ethnographies examine how specific forms of knowledge, truth, or fact are produced through practice, assemblage ethnographies generate insight into the ways in which certain problems, or better yet problematizations, take form. This is not to say that I have been uninterested in the experiences of sperm donors and couples undergoing AID [artificial insemination with donor sperm] or in the laboratory practices that generate knowledge about sperm, but rather it is to point out that the task of my ethnography has been to provide an account of *the making of sperm banking in China* through a heavy accumulation of patterned knowledges and practices, enmeshed within a very particular reproductive complex" (Wahlberg, 2018: 11. Emphasis original).

In this study, I do not begin from one specific site as such and make connections from there, as all my field sites (the committees, the maternity clinics and the homes) have been equally central, yet I have found fruitful the way of bringing different spheres of analysis into conversation—as implied in the assemblage approach—in order to explore how death through selective abortion emerges and is made possible across scales, sites and practices (Wahlberg, 2022: 126). Like Wahlberg, I too explore both the larger contours of the Danish welfare state's reproductive complex and the historically shifting forms of reproductive governance taking place within this complex (Chapter 4), the daily routines of committees and clinics (Articles 1 and 2), and the intimate experiences of women and their partners (Article 3) as termination following the detection of a fetal anomaly were set in motion. However, whereas Wahlberg draws heavily on policy documents,

regulations, media reports, grey literature and some witness interviews to unearth the historically situated "systems of relations" that made sperm banking thinkable within a restrictive one-child, and later, two-child policy, I rely mostly on ethnographic interviews that dig deep into the *practices and experiences* in all three realms: the juridical, clinical, and intimate worlds.

To glean insights into these everyday material and discursive practices in committees, hospital wards and homes, I have sought inspiration in the implosion methodology. Drawing on the work of Donna Haraway, Dumit proposes the concept of "implosion" as a step-by-step methodology for investigating "the embeddedness of objects, facts, actions, and people in the world and the world in them" (Dumit, 2014: 350). It is an approach that asks of the researcher to pick an item, an object, or a phenomenon and then begin asking a series of questions regarding this item to unearth its material, discursive, institutional, economic, social and symbolic elements and the connectedness between these elements. As Dumit notes, to understand a phenomenon, "we must understand its history, its smallest pieces and its connection to other things to tease out its embeddedness" (Dumit, 2014: 350). Building on implosion methodology's attention to the entanglement of human and non-human elements in the shaping of practice in conjunction with the assemblage ethnographic approach's attention to scale and levels of analysis, has allowed me to take into account both the significance of objects, such as paperwork, pills and knitted baby items, and the larger historical shifts that in conjunction shape how selective abortion is understood, justified and practiced. An effect of this methodological approach is that there are certain threads I have chosen to follow and others that I have not, leaving some things included while others are excluded from view. As Sperling writes: "The lines between and around both text and context will necessarily reflect [a] particular writer's capacity and preference to draw such lines and make such distinctions" (Sperling, 2013: 22).

I suggest that it has been by situating my ethnographic gaze beyond the critical moment of decision-making, towards the medico-legal-private domains that my take on moral labor as the work of legitimizing and stabilizing ambiguous and unsettling decisions and actions could be developed. It was by thinking and analyzing across these spaces that the normative "frames" (Butler, 2016) surrounding the myriad legal, medical care and intimate practices appeared, and that the divisions of moral labor were rendered visible. By juxtaposing transcripts of interviews with couples, committee members and health staff, I saw how the burden of terminating life was highly dispersed between people, between state institutions, and between bodies of expertise, even within a medical and cultural environment that prides itself on being dedicated to individualism and autonomy.

#### 1.4. The anthropology of selective abortion

Much of the anthropological and sociological literature that has investigated the intertwinement of prenatal testing and selective abortion has tended to focus on the thorny issue of "choice" (Gammeltoft, 2014; Hằng, 2011; Rapp, 1999; Risøy, 2009; Risøy and Sirnes, 2015). For instance, in her pioneering study of amniocentesis in the United States in the 1980s when prenatal diagnostic technology was being dispersed, Rapp described those women on the frontier of reproductive technology as "moral pioneers," showing the social implications of the sudden power that was thrust into the hands of ordinary people to decide what kind of lives are worth bringing to life. In Gammeltoft's monograph Haunting Images (2014), we learn about how Vietnamese women experience the disturbing ramifications of "choosing" abortion in a cultural environment where great pressure is put on prospective parents to procreate healthy offspring; pressure that follows both political and familial vectors. Other scholars have tied reproductive technologies and abortion to issues of fetal "personhood," "patienthood" and, more broadly, to "abortion politics" (Blum and Casper, 1999; Millar, 2016; Morgan, 1996; Taylor, 2002; Withycombe, 2013). In contrast, surprisingly little ethnographic attention has been directed towards the materiality of the abortion itself, to the legal and bureaucratic work enabling selective terminations to take place or to the medical care work involved in their effectuation. As feminist historian Ilana Löwy notes, researchers who study prenatal diagnosis have usually "stop[ped] short of asking what happened next to the women and the fetal remains" (Löwy, 2018: 25). Bearing in mind that termination is the typical response to fetal abnormality in Denmark, it is surprising that the practices and moral and affective responses related to selective abortion—from legal authorization, completion, when couples return home "empty-handed"—remain largely unexplored ethnographically. This begs the question: What do we know about the anthropology of selective abortion?

#### 1.4.1. The patient perspective: Coping with selective abortion

The majority of the ethnographic and qualitative health studies on selective abortion have examined the experiences of "patients," focusing especially on "the shock" of learning something was wrong, how women and their partners have "coped" with it and the "psychological impact" of going through termination of pregnancy (Fisher and Lafarge, 2015; Gammeltoft, 2014, 2007; Hằng 2011, 2017, Lafarge, 2016; Lafarge et al., 2014, 2019; Lou et al., 2018; McCoyd, 2007, 2009; Rapp, 1999; Risøy and Sirnes, 2015; Statham, 1994; Statham et al., 2000). The women Rapp spoke with in her study on amniocentesis all talked about the moment the diagnosis was delivered as being etched into their memory. She learned that some "decided" instantaneously to opt for abortion

while others arrived at a decision more gradually (Rapp, 1999: 223), yet what she also learned was that no matter how women arrived at their decision to terminate, it was experienced as troubling. Rapp writes: "The emotional recovery after what is medically labeled a 'selective abortion'" is lengthy. Women and their supporters experiencing this process share an existential territory with all who survive the death of loved ones; they also have much in common with those recovering from any pregnancy loss or stillbirth. But their experience is also distinct because it is a chosen loss" (ibid. 225). In a study of Norwegian women's experiences of selective abortion, Risøy and Sirnes likewise show how the decision to terminate is experienced as a "state of emergency" (Risøy and Sirnes, 2015. See also Risøy, 2011). Similarly, Gammeltoft shows how reproductive decisions in Vietnam are largely shaped by the opinions and voices of elders in households, as well as by a sense of social and moral obligation to the Vietnamese state, which has had as its central objective to improve the population quality as a precondition for the industrialization and modernization of the country. Gammeltoft writes: "Complying with the advice provided by medical doctors can be seen as an act of belonging, an acknowledgment of membership of a national community that is historically rooted in collective fight. By accepting a prenatal diagnosis, one also turns oneself into a proper citizen, someone who recognizes and appreciates the efforts invested in building the Vietnam of today. The abortion decision, then, concerns not only whether or not the mother-to-be is able to accept a disabled or less than perfect child but also what kind of citizen she aspires to be" (Gammeltoft, 2007: 156). What we learn from these studies is the haunting aftereffects of ending a desired pregnancy, no matter the cultural and social context. Yet, within this body of literature, surprisingly little attention has been directed towards death and dying itself<sup>8</sup>. While Rapp touches upon how her interlocutors responded to choosing between surgical and labor-induced abortion, descriptions of the abortion procedure and the bodily undertakings required are much less detailed.

Hằng's study of sex-selective abortion in Vietnam is one of the few that have examined abortion practices, demonstrating how these procedures are "marked by pain, stress and, most notably, silence" as well as by the dismembering of fetal bodies through surgical abortion with body parts being pulled out in pieces (Hằng, 2011: 91–92). Similarly, Gammeltoft and colleagues show how termination for fetal anomaly through labor and birth was experienced by Vietnamese women as psychologically painful, noting how women feared that the fetus would haunt them. Gammeltoft notes: "Out of fear that

<sup>&</sup>lt;sup>8</sup> In a meta-ethnographic study drawing on 14 studies, Caroline Lafarge and colleagues explored women's experience of termination of pregnancy for fetal abnormality before, during and after the termination, yet while they focused on the traumatic impact the event had on women, the experience of the abortion procedure itself was somewhat invisible within the context of the women's broader experience (Lafarge et al., 2014).

the sight of the deceased fetus would leave a lasting "mental imprint" on their minds thereby rendering them unable to ever leave this experience behind, nearly all the women avoided seeing the body of the fetus after the termination" (Gammeltoft, 2010, 2014; Gammeltoft et al., 2008: 50).

In this thesis, I provide an analysis of women's and couple's embodied and moral experiences of opting for abortion, of going through induction of labor, and of being confronted with dead or dying fetuses, as these experiences are shaped by clinical guidelines and ideologies of care (Article 3). Hereby, I engage a burgeoning literature that takes seriously that to understand the complexity of women's experiences of abortion, we need to take seriously the embodied nature of abortion (Harris, 2008; Ludlow, 2008a; Martin et al., 2017), bringing into view the ways in which the bodies of abortion-seeking women, and dead and dying fetal bodies, are framed, managed and cared for (Middlemiss, 2020; Mitchell, 2016). Focusing on the discursive and material shaping of secondtrimester selective abortion experiences through clinical care guidelines and practices not only brings the governance of birthing bodies and dead and dying fetal bodies into critical relief, but also challenges the dichotomy between pro-choice and anti-choice politics, through which (selective) abortion is turned into a polarized conflict between a woman's reproductive right to decide over her own body and a fetal "person's" right to life. Indeed, the late term abortion stories told by my interlocutors encompass both a declared support for abortion as a vital reproductive right and the moral anguish of having terminated an initially wanted and hoped-for life. I show how the visual confrontation with one's dead fetus plays a huge factor in the configuration of such moral tensions and ambiguity, as women and their partners must negotiate the social status of their terminated fetus/child; a status that is discursively pushed in seemingly opposing directions between "futile and expendable fetus" and "precious and grievable baby." I further show how couples experience a sense of social isolation after discharge from hospital. The contrast between highly intensified surveillance and care during prenatal testing and abortion, and the almost complete absence of formal care when people return home is stark (Article 3).

#### 1.4.2. The provider perspective: Handling abortion, confronting death

Several studies have explored the experiences and practices of abortion providers in different parts of the global north (Becker and Hann, 2021; Chiappetta-Swanson, 2001, 2005; Cignacco, 2002; Garel et al., 2007; Harris, 2008, 2019; Löwy, 2018; Ludlow, 2008a, 2008b; Martin et al., 2017; Mauri et al., 2015; Roe, 1989; Vinggaard Christensen et al., 2013) and the global south (Mizuno, 2011; Röhrs, 2017). For instance, sociologist Wendy Simonds' classic ethnography of American abortion clinics chronicles the challenges faced by abortion providers working in a highly polarized political landscape,

demonstrating the tension between abortion providers' personal pro-choice ideology and their discomfort both with the bodily violence that is part of doing abortion work, and the associated social stigma (Simonds, 1996). However, there is a remarkable gap in the ethnographic literature investigating abortion work related to disability-selective terminations. Catherine Chiappetta-Swanson's (2001) work on nurses' perspectives on caring for women who end pregnancies for fetal anomaly in Canada, and Vinggaard Christensen and colleagues' (2013) study on midwives' experiences of assisting couples during selective abortion in Denmark are important exceptions<sup>9</sup>. Chiappetta-Swanson shows how nurses delivering selective abortion care in Canada experience their work as "dirty work" and charts their responses to it, such as building clinical routines, organizing debriefings and developing post-abortive care practices, such as showing the dead fetus to the couples. She notes: "Though the hospitals have introduced GTs [genetic terminations] for fetal anomaly as part of an effort to be responsive to women's healthcare needs, their approach to GTs in fact suggests that there is a good deal of moral ambivalence about GTs at an institutional level. As a consequence, the service receives low priority. It is work that most would prefer not to do or even to know about" (Chiappetta-Swanson, 2001: 181). In a Danish study on midwives' experiences with and attitudes towards late termination of pregnancy, Vinggaard Christensen and colleagues show how midwives providing second-trimester abortion care are much more attentive towards the emotional reactions of the women and their partners than in the past, noting "Over time, there has been a change in the way late TOP [termination of pregnancy] is handled at Danish hospitals. This change involves a greater acceptance of and focus on the emotional reactions of the woman/couple going through late TOP. [...] it has gone from being a strictly clinical procedure to a potentially very emotional experience for both the woman/couple and the midwife 10" (Vinggaard Christensen et al., 2013: 916).

This dissertation adds to these insights by showing how the ways in which selective abortion care has come to be clinically organized and is performed in Denmark are aimed towards overcoming the moral ambivalence, or "dirty work", that disability-selective abortion invokes. By distributing professional duties and responsibilities between different healthcare professionals to get the process of selective abortion going—from fetal medicine specialists, who deliver the diagnosis and jointly sign the abortion application, to nurses and midwives, who provide late abortion care in ways that aim at

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<sup>&</sup>lt;sup>9</sup> For studies exploring the experiences of abortion providers assisting in sex-selective abortion, see Hằng (2011) and Kasstan and Unnithan (2020).

<sup>&</sup>lt;sup>10</sup> They cite one midwife who told them that in the past, "We just turned up the mask [with anesthesia] right before the baby came out so she became a little foggy, when we helped deliver a dead baby. And then; out with the baby and the placenta, the baby was put in the cleaning room, we put on her pants again and gave her a cup of tea. We didn't talk to her about it" (Vinggaard Christensen et al., 2013: 916)

helping to shoulder the moral anguish of choosing to end an initially wanted life—moral labor is divided and the making of death made bearable for both couples and professionals (Article 2).

## 1.4.3. The legal perspective: Governing fetal death

When it comes to qualitative research focusing on the governance of selective termination, only a handful of articles and research papers explore how legal committees and councils assess and arrive at legal decisions, and only one of these explores disabilityselective abortion. Rimon-Zarfati and Raz have studied how Israeli hospital committees and parents view abortion in cases of what they refer to as "mild or likely fetal pathology" (Rimon-Zarfaty and Raz, 2009), demonstrating how selective termination is favored by both health staff and parents (See also Rimon-Zarfaty and Jotkowitz, 2012). In a sociological analysis of public hospital ethics committees in Argentina, Irrazábal shows how religious constituencies appointed to sit on these committees influence decisionmaking in ways that impede women's access to abortion, even in cases where the pregnancy is the result of rape or threatens the woman's health (Irrazábal, 2015). Other studies have explored the historic emergence of hospital abortion committees in The United States (Reagan, 1997; Solinger, 1993). However, this is the first study to explore how abortion committees in Denmark operate. Approaching committee work as a form of institutionalized morality (Sperling, 2013: 57), I show how different forms of legitimation work are at play as justifications are put forward for already established and emerging legal practice. Here too, moral labor is divided within the committees, between committees and the Abortion Appeals Board, between committee members and external doctors—who assist in assessing the severity and prognosis of particular conditions—and between the juridical system and the woman or couple (Article 1).

In summary, to address the overall paucity, in ethnographic studies, of coverage of selective abortion in Denmark, in this dissertation I connect multiple sites and constituencies who are part of the enabling and handling of the ending of anomalous life. By going beyond "the decision" (Risøy and Sirnes, 2015) that has hitherto attracted so much scholarly attention, I position this thesis as part of a limited literature that focuses more explicitly on the intertwinement of the juridical government, clinical management and intimate experiences of death and dying at the beginning of life through the case of selective abortion (Adrian, 2020b). I hereby also position myself *alongside* my interlocutors, taking seriously the challenging legal, care and embodied work they must undertake, situated as they are within a state apparatus that privileges normal, healthy citizens over those who present themselves as different—chromosomally and otherwise (Spalletta, 2021).

### 1.4.4. Towards an anthropology of death and dving at the beginning of life

While very few social science studies have linked selective abortion with anthropological studies of technologies of death and dying, in recent years a number of studies on pregnancy and infant loss have been carried out, focusing on the personal experiences of and social and cultural responses to fetal and infant death (Earle et al., 2013; Layne, 2003; Navne et al., 2018), the historically shifting approaches to the governing and handling of miscarried fetuses and stillborn infants (Giraud, 2016; Memmi, 2011; Middlemiss, 2020), and, more broadly, the politico-economic and social conditions shaping how some parents come to abandon their fragile babies (Scheper-Hughes, 1992).

Anthropologist Linda Layne's (2003) groundbreaking study on experiences of pregnancy loss in the United States was one of the first to bring attention to the entanglement of reproductive technologies and experiences of fetal death, showing how miscarriage was pervasively silenced and miscarried embryos and fetuses rendered socially invisible. Several scholars have focused on experiences and practices of grieving in relation to stillbirth and infant death (Earle et al., 2013; Hvidtjørn et al., 2018; Jørgensen et al., 2022; Kofod and Brinkmann, 2017). Studies have shown how new grief paradigms have leveraged new "sites" for expressions of grief and loss following the death of a fetus or infant, such as body tattoos and memorial gardens (Christensen and Sandvik, 2016; Giraud, 2016). Other studies explore death at the beginning of life through the lens of neonatal intensive care and postmortem practices. Scholars have explored how doctors and nurses caring for premature and critically ill babies navigate the morally challenging entanglement of life-saving technologies and life-ending decisions (Anspach, 2019; Mesman, 2008; Navne and Svendsen, 2018). In a study on pediatric postmortem imaging, Reed and Ellis show how health staff engage in what they couch as hidden "death-work", encompassing for instance talking to the dead infants during examinations as well as showing emotional support for the bereaved parents. They note: "Because postmortem is hidden—taking place behind locked doors—parents, publics and staff working in other parts of the hospital do not always know that this kind of care work exists in the mortuary" (Reed and Ellis, 2020: 320). And in "Stitching Stories of Broken Hearts: Living Response-ably with the Technologies of Death and Dying at the Beginning of Life," Adrian (2020b) draws on media narratives and her own story of losing a newborn to the severe heart malformation, Hypoplastic Left Heart Syndrome, to develop her argument about ways to live more response-ably (being responsive and responsible at the same time) with the technologies of life and death. Her point is to show how technologies neither enable quick fixes nor control outcomes, but rather open multiple paths and choices, whereby it is possible to rethink the use and perception of the technologies at

hand, and the norms and responsibilities that follow, in ways that make the experience of living with technologies more "livable" for the actors involved.

Building on all the above studies, my dissertation aims to contribute to this burgeoning wealth of research on fetal, neonatal and infant death, which might termed an "anthropology of death and dying at the beginnings of life." Following Reed and Ellis, selective abortion can be conceptualized as hidden work in multiple ways; until recently, how abortion committees and the Appeals Board operate has been hidden from public scrutiny; the embodied and emotional work that selective abortion entails for health staff, women and their partners is invisible to the broader public, and couples' lived experiences continue to be largely socially silenced and surrounded by taboo. To counter this, my thesis shines light on the more or less hidden practices and processes that enable the termination of unborn anomalous life, as well as the cost of these practices for those confronting these deaths.

### 1.5. Research goal and contributions

In essence, while this dissertation has practices and experiences of selective abortion as the *empirical* object, moral labor as the *analytical* object, and implosion and assemblage ethnography as *methodological* inspirations, the larger story I chronicle regards how the Danish welfare state produces (ideal) citizens and sets boundaries around who belongs to the state. As the first ethnographic study of selective abortion in Denmark, this research brings attention to dimensions of selective reproduction that have been undertheorized. Through the articles that follow, it is my goal to make a series of scientific contributions.

Firstly, by beginning my project where most other social science scholars have ended theirs: with the processes and practices emerging *after* diagnosis and "the decision," and by centering on the abortion itself rather than on reproductive technologies such as amniocentesis, NIPT [Non-Invasive Prenatal Testing] or genetic testing, this dissertation sheds light on an element in selective reproduction that has hitherto gone relatively unnoticed: the governing and managing of fetal death in the Danish welfare state. Selective abortion follows a particular temporal and spatial order in and through which things are done. Selective abortion, once set in motion, links to an amalgam of medical procedures, medications, and objects, legal paperwork and juridical procedures; as well as to professional domains, such as law, gynecology, genetics, nursing, midwifery; and further to pregnant bodies, fetal bodies and those professional bodies given the task of providing abortion care. By bringing the different yet interwoven clinical, legal and private realms together, this dissertation fills a considerable knowledge gap within anthropological studies of selective reproductive technologies (Wahlberg and Gammeltoft, 2017) by focusing on *the making and handling of fetal death*, as well as

within the anthropology of the beginnings and endings of life (Adrian, 2017, 2020b; Anspach, 2019; Bleyen, 2012; Buchbinder, 2018; Franklin and Lock, 2003; Goodwin-Hawkins and Dawson, 2018; Jensen, 2011; Kaufman and Morgan, 2005; Komaromy, 2012; Lemos Dekker, 2018, 2019b; Scheper-Hughes, 1992) by showing how death as a prism is not only relevant in relation to aging or ill populations and in end-of-life care, but very much in relation to "beginnings."

Secondly, the dissertation adds to the field of moral anthropology by proposing the analytical framework of moral labor as a productive lens through which to observe and understand how people grapple with increasing biotechnological interventions into life and death. Echoing Angela Garcia's call to allow uncertainties to remain unresolved in our thinking and writing (Garcia, 2020: 35), my representational choices aim at retaining ambiguity throughout the dissertation. I show how, despite a multitude of ways in which moral tensions, confusion and discomforts are sought to be settled, selective abortion resides in an ambiguous space of moral friction. Hours of conversations with women and their partners have taught me that living with selective abortion entails continuous work to come to terms with the decision and the loss it has invoked while also attempting to "fit in" to the expectations and norms of society.

Thirdly, it contributes to the growing mass of social science literature on the politics of abortion by questioning the binary understanding of abortion as being firmly located in an either "pro-choice" or "anti-choice," "happy" or "unhappy," "right" or "wrong" stance. Rather than advocating selective abortion as morally good or bad, I demonstrate how selective abortion is both strongly supported and very difficult all at the same time (Ludlow, 2008a). Engaging with medical and legal professionals made it evident to me that while they do not carry the burden of abortion on their own bodies, they too have emotional stories to tell and moral conflicts to negotiate and should therefore be treated with the same sensitivity as the women and their partners (Adrian, 2015; Høyer et al., 2005; Jensen, 2011)

Fourthly, the making of this dissertation has resulted in conversations with journalists and numerous talks targeted at lawyers and healthcare providers to disseminate the insights I have gained through the study. This has been a pivotal driver along the way for me personally as well as a goal for the larger TechnoDeath project. I hope this research will continue to be responded to, thereby creating societal impact beyond the academic world.

Lastly, I hope this dissertation will contribute to current anthropological conversations around the imbrication of reproduction and differing state formations, as well by opening avenues for reflecting upon what characteristics define the valuing of citizens in present-day welfare state Denmark, a discussion to which I return in my

concluding remarks. As I will suggest, there is something particular at stake in the Danish welfare state that does not easily fit with notions of "back-door" or "flexible" eugenics nor with values of freedom and liberalism characteristic of more liberal states like the United Kingdom and the United States (Rose, 2009).

#### 1.5.1 Limitations

In some ways, the scope of this dissertation is broad. It could perhaps have sufficed to explore either the legal casework, the abortion provider's practices or the experiences of couples and still glean valuable insights into how technologies remake death and dying at the beginnings of life through selective terminations. Yet, I chose to include all spheres in order to follow the institutional route from the moment of diagnosis to completed selective abortion, and to bring together the different voices and experiences of people involved in the making and handling of death and dying at the beginning of life. Yet, in other ways, my thesis is narrow. While some of the work I draw on specifically approaches prenatal diagnosis by bringing together people from different strata of society, I have not designed this project with particular social categories in mind. As such, we learn little about what differences make a difference (Bateson, 1973; Ingholt and Tjørnhøj-Thomsen, 2014: 21) at the imbrication of, for instance gender, class, race, ethnicity, and educational background in the practices and experiences of selective abortion. There are two primary reasons for this limitation. The first is pragmatism. Because large parts of my fieldwork took place during Covid-19 lockdowns in 2020, I could not gain access to any hospitals from where I could have recruited a wider participant group. Instead, I had to rely on recruitment of women and their partners through self-enrollment as response to a post I had circulated on pregnancy- and maternity websites and on social media. Consequently, overall, my interlocutors represent white, Danish and, to my knowledge, heteronormative sections of Danish society probably because these are those most willing to share their late term abortion stories. Secondly, while there was a spread in relation to type and length of education (one woman was a hairdresser, another a medical doctor) and place of residence (some lived in urban spaces and others in the countryside), I have not chosen to pursue these social identifiers analytically. However, as the empirical data called for attention to gendered differences, or rather bodily differences, in the experience of late term abortion procedures, I do include gender as a topic (Article 3).

Recruitment of abortion committee members and health staff followed the same strategy of circulating a written description of my research and the purpose of the interview via committee secretaries and with the aid of healthcare professionals who acted as my gatekeepers. I did not select participants based on intersectional representation but

on their job description and willingness to be interviewed. All respondents were white, middle-aged to older people. I have not inquired about their sexual orientation, marital status, gender identity or other social categories. Some did, however, disclose more intimate details about their life, such as personal reproductive struggles or experiences of miscarriage and abortion in their wider family.

#### 1.6. Structure of dissertation

The format of this dissertation is article-based. I decided to write an article-based dissertation to make my work more easily accessible to, and to engage with, social science scholars from an international audience working on selective abortion and other technologies of death and dying at the beginning of life specifically, and moral and medical anthropology more broadly. It is my hope that the scientific articles will be relevant for my interlocutors and others working within the biomedical and legal systems. To engage with the broader public, I reworked one of the articles into a Danish format and held a number of talks at seminars and conferences for committee members and health staff, through which I have had the opportunity to present and discuss my findings.

The dissertation consists of a framework including an introduction to the overall theoretical framework, methodological approach, the local historical and political context, and a conclusion. This is followed by three scientific articles. In between chapters and articles, several photographs, drawings and watercolor paintings are included, providing the reader with visual portrayals of some of the elements that make up the world of selective abortion, and working as artistic pieces of the selective abortion assemblage that I draw together and analyze. Due to the article-based format, some repetitions will occur.

The opening vignette, *Prologue*, sets the scene for the dissertation, providing a glimpse into the moral landscape that demarcates each of the empirical sites I have brought together. The first and present chapter, *Introduction*, gives a general introduction to the dissertation; its main research questions, aims, central argument and contributions to the existing body of literature on selective reproduction, abortion and matters of life and death at the beginnings of life. The second chapter, *The Moral Labor of Death at the Beginning of Life*, introduces the overall theoretical framework for the dissertation and positions the thesis at the intersection of medical anthropology, moral anthropology and anthropology of the state. In the third chapter, *Studying Moral Labor*, I unfold my ethnographic fieldwork and unearth how moral labor emerged as an analytical lens. The chapter discusses some of the methodological challenges and reflections that have shaped the process and data. Chapter 4, *Selective Abortion in the Danish Welfare State*, provides an analysis of the Danish welfare state and its shifting political frameworks

circumscribing the issue of selective abortion, both to situate the dissertation in a localized cultural and historical frame, and to shed light on the guiding principles for the governing of selective reproduction in present-day Denmark. The framework is rounded off with some *Concluding remarks* that present general findings and reflections. These chapters set the background for the following three analytical articles. While the articles can be read independently, they form pieces of a puzzle that also give insight into how institutions and agents of the state think and operate by exposing processes within and across institutional (medico-legal-care) boundaries and between these institutions and the intimate. As Vike notes, the strength of anthropology is that it perceives the connections between state institutions and everyday lives as relational (Vike, 2015: 5). These pieces of the puzzle are however also temporally and spatially ordered in the sense that they unearth what selective abortion requires before (legal authorization), during (clinical management) and after the procedure itself (women's and couples' experiences).

In the first article, entitled Guardians of healthy Family Formation: The Legitimation Work of Danish Abortion Committees in Cases of Termination for fetal Anomaly, I explore how abortion committees make legal decisions and legitimize their legal practice, mobilizing the concept of "legitimation work" (van Wichelen, 2019) as a framework for understanding the intermingling of law and morality. I demonstrate how legal, epistemic, moral and emotional concerns are entwined in the concrete handling of specific cases, and how an unease about being responsible for drawing the line between which fetuses are legitimately discarded and which are not is sought to be overcome by dividing and outsourcing the responsibility for current legal practice to "precedence," to other doctors and to the applying couples themselves. Article 1 is under review in the journal BioSocieties.

The second article, Orchestrating Moral Bearability in the Clinical Management of Second-trimester selective abortion, scrutinizes the clinical management of second-trimester selective abortion, which in Denmark is almost exclusively organized and handled as induction and labor in public hospitals settings. Together with my co-authors, Camilla Bruheim and Stine W. Adrian, we show how efforts to perform selective abortion as "good" medical events permeate clinical guidelines, relational care and material practices, arguing that selective abortion care is being orchestrated in ways that make the production of fetal death, and the visual and visceral confrontation with it, morally acceptable to all parties involved, which is to say, the orchestration of "moral bearability." Article 2 is under review in Social Science and Medicine.

In the third and final article, Shouldering Death: Moral tensions, Ambiguity and the unintended Ramifications of second-trimester selective Abortion in Denmark, I draw on data gathered amongst women and their partners, exploring their experiences of

undergoing selective abortion. The article demonstrates how the decision to terminate a pregnancy following the detection of a fetal anomaly catalyzes a series of bodily, material and social events that are experienced as morally confounding and ambiguous, leaving couples caught in a series of moral tensions between how to think about their decision to terminate, the dead fetus or child and their entitlement to mourn their loss. Article 3 has been published in Medical Anthropology Quarterly.

All three articles have been slightly modified in style to streamline the entire dissertation to American English.



# 2. THE MORAL LABOR OF MAKING DEATH AT THE BEGINNING OF LIFE

Numerous ethnographic accounts of cultural conceptions of the beginnings and endings of life have demonstrated the profound biomedical and technological shaping of the management of life and death situations (Adrian, 2017, 2020b; Gammeltoft, 2014; Gammeltoft et al., 2008; Gammeltoft and Wahlberg, 2014; Kaufman and Morgan, 2005; Wahlberg and Gammeltoft, 2017b), and how borders of life and death are negotiated, tinkered with and experimented with, drawing attention to the moral experiences, dilemmas and strivings of health staff, patients and relatives (Anspach, 2019; Jensen, 2010, 2011; Lemos Dekker, 2018, 2019a; Lou et al., 2017; Mesman, 2008; Navne and Syendsen, 2018). Many of these studies take analytical point of departure in the concept of "care" (Buch, 2015), showing how care practices performed at the threshold of life and death are profoundly moral enterprises (Sharp, 2018: 3). For instance, in a study on neonatal intensive care in Denmark, Navne and Svendsen show how medical staff coordinate care for all actors involved in the decision of whether to continue or withdraw treatment of critically ill infants with a concern for the infant, the parents and society. They call attention to how doctors perform "decisions as care" in ways that help them overcome their own moral ambivalences about life and death decisions through a commitment to "best possible care for all" (Navne and Svendsen, 2018: 254). In her study on attitudes of family members caring for people with dementia in the Netherlands, Lemos Dekker conceptualizes a family member's wish to hasten the death of their relative who has dementia as an act of care, noting that "death was welcomed as an end to suffering" (Lemos Dekker, 2018: 326).

In this thesis, I build on these rich ethnographic studies, yet I suggest that there is more to life and death situations than "the decision" (Risøy and Sirnes, 2015) about whether to continue or terminate a pregnancy or to prolong life or allow death following detection of a fetal anomaly, which opens avenues for understanding the differing forms of moral labor involved in enabling, handling, experiencing and living with death following such decision-making. Studies taking place in clinical settings such as in NICUs naturally focus on decision-making processes, because these are the sites and moments in which critical decisions must be made; however, if scrutinizing how such decisions are managed, justified and lived with months and years afterwards, past decisions and actions might become questioned and re-evaluated in the present and future. 38-year-old Camilla, for instance, who had terminated her pregnancy after learning that the unborn child she was carrying had Down's syndrome, told me during an interview that she followed a mother on social media who had recently given birth to a girl with

Down's syndrome. Following the mother and her baby online made Camilla feel ambivalent about having chosen abortion. On the one hand, she could track the struggles of caring for a chromosomally different child who suffered several comorbidities and went in and out of hospital regularly. On the other, it confronted her head-on with what she had chosen to terminate: a child who, all things being equal, lived, smiled and played. When the mother of the girl with Down's syndrome made a post on Instagram where she took issue with opponents of abortion who she criticized for being out of touch with the reality of caring for a child with disability, Camilla felt immediately reassured about her decision. She went straight to the keyboard to express her sympathy and gratitude to the mother. She showed me the message in which she wrote: "Your post today reminded me that the decision we made was made in love for the child we already have, and that it would have been taking a chance letting him [the fetus with Down's syndrome] move into our lives. Now he lives in our hearts instead, and in the garden of the cemetery where I stopped by today to lay flowers." As this excerpt shows, the moral legitimacy of certain actions is not fixed but needs to be continuously stabilized (van Wichelen, 2019). Communicating virtually with a mother who Camilla did not know personally can be seen, I argue, as one instance of moral labor through which she morally strived to confirm the decision as responsible and compassionate towards both the affected could-have-been child and the child she was already caring for.

In this chapter, I expand upon my definition of moral labor, and present the primary theoretical inspirations I draw on in my development of the concept, as well as in each of the three following scientific articles. As Pryke, Rose and Whatmore (Pryke et al., 2003) remind us, theory is not an add-on when analyzing our material and "writing up" the dissertation. All stages of the research process, from beginning to end, have theoretical implications; the ways in which I have asked questions, imagined the field and generated materials also come with a set of theoretical assumptions about the world, social and beyond. The chapter as a whole reiterates the suggestion that moral labor is increasingly becoming intimately and inextricably tied to life and death situations and domains as a consequence of expanding possibilities for technological interventions into life and death, with selective abortion as one particularly illuminating case.

## 2.1. Conceptualizing moral labor

In this thesis, I propose that the concept of moral labor might teach us something about how people wrestle with the making and handling of death following selection, as a legal question of "letting die" (Foucault, 1978), as a medical question of how to care well for abortion-seeking couples and dead fetuses, and as an intimate ongoing lived experience of moral ambiguity, as the above extract with Camilla shows. Moral labor encompasses

the work of welfare state bureaucracies, where boundaries between which fetuses can be made to die and which cannot are drawn and maintained through particular justificatory frameworks, or what I, drawing on the work of anthropologist Sonja van Wichelen (2019), refer to as "legitimation work" (Article 1). Moral labor cuts across the moral horizons of medical care work as carried out by doctors, nurses and midwives working in public hospitals, where such terminations are handled. It is these healthcare professionals who help carry the moral burden of responsibility for "choosing" abortion while simultaneously working to make selective abortion care morally bearable for themselves by subscribing to certain norms for good abortion care, work underpinned by deeply held beliefs in the advantage of making kin with aborted bodies (Article 2). Furthermore, moral labor is also carried out by couples in all the ways they work to come to terms with their decision and the void it has created, while also trying to incorporate the dead "child" (the word most frequently used by interviewed couples) into their everyday lives in personally and socially meaningful ways (Article 3).

As already noted in the Introduction, I define moral labor as the processes of legitimizing and stabilizing (however temporarily) the legally, morally and socially ambiguous and unsettling decisions and actions of selectively terminating anomalous unborn lives. I suggest this work is relational, meaning it is both be an inner form of work (directed at the self as a form of self-evaluation) (Laidlaw, 2013) and an outward form of work (directed at others as a form of conforming to dominant values and norms) (Humphrey, 1997). And lastly, it exceeds, as already mentioned, the moment of decision-making as the need for moral labor lingers on. In other words, moral labor is expressed and exercised in heterogenous and subtle ways and spans several temporalities. While I above conceptualize moral labor as something distinctive, I hope to show throughout the dissertation that it takes different shapes and forms depending on the empirical vantage point. I propose to characterize my use of the term "moral labor" as what the late American sociologist Herbert Blumer (1954) has called a "sensitizing concept." Blumer writes that:

"A definitive concept refers precisely to what is common to a class of objects, by the aid of a clear definition in terms of attributes or fixed benchmarks [...] A sensitizing concept lacks such specification of attributes or benchmarks and consequently it does not enable the user to move directly to the instance and its relevant content. Instead, it gives the user a general sense of reference and guidance in approaching empirical instances. Whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look" (Blumer, 1954: 7).

In other words, sensitizing concepts can be understood as prisms or heuristics that guide empirical research. As interpretive devices they draw attention to important features of social interaction and practice while obscuring other features. Building on Blumer's original concept, sociologist Kathy Charmaz refers to sensitizing concepts as "those background ideas that inform the overall research problem" and states further that "sensitizing concepts offer ways of seeing, organizing, and understanding experience" (Charmaz, 2003: 259).

## 2.1.1. A note on morality

With the concept of moral labor, I inscribe this thesis within a growing slew of social science studies scrutinizing questions of morality and ethics as a distinct field of empirical research (Davis, 2014; Davis and Love, 2018; Fassin, 2012a, 2012b, 2015; Harris, 2019; Kuan and Grøn, 2017; Mattingly, 2010, 2013; Nielsen, 2018; Zigon, 2009). Within anthropology, this burgeoning "moral turn" has been fueled especially by existential and phenomenological anthropologists who approach morality from the vantage point not of moral order, codes and principles but of moral experience, being and becoming (Das, 2012, 2020; Kleinman, 2012; Mattingly, 2013; Zigon, 2007, 2009; Zigon and Throop, 2014). My take on morality is dual. In my broad understanding of what constitutes "the moral," I do not preclude the orientation towards dominant moral norms and values. Rather, I take morality to inhabit a mode of "reflective self-evaluation" (Laidlaw 2014, 3), a relational practice of doing "good" in the uncertain vagaries of everyday lives (Mattingly 2013) and an orientation towards socially accepted "codes" (Humphrey, 1997). I find that Caroline Humphrey's take on morality precisely synthesizes this theoretical split between moral code and ethical self-reflexivity as she defines morality as "the evaluation of conduct in relation to esteemed or despised human qualities" (Humphrey, 1997: 26). This definition suggests that in relation to moral self-making, people not only reflectively evaluate their decisions and actions but also subject themselves to norms and values to which they aspire to conform; norms and values within which their decisions and actions are also fashioned in the first place. Similarly, Keane urges us to consider that ethical reflexivity is more than an internal state; reflexivity is practically conditioned and situated within a social world (Keane, 2014: 451). Indeed, as numerous conversations with women like Camilla, and with men like Peter, have taught me, selective abortion brings about a need for ongoing self-evaluation as people work at coming to terms with not only their decision but also with how to mourn the loss and inscribe the dead fetus or child into their lives. Yet I also found that this orientation towards reconciliation took shape not in isolation from but in relation to couple's friends and family, whose comments (or lack thereof) in some cases compounded their sense of moral distress. Living with a "chosen loss" in a cultural context where neither the depth of such a loss nor the need for the inscription of the abortion as infant loss are necessarily socially acknowledged instantiates its own set of moral conflicts.

My take on morality is undoubtedly shaped by the kind of access I was able to gain and the kinds of questions I came to pursue throughout my fieldwork. Being concerned with how people deliberate, account for and reason about selective abortion, I have gotten insights less into the "ordinary ethics" of everyday life (Das, 2012, 2015), and more the narrative, discursive and material elements through which abortion decisions and actions are justified. Put differently, it is, respectively, the various registers of legitimization and stabilization that underpin highly rigorous procedural processes of legal case management; ideologies of good abortion care; and personal intricacies of choice, responsibility and moral despair that I aim at chronicling in the three subsequent articles. Yet, it is also important to note that the grammar of moral labor varies across the sites and constituencies I have immersed myself in. For couples, late term abortion constitutes a lived experience after which nothing is the same again. Here, moral friction surged right to the forefront during interviews and conversations. In my dialogue with some committee members and Appeals Board members, it took more effort to get a sense of the moral horizon of their work. For instance, when I asked one juridical committee member how she would describe what she associated with the phrase "late abortion" through a drawing, she used two seconds to draw a paragraph mark. To her, committee work was strictly legal, drawing on a legal methodology developed through training, Likewise, when I spoke with health staff, it was apparent that the abortion practices which were quite similar across hospitals were seen as a matter of course; however, by probing them to talk about why they did as they did, the moral elements of their practices surfaced.

### 2.1.2. Reading materiality into moral labor: Laboring without child

In *The Managed Heart: Commercialization of Human Feeling*, Hochschild (2012 [1983]) coins the term "emotional labor" to portray the conflict between the demand for authentic, idealized emotions (such as happiness) and the repression of disapproved emotions (such as irritation). Emotional labor delineates attuning to and empathizing with the needs of another human being *and* the simultaneous management of one's own emotions in order to meet those needs, which then come to constitute invisible "extra" work one must grapple with while keeping up appearances. It is about putting on a smile to every customer, regardless of his or her mood, in the name of good customer service. Similarly, in her work on fertility clinics in Denmark, Adrian has shown how fertility clinic staff members managed their own emotions as well as the emotions of the couples in treatment through what she terms "emotional choreography" (Adrian, 2015). What Hochschild's

and Adrian's work help illuminate is the analytical attention towards *emotions as labor;* something that requires work oriented towards others and work towards oneself. This is part of the reason why I have chosen to use labor rather than work.

Yet when I adopt the concept of labor I do so also for its figurative meaning. As a metaphor, the term "labor" encapsulates the actual embodied undertakings involved in second-trimester termination; women must literally go through labor to effectuate a decision to terminate their pregnancy. Here, "labor" clearly is the more accurate denominator for the medical fix to a fetal problem than the word "abortion"; a secondtrimester termination is very different than what is often associated with "abortion," such as the taking of a pill, or—as I did in the beginning—with a surgical procedure under anesthesia where a fetus is removed. In Denmark, second-trimester abortions are almost exclusively handled as medically induced birth, often referred to as "mini-births." While normal birth involves contractions and pushing, resulting in the live birth of a baby that the parents get to bring home, in the context of second-trimester selective abortion, it involves the bodily labor of laboring, resulting in the birth of a dead fetus one does not get to carry home. In a sense, it entails an emotionally disturbing situation of what might be thought of as "laboring without a child." As Chiappetta-Swanson writes, "this procedure creates ambiguity for patients and their nurses as it is viewed as an abortion procedure by the medical profession, yet mothers must experience a labor and delivery. It is different from a full-term delivery only in that they deliver a stillborn" (Chiappetta-Swanson, 2005: 94). Similarly, Kuberska and colleagues note how pregnancy loss, here as termination for fetal anomaly, can be "distinguished from other forms of bereavement due to the liminal status of what is lost and its close involvement with the body; a death has occurred inside the woman's body" (Kuberska et al., 2020: 150).

In the remainder of this chapter, I outline the elements of moral labor to which I give prominence in the subsequent theoretical articles. While I do not directly employ moral labor as a concept in all the subsequent analytical articles, each article shows how "the ambiguous" is sought to be stabilized, and how "the unsettling" is sought to be overcome through practices "on the ground." Taken together, what we learn from these articles is not so much what it means to terminate a pregnancy, but rather *what it takes to make a death* (Svendsen et al., 2018).

### 2.2. Legitimation work

To a certain extent, the juridical institutional work of processing and adjudicating applications for abortion can be grasped as a politics of death, meaning that it is within these state institutions that the line between who can live and who can die are drawn (Agamben, 1998; Foucault, 1978; Troyer, 2020). The enabling of selective abortion to

take place relies on such medico-legal evaluations. Yet this study does not so much center on the techniques of power, play of forces or strategies that have constructed these state institutions as self-evident and necessary, as on how legal decisions are arrived at, what is at stake for committee members when dealing with such cases, and how they deliberate their role and responsibility as agents of the state. In the first scientific article, I pursue the question of what moral horizons guide committee members' adjudications, and what underlying norms and values these reflect. The work of Didier Fassin has been helpful in thinking through these questions.

In his article "Another Politics of Life is Possible" (2009), Fassin proposes a shift from biopolitics to what he terms a "politics of life." In developing his idea, he delineates several shifts with respect to Foucault's theory of biopolitics. He argues that politics is not only about the rules of the game of governing, but also about its stakes; more than biopower, contemporary societies are characterized by the *legitimacy* they attach to life what he refers to as "biolegitimacy"—and hence the politics of life is not only a question of governmentality and technologies of power, but also of *meaning and values* (ibid: 52). In expanding his notion of biolegitimacy, Fassin gives the example of three dictators and war criminals, Pinochet, Papon and Barth, who all avoided prison because they were deemed too ill to undergo punishment. In all three cases, humanitarian arguments of threatened biological life superseded the valuation of the atrocities committed in their political life. This kind of biolegitimacy, Fassin argues, has become a crucial aspect of moral economies of contemporary societies that shape politics of immigration and asylum, showing how, with the introduction of a "humanitarian clause" in France during the 1990s, refugees who could prove to have ill health would have greater success in gaining asylum than those who could not. Hence, the life of the sick refugee was legally catalogued as more valuable than the life of the refugee who suffered in other ways. By drawing on this notion of biolegitimacy, I have for instance focused on the ways in which healthy fetal life and abnormal fetal life are evaluated differently, and on the underlying norms underpinning these evaluative frameworks. These forms of justification follow entangled and interconnected legal, medical and moral vectors.

Drawing on the work of Fassin, anthropologist Sonja van Wichelen (2019) has proposed the notion of "legitimation work," which refers to "the ways in which people, institutions, bureaucracies, laws, and states enact, perform, and put to use certain rationales and legitimacies over others" (ibid. 8). Based on ethnographic fieldwork at a Dutch adoption agency, van Wichelen shows how legal changes, assisted reproductive technologies and the increased medicalization of adoptees have shifted the justificatory framework of international adoption from a politics of compassion, driven by humanitarian incentives, to a matter of global governance, pointing to how a human rights

language permeates the present-day world of international adoption. International adoption, she writes, has become a matter of securing rights for the adoptive parents, such as a right to procreate, and rights for the adoptee, such as a right to health (van Wichelen, 2019: 5). It is through the language of rights, van Wichelen shows, that justifications for international adoption are being enacted in practice. Borrowing Annemarie Mol's (2002) notion of "enactment," van Wichelen highlights how enactments (in this case, of human rights in relation to adoption) are far from stable and need to be continuously stabilized. This means that justificatory practices should be understood as processes of negotiation and sense-making, or as she frames it, an "ethics in the making." As Wichelen writes: "Justifications do not emerge from a vacuum, nor are they stationary; they travel" (van Wichelen, 2019: 8). Building on this attention towards the grammar of justification and the work that goes into stabilizing these frameworks of legitimacy, I explore the legitimation work of the committees and Appeals Board.

### 2.2.1. Maintaining order

When Britta, the committee member whom I introduced in the opening vignette, insisted that legal practice is not sliding down a slippery slope—since not only is genetic knowledge evolving, but also compensating treatment technologies are under constant development, potentially flipping certain diagnoses away from being legitimate grounds for abortion—this is a way of arguing for the continued necessity of the committees. But, more importantly, I argue, it is also a way of countering the implicit eugenic connotations of her work. By not acknowledging a future in which more and more fetal conditions are added to the "positive list," she is creating an imagery of her work as being un-associable with a slippery slope towards eugenics. As she disclosed later in the interview, she found it emotionally challenging to set these boundaries and allow death to happen, especially when the prognosis for the unborn child was uncertain. Interestingly, as the following excerpt from my fieldwork shows, it is undeniable that the so-called positive list is growing. The excerpt illuminates the ethics-in-the-making that characterize the juridical realm; it elucidates how the legal institutions work to continuously stabilize the moral legitimacy of selective abortion.

In February 2021, I gained access to a handful of "full" cases which had been rejected by one committee. Up until then I had only been granted access to abridged legal documents, which included gestational age, diagnosis, and the grounds for the decision (See Appendix 3.1 and 3.2). In contrast, these full cases gave insight into entire medical records, diagnostic test results, sonograms, as well as a much more comprehensive description of the course of events, and the counselling provided the couple. One of the cases concerned an immigrant couple who had applied for abortion in gestational week

23+2 due a rare deletion anomaly on one chromosome<sup>11</sup>. The couple had been in doubt about what to do as the diagnosis and prognosis were ambiguous, yet they had finally decided to apply for abortion, yet too late. The committee rejected the case with reference to the threshold of viability, presently set at gestational age 22+6. The two other cases both concerned malformation of the lower arms, one of them also involving a potentially shortened leg. In both cases, the applicants were around 13 weeks along in the pregnancy. When I asked the committee member, Susanne, who had kindly helped me access the cases and who had been part of processing them, why they had rejected the cases, she said: "According to the Appeals Board's practice, missing or malformed lower extremities cannot in isolation give access to termination of pregnancy. It wasn't serious enough, based on the motto that everything operable with a good result, and a child missing a lower arm who will be disabled to some extent, we're not inclined to view that as a serious handicap." Both couples appealed their case. The Abortion Appeals Board then overturned the decisions and granted the couples approval. In the decision letter of one of the cases, the Appeals Board wrote that:

The parents see the best-case scenario being that the child will be born with a physical handicap, which will cause physical limitations but may also cause psychological effects. The Appeals Board finds that the character of the condition, where the child as a minimum will have malformations of the left arm, gives adequate ground for abortion also given that the time of the ultrasound scan was in gestational week 12 and the [applicant] is now in gestational week 13.

The overruling left the committee astonished. The rationale even more so. They had never experienced before that low gestational age should factor into the assessment of these cases in this way. When I asked Susanne what this meant for legal practice, she replied that they would bring up the case at an annual meeting scheduled later in the spring to discuss the implications, and that they had also asked the Appeals board to specify what it meant for future rulings, as they needed, as she put it, "clear guidelines." When I asked if they had discussed any societal implications, the following exchange took place:

Susanne: Well [sighs heavily]...We've had the pleasure of having The Ethics Council, ha [laughs briefly], would you believe, where we've discussed some of these matters, because we've had a concern, I cannot deny that, about whether couples are now going to be able to pick gender, and are abortions going to be permitted based on that, and can't people accept minor handicaps, are we on a slippery slope? But that's just not the case.

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<sup>&</sup>lt;sup>11</sup> To secure the anonymity of the couple, more accurate description of the anomaly has been omitted.

Laura: But you say that a missing lower arm, or shortened arm, is a minor handicap, or at least not serious enough. How is that not a slippery slope?

Susanne: Eech, well. I think the things that people apply for are not any different to when I began this work in 2007. It's the same diagnosis. And it's so rare that a couple after medical counseling applies [when it isn't serious], because the fetal medicine specialists have their own list in their head of what may be granted approval and what may not, and the fetal medicine specialist in this case has noted, and informed the couple, that it would probably be unlikely to get a permission. Then he also informs them about the possibility of getting an abortion abroad [laughs], and we might discuss whether that's a bit too much, but em... so... em... Well, so from a societal perspective [sighs heavily]... em...I'm not sure what to say. We had a case recently about an entire missing arm, and the Paralympic Games had recently been shown on the telly, and one of my colleagues who was part of processing the case, talked about what she had seen you can do, play table tennis without arms and legs. So of course you can't help being affected by that. We probably don't agree what is a small and [what is a] big handicap, and I don't think we can ever reach an agreement about that in society, because some might consider this to be a serious handicap and others not.

Laura: But isn't it you, and ultimately the Appeals Board, who draws that line?

Susanne: Yes, [sighs heavily] ehm... It's difficult for me to give an answer to. I would have to think about it some more.

A while later in the interview, Susanne reiterated that she did not consider the cases to have enough "tyngde" (weight) to warrant a permission. She then referred to the third case they had rejected, stating "The case with the woman who was in gestational week 23, which we had to reject because she had crossed viability, if anything was sick, it was this fetus. Had she come earlier, we would without a doubt have given an approval." I asked Susanne how she felt about that, to which she replied: "I feel really bad about it. [...] It makes me really sad that because she's coincidentally passed a certain week, she cannot, and then there's a couple assessing that a shortened lower arm is going to be an incredibly severe disability [sighs heavily]. That's what makes this job so difficult."

I do not know how the cases concerning lower arm malformations have been discussed between the committees and between the committees and the Appeals Board, yet I do know that the overruling has shifted the assessment of such cases so that similar cases may well lead to approval in the future, despite the tangible moral unease the overruling triggered. This resonates with what committee members repeatedly said: that the Appeals Board sets the standards for which fetal conditions warrant an approval and

which do not—what I, in the first analytical article that follows, refer to as "bureaucratic legitimation work." As one legal member said: "[the Appeals Board] assesses if we've done it right or wrong. If they look at a case in a certain way, then we should, legally speaking, have looked at it in the same way as them. If we decline the case ... [but] the Appeals Board subsequently gives approval, then we would be bound to give approval the next time." In line with Caroline Humphrey's notion of morality, the moral significance that comes to the surface here is not what I might have expected—that the Board's overturning of the abortion committee's decision would cause debate within the legal system about where to "draw the line" (Williams et al., 2002). Rather, the moral here is more "the moral of the story" which consisted of making sure that the social contract between the committees and the Appeals Board was intact; that they aligned themselves with their legal superior, and that they did so collectively. Through this form of legitimation work, they maintain, I argue, a certain social order (Fassin, 2015).

### 2.3. Orchestrating death and grief in the clinic

Fassin's notion of biolegitimacy and van Wichelen's concept of legitimation work both originate in research focusing on *living* bodies, such as the immigrant and the adopted child. While Fassin touches upon death as an implicit aspect of the politics of life, noting how "no politics of life does not have a politics of death for a horizon" (Fassin, 2009: 53), he does not, however, expand on which defining characteristics set the governing of death and dying apart from the governing of life. In this thesis, I expand upon Fassin's concept by showing not only what values and meanings are attached to certain unborn lives over others, but also how dominant values, and associated ritualistic practices, shape how dead fetal bodies are handled, and the ideologies for good care that underwrite these practices. Doing so, I have sought inspiration in anthropological work that has explicitly explored death and dying empirically.

In her study of organ donation in Danish neuro-intensive care units, Danish anthropologist Anja Marie Bornø Jensen (2011) shows how nurses orchestrate death, such as through careful coordination, negotiation, ritualization and narrative strategies, to transform "the strange figure" of the brain-dead patient into a graspable condition that enables organ donation to take place in both morally permissible and socially meaningful ways. Theoretically, the concept of orchestration calls attention to the arranging and performing of practices to meet certain ends (ibid. 14). While the medical practice of selective abortion differs in many ways from the practice of organ donation, they share a set of characteristics. Firstly, in both organ donation and selective abortion, life and death intersect in disturbing and unfamiliar ways. While the "breathing corpse" of the braindead patient is what must be orchestrated in ways that make organ donation a decision

that is feasible for relatives to make (Jensen, 2011), for instance by assuring that the death is "real," in selective abortion the production of death is embodied within the woman. The pregnant woman in a sense carries both life and death at the same time, not knowing exactly when the life of the fetus ceases and it becomes a corpse one has to birth. Next, second-trimester selective abortion, handled as it is in Denmark as labor and induction, is a death unfamiliar to those who do not directly experience it with their own bodies. There is little familiar terrain for grasping both what second-trimester abortion really "is" and what it takes, unless you have yourself undergone it, or unless you work as abortion care provider, because it lies somewhere between the more familiar processes of normal birth and, to some extent, miscarriage associated with bleeding, cramping and clotting. Thirdly, selective abortion provision is a healthcare field in which much effort is made to turn selective abortion into a meaningful and caring experience; meanwhile it can also be captured as what might be termed "hidden death work:" following being clothed and shown to couples, the dead fetuses are covered up and carried from labor rooms to dirty utility rooms and further to the mortuary in ways that hide the corpse from view.

Reed and Ellis note how neonatal post-mortem work involves a range of practices that take place behind closed doors. Because this work concerns dead bodies, sociologists have often explored post-mortem work through the lens of "dirty work" (Reed and Ellis, 2020: 315). The concept of "dirty work" resonates with a great deal of social science research on abortion. As sociological scholar and abortion providers Lisa A. Martin and colleagues for instance write: "Abortion is 'dirty work'—a socially necessary task or occupation generally regarded by others as physically disgusting, socially degrading, and/or morally dubious" (Martin et al, 2020: 110). Chiappetta-Swanson argues that the work of being a nurse providing termination for fetal anomaly carries a greater scope of responsibility than do many other nursing roles "due in large part to society's negative views of abortion and the reluctance of many physicians to associate themselves with the procedure" (Chiappetta-Swanson, 2005: 94). Yet none of the nurses and midwives I talked to, however, referred to selective abortion care as "dirty work." Most talked about it as professionally rewarding. However, the concept of dirty work also draws attention to outsiders' views of the work in question and the difficulties this raises for those who do it. This aspect of the "dirtiness" of abortion work became apparent to me one evening when I was at a dinner at a friend's house. One guest, a friend of my friend, told me after I told her what I was researching—that she worked as a nurse with responsibility for selective abortion care. After a longer conversation about my findings, she disclosed: "I seldom talk with anyone about what I do." This illustrates that even in a cultural climate where abortion is largely considered socially acceptable and no anti-abortion political discourse pervades either the streets or the media, abortion work is in many ways

undiscussable. Another "dirty" dimension of abortion work is the violence that is sometimes part of the handling of dead fetuses, such as when biopsies for genetic testing must be undertaken. Such moments were emotionally and morally unsettling to midwives. One midwife<sup>12</sup> for instance said: "When you just cut the foot off, when you have to have the Achilles tendon, I've seen a doctor do that. It's totally disgusting and disrespectful. It's really uhhh [...] because I don't see the fetus in the same way as she [the doctor] obviously does. It's obvious. I can't help but think that it's disrespectful that you just don't care, that just because it's a bit difficult to take the Achilles tendon because it's a tiny little fetus, she just chooses to cut off the foot."

Drawing on the concept of orchestration has helped me be attentive towards how selective abortion care is arranged, for instance in ways to mitigate the brutality sometimes involved, what purpose this arrangement is seen as meeting, as well as with what effect(s). These questions pointed me to the ways in which nurses and midwives work to create morally bearable situations for all actors involved—for couples and health staff—as they worked both to help carry the burden of abortion by confirming the existence of the abnormality through particular visibility practices, and meanwhile also shaping the abortion as a sorrowful event that could, or perhaps even should, be mourned. Indeed, as I will show, visibility serves two generative purposes: both to legitimize the abortion as "right" by accentuating the abnormal features, and to support couples in their (real and imagined) profound grief by personifying the fetus as a precious infant. As I, together with my co-authors, expand upon in the second scientific article, we refer to this form of moral labor as aiming towards "moral bearability," meaning that abortion is orchestrated to empower couples to bear going through termination; and the staff to, in turn, bear what the couples are bearing, and also to bear the fact that they themselves are complicit in the making of death.

## 2.3.1 The imperative of attachment

Among the changing practices of selective abortion care is the way in which it has shifted from being handled as a non-event to a highly grievable event, echoing similar developments in, for instance, France and Canada (Giraud, 2016; Kjærgaard et al., 2001; Memmi, 2011; Middlemiss, 2021; Mitchell, 2016). Grief is not only anticipated but actively encouraged and promoted. This promotion of grief can partly be explained by flourishing anecdotal evidence that the pregnancy loss care of the past was "cold," causing great suffering to bereaved women and their partners, yet partly it must also be explained by the lack of distinction in everyday clinical practice between different forms

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 $<sup>^{12}</sup>$  I here draw on an interview conducted by midwife Camilla Bruheim, whose empirical data we draw on in the second analytical article.

of reproductive endings. I learned that most health staff treat selective abortion as they do miscarriages and stillbirths, and during interviews, nurses and midwives would often conflate stories of abortion with stories of involuntary pregnancy loss, even though I asked them specifically to recount their experiences of caring for couples seeking selective termination. The main theme running through each of these stories was the ideology of attachment as pivotal for the couples' psychosocial healing. When, for instance I asked Monica, "Where do these ideas about attachment come from?", she replied, "You are being woven into a certain frame of understanding. You are. There is no doubt about it. Of course, it's based on research, and narratives, and cases, both written and in real life."

The imperative of attachment coalesces in material and discursive form, which shapes the performance of second-trimester selective abortion care and post-abortive care in certain ways, while also shaping normative expectations for how women and their partners should respond to these practices. Because health staff strongly subscribe to attachment as beneficial to the repair work needed to be done by couples following selective abortion, it matters to these health professionals' experience of doing "good" abortion care when, through subtle work of persuading or nudging, they manage to convince couples to see, hold and commemorate their dead fetus; or when they find that the needs of couples and advice from healthcare services are already aligned. While all nurses and midwives I spoke with emphasized that their approach to these events was guided by an ethics of individualized care, and all mentioned that they began by asking the couples "Is this a fetus or a child to you?" to attune themselves to the specific couple and their needs, many also revealed that they made efforts to present the dead fetus to the parents regardless of the couple's expressed wishes. As one midwife told me: "I cut the umbilical cord, wrap the child in a cloth, and show it to the parents. And if the agreement is that they want to hold the baby then I give it to them then. And if they want to wait, then I'm holding the baby and I'll typically speak about it as a fine little baby. And that's to help them see the child the way I see it." Recounting one abortion, who Anne, a midwife in her fifties, had recently cared for, she outlined what happened as follows:

I take this tray and say, "Then I'll put her here." And the mother didn't want to see her, but the father did. And then I said, "Well, I'll let her stay in the room and cover her, and then if you change your mind, you can go over and have a look." And of course she did after she had given birth. And then we also talked about how it would feel like giving birth, that it might feel like bowel movements, and that it might feel like an urge to push or a tension either in the vagina or the colon... and then, yes, we talked about pain killers and that she could have an epidural, but she did alright on morphine and nitrous oxide. And then I had to attend this C-section and do some other things, and then luckily, she hadn't yet

given birth when I returned. And when I checked her, the baby was actually crowning so I say; "Well, I can see her, so you'll give birth shortly, and if you feel like pushing, just push. And then she gives birth like "plop," and I say immediately "She's not alive." And the mother still doesn't want to see her, so I do as we've agreed on; I place her on the cloth I've prepared and cover her, and the father goes straight to see her, and I've experienced this before: if I let the child stay in the room, then eventually the mother will be ready.

When I probed Anne why she used these tactics to nudge some into seeing their dead fetus, she explained, "One thing [is] to lay to rest certain fantasies. The other is [begins to tear up] about memorialization. It can be difficult to say goodbye to something you've never known, so it's about saying a proper goodbye. That's why I pressure them a bit to look."

Selective abortion care is imbued with this form of discursive and material moral labor, which involves the work of making women and their partners see and respond to their fetus as heath staff do; not as aborted human tissue but as a precious baby to be commemorated and mourned. It is important to note that this is not done to dissuade couples from obtaining an abortion or to make them feel remorse for having done so. In the Danish context, from the health staff's point of view, the legitimation of abortion as the "right" choice and the personification of the fetus are not contradictory practices. Rather, they go hand in hand. The challenges health staff face then are not primarily discerning what might constitute the morally appropriate action in each clinical encounter, but how to perform these care "scripts" when couples occasionally resist them. Several of my interlocutors spoke of women and their partners refusing to see and hold their dead fetus as "being in denial," causing great worry amongst staff as they predicted that the couples' psychosocial healing would be impeded.

As a final yet crucial note, this moral labor is conditioned by an additional material reality: the fact that almost all second-trimester abortions in Denmark are managed as medically induced birth. The materiality of birthing bodies and of dead fetal bodies is part of constituting the moral domain. After all, knitted clothes and speaking of a "fine little baby" would make no sense in the context of surgical termination where the product of conception is suctioned or removed in pieces. In other words, the promotion of attachment relies on the existence of complete fetal bodies.

### 2.4. Moral ambiguity

In Moral Selves and Moral Scenes: Narrative Experiments in Everyday Life, Mattingly (2013) asserts that in the flow of everyday life the evaluation of what is the best course of action might be messy, muddled and difficult to judge. She notes: "Even if one is

assiduous in trying to work on one's moral character, there is always the possibility of mistakes, unintended consequences, moral failure, or moral tragedy in which every choice and every action is somehow, morally, wrong" (Mattingly, 2013: 306). This notion of the fluidity of moral goods and wrongs is central to the work of Abraham and van Schendel's differentiation between the legal/illegal and licit/illicit (van Schendel and Abraham, 2005). They argue that while certain actions are defined formally (for instance through law and regulations) as illegal they might be socially considered as licit (morally justified). This blurring of the boundaries around legality/illegality has been generative in my being able to grasp the social and moral complexity of couples' late term abortion experiences. In the third and final article, I focus on the personal and embodied experiences of going through a selective abortion from the "patient perspective." I pinpoint how the embodied undertakings required to effectuate a decision to terminate signing a piece of paper, taking a pill, and giving birth to the fetus—give rise to a series of moral tensions concerning how to think about the event, how to relate to the dead fetus. and how to live with the chosen loss it constitutes. The moral labor I allude to here is the couples' ways of coming to terms with this moral confusion, arguing that despite efforts to lay to rest and settle the legitimacy of abortion, it remains ethically unresolved. Peter, whose abortion story opened the thesis, is one example of how my interlocutors grappled with a sense of moral ambiguity. Peter felt shame that he had chosen to terminate a life that he felt he ought to have been "capacious" ["rummelig" in Danish] enough to take care of, while at the same time feeling that he made the right decision for his existing child. As an extra layer to his moral confusion, Peter (like many others) struggled with how to think about the loss: as an abortion or as the loss of a dead infant? Peter had photographs of his dead daughter on his iPhone, but none on display in their home because, as he said, he did not want to "impose his loss on others." Beate, who opted for termination in gestational week 19 following the detection of a neural tube defect, spoke about how she worked at integrating her dead daughter, Emilie, into her everyday life yet met silence from friends and family when talking about her. She explained: "We shouldn't cultivate it [Vi skal ikke dyrke det], but we shouldn't ignore it either. Emilie is here. She's here in some way. So, it's okay if I say, 'I was just at Emilie's grave the other day and left her some flowers.' Then it would be nice if someone said, 'Oh, okay, what did you buy for her?' But they prefer to talk about the next football match, or the weather forecast for the weekend. That's not nice."

The need to legitimize abortion as "the right decision," while also legitimizing it as experienced "loss" lingers on for many of the women and partners I spoke with, and while some of the women and couples I spoke with had reconciled the decision with themselves, for others the abortion had had detrimental consequences. Henriette, a

woman who likewise opted for abortion following the detection of Spina Bifada told me: "Den dag jeg begravede Sonja, der begravede jeg også min mor-følelse [The day I buried Sonja, I buried my sense of being a mother too]." She recounted how her grief overshadowed her ability to be a mother to the children she had had in the following years, ending in separation from her husband and years of therapy, which however had not succeeded in her regaining her capabilities to take care of her children. She was, eight years down the line, still devastated by the ordeal. One woman, in contrast, highlighted the abortion (the only one amongst my interviewees that had taken place surgically) as tough, but also personally transformative as it catalyzed seeing her husband—whom she had experienced as unsupportive and distant—in a new light, giving her the needed push to file for divorce and create a new life for herself.

In her study on end-of-life care for older people with dementia in the Netherlands, Natashe Lemos Dekker has shown how, when they die, older people with dementia are grieved for even though their life might have been considered undignified and unworthy of living; she argues that relatives' acceptance of death for their loved ones can be seen as a form of care (Lemos Dekker, 2018). While most of the couples whom I have engaged with in this study also implicitly framed abortion as an act of care, and many grieved the loss they had "chosen," this seeming contradiction between unworthy-yet-grievable, which challenges Judith Butler's notion of a certain correlation between life value and grievability, is perhaps even more complex in my study than in the context of the end of life with dementia. As I argue in the third scientific article, moral tension around selective abortion emerges not from an intrinsic moral distress caused by abortion, but through being caught in the conundrum of three seemingly contradictory discourses: a medical discourse (enacted by fetal medicine specialists) that typically casts fetal conditions as important to catch and hence the detected abnormal fetus as "dangerous" and "futile" and therefore legitimately terminated; another (enacted by nurses and midwives) that typically casts the abnormal fetus as precious and baby-like and hence mournable, and a third that questions that late term abortion is akin to baby loss in the wider society, which hence creates uncertainty about how (and whether) to legitimately express grief over something that has been opted out of (Abraham and Van Schendel, 2005).

This moral friction must be seen in light of the figure of the fetus occupying a socially contested space. In Denmark, a fetus that comes into the world after the twenty-second week 13 of pregnancy without showing signs of life is legally considered a stillborn

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<sup>&</sup>lt;sup>13</sup> The current threshold of 22+6 gestational age was reduced from 28 weeks in 2004, partly in consideration for the parents and their feeling of having lost a child, partly due to medical developments according to which premature infants can be saved earlier, and partly due to health staff's conscientious objection to performing abortion on viable fetuses (Dam, 1998).

child, who will automatically be given a CPR number, a death certificate and to whom the bereaved parents are obliged to bury. Given it is legally classified as a dead infant, the parents are granted paid parental and "bereavement leave" (URL 2). By contrast, a fetus born before 22 gestational weeks has no separate personhood, and the event is classified as an abortion. In this case, parents are not granted any paid parental nor bereavement leave but can ask for sick leave via their general practitioner. The fetal body is, from the outset, legally classified as biological risk waste and should be disposed of as such but can be, if the couple so wishes, handled differently. To complicate matters, in case a fetus younger than 22 gestational weeks is born showing signs of life (such as breathing and pulsation), it shifts from being classified as an abortion to a *live-born child*, triggering the same rights but also duties as outlined above. According to the Danish Board of Health, when a fetus shows signs of life and is classified as a live-born child, this does not mean it is viable and unlike infants born extremely prematurely, who might receive life-saving treatment, live-born fetuses that result from a medically induced abortion will not be given any treatment, only care. An irretrievably dying child will typically be swept and held until its heart stops beating. Thus, viability and life signs, as defined by biomedicine, act as the differences that make a difference regarding the value and meaning of the fetal being (Middlemiss, 2020). Though these rules and regulations clearly distinguish a nonviable and non-living fetus younger than 22 gestational weeks as a non-person, given that they intersect with prenatal visualization and monitoring technologies, such as ultrasound, personhood has in many cases already been tentatively ascribed to these fetal beings regardless of such legal classificatory boundaries (Rothman, 1993a, 1993b). Numerous social science scholars have shown the pervasive social production of fetal beings through biomedical technologies (Adrian, 2017, 2020a; Blum and Casper, 1999; Gammeltoft, 2014; Mitchell, 2016; Mitchell and Georges, 1997; Taylor, 1998, 2002; Tjørnhøj-Thomsen, 1999), through the regulation of material fetal bodies (Memmi, 2011), and through different practices of "making kin" with the dead fetus and its body, such as following the death of a fetus (Earle et al., 2013; Layne, 2003). Importantly, as will be expanded upon in the second and third scientific article, this personification extends into the realm of abortion, as terminations are set in motion and performed in the clinic.

Adrian (2020b) argues that "understanding how technologies remake death is relevant and important because the technologies "situate potential parents in moral dilemmas, while reconfiguring who and what may have the responsibility of fetal and infant death" (ibid. 156-157). Echoing this call for paying attention to selective abortion as opening questions of death and dying, I argue that these incoherent values attached to the fetus tie into the experience of the late term abortion as unsettling and ambiguous, while, in turn, also complicating care provision on the part of health staff, who must

maneuver a socio-legally fraught terrain. In my view, this incoherence between legal regulation and on-the-ground practice produces conceptual quagmire that co-construct the moral friction experienced by couples arising through and after the process of termination. I argue that the different legal and social renderings of the fetus turn it into a hybrid of sorts that is orchestrated into highly different "matter" depending on the biomedical, legal and policy thresholds and measures that define it, which leaves it up to the couples to make a series of additional "choices" about what meaning and value the fetus should be granted. As Christina, who went through induction of labor in gestational week 21, said:

They also say that if the baby is born before 22 weeks, it will not get a CPR number [personal identification number] unless it's breathing when it comes out. And it is referred to as an abortion. And I also think that's difficult. Am I really sitting here 5 months later crying over an abortion? Why is it an abortion and not a child? She was born 21+5. If she had been born 22+0 then everything would have been different. Now I don't have rights to anything. You can get sick leave, but you can't get bereavement leave, because you haven't had a child. Am I sick or am I not sick? Should I go to work, or should I stay at home and take care of myself? Who am I now when I didn't become a mother?

Thus, unlike an older person with dementia who has lived his or her life, whether and to what extent a fetus counts as a person, or even a life at all, is a highly politically and morally contested question, as well as an issue that is culturally and historically located and shifting (Conklin and Morgan, 1996; Morgan, 1996, 2002; Withycombe, 2015). American scholar and abortion provider Lisa Harris argues that women and their partners opting for abortion can hold a "tension of opposites" (Harris, 2019), meaning that they may experience abortion as both morally fraught and legitimate at the same time. Following this relational ontology, such apparent tensions of opposites do not, as we shall see, configure a contradiction in the Danish context. In the Danish welfare state, the logics and practices that enable second-trimester selective abortion to take place in automatized and routinized ways do, on the one hand, position couples, legal experts and health care professionals in emotionally and morally troubling situations, yet on the other, no one questions the acceptability of ending anomalous life. Indeed, as I hope to show, while women and their partners feel disturbed by having "killed" their own fetus, they also feel that it was the "right" and only choice graspable in a time and place that regards disability as a disaster. And while legal experts and health staff were confronted with ethical dilemmas and emotionally unsettling situations, the general subtext of the unsettling emotions is a sense of doing a state-appointed deed in the best possible way. In this way,

the need for moral labor converges with the moral imperative of selective abortion, fundamentally seen as being in accordance with "the social good".

To return to my overall research question (in what ways does moral labor shape how second-trimester selective abortion is legitimated, practiced, and experienced in welfare state Denmark?), in this chapter, I have showed how, across each of the three domains, moral labor is, despite the dominant rhetoric focused on individualism, choice and autonomy, highly shaped by a need to divide moral responsibility for life-ending decisions and actions, as well as to "fit in" and conform to the norm. In a place like Denmark, moral labor is not, unlike the Rabbinic model of moral labor, oriented to what is theologically permitted, but toward a different set of processes, including consideration for norms. For lawyers and doctors working in the abortion committees, this "fitting in" to norms is translated especially into an obligation to abide with legal precedence. For health staff this is, in turn, translated into performing grief-acknowledging care and promotion of bonding. And for women and their partners, a sense of individual responsibility for the loss inflicted upon oneself intersects with orientation towards how to handle and live with the loss. Couples work at reconciling their decision and loss while adapting their life as "bereaved" to what is socially accepted. In other words, the need for moral labor is prompted not only by confronting life-and-death decisions and actions but is also prompted by being confronted with competing and fractious discourses, which must be navigated and, to the extent possible, reconciled.



# 3. STUDYING MORAL LABOR

This chapter takes its point of departure in the methodological question: How does one study moral labor? To be sure, when I set out to explore selective abortion, I did not start out with moral labor in mind. At the beginning of the project, I was curious about how couples accounted for their decision to opt for termination, as well as how legal representatives and healthcare professionals reflected on the medico-legal practices surrounding selective terminations. It was their way(s) of describing, reasoning and adjudicating about selective abortion I was aiming at inquiring into. However, the diverse ways in which moral questions, concerns and practices emerged during fieldwork made it apparent that I was somehow witnessing how people actively wrestled with the moral ambiguities related to making, being complicit in and performing fetal death; meanwhile I was also witnessing how the field I was studying was moving and shifting. In this way, the concept of moral labor grew from the ethnographic encounters and the empirical data material that multiplied in size, breadth and complexity as the weeks and months of fieldwork went by. Looking back now, though, the seeds for developing the concept were planted early on. However, I did not realize this until thinking across the interrelated categories of "legitimation work," "moral bearability" and "moral tensions" which I address in the three scientific papers. Importantly, moral labor as prism also emerged through how I cartographed my "field imaginary" (Marcus, 1998; Massey, 2003: 84) to include three spatio-temporal sites—the authorization/committees, the effectuation/clinic and the experience/home—using a partly assemblage, partly implosion methodology. For me, the assemblage ethnographic approach (Wahlberg, 2018) helped me to make these spatio-temporal "cuts", while also embedding these within a larger politico-historic genealogy, while the implosion method (Dumit, 2014) informed my way of unpacking connections and complexities within and across each realm, especially the material and bodily elements of selective abortion. In conjunction, these approaches have inspired me to question practices and statements that appear "naturalized" and taken-for-granted, fueled by a commitment to demonstrating the intended and unintended social and affective implications of present-day selective abortion practices.

In the sections that follow, I expand on the description of moral labor that I gave in Chapter 2 by presenting the ethnographic avenues I pursued to bring the moral contours of selective abortion into view. In the following, I describe how the fundamental collaborative nature of my work was formative for my fieldwork and analysis, as well as for the ethical dimensions I have considered throughout the research process. I end the chapter by outlining the primary methods I used and my analytical strategy.

## 3.1 Methodological avenues and reflections

## 3.1.1 Collaboration, and the work of juxtaposition

When the TechnoDeath project was initiated in January 2020, I became part of an interdisciplinary group of three ethnographers and two legal scholars, including myself and my supervisor and the PI of the project, Associate Professor Stine Willum Adrian. In collaboration, the five of us set out to investigate different technological domains that could shed light on the overall research question: How do technologies remake death and dying at the beginning of life? The project was divided into three empirical sub-questions; How does death at the beginning of life emerge? How is death and dying managed? And how is death lived with? I was designated to explore the first question through selective abortion as my case, and because this question centered on death's emergence, an exploration of the abortion committees' case handling had been pre-defined. It was, likewise, already defined that I should corporate closely with one of the legal scholars, postdoctoral researcher Annika Frida Petersen, who was appointed to map the legal decisions with the aim of creating transparency around the operation of the abortion law. Preceding the TechnoDeath project, the second legal specialist in the project, Professor Janne Rothmar Herrmann had for years attempted to gain access to legal documents, yet previous requests had been declined with reference to the personally sensitive nature of the cases. Until 2011, the Appeals Board published an annual report, summarizing the board's criticisms and results of all decisions and a summary reason for these decisions, which gave further justification for denying access to their cases. Following an inquiry from the Data Protection Authority in 2011, it was concluded that guidelines for anonymization had not been followed sufficiently, leading the Appeals Board to delete all annual reports from the website. Consequently, the legal system regarding late term abortion became completely shrouded in secrecy (Petersen and Herrmann, 2021). Yet, when a reorganization happened in the Danish Board of Health and the Appeals Board was appointed a new secretariat, Herrmann's request for access to documents was accommodated. The board explicitly emphasized countering secrecy as their incentive for suddenly allowing access to documents, highlighting that they wanted to be "open" about their legal practice (ibid.: 2). Thus, thanks to the determined preparatory work of Herrmann, we were granted access to 663 legal cases, of which 43214 concerned fetal abnormality. The remaining cases concerned mostly socio-economic indication, few

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<sup>&</sup>lt;sup>14</sup> Of the 432 legal cases, only four had been declined. Of the four rejections, two were given due to viability, meanwhile the remainder were rejected due to lack of severity. One rejection concerned a monochorionic twin pregnancy, thus no fetal abnormality had been diagnosed, but the case was likely put forward because the prospective parents feared the elevated risk of prenatal complications associated with monochorionic twins.

young age or ethical indication (rape or incest). Yet, as the documents were all covered in black lines of redacted text to preserve the anonymity of the applying woman, there was much that could not be gleaned from the documents in themselves. This begged for an ethnographic study, as we had to talk with legal representatives to gain more substantial knowledge about the underlying logics behind these decisions, and to enter the "machine room" of the juridical system as best as we could.

In addition, I persistently tried to gain access to undertake participant-observation during committee meetings, as I wanted to be present *while* legal decisions were made, but my request was declined due to GDPR regulations and, yet again, the cases' sensitive nature. I would have to get informed consent from the applicants, which was considered strenuous work that would ultimately be imposed on already busy fetal medicine specialists or committee secretaries. Generally, the impression I gained was that, given the highly vulnerable position of the women who were applying for abortion, it was unethical even to ask them permission when the purpose was only to meet my own research interest. Moreover, it was felt that it could alter the relationship of trust between fetal medicine specialists and the women applying and add to the trauma of learning that one's fetus had been diagnosed as abnormal. Acknowledging the potential secondary trauma my research might cause, I decided to settle with the valuable data material that we could generate through interviews.

The legal documents proved extremely valuable in that they gave us an idea about the overarching pattern and statistical differences, such as between approval and rejection in each case type. Trawling through the documents, we saw that some of them appeared very similar yet had resulted in different outcome. The documents thus gave some answers, but raised a number of crucial questions, such as: What is the significance of gestational age when evaluating these cases? What forms of knowledge do committee members draw on? What is the tipping point between approval and rejection? How do they assess fetal medicine cases differently from socio-economic cases? What is required for a woman applying on socio-economic reason vis-à-vis fetal indication? Why are some cases given a thorough explanation for the approval while others were blank? What difference does a 15 % risk and a 50 % risk of developing a developmental disorder make for whether or not committees regard these cases as fulfilling the law's requirement of "seriousness"? Thus, as we began our collaborative work, we aimed at unraveling these questions, with Petersen wearing the hat as the legal specialist who could translate the law to me, meanwhile I wore the hat as primarily responsible for conducting interviews.

Due to our collaboration and Petersen's interest in all case types, and although my own focus was specifically on the fetal medicine cases, when we began conducting interviews with committee members (who had volunteered to take part in our research

following a dissemination of an invitation letter), we probed into all types of cases. In this way, we used a method of juxtaposition (Svendsen, 2022: 16). As Svendsen notes, juxtaposition has affinities with the traditional anthropological approach of comparison, yet where comparison moves across geographic differences and similarities, juxtaposition works by troubling "categories and framings" (ibid.). This approach turned out to be fruitful because it elucidated the differences in approach through which the logics pertaining to fetal medicine cases stood out more clearly. Juxtaposing different case categories made us see unexpected nuances in the "imperative of death" that dominated cases of fetal anomaly, and, conversely, the "imperative of life" that stood out more clearly when the fetus was deemed healthy. We learned for instance that while the criterion of viability at 22+6 weeks of pregnancy officially demarcates the upper limit of late abortion, in socio-economic cases, the committees operate with an unofficial upper threshold of 18 weeks, after which considerably more social and psychiatric "weight" [tyngde in Danish] must be made demonstrable to warrant abortion; meanwhile in cases of fetal anomaly, the viability threshold is strictly followed even though several committee members recognized that some fetal conditions are more serious than others, as the excerpt with Susanne in the previous chapter illuminated for a critical legal analysis of this unofficial 18 weeks limit, see (Herrmann and Petersen, 2021; Petersen and Herrmann, 2021). We also learned that whereas termination of fetuses deemed anomalous were generally considered legitimate to prevent suffering, normal fetuses that were close to viability were often framed as more "sacred". When I asked how they considered the implications of being born into an existence where you were unwanted and the socio-economic resources of the parent/s scarce, all committee members agreed that such normal unborn lives could blossom and live a good quality of life through the municipal interventions and aid, such as housing, that would be offered. Some replied that such children could bring joy to others through adoption. Thus, while the life of the unwanted yet healthy fetus was deemed prosperous, the fetus diagnosed as "pathological" and "abnormal" was

catalogued as futile, unless the abnormality could be "compensated", as several committee members mentioned. And not a single abortion committee or Appeals Board member mentioned the probability that a couple would even consider adopting an abnormal child. Adoption was simply not mentioned in relation to fetal abnormality. By bringing these different case types into dialogue, it became apparent to me that normality and the capacity for productivity and reciprocity constitute quintessential values of the Danish welfare state, at least if we take abortion committees and the Appeals Board as legal administrators who work as the extended arm of the state.

The interdisciplinary nature of the interviews, and my subsequent conversations with Petersen about the emerging data, were formative for my analysis, as Petersen's knowledge about what is dictated by the letter of the law and what is not, both enabled me to understand the abortion law better and made the cultural, emotional and moral dimensions of the committees and Appeals Board's work stand out more clearly. For instance, Petersen made me aware of the implication for unequal access to abortion caused by the informal 18 weeks threshold that the letter of the law does not dictate. Yet occasionally I also found myself caught up in the legal perspectives, and in Petersen's agenda of creating legal transparency, finding it challenging to distinguish the legal from the anthropological questions. In a sense, I had to distance myself from the myriad of critical perspectives embodied in these other case types that went beyond the scope of my study in order to focus on my own research agenda. Juxtaposing logics across the different case types thus became a way for me to maintain focus on the disability-selective cases while drawing on what I had learned about the juridical abortion system more broadly.

# 3.1.2. Probing the unfamiliar in familiar waters

While the legal question was central to my project, I had, as already mentioned in the Introduction, an interest in exploring the processes before, during and after the abortion itself, and the infrastructure around it. The theoretical backdrop of the overall TechnoDeath project was "socio-technical", meaning an approach which regards technologies not as separate from but always entangled with culture and society, and which involves an attention to technological practices relating to death as material-discursive in nature (Adrian, 2020b; Barad, 1998; Schwennesen and Koch, 2012). With this overarching feminist STS framework already laid out, we were all invited to take part in developing each of our subprojects further, both theoretically and methodologically. Thus, I decided to expand upon the initial design by inquiring perspectives of couples, as well as health care professional working as abortion providers. I was curious about how women and their partners experienced having to apply for an abortion. And I was curious about the clinical handling of aborting bodies and dead fetal bodies. In other words, the

scope of my project expanded to include both how death emerges, is handled and experienced.

In the first months of fieldwork at the beginning of 2020—preceding the interviews I would conduct with committee members—I described myself and the purpose of my research in a letter targeted at people, including couples, who had experienced late term abortion for fetal anomaly first-hand. I circulated this letter on several online maternity websites, on my own Facebook account, and on a closed Facebook group for bereaved parents after having obtained permission from the National Organization for Infant Death, *Forældre & Sorg* [Parents & Grief], which mediates the group (see Appendix 1.4). Upon posting the letter, I received more than 30 responses within three days from people wanting to participate. During the weeks that followed, I was already conducting the first interviews, traveling to meet the interviewees in their homes or setting up a Skype- or Zoom connection to meet them online, as the Covid-19 pandemic spreading in Denmark as well as around the globe at the time required taking social distancing into account. Simultaneously, I spent time searching the internet for blogs and trawled through Instagram to gain a sense of how lived experiences of late term abortion were portrayed on different virtual platforms.

As mentioned in the Introduction, I had previously conducted ethnographic research on motivations for using or refusing routine prenatal screening in Denmark, so at the time, I had certain expectations about what I would find. To be more specific, in 2011, I followed 12 women who had undergone routine prenatal screening and eight women who had refused either all or some of the prenatal and diagnostic tests offered routinely as part of standard antenatal healthcare. During interviews I probed a little, asking these pregnant women what they would do if learning that something was wrong with their fetus. Through these conversations, I learned that for the "users" of prenatal screening, the screening occupies a taken-for-granted stage on the route to parenthood, while for the "non-users," prenatal risk information was to be avoided to escape having to make a difficult choice between keeping or ending a pregnancy they fiercely wanted. I also learned that the users regarded the hypothetical scenario of opting for selective abortion in the event of a positive diagnosis as a seemingly morally unproblematic "way out" of the pregnancy (See Heinsen, 2017). These women, by and large, depicted termination as a recommendation by the state and therefore not a morally troubling choice, notwithstanding its hypothetical quality. One pregnant woman for instance 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" (ibid. 79). I also felt I had a good general understanding of the culture of pregnancy and prenatal screening in Denmark due to my own lived experiences of pregnancy and birth. Being a mother of two children, I have myself experienced the

sense of tentativeness (Rothman, 1993a) and anxiety that uptake of routine prenatal screening brings about, as well as the relief that comes when you are reassured that the fetus is healthy and growing. Yet when I began interviewing women and their partners about their experiences of selective abortion, I did not expect to hear accounts of moral conflicts; I expected to hear stories about sadness, disappointment or disillusion over the fact that they were the ones being struck by reproduction "gone awry." I would soon learn about the "seriousness" of choice, to paraphrase Rapp (Rapp, 1999: 226), and its gendered configuration.

Christina terminated a pregnancy after the fetus she was carrying was suspected to have a rare genetic disorder. She called me shortly after I had posted the call for participants on Facebook. I told her that "I would like to ask you a bunch of questions covering the entire process from when you and your husband received the diagnosis, to when you and your husband signed the application, to when you went through the abortion itself." During the intense, emotionally charged conversation, she replied with dismay: "You know, my husband is not upset. He's already planning for the next baby. He feels this was for the good of us as a family, but I feel I've lost my child. And it was all laid on me. He didn't sign. I signed the paper. I took the pill. I killed my baby. That's how it feels, because really, I was the one who had to do all these things".

This sense of having to shoulder the responsibility for a chosen (but not wishedfor) death, and the ensuing guilt and shame, was very different from the stories told by the pregnant women from the previous research project. They talked about abortion as normalized and recommended by the state, whereas Christina and other women talked about abortion, notwithstanding the state's permission, as an individual responsibility they had to carry, marking their bodies, lives and worldview in unpredictable and unexpected ways.

One day, I stumbled upon a written piece on the website of the National organization of infant loss, *Forældre & Sorg* [Parents & Grief]. The author, who together with her husband [Thomas] chose to terminate her pregnancy following the detection of a serious kidney malformation, wrote:

I don't think you can as a human being be confronted with any bigger and more serious choice than the choice between life and death. It brings us to the very edges of our own life [...] I felt guilty that my son didn't get a life among us. I talked about [the fact that] that I was going [to the hospital] to sign the paper that I would kill my child. Thomas decided very quicky that he too would sign to take responsibility and try to share the guilt and pain with me, take it on him, even though it was my body. It helped a lot although of course there is no line for the father to sign. Thomas had a particular way of thinking about it, which I've stuck to, which was that by making the ultimate decision that our son's life should stop, we carry

the pain that he would have carried if born into this world. Thomas made it possible for me to think more gently about myself and our decision. By learning to think that we could take away the pain from all the operations he would have had to go through, the suffering from being this hospital kid with acute hospitalizations, examinations, blood work, constant nausea and fear of death. We literally took on the most brutal pain and grief when we chose to induce labor in week 22. But it helped thinking that we carried the pain for our son (emphasis added). Then at least we did something for him, and took on the responsibility as parents (URL 3).

According to anthropologist Michael Jackson, storytelling can be a resource of meaning-making as "in telling a story with others, one reclaims some sense of agency, recovers some sense of purpose and comes to feel that the events that overwhelmed one from without may be brought within one's grasp" (Jackson, 2002: 36). This narrative of abortion as an act of parental responsibility, expressed as "carrying the pain for our son" no doubt serves to make sense of an excruciating decision imposed on the couple as well as the loss brought in its wake, yet it seemed to me to encompass something more than meaning making. It expressed something that seemed to aim also towards negotiating and legitimizing ones' own moral self in relation to others.

Again, juxtaposing old and emerging data sparked a sense of treading unfamiliar ground and, more importantly, proved that I had to reconsider what I thought I already knew and would come to know about selective reproduction in Denmark. Through hours of deeply moving conversations, as well as through reading blogs and social media posts, I realized that despite selective abortion being the social norm to which most subscribe, it is profoundly morally unsettling for those who embody these chosen losses, which people try to settle and lay to rest in the days, weeks, months and, for some, years that follow. And as I would later learn, when my fieldwork expanded to include fetal medicine specialists, gynecologists, nurses and midwives, moral unease and the need for moral labor runs across all realms.

## 3.1.3. Thinking with materialities

The sense of the moral load of having to sign a piece of paper, take a pill and actively give birth, as highlighted in Christina's words earlier, did much more than give me a sense of unfamiliarity within familiar waters. It also pointed me in a direction to which I had not given much consideration before embarking on fieldwork. Though having done research on selective reproduction "at home" for several years—exploring the existing literature on prenatal screening and diagnosis primarily, and, secondarily on abortion in Denmark and beyond—I did not know anything about how such terminations are carried out. Christina's words alluded to the importance of the materiality of late term abortion

processes and procedures, which called for an analytical approach and ontological thinking that could take seriously the entanglement of, and connections between, discursive and material elements and frictions in the becoming, shaping and performance of selective abortion and the implied handling of fetal death.

In the past decade, a considerable body of literature termed "the material turn" or "new materialism" has formed, giving more prominence to material things, objects and technologies in social life, arguing that not only humans have agency; material matter also does, and is actively part of making the world. Central to this perspective is a rethinking of the relationship between nature and culture to overcome the binary between social constructivism and essentialism. Critiquing postmodern thinking for favoring "mind over matter, soul over body, and culture over nature," as Rick Dolphijn and Iris van der Tuin write in their selection of interviews with new materialist thinkers (Dolphijn and Tuin, 2013: 119), scholars such as Donna Haraway, Karen Barad, and Bruno Latour have questioned the distinction and hierarchy between entities, arguing for a perspective that understands entities such as mind and body, discourse and materiality, as related, connected and entangled. Donna Haraway's extensive authorship has made her famous for her figurations, such as the "cyborg," and for her conceptualization of "imploded knots" as a methodological approach to exploring the interweaving of materiality and culture (Haraway, 1997). In an interview, Haraway explains her approach in the following way: "I have this family of entities, these imploded objects: chip, gene, cyborg, fetus, brain, bomb, ecosystem, race. I think of these as balls of yarn, as gravity wells, as points of intense implosion, or as knots. They lead out into worlds, you can explode them, you can untangle them, you can somehow loosen them up. They are densities that can be loosened, that can be pulled out, that can be exploded, and they lead to whole worlds, to universes without stopping points, without ends. Out of the chip you can in fact untangle the entire planet, on which the subjects and objects are sedimented" (Lykke et al., 2008).

Reading Dumit alongside listening to women describe their abortion experiences as one haunted by the material undertakings they had to bear, heightened my analytical awareness of the material objects and practices that are part of constituting selective abortion, such as the legal application form—a single piece of paper—and the tiny pill of Mifegyne (consisting of mifepristone) that sets off the abortion procedure by blocking the hormone production, and which, notwithstanding its small size, had a very palpable impact of my interlocutors' abortion experience. Thinking with these materialities as I listened again to the moving personal abortion narratives, sparked in me a curiosity regarding the historically shifting approaches to the clinical management of abortion, and to the normative underpinning of legal decision-making and selective abortion care. Wahlberg's concept of assemblage ethnography and Dumit's implosion methodology

helped me to see that the ways in which selective abortion is "done" in contemporary Denmark is not a natural "given," but the outcome of a complex web of social, legal, medical, technological, and ideological relations and contingencies that have emerged and developed over time. This shaped my probing questioning when my fieldwork expanded to include healthcare professionals, such as gynecologists, doctors and nurses, as well as my literature search and reading of clinical guidelines and medical instructions, as I wanted to understand the embeddedness of these naturalized material undertakings and objects in a broader medico-historic genealogy.

The ontological thinking underpinning the material turn has inspired several ethnographers working in the field of reproduction in Denmark, such as Adrian's study on fertility treatment and sperm banking, as well as her more recent study on death at the beginnings of life (Adrian, 2006, 2015, 2016, 2020a, 2020b), and Schwennesen's study on first-trimester prenatal risk assessment (Schwennesen et al., 2008, 2010; Schwennesen and Koch, 2009). While these studies treat the social and the material as equally important, I have not explored selective abortion by untangling material matter as my primary object. The ethnography at the heart of this dissertation is human-centered. To paraphrase Charis Thompson, "I care about people more" (Thompson, 2005: 17) than I care about pills, paper and knitted objects, while acknowledging the importance of such objects for the forging of experience. Indeed, while I realized that these material objects and practices were differences that made a difference to the experience of abortion, it was towards understanding and unpacking the moral universe surrounding selective abortion that I was drawn. Such moral worlds are, after all, inhabited by people. Here, I walk in the footsteps of ethnographers such as Rapp (1999), Svendsen (2022), Sharp (2019), Gammeltoft (2014), Navne (2018) and Jensen (2011), who have all studied, with a human-oriented gaze, life-and-death relations in which people and technologies entangle. These studies have shown how people—in relation to a range of activities and subject areas including prenatal diagnosis, human-animal encounters, neonatal intensive care, and organ donation-make sense of these technologies and what moral questions and concerns these sociotechnical realms catalyze.

#### 3.2. Ethical considerations

## 3.2.1 Bearing witness, fetocentric grief, and the power of language

A key principle in fieldwork is the inseparability of ethics and methodology (Meskell and Pels, 2020). Going into this project, I was, considering the sensitive and largely taboo nature of the topic of selective abortion, first and foremost preoccupied with the ethical and emotional challenges that I, when collecting personal abortion stories, might pose to the couples, and to some extent to myself also. I feared that asking couples to outline their

abortion experience, along with their motivations for opting for termination, would be experienced as intrusive. I further worried over the ethical considerations involved in asking for possible photographs of the abortion process, the dead fetus and other material objects that might help me gain a sense of the lived reality of such events. I decided to clarify my interest in these objects when arranging for interviews, as I figured it would be easier to decline my request via email or a text message than during the face-to-face encounter. To my surprise, all my interlocutors who had photographs and other objects shared these with great zeal. When I arrived at Christina's house, she had already placed a box of memorabilia on the sofa ready for inspection. When I wrote to Sofie, who had terminated her second pregnancy due to the fetus having a brain abnormality, she immediately sent several photographs of herself holding her dead daughter wrapped in a knitted blanket. A third woman replied that she would happily show photographs of her dead child, stating, "I love when people want to see her."

Preceding my meeting with Anja, a mother of two children who had been through an abortion approximately one year before our encounter, I had prepared her for my interest in photographs before the interview, just as I had done with other women and couples. Yet when I arrived, no photographs or mementos had been made ready. I reckoned that she might not have any or did not want to show them. As our conversation went along, I learned that in fact she had many photographs, but there was something about her that made me hesitate to ask to see them. Arriving home, I wrote the following fieldnote:

Anja said that she hadn't looked at the photos for a long time. I asked if she had shown the photos to anyone in her family or to friend. "No," she responded, "it seems a bit intrusive." She elaborated by saying that she thinks no one would want to see them. I couldn't get my mind around whether this was to protect others or to protect herself. Later in the interview, it became apparent that her sense of lack of interest also came from experience. She mentioned how only her living children were mentioned at family gatherings. That most avoided the conversation about the loss she had experienced. It was apparent that for Anja, she had not lost a fetus or a pregnancy but a child. Her dead daughter has a name, and a drawing of her dead body hangs on the wall by the dining table. When I asked what the photos mean to her, she responded: "They mean everything. That's all I got from her." I was unsure about whether to ask if I could see them. I was trying to read her facial expression but found it difficult. She appeared fragile and private, and it made me consider those memorabilia she had collected as something to be guarded and treated with respect. So I didn't ask. When the interview was about to come to an end after spending two hours together, I thanked Anja for her time and openness and asked if I could return with follow-up questions later. "Do you want to see her?" she asked as we both simultaneously got up from the sofa. I responded straight away: "I would love to... if you want to show them?" "You're welcome to see them," she said, walked towards the kitchen and returned with an iPad in her hands. She swiped the screen a few times until a tiny creature, the size of the palm of a hand, appeared on the screen. The tiny lifeless naked body had reddish, almost see-through skin. The ears hadn't fully formed but you could clearly distinguish them. The body was lying in a cloth in an adult hand. "It's my hand," Anja said. I struggled with what words to express myself. "Wow, it's so tiny but everything has already formed. She looks like she's sleeping," I found myself saying. Anja nodded with a smile, visibly proud to show off her dead daughter. Seeing pictures of my interlocutors' dead children seems like an important way not only to validate the experience of loss, but also to bear witness to and acknowledge the existence of the child. Considering there are so few or, in some cases, no witnesses with whom to share one's dead child, asking to see pictures seems like the right thing to do. (Field note)

As this fieldnote shows, it was apparent to me that showing interest in physical mementos of dead fetuses or children was a positive way of navigating the field, even when no photographs or other memorabilia had been made ready or shared before my arrival. Though every encounter was different and what language to use and whether to ask for visual material had to be negotiated case-by-case in each situation, I generally found myself engaging in what Erica Millar has termed "foetocentric grief" (Millar, 2016), which she defines as "the perpetual mourning of the death of an unborn child" (ibid. 501). Yet, whereas Millar is highly critical of fetocentric 15 grief because "[it] is a powerful means by which anti-abortion rhetoric has been disguised and its normative effects amplified, transmuted from politics into truths regarding what abortion entails and how women experience it" (ibid.), precisely because lack of acknowledgement of the importance of the dead child as a mourned family member was one thing several of my interlocutors struggled with, I found it ethically imperative to meet my interlocutors in ways that acknowledged their loss not as a terminated "product of conception" (Gerber, 2002) or "fetal remains" (Mitchell, 2016), but as a lost child. My position as researcher with the power of turning their personal abortion stories into anthropological analysis has been created in part by their confidence in me, and their reliance on me to do something productive with their experiences. As Camilla for instance expressed it, as long as just one person could "gain something" by her sharing her story, she felt her suffering and grief had not been in vain. Therefore, in my view, to care for the women and their partners thus also means to care for their dead babies as well by acknowledging these babies' earthly existence, however short.

 $<sup>^{15}</sup>$  I have amended the original concept 'foetocentric grief' to American English in accordance with the rest of the manuscript, why I spell it "fetocentric".

However, how to bring their moral language of remorse, guilt and shame, such as words like "killing" and "murder," into scholarly representation and dissemination about abortion turned out to represent a conundrum in my research. Millar's point that fetocentric grief might provide fodder for anti-abortion propaganda has lurked in the back of my mind throughout the process of analysis and writing and continues to do so. Could I take up such emic terms in my writing, considering the potential antichoice connotations such words espouse? Can we as anthropologists, conversely, censor our informants in the name of a political agenda? Considering the setback to women's reproductive rights in the United States with the 2022 Supreme Court's decision to overturn the 1973 ruling in the case of Roe versus Wade which had established the constitutional right to abortion, and the blossoming proliferation of anti-abortion movements in various parts of Europe, is now an ever more crucial time to stifle pro-life rhetoric? Or should we as abortion scholars make sure we allow space for women's and their partners' complex feelings, as well as abortion providers' ambiguous experiences in relation to "doing" abortion, by using their words of reference? What responsibility do I carry as a medical anthropologist studying abortion in a changing, globalized world, where knowledge gleaned from a Danish context might easily move to another political context and be used for purposes outside my will and volition? To whom and to what am I really accountable?—And is an extra layer of accountability necessary when studying a politically and morally charged topic like abortion?

In her critical article on anthropological ethics, Nancy Scheper-Hughes contends that most anthropologists tend to—cautiously—position themselves "above and outside the political fray" and proposes a "militant anthropology" that is overtly ethically and politically grounded as a way to make anthropology really matter (Scheper-Hughes, 1992, 1995: 414). In response to this activist stance, Roy D'Andrade (1995) suggests that at the heart of the discipline of anthropology is its aim towards objectivity, not the centrality of the ethnographer's own political worldview. Similarly, Jöhncke suggests that anthropological critique should not be normatively driven by a particular political cause but be managed as an academic discipline (Jöhncke, 2002: 30). As a middle-ground proponent, Høyer (2018) argues that central to performing anthropological ethics is to doubt. Høyer's point is that doubting is generative for ways of relating to one's interlocutors and the field under study, and that good can come from asking curious questions rather than trying to fixate on determining what the "right" course of action is. No matter where one identifies oneself on the continuum between political activism and scientific objectivity, it is widely recognized in the methodological literature that we as anthropologists use ourselves as "tools" or "instruments" for ethnographic knowledge (Nimb and Rubow, 2018: 109). In the words of Donna Haraway, we always create

"situated knowledges" (1988: 575), which necessarily requires us to describe and reflect on our position(s), both the ones we take on and the ones we are given. As such, there are only "views from somewhere" (Haraway, 1988: 590), never from nowhere.

As will become clear in Article 3, I ultimately chose to use the word "killing" in my representation of women's and couples' late term abortion experiences in order to be true to my interlocutors' choice of words. Yet, the fact that I raise the above questions reveals how I remain somewhat doubtful about this decision. When I submitted the paper to the journal (Medical Anthropology Quarterly), my sense of treading an ethically disputed terrain that went beyond the situatedness of my own analysis was confirmed. One reviewer wrote: "I did worry that some of the language and framing in the article would provide fodder for anti-abortion rights activists given the incredible hostility toward abortion, let alone 2nd trimester abortion, in the US. One example is the apparent sense of regret that is suggested [...] Given the constant rollbacks of access in the US, I do have a knee-jerk reaction about writing in ways that seem to reinforce these claims. [...] I would make clear that the debate around 2nd trimester abortion in Denmark is around the lack of choice of abortion method—that pregnant people must give birth rather than have a surgical termination—than around availability of the procedure itself. Given the efforts to roll back 2nd trimester abortion in the US, this needs to be made crystal clear" (peer-reviewer, Medical Anthropology Quarterly). In my re-writing I did what I could to make the Danish case culturally specific to distinguish it clearly from other political contexts, like the American, accentuating how language of fetocentric grief should not be conflated with anti-abortion talk, and I further stressed that no one I had met questioned the availability of abortion as a health service. Moreover, I chose to "come clean" and disclose my personal pro-abortion stance to do away with any confusion on my moral standing. However, the point I want to make here is not how being transparent around one's own moral-political stance might solve some of these challenges. Rather my point is, notwithstanding political differences between Denmark and, say, the United States, my representational choices are caught up in the larger controversy surrounding abortion. The current global climate around abortion impeding women's access to such an important health service threatens to render my analysis less legitimate, in some eyes, than that of others more aligned with a pro-abortion rhetoric of "happy abortions" (Combellick, 2021; Millar, 2017). This embedding of the stakes for the women and men I have met into the stakes for abortion-seeking women and their partners on a grand global arena has forced me to reflect more thoroughly on my own positionality in these debates.

Here, the blossoming literature on the complexity of women's and abortion providers' experience of abortion has provided a helpful frame of reference because it blurs the discursive gap between pro- and anti-abortion rhetoric, enabling a way of writing

about abortion without either eclipsing the woman or the fetus. For instance, Ludlow (2008) argues that the pro-abortion movement has created an unfortunate hierarchy of abortion narratives. The first category of stories is what she refers to as the "politically necessary" stories, meaning those which pro-choice advocates routinely draw on to keep abortion legal, such as when the pregnancy is the outcome of rape, incest or domestic sexual violence. Also abundant are the "politically acceptable" narratives that tend to conjure sympathy, such as in case of fetal anomalies and contraceptive failure. The latter category, which Ludlow calls "the things we cannot say," includes those stories that are largely absent from pro-abortion discourse because they are often manipulated into prolife rhetoric. Grief after abortion is one such example of "the things we cannot say." Ludlow's point is that if abortion scholars perpetuate this silence around, for instance, grief after abortion, we also perpetuate abortion-seeking women's feelings of shame and guilt. Moreover, as abortion providers Lisa A. Martin and colleagues (2022) note, suppression of what they refer to as "danger talk" also comes with personal and social costs for abortion providers. Self-censorship around the things we cannot say hinders open discussion and the emotional outlet that talking about these matters may invite. Such stifling, they argue, ironically works against a strong pro-abortion movement (ibid. 128. See also Harris, 2008, 2019). Similarly, American abortion activist Francis Kissling has argued that the pro-choice movement must rethink its disregard of the significance of the fetus, noting how "The fetus is more visible than ever before, and the abortion-rights movement needs to accept its existence and its value. It may not have a right to life, and its value may not be equal to that of the pregnant woman, but ending the life of a fetus is not a morally insignificant event" (Kissling, 2011). Indeed, my thesis engages what some might construe as "danger talk." I can only hope it will do good, not damage.

# 3.2.2 Dis/entangled: Doing critically engaged ethnography in collaborative research

The centrality of representational ethics proved important in relation to writing about "my" other interlocutors too. Having had conversations with couples about the moral confusion that seeing their dead fetus had evoked for some, especially those who ended up seeing without having expressed a wish for it, tended to color my framing of the nurses and midwives' clinical practices in negative terms. Though I intended to merely question the taken-for-granted assumptions about medically induced abortion and ritualistic visibility practices as "best practice" to demonstrate that such practices were far from neutral nor grounded in solid evidence-based research (Asplin et al., 2014; Bryant et al., 2011; Mitchell, 2016; Sloan et al., 2008), I often found myself phrasing my critique in normative rather than descriptive terms. It was only later I became cognizant of why that

was a problem. Because of the interdisciplinary nature of the TechnoDeath project, our researcher group was from the beginning extended to include both clinical and teaching midwives, as we hoped our knowledge could be disseminated more broadly through these collaborations. We held bi-monthly seminars, where we presented insights from our projects or invited external scholars to present work relevant for our research agenda. At one point, to set up a webinar for midwives and midwifery students, we teamed up with one of our collaborators, Camilla Bruheim, a midwife from University College Copenhagen, who had previously conducted a pilot study on midwives' experiences of providing late abortion care, and who had also been part of setting up a network of midwives who were working at developing clinical guidelines for the management—by health staff—of pregnancy loss and stillbirth at the time. For me, the webinar served as a platform for communicating some of my insights into how women and their partners experienced meeting "the system," here amongst the health staff, and the care needs that had not been fully met. We had several preparatory meetings about the webinar, where I had the chance to present my thoughts and ideas. I raised my misgivings about the unwavering belief in the physiological and psychological benefits of labor and induction amongst clinicians, and the strong belief in the advantages of seeing and holding the aborted fetus, which Bruheim confirmed as "best practice" in most cases. One day, Bruheim wrote me:

I have looked into methods for late abortion > 12 weeks; surgical >< medical, and yes, there are actually not as hard-hitting arguments for medical abortion as I thought! DSOG's [Danish Society for Obstetrics and Gynecology] argument for not performing surgical abortions > week 12 is primarily that the Danish obstetricians do not have much experience with it, but in terms of evidence it does not necessarily appear that one way is better for the woman than the other, physiologically speaking. However, I want to emphasize that I haven't really gone nuts with it, but what you said at least now gives even more reason to question [it]...

Feeling confident that I was onto something, I continued to raise my critique of "how things are done" during meetings, not fully reflecting on the fact that Bruheim not only was part of the professional group my critique targeted, but also because she had been part of developing some of the care models for present-day abortion care. At one meeting, Bruheim said something akin to,

It's thought-provoking and a bit difficult to hear that we might not have been doing the right thing for all. It puts me in agony. But you have to remember that we did it because we believed it was the right thing, and because there was a need amongst women to be cared for in a different way than the care given at the time. But we might not have thought about the *specific* needs of couples terminating a pregnancy,

that their needs sometimes might differ from those losing their baby to stillbirth. (Camilla Bruheim, midwife, University College, Copenhagen).

At several meetings that followed, Bruheim repeated how performing late abortion care is worrying to many newly educated midwives, because "they fear doing or saying something wrong," and therefore it was "important to think about how to communicate findings in a way that did not compound their anxiety." Indeed, Bruheim reminded me that midwives make great efforts to meet the care needs of all couples who lose a fetus or infant, and that my critique should not be aimed directly at them, or at other healthcare professionals working in abortion care, for that matter. She also reminded me that performing abortion care is tough on health staff, and this point became instrumental for the argument brought forward in the second scientific article, which we later chose to write jointly. These interdisciplinary conversations have been vital for my ability to think critically about my own assumptions, normative adjudications, and for how to care well for all parties that I engaged with as part of doing research. It was not only my interlocutors I had to make sure not to harm. I also had to deliberate on how to represent my findings in ways that did not harm my collaborators either (American Anthropological Association, 2012).

Svendsen (2009) has proposed the concept of a "critically engaged science" as productive when doing collaborative research. Being "critically engaged" means to position oneself within rather than outside one's research field and to take seriously "the professionals and their conditions" at the same time as critically exploring and questioning their concrete healthcare practices, and "the state-citizen relations that they seem to actualize" (ibid. 48). Thus, the position I assume here and in the subsequent articles seeks to foster radical knowledge production through research collaborations and collegial relations by being "part of the scene together with a number of other professionals and at the same time shed light on the genesis of the scene and its social and cultural roots" (ibid. 40) rather than distant from it. From such a position, "solidarity with the field" in question is the ground from which logics, values and norms can be made visible, problematized, and discussed rather than criticized by pinpointing flaws and inconsistencies.

Yet, such solidarity with the field, and the ethnographic diplomacy (Navne and Segal, 2018) that is required to ensure that collaborative relations are nurtured, also came with frustration. As mentioned earlier, I tried to gain access to conduct participant-observation during committee meetings in order to gain insight into what kinds of exchanges preceded the arrival at a legal decision, but my attempts were declined; however, subsequently—towards the end of my fieldwork—I was excited to be able to

participate in an annual meeting for all regional abortion committees. I went together with Annika Frida Petersen. We attended the meeting to present insights from our studies with Petersen focusing on the legal dimensions and I on the anthropological. Prior to the meeting, Petersen asked our contact person from the host committee if we could attend the entire meeting, to which the committees agreed. I thought to myself that this would be an occasion to gain more knowledge about how committee members discussed pressing issues in action. More specifically, I was curious about how and to what extent the cases concerning the malformed lower arms, as mentioned in Chapter 2, would be discussed. I thought that given my position as a researcher, by being allowing to attend the entire meeting, we were also being given indirect informed consent to observe and make notes about what took place during the meeting. After all, everyone knew I was there doing anthropological research on the committees' work. I wrote about my observations in fieldnotes and in a draft version of the dissertation. As a precaution, I wrote to my key informant who had been present at the meeting asking whether she would circulate amongst her colleagues a few sentences referring to my observation, explaining how I wanted to use the notes in the dissertation, as well as with what purpose. I figured it was the right thing to do given formal, written informed consent had not been obtained, and this would enable them to object to my wording or go into dialogue with me about my interpretation of the meeting. A few hours later, she responded in a friendly tone that she would return to me as soon as possible. A few days later, I received an email from her in a more formal tone. She wrote:

I find it deeply problematic that references are made from a "closed meeting"-Network meeting. If I, as a participant in the Network Meeting, had known the premise, I might have expressed myself differently. I consider the Network Meeting to be a confidential forum with the opportunity to discuss difficult ethical issues and dilemmas. I am completely in line with the fact that we want as much openness as possible around our work, but I think it can become unsafe when researchers, journalists and presenters participate with a different agenda than agreed. It must therefore be a clear "No" on my part (Legal committee member.)

Privacy, confidentiality and informed consent are some of the most central basic ethical tenets of ethnographic research. Yet, according to Meskell and Pels (2020), ethics is not just a ritualistic tick-box process that once done at the beginning of the project can then be ignored but is a practical engagement, or what they refer to as "embedded ethics," running throughout the lifetime of a project. In such practical engagement, however, formal consent might be unfeasible to obtain in practice (Calvey, 2008: 906) or be at odds with other basic ethical principles. When I did not make transparent my interest in the committee members' potential discussion of the arm malformation cases and did not

make sure to collect written or verbal consent to note-taking during the meeting, my intention was not to undertake covert ethnography, but had to do with the fact that my own prior knowledge of the arm malformation cases should not be disclosed to other committee members present at the meeting, as it would tamper with the anonymity of my key informant, who had shared this information with me. What frustrates me in this situation is less the fact that having been transparent might have been the right thing to do, and more the fact that I cannot share knowledge I find has societal importance. Yet, doing critically engaged science encompasses showing respect for one's collaborators, who have something at stake. Committee members are people making life-and-death decisions on behalf of the state, and perhaps especially because of that, they are vulnerable to criticism from many directions: the Appeals Board, applying couples (if their application is rejected), journalists and, not least, a critical anthropologist like me. Had I successfully gained access to their everyday work, shadowing them while they were reading and ruling on applications and at their meetings, I might have gained a position as a trusted insider who had the credentials to take notes during meetings, and use such notes in a dissertation. My researcher position in relation to these constituencies was, then, not critically engaged by being accepted as "one of them." Far from it. Thus, my position as a critically engaged researcher is just as much an ethical stance of regarding all my informants, also those in power, as vulnerable subjects that should be engaged with through respect, solidarity and diplomacy.

representational politics is always an important ethnographic research, the fact that I have been closely involved—"entangled"—in a larger project with research goals extending my own has, in a sense, intensified the centrality of such politics. More people than only myself have something at stake, as we—with our joint project—aim to set a new research agenda on the remaking of life and death through technologies, and make a practical impact on legislation, clinical practice and the wider public. Like Ginsburg and Rapp's concept of "entangled ethnography", which delineates the conducting of ethnographic research on a territory known to oneself—in their case about being a parent to a child with learning disability (Ginsburg and Rapp, 2013)—the TechnoDeath project was conceived of because losing a child was known territory to Stine Adrian. However, as I do not share this personal experience, my position from where to undertake research and speak about the meaning of making fetal death has been more detached whilst being intimately entwined in the ambitions of the larger project. This comes with a level of responsibility and accountability to a myriad of "others," not only one's interlocutors. This larger commitment has added a layer of complexity to the already difficult undertaking of learning to do good, or "good enough," ethnography (Scheper-Hughes, 1992: 24). 79

#### 3.3. Fieldwork and methods

This thesis builds on approximately 12 months of on-and-off fieldwork stretching between March 2020 and February 2022. The fieldwork took place in different sites and places and is to some extent "multimodal". Without going whole-heartedly "digital" or "netnographic" (Kingod, 2020; Kingod et al., 2017; Kozinets, 2012), I have gone through several online blogs about selective abortion, trawled through Instagram, and searched the internet for news stories, clinical guidelines and medical instructions, legal documents, and annual reports. I used these as initial entry ways into gaining a sense of the narrative, practical and discursive realms surrounding selective abortion across law, biomedicine and the intimate, which then informed my preparation for interviews and attention towards relevant themes. However, my thesis relies first and foremost on indepth semi-structured interviews with women and couples; with legal specialists and judges; and with social workers, gynecologists, fetal medicine specialists, geneticists, nurses and midwives.

#### 3.3.1. Mapping legal decision-making practices

To answer how legal decisions are arrived at in the legal system, I conducted interviews with 15 abortion committee members and three Appeals Board members, representing lawyers, doctors, judges and social workers, together with Annika Frida Petersen. These members were recruited following the circulation of a call for participants via the abortion committee secretaries (see Appendix 1.1). Furthermore, I listed approximately 200 of the 432 legal documents we had gotten access to through Janne Rothmar Herrmann on Excel spreadsheets and noted questions I considered important to ask (See Appendix 4.1). I was particularly interested to know how our interviewees assessed the criteria of "danger" and "seriousness," and which cases they found difficult to decide, and why? Which cases were easy? What ethical challenges and dilemmas did they encounter when making such assessments? And what did they do to overcome these? I used these documents and questions as methods to probe for answers during interviews, combined with more descriptive questions such as "How does a case land on your desk"? (See Appendix 2.1 for interview guide).

When I began contacting members by telephone, setting up interviews at their preferred times and places, some seemed a little perplexed by our interest in their work, while others expressed support for the fact that we wanted to turn their work into an object of legal and anthropological research. Overall, I experienced both an openness and willingness to invite us into their world of legal management and an apprehension towards the purpose of our research. Eight of the interviews were conducted online on Zoom or Microsoft Teams. Two were conducted by telephone. All other interviews were carried

out in person, either at interviewees' workplaces or in their homes. One interview was set up as a focus-group interview with two lawyers and a doctor from one region. All other interviews were conducted individually. Two committee members became key informants, with whom I had repeated conversations and follow-up interviews. During the interviews with committee members, it became clear that the Abortion Appeals Board played an important role in how committee members thought and operated. Committee members kept referring to the Appeals Board as "laying out guidelines" for legal case handling. To get a clearer understanding of the entire juridical system, Petersen and I recruited three Appeals Board members who were interviewed jointly online (see Appendix 1.2. for recruitment letter). Some of the interviews with legal representatives took one hour, yet most lasted two or more hours.

While the online format possibly eased access and enhanced the abortion committee member's willingness to set aside time to talk to us, it was obvious that the online format also helped facilitate access to the Appeals Board members, two of them judges and one a doctor, as they were located in different cities across the country. I was told when setting up the interview that a maximum of one hour could be arranged, giving me a sense of exclusivity in being allowed to take up their time. Yet, when the online interview was about to begin, one of the judges not only announced that she had almost forgotten the meeting, but also that she had family over for a visit. During the interview, her grandson was playing in the background, running over to her occasionally, sitting on her lap, then jumping down to play again. Thus, my sense of taking up very important people's time somehow became replaced by a sense of talking to ordinary people; this person might have been a judge, but she was also a grandmother. This ordinariness took away some of the pressure I felt having to interview a group of professional people I am not familiar talking to.

In addition to data generated through legal documents and interviews, I collated and read annual reports from the Danish regions and participated in an annual meeting (where I also presented findings from my study). This event gave me a chance to go into dialogue about my findings with both some of my interlocutors and other committee members. Additionally, I conducted in-person interviews with two fetal medicine specialists and a geneticist to inquire into their role in illuminating and informing legal cases, as well as their perspectives on the collaboration between abortion committees and fetal medicine and genetics units. One of these fetal medicine specialists had also worked as legal representative in one of the regions for many years, thus I used this occasion to juxtapose what he considered challenging as a clinician vis-à-vis as a legal representative responsible for making legal decisions on behalf of prospective parents.

## 3.3.2. Mapping clinical abortion practices

To gain insights into how selective abortion care is organized and practiced, as well as what notions about good abortion care these practices rest on, I conducted interviews with health care professionals who were directly or indirectly involved in selective abortion care. In addition to these interviews, I collected information pamphlets and medical instructions from various hospitals, as well as clinical guidelines from Danish Society for Obstetrics and Gynecology. I used these both as probing devices during interviews, and as data material in and off themselves. I interviewed three gynecologists, four midwives and three nurses, who were recruited by circulating a call for research participants at a closed Facebook group for practitioners (see appendix 1.3. for recruitment letter). Some were recruited by contacting them directly by mail. Again, these interviews were either conducted online or in the home or workplace of the interlocutor. Some of these interviews took between two and three hours, while some took an hour. One nurse gave a tour around the gynecological ward following the interview, demonstrating the rooms in which selective terminations are managed, the "dirty utility room" where the dead fetuses are cleaned and made ready for viewing, the refrigerator where the fetuses are kept cold until being moved to the morgue, as well the cabinets stocked with various knitted objects offered to couples during the handling of these procedures. While the interviews with gynecologists aimed at inquiring how abortion care was organized and the historically shifting approaches to such care, as well as to gain more knowledge about the clinical difference between surgical and medical second-trimester termination, the interviews with nurses and midwives aimed at coming as close to their care practices and values as possible, asking them to share what they do when a couple arrive for selective abortion as well as giving as many concrete examples as possible (see appendix 2.2 for interview guide). Here, I learned that nurses and midwives strive towards not only securing the safety of women but also her mental health. They strive for presence, individualized care, and support of her decision, which relies on getting to know each and every couple and their specific needs as good as possible. Yet, I also learned that while all emphasized individual care, the care practices being performed are powerfully shaped by ideologies of bonding. There are certain ways in which care should be done to make selective abortion clinically, physiologically, and not least psychologically appropriate, which involves seeing, holding and becoming attached to the dead fetus. And I learned that it is challenging for some health staff when couples resist these ideologies. In Article 2, I argue—with my co-authors—that this mixture of individualized and ideological care revolves around the need to make selective abortion morally bearable for both couples and health staff.

#### 3.3.3. Mapping intimate stories of selective abortion

As already mentioned, I began fieldwork by recruiting women and their partners for interviews. In total I recruited 22 women and men for interviews, making up a total of 16 abortion cases. Of the 16 interviews, 10 of the individuals/couples had found the post via the National Organization of Infant Death Forældre & Sorg. One heard about my research project through the midwife that assisted her during her medically induced abortion. The resting five, four women and one man, had found my post on my Facebook account, which had been circulated by people in my own Facebook network and then ended up in their Facebook feed. Two responded to my post because we are acquaintances on Facebook. All of the respondents were in their 30ies or 40ies. All but one couple had small children, either children they had had before the abortion or after. All were white and persons from the middle-class with, short, middle- to long educational backgrounds. Several were academics themselves, such as architects, lawyers and doctors, while others were hairdressers or worked in the service sector or as craftsmen. Most preferred to meet in person. I conducted four online interviews and 13 in-person interviews. The respondents lived across Denmark, both in Zealand, Funen and Jutland. Four lived in Copenhagen in apartments; the resting lived in houses in suburban areas or small towns. Three of the women I interviewed had recently split from their husbands, one of them because of the aftereffects of the termination. The resting was still in a relationship with their partner. Of the 16 interviews, three had been through the abortion in 2020. Three had been through it in the end of 2019. The case that temporally was the most distant had occurred in 2008. Thus, the cases stretched from 2008-2020, but with the most cases being between 2018-2020, thus relatively recent events. As such, the interviews gave insight into not only the embodied experiences of going through selective abortion, how such endings of life are managed and handled in contemporary Denmark, but also insight into the immediate and long-term emotional and moral responses to the event and how they had come to "live with" it. Most women responded to the post. One man, Peter, responded solo. I did five couple interviews. All couple interviews were set up when I asked whether the woman's partner wished to partake, thus the woman did not see the partner as part of the interview until I asked for it. In a sixth case, the husband came home and became a part of the interview towards the end on my initiative. The resting interviews were with women individually.

Based on her studies of death and funeral rites in Denmark, Rubow argues that the interview can take shape as a form of participant-observation, because "in an interview you are not necessarily two steps from life as it is lived. On the contrary, you can bring yourself close to it and practice it, while you are studying it" (Rubow, 2003: 227). This notion of the interview as a gateway to people's lives "as they are lived" proved especially

true in my encounter with women and their partners. In these cases, I had prepared questions like I had when conducting interviews with legal and medical professionals, but it formed much more as dialogic conversations that extended for hours and hours. By conversation I do not mean to imply that I came without a particular research agenda or that the relation was symmetrical, but that it developed into a dialogue where I also spoke about my own experiences and thoughts, either on my own initiative or on theirs. The interviews lasted between two and six hours, most with a three-four hour-long duration. In one interview, the couple's child was home from nursery. In another, the woman's partner came home from work. In a third, children came home from school, giving me a chance to meet them and get a sense of how and to what extent the abortion inhabited the familial space. Such situations demand improvisations and going along with what occurs in the encounter. And it gave insights, as Rubow argues, into dimensions of how my interlocutors lived with the loss they had endured. To give an example, I spent four hours in the home of Christina. Returning home, I wrote the following fieldnote:

Christina's house was huge. Rooms after rooms followed one after the other as I followed her steps, through the hallway, the combined kitchen-dining area, the fireplace, stairways going up and down as a kind of roundabout of the villa that connected the rooms of the basement and the rooms of the first floor, where her children's rooms were located. A baby carriage in black stood in the basement. New, neat and empty. I felt saddened by the look of it standing there unused. Five steps led up to the living room where she had made ready for the interview. She had placed two diet cokes, two bottles of water, crisps and two bags of handkerchiefs on the round glass table fronting the large grey corner sofa. Christina lost her daughter in 21 weeks of pregnancy after a series of ultrasound scans detected a bladder anomaly. It wasn't until the results came back from the biopsy that the genetic defect causing the enlarged bladder was determined. She chose and was permitted termination on the assumption of a fetal defect and the inconclusive ultrasonographic "evidence" of something gone awry. After full 22 weeks of gestation, abortion cannot be authorized according to Danish abortion law, unless the fetus is incompatible with life. The doctors had emphasized that they had to act quickly, otherwise the application for abortion risked being dismissed, as the genetic disease they suspected was not incompatible with life. During the interview, Christina took control of the conversation. Sometimes I would ask a question luring in the back of my mind, to which she would respond "I just need to finish this. There is more." "Please, go ahead," I responded. She talked about her husband, the renovation of their house, about the grand-farther, who had died a day before her daughter. All these snippets of her life were told in between talking about the course of events around the abortion itself. The narrative branched out into conversation about life, family, dreams and fears. At one point, she got up from the sofa and walked to a wooden shelf on which three framed drawings depicting her dead daughter had been placed. She said she had commissioned them while she was hospitalized as mementos. She got up and took one of the three frames in her hand and said: "You know, I don't know where to hang these. Then I place them here (pointing towards a shelf), then I place them in the garbage cabinet. I really struggle with whether I'm allowed to hang them on the wall or not. You know, my fatherin-law told me I shouldn't turn my home into an altar. It's just really difficult". Towards the end of the interview, Christina's children came home from school. They ran into the house. Two resumed to their rooms upstairs while her youngest daughter joined us. "I've lost my tooth," she told Christina with excitement as she approached the sofa. She unfolded her closed hand, revealing the tiny white tooth in the palm of her hand. Christina gave her a hug, followed by a kiss on her cheek. "Now you're like Toothless the Dragon," Christina said smiling. The daughter looked at me, like she wondered who I was and if she would dare to ask. "My name is Laura, I'm here to talk with your mother." Pause... "My son just lost the exact same tooth." "How old is he?" "He's seven". "I'm six". She stood for a few seconds still with the tooth in her hand. "It should be here with Bønne", she said and placed the tooth on top of another memento Christina had commissioned; a necklace with Bønne's footprints engraved. She had taken it off and placed it on the coffee table in front of us for me to capture it in a snapshot with my smartphone.

This excerpt demonstrates how much more could be gleaned from the interview than knowledge about the experience of the abortion. It opened both a window into how Christina's relatives talked about and related to the dead girl, and it gave insights into Christina's doubts about how she could legitimately mourn her loss. In the relationship with her youngest daughter, it was legitimate to talk about and engage with Bønne, in this case through the necklace, but with extended family, she struggled with striking the right balance. When I transcribed and relistened to the interview with Christina, I became much more cognizant of the various ways in which her story touched upon not only what had happened but how she was trying to come to terms with what had happened through our conversation. Thus, this interview cracked open that Christina was navigating and negotiating *how to live on* from her loss, and as such my encounter with her generated both valuable knowledge about how selective abortion takes place and is experienced personally, *and* how it continued to shape her everyday life. In this way moral labor was enacted intersubjectively as we talked and spend time together.

#### 3.3.4. Drawing selective abortion

As a discipline, anthropology has traditionally been word-based, using fieldnotes and interview transcripts as the main source of data on which ethnographic accounts were based. Though some classic ethnographers, such as Margaret Mead and Gregory Bateson,

have pioneered in the use of photography as part of ethnographic research (Hammond, 2003; Mead and Bateson, 1977; Ruby, 2001), and though the use of visual methods has become more prominent within social sciences over the last two decades (Møhl, 1995; Nakamura, 2013; Pink, 2008; Waltorp, 2020, 2022), the use of drawings as research method is still marginal. Some of those who have adopted drawings as part of their tool kit have argued that the use of drawings is especially useful for exploring experiences of health and illness, as well as for engaging vulnerable persons and sensitive and stigmatized topics, where people struggle to articulate meanings and emotions in words (Guillemin, 2004; Guillemin and Westall, 2013). Scholars have used drawings to explore what meaning their interlocutors attached to for instance the immune system (Martin 1994), the reproductive system (Victora and Knauth, 2001), prenatal testing (Shih, 2017) menopause and heart disease, as well as postnatal depression (Guillemin, 2004; Guillemin and Westall, 2013).

When I began conducting interviews with women and their partners, I worried, as already mentioned, that my probing would be experienced as intrusive. When I eventually went into the field, I decided to pack blank papers and drawing utensils. I figured it might ease my worrying sense of meddling into people's intimate lives if I allowed my interlocutors to guide my questions and probing, using the drawing as a point of departure for where to begin the interview and in what direction to take it. My interest in using drawings to understand selective abortion was triggered especially by reading the work of Li-wen Shih, who used drawings in her study on prenatal testing in Taiwan (Shih, 2017; Shih and Schrøder, 2022). Shih and Schrøder argue that "participant drawings can be used as a valuable feminist method that empowers women by providing an additional means of communication, which is particularly useful for sharing emotionally loaded experiences" (Shih and Schrøder, 2022: 2). Following Haraway's emphasis on "situated knowledges", they propose that drawings, being intrinsically visual and situated, enable researchers to explore the situatedness of different women, as well as to be reflexive about the vision of the researcher her/himself (ibid.). My adoption of this method drew on this feminist position, yet I wanted to expand the scope from women's experience to include their male partners, as well as to include legal and healthcare professionals to explore how selective abortion might be portrayed differently or similarly across gender and lay and professional groups in the form of an image. In practice, the drawings came to occupy several functions, both as a kind of icebreaker, as guiding method and as empirical data. Many giggled when I pulled out the bag of children-like markers and pencils from my backpack as we sat down to do the interview. I would joke that "I appear like a kindergarten teacher", which made most laugh and triggered comments such as "I'm really not good at drawing". No one refused to draw besides one midwife and one

psychiatrist who instead explained in words what they would have drawn. No one seemed taken aback by the assignment, neither the legal specialists, doctors or nurses and midwives. Rather, those refusing explained that their drawing skills were so poor that they would rather not even try. In some interviews, where I knew the participant had limited time, I decided not to use time on the drawing. This was the case when interviewing two fetal medicine specialists and one gynecologist. In a telephone interview with a gynecologist, I did not use drawings either. Some interviews with women, for instance one online interview did not include the use of drawings either, mostly because of practical infeasibility.

The task I assigned all others was the following: I asked them to draw what came to mind when thinking about the word "senabort" [late abortion]. I specified that they could pick any pencil or pencils, use as much time as they needed to draw, and that I had no expectations regarding the creative quality of the drawing. I explained that I used the method because it might elicit themes that were important for the person to talk about that I had not prepared beforehand, and I explained that I would ask them to tell me what they had chosen to draw and why after finishing the drawing. This resulted in a total of 14 drawings from women and their partners, nine drawings from abortion committee members, one drawing from a gynecologist, three drawings from nurses and one from a midwife. The images depicted in these drawings gave clues to central themes and perspectives on selective abortion. One midwife for instance drew a heart surrounded by wooden-stick people. She explained that the heart represented her experience of selective abortion procedures as being "thick with love, grief and loss", and the people around symbolized the healthcare providers doing their best to aid them through the ordeal. Her emphasis on love showed me that selective abortion is not only seen as acts of compassion and love on the part of couples, but also that a central value underpinning abortion care is to turn these procedures into caring events.



Figure 1: Drawing made by midwife



Figure 2: Drawing made by legal specialist

Indeed, the figure of the heart, in some drawings depicted as a broken heart, was recurrent across lay and professional groups. Other recurrent themes were crosses, blood, and caskets, as well as the use of red and black colors. All in all, the drawings represented a variety in terms of color and image. Some mirrored the hospital room in which the abortion had happened. Some, all men, depicted what they remembered the dead fetus looked like. In Article 1 and 3, I build on some of the collected drawings as both a methodology that helped illicit the central themes of this thesis and as data in and of themselves.

## 4. Analytical strategy

I consider all the above data—from clinical guidelines, interview transcripts, legal documents to drawings—as ethnographic data. All interviews were conducted in Danish, and fieldnotes were written in Danish. Data gleaned from interviews have been organized and analyzed using different approaches and software. All interviews, except one interview with a geneticist, were transcribed, the majority by me and some with the aid of student assistants. The transcripts were subsequently thematically analyzed using Nvivo or in the "old-fashioned" way using pen and paper. While the process of analysis was continuous and parallel to still conducting fieldwork, coding and analysis on particular bundles of data (e.g. interviews with women and couples or with committee members) intensified during the writing on each of the three analytical articles. As such, coding, analysis and writing overlapped temporally rather than succeeding one after the other on a string.

As already mentioned, because the heuristic of moral labor emerged from the ethnographic encounters, I was in some ways paying attention to 'the moral' during interviews conducted in the later stages of fieldwork, such as with committee members and health staff, which naturally then also shaped the subsequent process of coding and analysis. For instance, when I began transcribing and coding interviews with nurses and midwives, which happened after having read and submitted my article on the abortion committees' work, I used some of the same coding nodes as with the previous, such as "legitimation work" and "discomfort" as these themes recurred. In this way, the overall analytical approach might be best described as 'abductive' in the sense that I have tacked back and forth between empirical materials and the conceptual means of expressing them and pulling them together under an overarching analytical umbrella (Timmermans and Tavory, 2012). As Timmermans and Tavory note, abductive analysis is not to be conflated with deduction, as theory development happens not through the testing of hypothesis but through a double engagement with theory and methodological steps (ibid: 181). There is a caveat to this approach in that it might have colored my orientation and questioning as

well as prevented me from seeing other elements in the empirical data material that could have pointed in other relevant directions.

All participants have been given alias names and I have altered personal and other identifying details, such as gender, profession, age and number of children. As some of the couples I spoke with had not told close friends about their choice to opt for selective abortion, and some of the couples coincidentally turned out to know each other peripherally, anonymization was crucial. Out of concern for anonymization, I have had to omit one late abortion narrative shared by a woman from the thesis as the details of her abortion—the only one taking place in the third trimester outside of Denmark due to the length of her pregnancy—might make her recognizable to doctors. Given that the worlds of selective abortion care provision and committee work are fairly small and "siloed", anonymizing data drawn from committee members and health staff has also been vital. While there is the risk that committee members might identify which region I am referring to when analyzing particular legal cases, as some of these cases are being discussed at cross-regional meetings, done great efforts to alter the committee member's identity to preserve his or her anonymity.

While some of the women and their partners have been willing to let me share for instance photos of themselves and their dead fetus for publications, I have, in respect of the vulnerable position they are in and the fact that such wish to be open might shift, I have chosen to corporate with an artist and midwife (who herself has experienced pregnancy loss), to artistically "re-make" and alter some of the photos shared. I have found such an artistic representation ethically sound because it demonstrates the materiality of selective abortion (what has hitherto largely been omitted from ethnographic accounts hereof), while maintaining the anonymity of my interlocutors.

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## 4. SELECTIVE ABORTION IN THE DANISH WELFARE STATE

This chapter is dedicated to the larger political and historical context of welfare and antenatal healthcare in Denmark to situate the central issues of this dissertation in a cultural frame, as well as to provide insights into two central epistemological shifts between past and present governing strategies for practices of selective abortion, namely the shift from state-promoted eugenics to "informed choice," and the shift from targeting "feeble-minded" pregnant persons, whose offspring were considered undesirable in the eyes of the twentieth century burgeoning Danish welfare state, to, presently, targeting the identification of specific fetal conditions considered, by prospective couples/the welfare state, as leading to a life of suffering and hence unworthy of living. I here draw on Lynn Morgan and Elizabeth Roberts' concept of "reproductive governance," which calls attention to how a variety of forces, including the state and its biomedical and legal institutions, direct and manage reproductive behavior at particular historical periods (Morgan and Roberts, 2012). In the following, I chart the ways in which eugenics in Denmark was conceived of in its origin; to what it was seen as a solution; how it was later problematized; and how these transformations overlapped with problematizations of abortion. The notion of problematization derives from Foucault, who defined it as "how and why certain things (behavior, phenomena, processes) became a problem" <sup>16</sup> (Foucault, 1983: 65). Chronicling this history helps illuminate how the very foundation of the Danish "welfare state collectivity" (Svendsen, 2022), referring to how Danes place themselves in a reciprocal relationship to the welfare state, today as in the past—although through different political means—builds equally on including and excluding lives from this collectivity. This chapter ties into my overall research question—in what ways does moral labor shape the legitimation, practice and experience of second-trimester selective abortion?—by showing how this shaping is also historically and culturally constituted.

## 4.1. From eugenics to "informed choice"

In July 2011, a debate broke out in the Danish daily newspaper *Information*, when it published an op-ed written by two fetal medicine specialists, one of whom was a member of the Abortion Appeals Board at the time. The doctors were pleading for a publicly

<sup>&</sup>lt;sup>16</sup> Hereby, Foucault was not rejecting any notion of reality. He clarified that "when I say that I am studying the 'problematization' of madness, crime, or sexuality, it is not a way of denying the reality of such phenomena. On the contrary, I have tried to show that it was precisely some real existent in the world which was the target of social regulation at a given moment. The question I raise is this one: how and why were different things in the world gathered together, characterized, analyzed, and treated as, for example 'mental illness'? What are the elements which are relevant for a given problematization?" (Foucault, 1983: 66).

available "positive list of fetal defects that trigger abortion" (Uldbjerg and Becher, 2011.) The list was supposed to act as a support tool for the Abortion Appeals Board and expectant couples by creating transparency around the legal practice that had developed over the years, and to make the interpretation of the abortion law, which they categorized as "vaguely defined," easier. In an interview with *Information* the following day (Carlsen, 2011), one of the doctors, Niels Uldbjerg, stated: "What offends me is that we, who sit in the Appeals Board, have the list in our heads, but you can't look it up anywhere." The proposal did not resonate, neither among politicians nor among medical colleagues, but it sparked a short-lived debate. When the liberal party Venstre's health spokesperson at the time, Birgitte Josefsen, was asked about her opinion on the proposal, she replied: "After all, there are experts who sit on the board. It couldn't be more accurate. They have to decide on the [i.e. each] specific case. We do not live in a society that practices racial hygiene."

The debate that ensued came to be about the practical feasibility of such a list, and about what it *signaled*. Two doctors, also working in fetal medicine, issued an op-ed in response to the first in which they reasoned that it would be "stigmatizing" towards the groups of people living with the diseases and conditions that the list would pinpoint. Also, it would not be, practically speaking, feasible to develop such a list because there are "thousands and thousands of syndromes," hence it would be impossible to "make such [a thing] as [a] positive list encompassing all known serious diseases and malformations." They concluded by stating: "Instead of pretending that positive lists are both possible and would make these choices easier, one should recognize that part of new technological breakthroughs such as fetal diagnostics occasionally result in difficult but *privileged* choices" (Tabor and Lidegaard, 2011. Emphasis added.)

As this short bout of media attention shows, eugenics is a thorny question and something that contemporary politicians and state agents adamantly refuse as being linked to present-day practices of selective abortion<sup>17</sup>. The fact that legal decisions *are* made today with such a list in mind, seemed entirely overlooked in the debate. What intrigues me about this is not only how certain practices are designated as being within (lists) and outside (practices) the scope of eugenics, but also how eugenic practice is being mobilized as an evil figure that is unrelated to and different than the practice of selective abortion today. This makes me wonder: if we take seriously that present-day practices of prenatal testing and abortion for fetal anomaly are in fact *not* equivalent either to eugenics, neo-

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<sup>&</sup>lt;sup>17</sup> This is in line with Danish historian Lene Koch's point that modern genetics has legitimized itself as a scientific body of knowledge against the dark and "unscientific" eugenics of the past, yet, as she notes, eugenics is "a tradition from which [modern geneticists] cannot completely dissociate themselves" (Koch, 2004: 316).

eugenics, liberal eugenics or flexible eugenics, as has otherwise been suggested (Shakespeare, 1995, 1998; Taussig et al., 2008), but are rather motivated and shaped by a different kind of logic, how did we reach a point in time in which approximately 600 second-trimester selective abortions are carried out each year? How to account for the close to 100 percent of Down's syndrome abortion rates? Why the opaqueness around the list that every committee member and doctor I have spoken with knows exists—and is actively used in the juridical system—but cannot be made accessible to the public? To try to provide some answers to these questions, I begin by going back to the landmark year of 2004.

In 2004, the Danish Board of Health issued new guidelines for prenatal screening and diagnosis, which expanded the scope of the offer of testing to include all pregnant women, regardless of age and risk profile (Danish Board of Health, 2004). Preceding the publication of the new guidelines, a medical working group had been commissioned by the Danish Board of Health (comprised of doctors and midwives) to gather material for a possible revision of the guidelines in place at that time (Danish Board of Health, 1994). The work resulted in the report Prenatal Diagnosis and Risk Assessment (Danish Board of Health, 2003a), which recommended a significant revision of the previous organization of prenatal testing. It was argued that the previous program was problematic as it centered on a pre-defined group of pregnant women considered at elevated risk due to their age (above 35) and/or known genetic or chromosomal disease, which the group considered as belonging to a "paradigm of prevention," as access criteria were established on the basis of economic calculations and a preventative rationale. This, they found, indirectly obligated women to participate in prenatal testing. As a solution, they suggested a future organization around a new principle: "informed choice" and "self-determination." These were seen as more aligned with current legislation on patient rights and contemporary ethical principles of patient autonomy and integrity (Danish Ministry of Interior and Health (Indenrigs- og Sundhedsministeriet), 1998; Schwennesen et al., 2008). While informed choice was the new philosophy, the offer of non-invasive screening became the means, consisting of a combined risk assessment for Down's syndrome and other chromosomal disorders in the first trimester, based on a combination of maternal age, nuchal translucency scanning and a biochemical test for serum-free beta human chorionic gonadotrophin and pregnancy-associated plasma protein A, as well as a second-trimester malformation scan. Some disability rights advocates and organizations, such as Landsforeningen Downs syndrom [the National Organization for Down's syndrome] raised concerns that widened prenatal screening was economically driven, which seemed

corroborated when an executive board meeting held in Københavns Sygehusfællesskab (H:S)<sup>18</sup> in March 2003 was leaked to the press, in which the chair of executive board, politician Lars Engberg, had stated that:

Annually, 12 Mongol [sic] children are born in the capital, and the management of HS expects that with the scan, 10 of them will be found, who will subsequently be aborted. These 10 would cost society two million kroner a year, and since a person with Mongolism on average lives 55 years, the societal savings will be well over 100 million kroner (Hansen, 2004).

Likely to silence any speculation—and further dissemination in the public—of the economic incentives behind the expansion of the program, the medical working group asked for a clear statement from the Danish Parliament about what Parliament considered to be the primary aim of prenatal testing: prevention or choice? Subsequently, the Danish Parliament issued a statement in which they clarified: "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 right to know as well as the right not to know must be respected [...] The aim of prenatal testing is not to prevent the birth of children with serious diseases or handicaps." (Parliamentary Decision on Prenatal Diagnosis, May 15, 2003). Thus, the new guidelines, which covered the whole country by June 2006 (Ekelund et al., 2009), not only launched choice as the answer to a problematic former arrangement, but also rhetorically wiped out any conflation of prenatal screening with state-mandated eugenics of the past.

## 4.2. 20th Century reproductive governance: Targeting the "feeble-minded"

Eugenics, which etymologically means "well-born", represents a theory and practice that aimed to improve the genetic quality the population (Galton, [1883]2007; Koch, 2000, 2004, 2006). A highly polarizing term amongst scholars, politicians and the public in Denmark and beyond, eugenics invokes gruesome images of the atrocities committed against millions of Jews, people with disabilities, and other groups considered unwanted or "untermench" during Nazi Germany. The direct link between eugenics and disability was profoundly shown in the "Aktion T4" program, which officially ran from 1939 to

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<sup>&</sup>lt;sup>18</sup> Hovedstadens Sygehusfællesskab (H:S) was a Danish health trust, which was founded on 1 January 1995 to run health care services in Copenhagen and Frederiksberg with five hospitals under its command. After the "structural reform" in 2007 [Strukturreformen in Danish], which drastically reorganized the division of tasks in the public sector in Denmark: 14 counties were abolished and replaced by five regions, and 271 smaller municipalities was reduced to 98 large municipalities. As part of this re-structuring, Hovedstadens Sygehusfællesskab was closed down, and from 2006, its responsibilities were passed to The Capital Region of Denmark [Region Hovedstaden] (URL 4.)

1941 (but unofficially was said to run longer), whereby German SS doctors and nurses systematically euthanized more than 100,000 physically and mentally disabled children and adults, using primarily gas as method (Thomas, 2017: 28). Yet, twentieth century eugenicists in Denmark were not oriented towards racial purity but rather envisioned themselves as "humanistic architects of a better society" (Spalletta, 2021: 94), who pursued the preservation of a healthy population.

The Danish welfare state was founded on the pillars of a comprehensive mass of social reforms in the 1930s, which gradually came to set the conditions for the lives of Danish citizens from "cradle to grave" (Broberg and Roll-Hansen, 2005). Publicly funded general healthcare, prenatal care, maternity leave, day care, public education, old age pension and elder care, as well as a public pension independent of income, were implemented to all citizens, and are still firmly in place today (Koch, 2000; Svendsen, 2022). These reformist laws were suggested by the minister of Justice in the newly elected Social Democratic government, Karl Kristian Steincke, who wrote a book in 1920 in which his visions for the Danish welfare system were presented: the formation of a morally and economically sustainable society (Svendsen, 2022: 118). These visions were propelled by political tensions forming in the interbellum of World Wars I and II, against which the small and vulnerable Danish nation had to defend itself (Jöhncke, 2007: 48). Of the two hundred pages that constituted Steincke's book, 28 were devoted to eugenics (Hansen, 2005: 28). Steincke was a firm believer in hereditarianism, degeneration and the dangers of differential reproduction: the idea that the "superior" sections of the population reproduced at the lowest rate, while the "inferior" reproduced at the highest (ibid.). Thus, eugenic thinking merged with the political vision of a strong welfare state when a test act was tried in 1929 by Denmark, the first European state to do so, offering voluntary sterilization to the "feebleminded" (e.g. people with cognitive impairment, learning difficulties and those with psychiatric problems), as well as to mentally normal citizens at risk of transmitting hereditary defects to their offspring.

In 1934, a law was passed allowing the state to enforce compulsory sterilizations and internment in institutions for those considered a social threat to the welfare state project. When the first Danish eugenic law was proposed, Steincke said: "Every human being should have a right to the utmost fulfillment in life and if necessary, be protected and cared for. Only in one respect, society needs to be alert: as regards reproduction... We treat the unfit with all kinds of care and love, but in return only forbid them to reproduce themselves" (Koch, 2000: 24–25). As such, Steincke launched the welfare state as a power performing the dual role of both regulating citizens' reproductive lives and, in return, providing them with free care and social benefits (Vallgårda, 2013). As Svendsen

notes, to gain social security, "the individual citizen was expected to behave responsibly in social matters, including reproduction" (Svendsen, 2022: 117).

Eugenic thinking reverberated in the first abortion law from 1937 that would grant legal access to abortion on the so-called "eugenic indication." Up until the 1930s, abortion in Denmark was prohibited. During the rule of Danske Lov [Danish Law] from 1683, the termination of a pregnancy was considered murder and unmarried women who were accused of this were sentenced to death by decapitation, as the letter of the law read: "Frivolous women who their fetus killed should have their throat cut and their head placed on a candlestick<sup>19</sup>" (Andersen Nexø, 2005: 57; Esbensen, 2014: 20). In 1866, abortion was separated from the general law and placed into the first Danish Criminal Code with a significant change in penalty: now abortion was penalized by up to eight years of imprisonment and labor, and for the abortionist by up to 16 years, with the only exception being if the life of the pregnant woman was in danger. In 1917, a commission was put together to develop guidelines for a revision of the Criminal Code, amongst these the provisions for abortion. When a new Criminal Code was issued in 1930, the penalty for induced abortion changed once more, now calling for imprisonment of only between a minimum seven days and a maximum two years. In 1932, the Council of Coroners<sup>20</sup> approached the Minister of Justice regarding the observation of several cases of illegal abortion that had ended in no penalty. They found there to be a great discrepancy between the requirements of the law and the fact that the jury acquitted the few women who were prosecuted, which, it was argued, was "harmful to the general legal awareness [retsbevidsthed in Danish]" (Andersen Nexø, 2005: 65). It was thus because of the coroners' alarm that unwanted pregnancy and illegal abortion were perceived as problems be tackled, demanding separate political action. In November 1932, Svangerskabskommissionen [The Pregnancy Commission] was established, made up of 19 members: eight doctors, four jurists, one midwife, five politicians and one priest (ibid. 58). The commission's conclusive report, consisting of almost two hundred pages of documentation and characterization of the abortion issue, proposed the restricted legalization of abortion under four conditions: 1) If the woman's life or health was in danger due to illness in relation to the pregnancy (known as "the medical indication"), 2) When the pregnancy was the result of sexual crime or incest (known as "the ethical indication"), 3) when the fetus was in danger, due to hereditary trait, of suffering serious physical or mental disease (known as "the eugenic indication", as already mentioned),

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<sup>&</sup>lt;sup>19</sup> Translated from Danish: "Letfærdige Qvindfolk, som deres Foster ombringe, skulle miste deres Hals og deres Hoved sættes på en Stage" (Andersen Nexø, 2005: 57; Esbensen, 2014: 20).

<sup>&</sup>lt;sup>20</sup> The Council of Coroners, in Danish "Retslægerådet", is a Danish institution under the Ministry of Justice, the job of which is to guide public authorities on medical questions.

and 4) when the pregnancy or birth constituted a danger to the condition of the woman that could not be averted in other ways (known as "the social" or "humanitarian indication").

In her comprehensive comparative analysis of the political debates on abortion in the 1930s and 1970s, historian Sniff Andersen Nexø argues that two entirely different rationalities shaped the political discussions and how the subjects of abortion—the woman and the fetus—were conceived in these two periods. In the 1930s, reproductive issues were tied, as were the sterilization laws, to securing a population that consisted of enough and sufficiently healthy and fit citizens. In this light, abortion was largely considered a problem that had to be tackled not by setting abortion free, but by curbing illegal abortions and the health risks they posed. What stands out in these political debates of the 1930s was the extent to which all politicians across political divides approached eugenic abortion as "natural" and "responsible." In contrast to the debates that took shape at that time around the commission's proposition of introducing abortion for social or humanitarian reasons (which was not passed), the eugenic indication was "not a focal point in the debate but belonged to the few 'unproblematic' fields that caught little attention" (Andersen Nexø, 2005: 101). Andersen Nexø further writes that a majority of the parliament was of the belief that while eugenic abortion could not be enforced upon women, with time "a sense of duty may arise in the woman herself" (ibid. 102). The Danish political consensus of the 1930s around eugenic abortion as a reasonable measure to combat the birth of children with handicap was thus directly linked to the general zeitgeist in Denmark that saw eugenic policies as crucial to the building of an economically strong and sustainable welfare state. The point of contention surrounding the issue of restricted legalization of abortion that made it unthinkable to grant legal abortion to healthy women who were carrying healthy fetuses was an understanding of the necessity of protecting unborn life, not because this life was imbued with fetal personhood, but because it was seen as a life that should safeguard the future of the population. Within this logic, it became thinkable to establish legal abortion as an emergency solution, and to professionalize a medical procedure—abortus provocatus which was not only considered a safe alternative to clandestine abortion practices, but hereby also redefined the former juridical and moral framework surrounding the termination of life from being "murder" and "killing" to being a health service.

The understanding of the fetus as mere biological life changed during the 1960s and 1970s. The reason why the abortion issue was raised politically again was still the many illegal abortions that had not been successfully prevented, yet the answers to the same problem took very different forms. The number of abortions was no longer paramount as population size had ceased to be a political concern, yet abortion, especially

the number of illegal abortions, was still considered a problem to be solved (Andersen Nexø, 2005: 221). In 1967, the Socialist People's Party put forward a proposal on the right to free abortion. In the political debates that ensued, abortion was discussed in terms of preventing unhappy lives, and how to ensure that childbearing consisted of planned pregnancies and the birth of wished-for children. Core to this social rationality was a notion of both pregnancy and abortion being private matters, and there was recognition of the importance of the social environment in the child's development. As such, it was the notion of creating healthy and well-functioning social individuals that lay the ground for the liberalization of first-trimester abortion in 1973 (ibid. 263). While some conservative and Christian politicians raised a concern for the "unborn child," most political voices rejected this notion, largely ignoring the fetus as a figure. For most of the Parliament, the fetus might have been human, but it was regarded a bodily substance of the woman rather than a person with legal rights, at least in the early days after conception. Along with this idea, a new understanding of responsibility also emerged. While women in the 1930s were considered bodies of the state who had a moral obligation to help sustain it, women of the 1970s were given the restricted power to decide over their own reproduction, yet this entailed "freedom under responsibility" (Andersen Nexø, 2005: 239). What is striking about the political debates of these two historic periods, the 1930s and the 1970s, is that, despite the radical changes as to how abortion became problematized, and the very different solutions that were thinkable in each period, selective abortion remained conflict-free terrain throughout. Indeed, during the 1970s' political debates, the eugenic indication was largely not touched upon.

Parallel to these shifts, politicians became occupied with the prospect of rolling out prenatal diagnostics after chromosomal analysis had been introduced into antenatal healthcare on an experimental basis. In 1975, the Ministry of Interior set up a committee to create and present a plan for the expansion of fetal diagnostics, and in 1977, the committee published its report, stating that the primary purpose of prenatal diagnosis was to prevent the birth of children with serious, life-long handicap, which tied directly to health economic calculations. The commission's report concluded that a "cost-benefit analysis of prevention of mongolism [sic] [Mongolisme in Danish] shows that the public [system] will gain [annual] economic benefits of more than four million kroner. This is due to the fact that the incidence of mongolism is higher than previously shown, and that expenses used on institutions have increased considerably since 1971–1972, while expenses for puncture and lab analysis have decreased" (Betænkning om prænatal genetisk diagnostik, 1977: 7). The report specified that "the consequence of a pathological finding is, as a main rule, offer of abortion." (ibid. 20). As such, the legalization of abortion on eugenic indication that was initially passed in 1937 and continued into the

1970s was thus argued for primarily on societal grounds. Diagnostics leveraged cuts in public spendings and, in the commission's words, a means to prevent "great human tragedy" (Betænkning om prænatal genetisk diagnostik, 1977: 37; Danish Council of Ethics, 2009: 22).

## 4.3. 21st Century reproductive governance: Targeting fetal conditions

Fast forward to the twenty-first century: these economic incentives had been completely omitted in the working group's 2003 report. Perhaps to lend itself moral credence amongst the Danish public, the working group did efforts to dissociate abortion as linked with prenatal diagnosis. In the part of the report that dealt with the issue of abortion, the working group wrote:

Some fear that the increased diagnostic options may contribute to shifting the boundary of what is perceived as serious towards the less serious, so that the possibility of abortion is trivialized [...] In a historical perspective, however, it can be stated that for these severe malformations, there has generally been a shift in the opposite direction to that which was assumed—the previously severely debilitating and life-threatening has, thanks to modern treatment, become a malformation which almost never—where it is isolated—leads to the choice of induced abortion, regardless of the fact that it may be a long-term and burdensome course of treatment.

(Danish Board of Health, 2003a: 140)

The association between prenatal testing and selective abortion as the typical "remedy" is here rhetorically troubled by bringing forward the figure of the pregnancy that, despite detection of a fetal anomaly, happily and willfully ends in a live birth thanks to technological advancements. Nonetheless, since 2004, the habitual use of prenatal screening has come about with great haste<sup>21</sup>, and termination rates for chromosomal anomalies have increased exponentially. Again, I have not been able to find an overview of the outcome (live birth vs. abortion) of all detected malformations that could confirm or challenge this image of reproductive technology as facilitating both abortion and more treatment, an absence that in itself merits future scrutiny<sup>22</sup>. However, what we do know

<sup>&</sup>lt;sup>21</sup> In contrast, in 2012, Sweden offered prenatal screening to all pregnant women in only six out of 21 counties with an uptake rate of 32% in 2012 (Mödrehälsovårdsregistret, 2013: 13). While some countries have a system equivalent to the Danish, uptake rates have shown to be lower. For instance, in England and Wales, only 68% of women accepted the offer in 2011 and in the Netherlands, where a national screening program was implemented in 2007, women below 36 have to pay 150 Euros to get tested (Bakker et al., 2012; Engels et al., 2014; Lichtenbelt et al., 2013; Lou, Petersen, et al., 2018; Morris et al., 2016).

<sup>&</sup>lt;sup>22</sup> We might ask: Are such statistics not produced and made public deliberately, or is it rather an expression of lack of political interest?

is that the expansion of the program was seen, as mentioned earlier, by some politicians as a health economic benefit. What we also know is that almost all fetuses prenatally diagnosed as having Down's syndrome and other chromosomal differences are terminated with great automaticity. When I asked one committee member "How much time do you spend on case management, and are there any particular cases you are able to decide quickly?" she responded: "Try guessing. It's Down's."

In her ethnography of the everyday lives of parents of children with Down's syndrome in Denmark, American anthropologist Olivia Spalletta (2021) eloquently shows how parents have to cross swords with the municipality to access services and resources they are legally entitled too, noting how the parents had to prove that their child was lagging behind developmentally in order to meet the access criteria for aid. This presents a conundrum: How come children born with a condition considered so serious that it triggers a permission for abortion "carte blanche" must prove to be seriously disabled in order to access services? As Spalletta demonstrates, the parents she followed measured their child's moral citizenship through the state's willingness to invest in its future. When parents faced difficulty in accessing resources, they were not only concerned that their son or daughter would not develop important functional skills. They were also upset by the fact that the Danish state "had already seemingly 'given up' on their child, and that their child would always live on the periphery of society" (Spalletta, 2021: 185). Nikolas Rose has proposed the concept of "ethopolitics" as referring to the sentiments, moral nature, or guiding beliefs of persons, groups, or institutions, which provide the medium within which self-government of the autonomous individual can relate to the imperatives of good government. Individuals are expected to regulate themselves in accordance with the norms of a moral life, where responsibility for the avoidance of risk is conferred upon individuals, who are supposed to regulate themselves in line with the directions of health authorities (Rose, 2001). Following Rose, it may be argued that although prospective parents do not want healthy children for the benefit of the state, as Rapp has noted (Rapp, 1999: 16), the Danish welfare state has institutionalized prenatal screening (and selective abortion) as an offer, free of charge while other public institutions impede the flourishing of children with disability by refusing or withdrawing social aid and benefits, and therefore this indirectly sends the message to prospective parents that selective abortion is the way to go<sup>23</sup>. And this was something that at least some of my interlocutors considered. In the late term abortion stories I gathered, disability largely figured as a negative stereotype that the Danish state (though my interlocutors seldomly spoke directly about "the state") was seen as

<sup>&</sup>lt;sup>23</sup> This is what I have elsewhere referred to as "structural directiveness" (Heinsen, 2017).

perpetuating by creating more and more tough conditions for parents of children with disability. As Peter for instance said: "We would have had to move to a different municipality, like Gentofte or some other rich municipality, to gain access to the necessary help and resources."

In "Serious Disease as Kinds of Living," Wahlberg (2009) argues that prenatal diagnostics and selective abortion form around not only biological "faulty modes of living," such as errors in cell division, but also around the social "burden" a particular abnormality is seen as catalyzing for parents and siblings. It is the suffering that a particular disease or disability is seen as projecting that is sought to be prevented by opting for and authorizing selective abortion. One committee member put it like this: "It won't do any good if you create a non-functioning life and destroy three well-functioning lives." Yet, as Peter's words illustrate, the imagined suffering far extends the pathology of a particular diagnosis. It is the kinds of living, as Wahlberg suggests, in which both pathology and social life intertwine that prospective parents orient themselves towards when making their decision to terminate. This also applies to the abortion committees. When I interviewed a gynecologist and member of one of the abortion committees, she said: "When a couple has asked to have a pregnancy terminated, I actually think that the worst thing you can do to them is to say 'No.' [...] In the medical cases, there are very few refusals. And the fetal doctors have done all the work for us in terms of describing what is wrong with this fetus, and they also only recommend that people seek an abortion if they are quite sure that they will get permission." In my attempt to understand how the committee assessed the severity of different anomalies and chromosomal differences, at one point I asked her, "As a layman I can't help but think that immediately there is a big difference between Patau's syndrome and Turner's syndrome. What kind of talk has led to people now thinking that Klinefelter's and Turner's should also trigger a permission carte blanche?" She gave the following explanation:

So this has happened at The Appeals Board level. After all, it started with someone refusing, and the decision was appealed, and then the Appeals Board granted permission. And then there was an agreement that they can get permission for chromosomal abnormalities when they apply. I have a really good friend, who has Turner's, and she has had a good life. It hasn't been without problems. Several operations and things like that. But she would not have been born if her parents had applied or had had the opportunity. But even the Turner's association, as I understand it, thinks it's okay that if the family applies for it, then an abortion is performed. It's not like they stand with posters and say, "Someone like us must be born."

This quotation illustrates three crucial things about the moral economy of selective abortion in Denmark. Firstly, it is, I contend, "the list" of these conditions, and the welfare state bureaucracies built around it, that enable routinized selective reproduction to take place. As soon as a condition is brought under the guise of legal precedence, it is also added to the informal list that the juridical system employs to make decisions—as quickly and uniformly as possible. This list identifies the fetal conditions that, through the specifications of geneticists and fetal medicine specialists, are considered equivalent to an unworthy life, or a life that will cause suffering to individuals and families. Secondly, this takes place within a cultural environment with no strong right-to-life ethos (Svendsen, 2015; Svendsen et al., 2018). Since pregnant women in Denmark were granted a statutory right to demand abortion in the first trimester of pregnancy in 1973, the political and public opinion on abortion has largely gone unchanged. While the Christian People's party, and the anti-choice association, Retten til Liv [The Right to Life] have occasionally thundered against the present abortion law<sup>24</sup>, the recent World Health Organization's report in which a full abolishment of abortion limits has been proposed (World Health Organization, 2022), and the American Supreme Court's decision to overturn the historical landmark decision Roe v Wade on June 24, 2022, have in fact stimulated increased support for abortion. For instance, Danish Prime Minister Mette Frederiksen posted a statement on her Facebook account in which she stated that "It must be possible to make the, for many, difficult choice to have an abortion. Let us hold on to the victories we have achieved. Whether it is called 'abortion' or 'free abortion' makes no difference in my world. Women's unrestricted right to decide on their own bodies and future does however" (Nielsen, 2021). Similarly, following political pressure from especially the leftwing party Enhedslisten, the Danish Council of Ethics has agreed to, in the nearby future, discuss whether the current legal threshold for access to abortion on demand is up to date (Friis, 2022). And several gynecologists and fetal medicine specialists have expressed support of extending the limit to make the abortion legislation more aligned with the current offer of routine prenatal screening and diagnosis (Lidegaard, 2022; Rabøl, 2022). Third, but not least, while Danish media from time to time have called attention to the social implications of routinized prenatal screening and testing, and some organizations for people with disability have attempted to spread awareness both of the positive sides to parenting a child with chromosomal difference or of living with a disability as an adult, and the purported negative implications that prenatal screening has for the stigmatization

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<sup>&</sup>lt;sup>24</sup> As an example, at the 40-year anniversary of the 1973 abortion law in 2013, the small Christian association *Retten til Liv* [The Right to Life] erected 16,000 white crosses (the annual number of induced abortions in Denmark) on a field opposite a highway where 46,000 cars pass daily to "give the silent unborn child a voice" (URL 5).

of people with disability (Glerup, 2022; Vaaben, 2009a, 2009b), a unified and vocal disability rights movement critiquing selective abortion has not gained traction in Denmark (Richter, 2011b). As the committee member above mentioned, you do not see people on the streets of Denmark advocating for the right to life of those conceived with conditions for which abortion is applied and routinely granted approval.

When the Danish Board of Health revised the 2004-guidelines once again in 2017 because of recent technological advancements, keeping the structure of the regime of prenatal testing the same but adding two new non-invasive methods<sup>25</sup> to the amalgam of tests offered (Danish Board of Health, 2017), the Board of Health commented briefly on the critique brought forward by some associations for people with disability that prenatal testing fosters intolerance and stigmatization. The Board wrote:

Fetal diagnosis is regularly the focus of debate in society. The debate ranges from dealing with the ethical aspects associated with the possibility of terminating the pregnancy in the event of a serious illness or disability in the fetus, to questions of social stigmatization of the parents who choose to give birth to a child with, for example, Down's syndrome. [...] The concern can be more specifically about the fact that this leads to a generally poorer understanding of people with disabilities. However, the presence of various diseases, conditions and disabilities is generally not prioritized in the healthcare system for reasons of the perception of normality. Furthermore, consideration of women's self-determination will, as a general rule, weigh more heavily than consideration of a given normative perception of normality or of a desire for diversity at the societal level.

(Danish Board of Health, 2017: 6. Emphasis added).

Thus, on the systemic level of the healthcare system (and hence the Danish welfare state), working against intolerance and risk of stigmatization of already existing people living with disabilities are clearly catalogued as less important than working for the facilitation of selective abortion. While this is argued for, once again, through the ethos of choice and self-determination, it confirms that diversity and difference are not desired qualities in the eyes of the welfare state. I am left wondering, what values about life, citizenship and belonging does the prevalent agreement on disability as constituting "family tragedy" hinge on in the realm of selective reproduction? Do these values perhaps explain why the counter-narratives of what a life with disability is like are almost absent amongst my interlocutors, and in public discourse more broadly? Can we perhaps understand the

and, hence, lead to ambiguous and uncertain diagnosis and prognosis (Danish Board of Health, 2017).

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<sup>&</sup>lt;sup>25</sup> The new 2017-guidelines expanded the 2004 organization with two tests: NIPT (Non-invasive Prenatal Testing), which may detect the well-known chromosomal anomalies, such as Down's syndrome, Patau's syndrome and Edward's syndrome, and Microarray analysis, which is a much more fine-grained technology that may detect smaller chromosomal and genetic differences, many of which are of unknown significance

cultural tendency to take selective abortion for granted as mirroring how *everyone* engaged in the making of death through selective abortion—the committee members, health staff and couples (and Danish people in general?)—conforms with and adheres to the idea that preventing the birth of anomalous lives serves good ends?

Several recent ethnographic studies have shown how the Danish welfare state is imagined as a naturally existing unity and integrated whole, in which the population is tied together through imagined connections and solidary welfare schemes (Jöhncke, 2007). The welfare state is to most Danes a matter-of-course framework for everyday life, entrenched in the identities and self-understanding of what it means to be Danish (Bruun et al., 2015; Gilliam and Gulløy, 2012, 2017; Gulløy, 2011; Jöhncke, 2007). While neoliberal ideas about public management, necessary efficiency improvements, and privatization have gained traction, not least within the public health sector since the 1990s and 2000s, the general thrust of the welfare state project, building on community, collaboration, reciprocity and responsibility, continue to this day (Møller and Johansen, 2015; Olwig and Pærregaard, 2007; Rytter, 2019; Spalletta, 2021). For instance, anthropologist Laura Gilliam has shown how Danish welfare state governance operates by "civilizing" children through school institutions by "working with the social," forming children to be socially thriving individuals, but by fitting in to the community and not transgressing boundaries for solidary behavior (Gilliam, 2010; Gilliam and Gulløv, 2014). In their study of cancer rehabilitation, Helle Ploug Hansen and Tine Tjørnhøj-Thomsen demonstrate how the political focus on rehabilitation instantiates a moral obligation to make oneself "as-if-cured" through technologies of the self in order to get "back to normal," arguing that rehabilitation essentially is about normalization and deviance (Hansen and Tjørnhøj-Thomsen, 2008). Ethnographic studies on aging in Denmark have shown how a pervasive political discourse on "active aging" has blossomed, operationalized in municipalities through policies of help-to-self-help as preconditions for access to elder care, which has cemented the notion that "dignified aging" equals independence and self-care (Oxlund, 2021; Teglgaard Christensen, 2020) For instance, Henrik Hvenegaard Mikkelsen has shown how older people living in solitude are encouraged by social workers not only to be active through physical training and self-care, but to be socially active. The underlying policy behind this expectation for older single people is what Mikkelsen calls "the politics of potentiality," understood as envisaging these people as having an unfulfilled potential that must be activated by the municipal workers. Successful aging thus translates into being healthy, fit and independent within a social community (Mikkelsen, 2019). In a similar vein, Rytter argues that public debates around the integration of migrants and refugees reflect a strong notion of Denmark as a "welfare reciprocity," meaning a system of "lifelong generalized

reciprocity in which citizens reciprocate the free education they have received in their youth by paying high income taxes during adulthood" (Rytter, 2019: 686). And in her study on neonatal intensive care, Navne has shown how the process of imbuing infants' lives with value rests on the negotiation of parents' investments in and abilities to care for the infant (Navne, 2018; Navne et al., 2018; Navne and Svendsen, 2018). Thus, not all premature lives are invested equally. Parental detachment from the child often disqualified it as viable, meanwhile, conversely, couples with particular family histories of reproductive struggles gained authority in the assessment of an infant's worth. From this, we learn how the imperative of life in the twenty-first century Danish welfare state is closely linked to a strong imperative of family life, and of families that are able and capable of sustaining themselves and hence the welfare state collective.

The question that remains is what we learn about the Danish welfare state through the case of selective abortion? The normalization of prenatal screening and diagnosis, and selective abortion for genetic and inborn anomalies can be seen, I contend, as a commentary on which lives are valued or not in the Danish welfare state. In the concluding remarks, I will give some tentative suggestions for what kind of ideal citizen you must be to be granted access to and membership of Danish society.



### 5. CONCLUDING REMARKS

This study aimed to explore how a particular form of death at the beginning of life—selective abortion—is authorized, practiced and experienced at the nexus of law, biomedicine and everyday lives in the Danish welfare state. In the prologue that opened the dissertation, I presented Peter, who expressed moral ambiguity around his choice to opt for termination following the news that the unborn child his wife was carrying had been diagnosed as having Down's syndrome; the committee member Britta, who tiptoed around the expanding "positive list" that is morally fraught due to its eugenic connotations, by mobilizing a counter-image (that fetal conditions may be taken off the list); and the nurse Monica, who expressed professional pride in the way they had introduced knitted objects on the gynecological ward because they, in her view, supported ethical and compassionate second-trimester abortion care. I have explored these (and many other empirical cases from my study) as examples of what I came to analytically conceptualize as *moral labor*.

Taking my point of departure in the question of how abortion committees and the Abortion Appeals Board arrive at legal decisions, the first analytical article demonstrated how some committee members felt discomfort at being responsible for drawing the line between which lives are worth living and which are not in Danish society, while also working within a clear hierarchical order of juridical power to which they all complied. I used the concept of "legitimation work" to identify three types of logics underwriting how selective abortion is authorized, notably the bureaucratic logic of legal precedence, the collaborative logic of dividing responsibility for ascertaining seriousness, and the ethopolitical logic of facilitating prospective couples' ability to exercise informed choices in line with what the prenatal screening policy has promised.

In article 2, Camilla Bruheim, Stine W. Adrian and I asked: How do health staff perform selective abortion care, and what norms and values do these care practices reflect? We showed how selective abortion care has been orchestrated in ways to create a sense of moral bearability both for couples and health staff. By cementing medically induced second-trimester abortion procedures as irrefutably "best practice", selective abortion care has been placed firmly in the hands of nurses and midwives, who, guided by new grief paradigms and anecdotal evidence of an uncaring past, have developed care practices that facilitate and support grief through parental-fetal bonding. We approached these care orchestrations critically, showing how they are not neutral but practices that shape how to act and respond correctly as health staff (promoting grief) and as abortion-seeking couples (seeing and holding the fetus, and taking on the identity of "bereaved parents").

In the third and final article, I shifted from the professional to the personal point of view. Focusing on how women and their partners experienced late term abortion and abortion itineraries, I showed how couples were unprepared for the world of action that opened as soon as a decision to terminate was set in motion, and how they ultimately felt caught between disparate expectations—that to be a responsible prospective parent they must choose abortion, that they must bond with "the baby" they chose to terminate, and that they must also resume their ordinary life as though what they went through was nothing akin to infant loss. I argued that these moral tensions and emotional struggles experienced by parents are compounded by a resounding absence of institutionalized, publicly financed post-abortive care.

Taken as a whole, the findings of this study show how moral friction and unease permeate the juridical ("acting like God"), clinical (confronting death while optimizing good patient outcomes through the ideology of attachment) and private realms (bearing individual burden for choice and for how to live on in socially accepted ways), and how all involved persons were engaged in efforts to overcome this friction by dividing and distributing the moral load involved in selective abortion (Ivry and Teman, 2019; Mesman, 2008), as well as by discursively and materially framing these deaths as compassionate acts of love that are sensible because they curb suffering on individuals and entire families. In these ways, moral labor is performed by everyone, because moral labor is necessary (for everyone involved) to make these private, yet state-sanctionedand-effectuated "routine" deaths manageable. For professionals, moral labor is vital to be able to do their tasks again and again. For couples, moral labor is part and parcel of learning to live with the decision and the sense of loss and grief brought in its wake. However, I also argue that despite the division and distribution of moral responsibility for making death, the moral and emotional unease that selective abortion triggers are not really resolved or fully reconciled for anyone. This is not least due to the fact that the field of genetics and prenatal diagnostics is constantly moving, raising new dilemmas on both prospective couples and state agents. One abortion committee member put it like this:

The damn thing about technology is that when you do these tests, you can find all sorts of coincidences. Erm and that's... where I come from uh..., first of all, I work in psychiatry and I grew up... in uh in crazy town, where there were more crazy people than normal. [...] So, in my childhood, I've seen many of those whom I today sit and say do not have a dignified life. And that's not how I saw them. And I'm marked by it in this work, and I'm marked by it in my work in psychiatry, because what I think... and I'm not religious at all either, but I think there's a... a pandering for the perfect child. We've seen some glaring cases of that. It troubles me because I think that the non-perfect child, who may have some quality of life but who is a little crooked, it can give... something good to society. And remind us

where we are in terms of diversity. And the fact that we can now go all the way down to the fact that with an 80 percent probability they will develop schizophrenia, well then, I think half of the clientele I work with is gone, right? And dyslexia and learning difficulties... so it can get all the way down to where uh... you get some associations with... Germany.

While these moral tensions and unease permeate and persist, I have also demonstrated throughout the dissertation how moral labor is exercised within a cultural environment that, by and large, regards selective abortion a positive and responsible, even "privileged" choice, to reiterate the words of one fetal medicine specialist. Importantly, moral labor is not exercised as a way of tackling a politically and morally charged anti-abortion environment, but rather to make such terminations as efficient and "ordinary" as possible. To conclude, I summarize a set of original contributions:

First, I hope to have contributed with novel insights to social science studies of selective reproduction by moving beyond the moment of prenatal diagnosis and "the decision" (Risøy and Sirnes, 2015), as well as to studies of life and death by eliciting how selective abortion should be approached as a complex process of making death, involving a myriad of discursive, material and bodily elements, practices and, not least, moral frictions.

Second, my method of drawing partly on the assemblage ethnographic approach and partly on the implosion methodology in my exploration of the legal, clinical and private realms, taking seriously the moral concerns of every person involved in the making of death and juxtaposing these concerns across domains, contributes to the assemblage ethnographic approach by showing that this approach is not only useful in studies of the "making" or "routinization" of particular technologies but is also highly useful for getting to the "heart" of how state institutions operate on a daily basis, how state actors think, feel and act, as well as how woman and their partners who are the "target" of these institutions experience them.

Third, and related to the above points, I propose a new analytical concept for understanding the labor involved when actively *making death happen*, in this case at the beginning of life. I propose moral labor as a concept that encompasses the complex process of legitimizing and settling the moral permissibility of terminating or ending life, as well as stabilizing contradictory discourses that leave people feeling caught between disparate expectations and norms. I hereby offer two distinctions from the version of moral labor that Ivry and Teman (2019) have proposed: that moral labor is exercised beyond the site where diagnosis and decision about the future of the pregnancy is made and that it involves multiple temporal horizons. The forms of moral labor I have analyzed are oriented towards the past, the present and the future. For couples especially, moral

labor is not only exercised to arrive at a decision about whether to terminate or continue the pregnancy. Moral labor continues as people work to lay to rest the decision, the abortion experience, and the sense of self-inflicted grief that, for many, lingers on. I suggest that moral labor might be useful as a thinking device in other studies of death and dying within medical anthropology and medical STS. Importantly, as moral labor takes shape in the Danish welfare context in particular ways, transporting and using the concept in other political and cultural contexts would necessarily involve careful attention to the ways in which life-ending decisions and actions call for similar or disparate forms of moral labor. I suggest that juridical justificatory frameworks or "legitimation work", medical care practices or orchestrations of "moral bearability" and lived experiences of "moral tension" serve as generative operationalizing concepts for seeing, organizing, and understanding what might be apprehended in other cultural settings as moral labor.

Four, I argue that central to questions of research ethics are issues of representational politics, especially when studying a politically charged subject like abortion. I have argued for a stance on abortion that does not eclipse the plural and muddy morality and emotionality that abortion may evoke. My normative position is that we need to make room for complexity rather than dichotomy (Harris, 2008; Ludlow, 2008a; Rapp, 1999).

Five, I hope to have contributed with novel insights into the logics, norms and values of the Danish welfare state, and hence to anthropological studies of the state.

Six, last but not least, through my collaboration with legal scholars and healthcare professionals, as well as my engagement with these audiences through talks and presentations, I hope to have contributed with an awareness of the care needs of women and couples—needs I have found to be unmet and unspoken. In the remainder of this conclusion, I expand upon the last two points.

### 5.1. Legitimate deaths: The (un)productive citizen

The numerous studies that have explored lives hovering at the boundary between life and death (Jensen, 2010, 2011; Mesman, 2008; Navne et al., 2018; Navne and Svendsen, 2018; Svendsen et al., 2018) overall show the strong imperative of life that circumscribes these fragile lives. Indeed, expanding technological and medical capacities for sustaining and prolonging life inside and outside hospitals have made decisions to let people die, or let people who have died stay dead, near impossible (Kaufman 2006; Timmermans, 1996). Death, once something that just happened, has become something to be tamed and timed (Green, 2011; Kaufman, 2015; Lau et al., 2020), and consequently these lives—whether the premature infant, the critically ill patient or the patient with dementia—are invested in with care, resources, time and hope. As Svendsen (2022) has illustrated, the

substantial ventures into research on premature piglets to improve the health of premature human infants underscore this "life-prolonging project" of the Danish state. Thus, we might say that the Danish welfare state invests intensively in some of its citizens while (much) less investment is put into others. What I hope to have contributed to is illuminating how anomalous unborn fetuses are profoundly circumscribed by an imperative of death. Unlike the investment in treatment and hope that unfolds in the NICU, in the realm of selective abortion there is little room for associating fetal diagnosis, such as Down's syndrome, sex-chromosome anomalies, even missing or malformed lower arms, as lives carrying hope for a good life, no matter the social and economic conditions the child would be born into. In this way, these findings reflect central insights into the larger moral fabric of the Danish welfare state in the twenty-first century. My study elicits that, for a premature infant to be invested in, it is not just the capacities of the family that are important; it is the *healthy and productive family* that is a quintessential building block on which the welfare state rests. The "politics of potentiality," as Mikkelsen (2019) calls it, that steers the investment in certain people, seems to be completely absent in the area of selective abortion. We might say that in the context of the diagnosis of a fetal anomaly, politics and practice are guided by an implicit "politics of futility": my study shows that in relation to prenatal diagnosis and selective abortion, low (or no) quality of life is anticipated from the start.

In my view, the main underlying protagonist who appears in all the empirical spheres I have examined is the productive citizen. Being productive is what grants you worth, deservingness and access to the Danish society. That is, I argue, what "the list" embodies. It all comes down to the critical question: Can you reciprocate the investment put into you by working and paying taxes? Or are you expected to only "drain" the treasury of the Danish state? In this way, the imperative of death unfolds within a biopolitical "logics of vitality" (Rose, 2007: 70). Fetal deaths are enabled and legitimated implicitly in the name of the government of good citizenship, where potential citizens-tobe who are seen as lacking capacity (mentally and physically) to sustain the welfare state are rendered "expendable." In this way, moral labor ties citizens and state actors to the welfare state collectivity through conformity with and adherence to ideas about selective abortion as serving positive ends, namely the making and sustaining of well-functioning and productive individuals, families and the welfare state as a strong unity. While this is perhaps less apparent in relation to the clinical management of selective abortion, the fact that so much attention has formed around psychosocial coping and healing might implicitly speak to a notion of productivity—of being able to return to "normal" (Ploug Hansen and Tjørnhøj-Thomsen, 2008), to resume life (and work) just as before the

termination—and that this is what is ultimately the goal of steering people well through the abortion procedure. But is this analogous to eugenics? Is it neo-eugenic?

Karen-Sue Taussig, Rayna Rapp and Deborah Heath have argued that eugenic thinking persists in present-day United States, as genetic technologies have turned "many people across a broad spectrum of social groups [to] consider the genome to be the site at which the human future must or can be negotiated" (Taussig et al., 2008: 197). They propose the concept of "flexible eugenics" that delineates a tension between genetic normalization on the one hand, and biotechnological individualism on the other, arguing that reproductive decision-making increasingly takes place within a tension of "free choice," "market orientation of the recent neoliberal era" and "discourses of perfectibility" (ibid. 196). Others have similarly proposed concepts that tie the ideology of choice with eugenics, such as Margaret Lock's notion of "laissez-faire eugenics" (Lock, 2007) and Tom Shakespeare's "contemporary eugenics" (Shakespeare, 1998). In contrast, Rose argues that the biological, biomedical and individual way of thinking in contemporary liberal states has nothing in common with the eugenic thinking and coercive and paternalistic state interventions of the past that in the name of improving the gene pool of the population took extreme measures-from forced sterilizations to euthanasia of mass populations. As he argues, present-day ways of governing the self and others "deserve analysis on their own terms" (Rose, 2007: 69). Following Rose, I suggest that something else is at stake in the Danish welfare state than "laissez-faire" or "flexible" eugenics. What might we call this form of reproductive governance, which operates neither through eugenics, nor liberal individualism but rather through a moral obligation to welfare reciprocity, productivity and collectivity to meet the standards of ideal citizenship? Might it be that selective abortion in the Danish welfare state is a form of euthanasia on behalf of an unborn life?

While I leave these questions open for debate, in my view what makes moral labor, and the associated terms—legitimation work, moral bearability and moral tensions—specific to selective abortion in Denmark is to enable these terminations to happen as smoothly as possible on a daily basis, while keeping the unpleasant and refuted association with twentieth century eugenics at arm's length. To make death happen against the background of such frictions is laborious work, and work that is largely not appreciated and acknowledged as challenging.

### 5.2. A care gap appraisal

I wish to end this dissertation by pointing to what I see as a "care gap." In Chapter 3 on methodology and ethics, I raised my ambivalence around the power of language and representational politics. While I am adamant about the importance of abortion access as

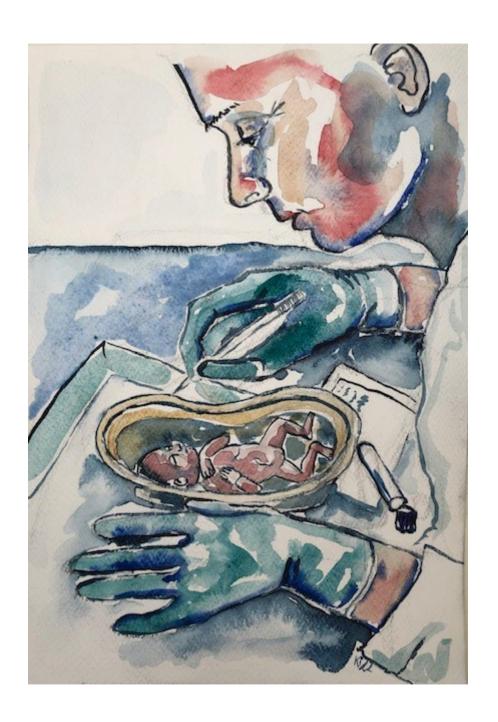
vital for women's reproductive health, I am also ambivalent around the "slippery slope." This has become apparent as more and more fetal conditions (of unknown significance) are turned into legal and legitimate grounds for termination (as the words of the legal specialist above illustrate), while these terminations are politically framed as mirroring prospective parents' choices—whereby responsibility for not only choice, but also loss and grief, becomes individualized. My ambivalence is not grounded in the notion that more fetuses with disability ought to be born because fetuses (normal or abnormal) carry intrinsic worth, or because the value of a neurodiverse society outweighs the (good and valid) reasons for wanting to terminate an affected pregnancy to prevent suffering, but because such imageries of prevention of suffering through abortion undermines the suffering that comes with selective abortion. As one gynecologist said when I told him about the struggles some couples faced following the abortion: "Well, the alternative is much worse."

One way to look at this is that there is a hierarchy of legitimate "problems." Another way to look at it is that there are different ways of understanding what the real problem is or how it can be defined (Koch and Nordahl Svendsen, 2005). While I do not want to minimize the problems that come with having a child with disability in contemporary Denmark (Spalletta, 2021), I contend that the stifling of the debate around the personal costs and private pain of selective abortion inhibits any substantial recognition of the care needs of women (and their partners), who carry the burdens (along with the benefits) of selective reproduction, as well as for those involved in its making. I am left wondering: Who cares for women and their partners when they return home empty-handed? Who cares for the committee member who struggles with having agreed to terminate a pregnancy even though the severity of the malformation is uncertain? Who cares for the midwife who receives a fetus that shows signs of life and ends up dying in her arms, or who must seamlessly switch between receiving living full-term babies in one room and a dead fetus in another in an already busy and understaffed maternity clinic?

Summing up, in today's Denmark, even though state-sanctioned-and-effectuated late term abortions due to fetal problems occur routinely, the women, couples, committee members and health care professionals are immeasurably alone with the difficult emotions and actions that accompany these events. Affected women and couples have to give meaning to the abortion, define the aborted fetus/child and find a (socially legitimate) parental/non-parental identity. Committee members and health staff are obliged to sanction and exercise these fetal deaths in ways that obscure the moral unease associated with the "dirty work" implied, because the Danish state (as embodied in its prenatal screening policy) is unwilling to be honest and transparent around the systematic sorting

of particular fetal conditions that is taking place. After all, the (growing?) list is still not publicly accessible, although it exists.

As I hope is clear to the reader by now, my aim of focusing on the moral labor involved in selective abortion has not been to question the morality of abortion. I have, conversely, sought to show the social impact of the moral load it invokes, and to point towards ways in which this load can be lifted, as well as to consider seriously how people with power can become more responsive to the care needs emerging in and through our relations with technologies of death at the beginnings of life (Adrian, 2020b). We need to find ways to acknowledge these chosen losses as significant, without tying them to fetal personhood, nor by undermining them as inferior to the problems that becoming parents of a child with disability are seen as catalyzing. Moreover, as the Danish welfare state invests intensively in prenatal screening and diagnosis to facilitate selective terminations, the state ought to prioritize exploring and meeting the care needs of all actors involved that such state-sanctioned-and-effectuated terminations bring about.



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## **OVERVIEW OF ARTICLES**

	Article 1	Article 2	Article 3
Title	Guardians of Healthy Family Formation: The Legitimation Work of Danish Abortion Committees in Cases of Termination for fetal Anomaly	Orchestrating Moral Bearability in the Clinical Management of Second-trimester Selective Abortion	Shouldering Death: Moral Tensions, Ambiguity, and the unintended Ramifications of State-sanctioned Second-trimester Selective Abortion in Denmark
Authors	Laura Louise Heinsen	Laura Louise Heinsen, Camilla Bruheim and Stine W. Adrian	Laura Louise Heinsen
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### ARTICLE 1

# Guardians of healthy family formation: The legitimation work of Danish abortion committees in cases of termination for fetal anomaly

#### Abstract

In Denmark, pregnant women have a statutory right to abortion on-demand in the first trimester of pregnancy, after which abortion must be sanctioned by a regional abortion committee, comprised of legal and medical representatives. Second-trimester abortion may be warranted if there is danger that the fetus will suffer a serious mental or physical disability, yet what precisely constitutes "danger" and "seriousness" are left in the hands of the juridical abortion system to interpret. In this article, I explore how jurists and doctors operate to make sense of these ambiguous concepts, and how they arrive at and legitimate the authorization of termination for fetal anomaly. Building on van Wichelen's (2019) concept of "legitimation work", I demonstrate how committee members authorize termination through what I term "bureaucratic legitimation work", "collaborative legitimation work" and "ethopolitical legitimation work". I argue that central to how abortion committees work is a strong commitment to adhere to legal precedence as well as to facilitate prospective parents' autonomous, informed choices, through which the juridical system configures itself as a technical bureaucracy and by the same token distances itself from the ethical dimensions and moral dilemmas of sanctioning the sorting out of anomalous unborn lives. In conjunction, these forms of legitimation work turn termination of almost every anomalous fetus into legitimate acts, hereby safeguarding healthy family formation.

Keywords: Abortion committees, legitimation work, ethopolitics, selective reproduction, Denmark

#### Introduction

We're not a discussion forum that sits and exchanges personal opinions about this, that or the other. We're not. We're a committee that makes decisions on the basis of practice and the law. (Legal abortion committee member, region A)

Not all are being terminated because of serious defects. Some are being discarded, where you think, it might not be a standard child, but it might be a really okay child (Gynecological abortion committee member, region E)

In 2008, the Danish newspaper *Politiken* issued an op-ed written by Julie Rask-Larsen, a woman in her mid-twenties, who had applied to the regional abortion committees for permission to terminate a pregnancy after it was discovered at her routine malformation scan in week 20 that the fetus she was carrying was missing the part of the left arm from the elbow down (Rask-Larsen, 2008). The abortion committee rejected her application on the basis that the fetal anomaly was "not serious enough". Infuriated by the lack of recognition of her request, which she herself regarded as an informed decision—the ethical mantra with which routine prenatal screening and testing for all pregnant women were propelled into standard antenatal health care in 2004 (Schwennesen, 2010; Heinsen, 2017) —the woman traveled to the UK to have the abortion procedure done there. In Denmark, such cases of legal refusal are very rare. Statistics show that the annual approval rate for termination for fetomedical reasons exceed 95 percent (Lou, et al., 2018; Abortion Appeals Board, 2019), ranging from cases of malformation of the vital organs, genetic diseases, to chromosome aberrations, cleft lip and palate and missing or malformed extremities. In tandem, The Rask-Larsen case and the high approval rates beg the questions of what constitutes a "serious handicap" (Scott, 2006; Wahlberg, 2009), where to "draw the line" (Williams, et al. 2002), and who should decide on these questions. Notwithstanding the importance of these bioethical questions, rather than trying to answer these, the purpose of this article is to ethnographically chronicle how such questions are deliberated by those who have been entrusted the societal task of deciding who qualifies for second-trimester abortion. In Denmark, this task is managed by five regional abortion committees<sup>1</sup>, comprised of legal, gynecological and psychiatric representatives (Herrmann, 2008). Above them is a cross-national Abortion Appeals Board, which acts as both an appeals organ with legal power to overturn decisions undertaken in the regions and as a supervisory authority. Under the jurisdiction of Danish abortion law, the state-

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<sup>&</sup>lt;sup>1</sup> Other than handling applications for termination of pregnancy, the committees process cases regarding fetal reduction and sterilization, however these cases, as well as abortion cases that regard other indications such as ethical (rape, incest), maternal health (psychiatry) or social (lack of resources), are beyond the scope of this article. I do however draw on social cases to elicit the particularities of how selective abortion is legitimated.

financed health services offer free access to abortion until the end of the 12th week of pregnancy, after which termination must be sanctioned by one of these committees. Each year, the regional abortion committees receive approx. 900 applications for termination with 80 percent<sup>2</sup> of these made on the basis that "there is danger that the child will suffer a serious physical or mental illness due to hereditary predisposition or damage or disease in the fetal state" (Healthcare Act, consolidated Act no. 903 of 26/08/2019 § 94). Thus, according to the letter of the law, danger and seriousness are the guiding principles, yet the law does not spell out what constitutes "danger", or what fetal aberrations fall under the category of "serious". To this day, no ethnographic study has explored how the jurists and doctors operate to make sense of these ambiguous concepts. This is a significant gap, not least in light of constantly expanding technological capacities for detecting congenital and genetic defects or differences, which not only influence the complexity of parental reproductive decision-making, but also influence the juridical institutions who must govern abortion. As socio-legal scholars Petersen and Herrmann (2021) have documented, for years, the legal practice of the committees and the Appeals Board have been shrouded in secrecy, making the operation of the law inaccessible for scholarly scrutiny, and how to get access to second-trimester abortion unclear for the broader public (see also Herrmann and Petersen 2021). This study thus aims to contribute to our understandings of the juridical administration of women's reproductive lives in Denmark through an anthropological lens. I ask: How do committee members negotiate and settle the criteria of danger and seriousness? For what purpose does the Danish state safeguard selective abortion when so rarely rejected? And what exactly is being guarded?

In what follows, I will map out what forms of justificatory practices abortion committee and Appeals Board members enact to make selective<sup>3</sup> abortion authorizations feasible. Expanding on anthropologist Sonja van Wichelen's (2019) conceptualization of legitimation work as an "ethics in the making", I show how committee members justify the authorization of selective abortion by discursively engaging in three different forms of, what I term, *bureaucratic legitimation work*, *collaborative legitimation work* and *ethopolitical legitimation work*. I show how, in stark contrast to how several committee members insisted their work was strictly legal, social, emotional and moral reasoning underpin legal decision-making and justifications for approving termination following the

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<sup>&</sup>lt;sup>2</sup> The remaining 20 % are made on the basis of social, ethical or maternal health reasons.

<sup>&</sup>lt;sup>3</sup> By the term "selective", I draw on Wahlberg and Gammeltoft's (2017) definition of selective reproductive technologies as technologies used to prevent or allow the birth of *certain kinds of children* as opposed to the prevention of unwanted pregnancies. Selective abortion is not a term used by my interlocutors but is my term for the act of terminating a pregnancy due to unwillingness to parent a *particular* child, whereas "elective" termination denote the act of terminating a pregnancy due to unwillingness to parent *any* child (See also Scott, 2006: 16). In the juridical world, selective abortion is mostly referred to as "fetal defect cases" [fosterskadesager in Danish].

detection of a fetal anomaly. I argue that in conjunction, these forms of legitimation work portray the juridical system as one of simply upholding legal practice, hence relocating the responsibility for making selective abortion medically and morally legitimate away from the juridical system, and in turn enabling committee members to distance themselves from the ethical and political dimensions of sanctioning the "sorting" of anomalous unborn lives. In conjunction, these forms of legitimation work turn termination of almost every anomalous fetus into legitimate acts, hereby safeguarding healthy family formation.

## Legitimation work in the ethopolitical era

In order to shed light on the negotiations that take place among abortion committee members, I take point of departure in anthropologist Sonja van Wichelen's concept of legitimation work, which refers to "the ways in which people, institutions, bureaucracies, laws, and states enact, perform, and put to use certain rationales and legitimacies over others" (van Wichelen, 2019: 8). Van Wichelen writes that "justifications do not emerge from a vacuum, nor are they stationary; they travel", thus legitimation work is also about creating stabilizations or "coherent narratives in a fractured world" (ibid). According to the Merriam Webster dictionary, legitimation connotes "complying with the law" or being "in accordance with established or accepted rules and standards". However, different from the notion of ethical decision-making, which refers to the process of evaluating and choosing among alternatives in a manner consistent with ethical principles, I view legitimation work as an empirical phenomenon that cuts across legal, ethical, biomedical, social and affective realms. Echoing van Wichelen's definition of legitimation work as a form of socio-ethical engineering, I define legitimation work here as the discursive and material labor of stabilizing potentially legally and ethically ambiguous decisions and practices in relation to legally sanctioning the sorting of particular kinds of "defected" unborn life.

To specify how this discursive work also takes a particular political form, I draw on Nikolas Rose's term "ethopolitics" (Rose 2001). In the ethopolitical age, Rose contends, governmentality is less about managing the health of the general masses as about giving individuals responsibility for enhancing their own health, vitality, and happiness. This shift allows for a conduct of individuals to be governed "at a distance', by shaping the ways they understand and enact their own freedom" (ibid. 6). Thus, the state no longer is directly in charge of the health of the people but relies upon an accordance between the aspirations of the state and the aspirations of individuals. As I hope to show, ethopolitical reasoning seeps into the operation of the juridical system to enable personal ethical endeavors, hereby enabling the juridical system to—to some extent—disclaim responsibility for the decision to take life.

STS-scholar Stine Adrian notes that understanding how technologies, such as prenatal diagnostic technology, remake death and dying at the beginning of life is important "because technologies situate potential parents in moral dilemmas, while reconfiguring who and what may have the responsibility of fetal and infant death" (Adrian 2020, 156-157). Yet in this article, I focus less on the materialities that go into rendering a fetus anomalous (see Schwennesen and Koch 2009) and more on the ways in which committee members reason about their own legal practice, and how differing forms of reasoning entangle as they justify approving termination. According to Burnett, "approval of an abortion by a hospital committee effectively makes that abortion legal" (Burnett 1970: 34), yet I suggest that it also makes it legitimate, meaning that not only is the law but also ethics being negotiated and settled as legal decisions are made.

Didier Fassin has argued that it is by exploring the "actions of the agents within public institutions that the policies of the state can be grasped" (Fassin, 2015: 4), noting how "institutions are governed by rules and procedures as well as values and emotions" (ibid. 94). Thus, I take the concept of legitimation work as a lens into studying the moral economy of selective abortion in welfare state Denmark, meaning the production, circulation, and appropriation of values and affects (ibid. 9) regarding the issue of selective abortion. Here, I tread in the footsteps of the rich body of literature that explores how human lives and human reproduction are governed and administered (Koch, 2004; Meskus, 2009; Sreenivas, 2021; Zhu, 2013; Morgan and Roberts, 2012; Novas and Rose, 2000).

To shed light on legitimation work in the field of "late abortions" in Denmark, I especially zoom in on deliberations around boundary cases, by which I mean cases that have not yet come to figure under the umbrella of "legal precedence" and therefore not given permission as a matter of routine. Notwithstanding the extent to which especially Down's syndrome has become iconic of fetal testing (Rapp 2000), in a Danish context, applications on the grounds of Down's syndrome are given approval "carte blanche", as several committee members expressed it. In these cases then, authorization of termination has already been made legitimate. In contrast, boundary cases offer a privileged vantage point for studying the legal, ethical and social distinctions and negotiations made by committee members as they justify how a particular fetal problem fulfills norms of danger and seriousness. In other words, boundary cases are those that bring the discursive labor of stabilizing potentially legally and ethically ambiguous decisions to the forefront. Moreover, I make occasional detours to the management of late term abortion on socioeconomic indication, as the boundaries drawn between what is considered medical versus social reveals the extent to which such boundary making in practice is blurred or collapse. But first, let me situate my analysis both scholarly and genealogically.

#### **Legitimating selection practices**

In recent years, several qualitative studies have shed light on the reasons why prenatal testing and selective abortion have settled as the norm in Denmark (Schwennesen, 2010; Lou, 2014; Heinsen, 2017; Barrett, 2017), as well as elsewhere (Rapp, 1999; Meskus, 2009; Ivry, 2010; Gammeltoft, 2014; Risøy and Sirnes, 2015). However, much less explored has been how juridical decisions are arrived at. Writing in the context of Israel, Rimon-Zarfati and Raz (2010) have explored how hospital committees and parents view selective abortion in cases of what they refer to as "mild or likely fetal pathology". Engaging an analytical framework of "eugenics", they show that even though Israeli abortion law, like the Danish, is ambiguous, selective termination is favored (see also Hashiloni-Dolev, 2007; Rimon-Zarfati and Jotkowitz, 2012). In a sociological analysis of public hospital ethics committees in Argentina, Irrazábal shows how religious agents appointed to sit in these committees, influence decision-making in ways that make it difficult for women to access abortion, even though the pregnancy is the result of rape or threatens the woman's health (Irrazábel, 2015). Only a handful other studies provide insight into other domains, such as legal (Barnett, 1970) and bioethical issues (Woodrow, 2003) conterminous to such committees, as well as to the historic emergence of hospital abortion committees (Solinger, 1993; Reagan, 1997). Thus, this is the first anthropological study to explore how abortion committees in Denmark reflect on the legal, medical and ethical basis on which they make legal decisions and deliberate their role as agents of the state.

While abortion committees have not been the object of much anthropological scrutiny, several ethnographic studies have focused on how selective reproductive practices have been justified. Using written information material aimed at parents about to undergo carrier testing, preimplantation genetic diagnosis and prenatal diagnosis in the UK, Wahlberg (2009) shows that in defining the "seriousness" of a prenatally diagnosed condition, social rather than biological norms are invoked, pointing to how social imaginaries around disabilities as certain "kinds of living" are central to how selective practices are justified. Williams and colleagues (2002) demonstrate how health practitioners involved in prenatal screening and testing elicited a strong commitment to women's individual autonomous choices. In her analysis of the historical transformations of the ethical justifications for prenatal diagnosis and selective abortion unfolding in Finland from the mid-1950s to the present, Meskus argues that whereas prenatal testing technology and selective practices were initially seen as connected, the rationale of clinical genetics shifted at the turn of the century to what she terms a "personalized ethics". With this shift, it was the "difficulties parents encounter by the developing child's

anomaly or serious illness" that became "the only acceptable principle for selective abortion" (Meskus, 2012: 380-381).

Analogous to the Finnish case, the outlook on abortion in Denmark went from total criminalization to restricted liberalization. In 1938, the first abortion law came into force that allowed abortion when there was danger to the woman's life or on eugenic (prevention of undesired hereditary traits) or ethical (rape and incest) grounds. The eugenic indication was not regarded as unnatural or morally wrong, but rather as a means to enhance the health of the population, argued for through pure societal goals, rather than a concern for the pregnant woman (Andersen Nexø, 2009: 381-382; Herrmann 2008, 137). Thus, eugenic abortion was intimately tied to the creation of the Danish welfare state (Koch, 2000, 2004). The Abortion Act gradually became more liberal with amendments in 1956 and 1970, up until first-trimester abortion was liberalized in 1973.

Parallel to these shifts, developments within prenatal diagnosis took shape. During the 1970s, chromosomal analysis was introduced into antenatal health care on an experimental basis, leading to the Ministry of Interior convening a committee in 1975 that was charged with presenting a plan for the expansion of fetal diagnostic services in Denmark. In 1977, the committee published its report, stating that the primary purpose of prenatal diagnosis was to prevent the birth of children with serious, life-long handicap based on an economic logic of "cost-benefit" to prevent "human tragedy" (Betænkning om prænatal genetisk diagnostic, 1977; Danish Council of Ethics, 2009: 22). This paradigm of prevention was later discarded in favor of a new framework that rested on the ethos of "self-determination" and "informed choice" when the Danish board of health issued new guidelines for non-invasive prenatal screening in 2004 (Danish Board of Health 2004a-b, Schwennesen et al., 2008). The guidelines recommended that noninvasive prenatal screening, consisting of a first-trimester prenatal risk assessment for chromosomal anomalies and a second -trimester malformation scan, should be offered to all pregnant women, regardless of age and risk profile, on a routine basis and free of charge (Danish Board of Health 2004a). These guidelines were seen as more aligned with current legislation on patient rights that emphasize patient autonomy, integrity and selfdetermination, while simultaneously refuting any links to past state-mandated eugenics (Koch 2004). This was made clear in a statement issued by The Danish Parliament, where it was noted that "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. [...] The aim of prenatal testing is not to prevent the birth of children with serious diseases or handicaps" (Parliamentary Decision on Prenatal Diagnosis, 15 May 2003). Following the national roll out of the offer of prenatal screening to all pregnant women, selective abortion rates however increased markedly, normalizing

prenatal screening to the extent that it is seen as intrinsic to the experience of pregnancy today (Heinsen, 2017).

#### The study

My passage into studying the Danish abortion committees and the Abortion Appeals Board was shaped by an interest in exploring what could explain the high selective abortion approval rates found in Denmark. I did, however, not begin my research with a search for legitimation work, rather, it emerged through the process of immersing myself into my "field imaginary" (Marcus, 1998), that is, how legal decisions are arrived at through interpretations of what seriousness and danger denote. During one of the first interviews with a legal representative who had worked on one of the committees for well over a decade, I asked how assessments of danger and seriousness were made, to which she replied: "You have to understand that as a legal specialist, you learn what danger means and what serious means and what substantial means. All these concepts are words imbued with legal logics, and that's called the legal method". Shortly after, addressed to my co-researcher with whom I conducted a large part of the study, she remarked with a slightly condescending tone as she leaned back on her chair: "You must explain to Laura what the legal method is". I laughed as I tried to brush off the sense of being cast as ignorant. Yet, this social positioning also afforded me an effective position from where to ask "stupid" questions, which my co-researcher could not ask to the same extent, as she assumed her to be knowledgeable about how legal specialists work. Latour has developed the term "black box" to denote the fact that very complex processes of knowledge production, when stabilized as facts, can be described entirely and without reference to their intricate content (Latour, 1987: 2-3). The legal specialist's reference to "the legal method" as embodying what legal decision-making entails could be seen as serving to legitimate both the committees' legal practice and its lack of transparency at once by questioning whether the inner workings of such juridical institutions need to be accessible to scrutiny from outsiders. Yet, the reference to the legal method also made me realize that not only do such simplifying logics exist within the committees, but, more importantly, my task as an ethnographer was to attempt to pry open this black box. Thus, as more interviews were undertaken, legitimation work as a heuristic lens took shape (Blumer, 1954). As I hope to show, when probing about how the committee members pondered legal decision-making, it unraveled something a lot messier than what this legal specialist seemed to claim.

The analysis draws on five types of data, generated sporadically between October 2020 and February 2022. Some I bring to the forefront of the analysis and others I use more tacitly. I draw on 200 recent anonymized legal decisions on applications for

termination for fetal anomaly from the committees. Of these 200 cases, only four had ended in rejection. The documents are very brief, giving insight only into gestational age, diagnosis and legal decision. Depending on the region and the abnormality detected, the level of detail is varied; in some cases, no reason for the approval of termination is listed other than the diagnosis itself<sup>4</sup>. In other cases, permission is explained by reference to for instance "shortened life expectancy", "high mortality" or "lethality." To go behind these truncated documents, I conducted semi-structured interviews with 15 abortion committee members from all five regions in collaboration with a legal specialist, who is part of the overall research project of which the project is part. During the interviews, it became clear that the Appeals Board plays an important role in how committee members think and operate. To get a better understanding of the entire abortion juridical system, three Appeals Board members were interviewed jointly. All interviews were audio-recorded and transcribed verbatim. Third, I draw on annual reports from the Appeals Board covering years between 2001-2020, as well as on four anonymized "full" cases, which one region was kind to share with me. Lastly, I draw on 10 drawings made by committee members during interviews. The drawings were used as a participant-led methodology to guide questions and probing (Shih, 2017). These methods together have produced empirical insights into the work that goes into ensuring that second-trimester abortions for fetal anomaly are legitimate, as well as the dissonances and discussions that are sometimes part of this work. I begin the analysis by showing the importance attached to a streamlined juridical practice, which has created a dominant view of abortion committee work as devoid of socio-moral incentives. Later, I however show that in legal decisionmaking, law, morality and affect entangle.

#### Bureaucratic legitimation work: Toward a uniform practice

When an application for termination following detection of a fetal anomaly is sent to the abortion committee from the fetal medicine unit, it lands on the desk of the committee secretary, who collates all necessary documents to form "the case", which consists of various sonographic and/or diagnostic test results, prognostic assessments as well as accurate measurements of the fetus to assess its gestational age. The secretary then contacts the committee members on duty that day and sends the documentation via secure mail. In all regions, fetomedical cases are handled on an *ad hoc* basis through either email correspondence or telephone conferences. Only in the very rare event of disagreement do they consult each other. Pregnant women applying on fetomedical indication do not have give a reason for their wish to terminate. The necessity for abortion is seen as

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<sup>&</sup>lt;sup>4</sup> For instance, cases concerning Down's syndrome only include a short note such as "Trisomi 21".

encompassed in the medical documentation in itself. Conversely, pregnant women who apply for termination on socioeconomic grounds must show up for an interview with a caseworker, which entails being asked a number of private and invasive questions—from conditions of upbringing, current socio-economic conditions to current social relations. This interview is used to create a social anamnesis, which forms the basis for the legal decision. As one gynecological member explained:

We have statements from pediatricians or geneticists who assess the significance [the anomaly] will have for the child's development, so the cases are informed to the extent relevant. If a child has Down's syndrome, it's irrelevant if the parents live a life of glamour or whether they have financial problems, whereas the social cases are exactly about informing them on a social or psychiatric basis.

These distinctions are of course not as neutral as they are presented here. In conventions regarding adequate "case documentation", a foundation for legality is crafted in particular normative ways, leaving pregnant women who apply on the basis of fetopathology as opposed to those who apply on socioeconomic grounds on different turfs. The distinction rests on a notion of biomedical knowledge about the condition of the fetus as "objective facts", as many committee members said. Generally, fetomedical cases were seen as easy and quick. As a gynecological member said: "The fetomedical cases, I don't think people discuss them that much. I mean, they are pretty much expediting cases".

It struck me how little space the political and moral dimension of such automatized approvals took up. Instead, they attached much more importance to securing a uniform practice, meaning they expressed a duty to comply with legal precedence set by the Appeals Board, as well as the accumulated practice set within one's own committee. As one legal specialist explained: "It's the role of the legal specialist to ensure that cases are handled according to the rules. It might be ensuring the case is properly documented. It might also be by connecting threads back [in history]". When asking another legal specialist where current legal practice "comes from", she answered:

From the Abortion Appeals Board. Three months a year, I think it is, we have to send every single decision over to the appeals board. Then they sit and go through them to see if we follow practice, and as a result, they might announce something like, 'here, you have to be aware of this and that'. And then we align.



Figure 1. A drawing by a legal specialist depicting the symbol of the paragraph to elicit how she considered her committee work as one of simply managing the law.

A wide range of fetal abnormalities fall under the category of legal precedence. Down's syndrome, Edward's syndrome<sup>5</sup> and Patau's syndrome<sup>6</sup>—all routinely screened for as part of the offer of prenatal screening offered to all pregnant women in Denmark—are given approval automatically. As a legal representative said: "I must admit, I haven't really thought so much about Down's, because it's just on the check list." Such an answer shows that when legal practice has been settled, termination is by the same token indexed as not only legal but also as ethically legitimate, making critical debate on the societal implications of automatically allowing termination for certain diagnoses redundant. As one judge from the Appeals Board said in a rather brusque tone: "We don't manage ethics. We manage the law". This underscores not only the importance these medicolegal bodies attach to ensuring uniformity, it also shows the extent to which the moral dimension of the legal system was compartmentalized. When asking the Appeals Board members how they experienced having the responsibility of making legal precedence, a judge shippn't think I've thought a lot about it, because that's just how the system is. It's

the same as the city courts having high courts above them, and when you sit in the high courts, you make the legal decision you find best. I don't consider myself a "bessermachen" or anything.

Such quotations also demonstrate that a notion shared by many committee members (and Appeals Board members alike though they are those who formulate directives and regulations) was that ethics is built into the law, thus, what is right and wrong has been established by lawmakers, not those who regulate and put the law into practice. Especially legal representatives see their role not as one of judging the morality of the law or current

https://www.nhs.uk/conditions/edwards-syndrome/

<sup>&</sup>lt;sup>5</sup> Edward's syndrome, also known as trisomy 18, is a rare condition. Most babies with trisomy 18 will die before or shortly after being born, with 13 in 100 babies living past their 1st birthday.

<sup>&</sup>lt;sup>6</sup> Patau's syndrome, also called trisomy 13, is a rare genetic disorder. More than 9 out of 10 children born with Patau's syndrome die during the first year https://www.nhs.uk/conditions/pataus-syndrome/

legal practice but one of simply upholding it in a lawful manner. The Appeals Board has worked on aligning practice by setting up much more clear directives for what should be included to ensure that all patients have their cases handled based on the most comprehensive groundwork possible. Such agreement on what comprehensive case material implies, makes legal decision-making more efficient while simultaneously giving the legal system a sense of delivering high quality decisions. As one legal member said: "you have probably seen the statistics, which show that it's super seldom that the Appeals Board overturns our decision, so on some level, we are pretty well aligned with the legal position." Yet, such bureaucratic legitimation work not only separates legal practice from ethics but also by the same token purifies it, so it stands out as value-free. Within this framework, it is understood as difficult to challenge or resist the power of established practice:

It's beyond dispute that there is a law. It's beyond dispute that those cases that have slipped through and those that have been overturned by the Appeals Board come to constitute what's legal and not. It's beyond dispute. We have to stay within that framework. We could always discuss whether it's fair, but that's the framework for now.

(Gynecologist, abortion committee member, region C)

Thus, one thing that is safeguarded by the juridical system is ensuring applicants an equal legal position, seen as foundational to the constitutional principle of the rule of law, while also guarding committee members' own back from criticism from the Appeals Board. While following the letter of the law is one form of legitimation work, it was clear however that there was more to it than mere expediting. Collaboration, I learned, is vital to gauge "danger" and "seriousness".

## Collaborative legitimation work: Settling legality through predictive risk assessments

To assess an application based on the detection of a fetal problem, the case documentation must include a clear diagnosis, and in many cases a clear prognosis. Depending on the malformation detected, such case documentation is produced through engagement of medical specialists, from fetal medicine specialists, geneticists, pediatricians, cardiologists, neurologists and so forth, who each have their specialized knowledge of the potential outcome of a particular diagnosis. When a condition can be prenatally diagnosed with certainty, the criterion of danger is seen as unequivocally met. However, as fetal testing in many cases only reveals a *probability* that the fetus has a particular disorder, and that the disorder will *likely* lead to for instance mental disability, the establishment of danger is inextricably linked to the medical concept of risk (Herrmann 2008, 138). This means that risk assessments have become central in the work of yielding legality. In

January 2005—the same period when routine prenatal screening was rolled out nationally—the Abortion Appeals Board issued a briefing in which they informed that:

The Appeals Board predicts an increasing pressure on the abortion committees to have abortion approved as a result of a risk of fetal defects. The Appeals Board would like to draw attention to the fact that according to the letter of the law not every risk or suspicion constitutes "danger". At least, it must be required that the risk is markedly higher than the risk pertaining to the population at large. Furthermore, it must be required that possible diagnostic testing is undertaken to confirm or refute the suspicion

(Abortion Appeals Board, 2005: 32).

Later in the report, there is reference to a case that had been given permission for termination based on a three percent risk of the child developing a malformation or a developmental disorder. The Appeals Board noted that as a three percent risk is close to "the risk of the population generally" (Abortion Appeals Board, 2005: 32), approval should not have been granted. However, the Appeals Board did not define a lower limit of what counts as sufficiently high risk. Maybe not surprisingly, the legal documents I have gotten access to show that approval has been given in cases that span from six percent (risk of mental retardation) to 90 percent or more. When probing how everything within this spectrum could qualify as "danger", the most frequent answer was that such qualifications take place outside the committee, which the gynecologist in the committee then "translates". Several highlighted that the mere fact that a case lands on their desk merits "danger". As one member said: "What people apply for are not trifles. They never have been. That's also why so few rejections are given in these cases".

Yet following genetic advancements, more and more fetal aberrations are being detected, some of which are of unknown significance, which challenge the committees' assessments of what constitutes danger and seriousness. During an interview with a gynecological committee member, the following exchange took place:

I: In our region, we don't have any fixed boundaries of, like, for instance 30 percent risk. It's an illusion to think that you can with precision fix such probabilities. If there is a considerable risk that the child will be mentally disabled, then we of course consider that. It has actually happened in a few instances that we've been dealing with statements from a neuropediatrician or the like, and they have written something we really cannot use. They formulate themselves inaccurately. So it's happened that I've called them and said: "you have to be more accurate." Because our situation is that our cases are sent to the Appeals Board [...] and we work with the conscience that we are being surveilled. So therefore, we have occasionally asked; 'now make up your mind: Is there a risk or not?'

L: Does that mostly lead to a sharpening of the seriousness of the condition, or does it mostly lead to a statement that the condition is not as serious and it [the fetus] might be alright?

I: Well, such an interaction, which is not that common, because they also learn, they understand our situation, so they know they have to give us something we can use. But mostly, it leads to a sharpening of their description, so it's more likely to end in approval.

In one case from one of the regions concerning the detection of a chromosomal microdeletion, the committee emphasized, "15 percent of cases leads to mental retardation, mental developmental disorder, epilepsy and autism. The committee finds that 15 percent risk of mental retardation constitutes danger of serious abnormality even though at present, it is not possible to predict to which extent the child will be affected". In another case, the committee authorized termination based on the geneticist's assessment that "in 50 percent of cases it will lead to moderate to severe retardation, and the committee therefore estimates that there is danger of serious mental or physical suffering". Thus, the risk assessments made by doctors outside the realm of the committees not only form the basis for the diagnosis and prognosis for a particular pregnancy and fetus but form the very basis for legal decision-making by transfiguring dangers into calculable objects that committee members can act upon (Helén, 2004: 32). Risk estimates, however uncertain, come to construe all cases where the risk is higher than the risk of the background population as defected (Latour and Woolgar, 1986: 170). As one legal specialist said: "[the doctors] are the ones who have to say 'this is serious'. Because I don't have any prerequisites for assessing that. And the more precisely they describe it, the better we like it." In other words, it is not whether or not the risk estimates are sufficiently trustworthy as prediction devices, but whether they are there or not.

However, not all types of medical knowledge count as authoritative. Some depend on whether members of the committees bring these into play. In a social case concerning a young refugee, whose pregnancy was the result of a rape, rejection was given because the pregnancy had exceeded the criteria of viability (presently set at gestational age 22+6). Questioning why she was denied access, the response from all but one was that the threshold of viability is adamant; after that moment, access is no longer possible unless the fetus is incompatible with life or the woman's health is in danger. One gynecologist with specialty in rape victims replied differently. He stated that carrying a child who is the result of a rape constitutes threatened maternal health, thus he would have argued for approval had the case landed on his desk. Such a case shows that unless biomedical knowledge is standardized as part of case documentation, pregnant women are at risk of

having their case processed differently depending on the composition of the committee, which in this case spoke against the woman's interest. In cases of termination for fetal anomaly on the other hand, the routinization of collaboration works to make legal decision-making efficient, turning it into a smooth engine, where decisions can be made without questioning the underlying knowledge production and its intricacies. However, when digging into the limits of risk estimates as prediction devices, jurists and doctors alike declared the uncertainties of such knowledge. One Appeals Board member for instance said: "we have to live with the fact that there is nothing that's one hundred percent certain, and we can only give our best guess of what the risk is and make a decision based on that. And, we try the best we can. This is not black and white". Yet, these uncertainties were distressing to some. During an interview, a gynecologist made a drawing depicting a male, bearded figure sticking its head up above a cloud. Below, he had drawn a heart, three crosses, four teardrops and a small casket. He explained:

I'm essentially an atheist [laughs], but em... it's because our, and my role is kind of like going in and acting like God. Like being a master of life and death. And, I think it's really important to remind myself of that. Because it's so easy to say, "oh well". But, then there are all the emotions, the heart, and the tears, which are connected with it. When we give an approval and when we don't. And sometimes we're juggling with percentages. When we're discussing, well 90 percent likelihood this is not a life worth living, because it's non-viable or deeply disabled, but what about the last 10 percent? What if the fetus belongs to the last 10 percent?



Figure 2. Drawing made by gynecological member

A statement like "acting like God" elicits, I suggest, the moral and emotional side to abortion committee work. Through bureaucratic and collaborative legitimation work, diagnostic uncertainties and the risk of warranting termination of a potentially healthy fetus or a fetus whose life might be worth living might be tamed. Yet for some, juggling with percentages comes with a sense of discomfort. When there is no precedence nor clear diagnostic or genetic prognosis to lean on, committee members are forced to not only act as guardians of the abortion law but to act as moral philosophers of the private by adjudicating the societal *standards for entering into the human collective* (Rapp, 1999: 3), which by some was experienced as troubling. One psychiatrist said:

When we have a case that's new, when an anomaly is new, I kind of wish that it didn't land on the committee's table. You know, what capacities do we have to assess society's opinion about whether this or that fetal defect should get an approval? [...] So, there have been cases where I've felt that it's a bit unfair that we're the ones deciding, when we don't have the knowledge. But no one does, and someone has to do it.

Indeed, probing committee members about why a chromosomal anomaly such as Down's syndrome and shortened or missing extremities were considered serious, both social and ethical justifications came to the surface, some of which question what seriousness is. In fact, seriousness is not always legitimated in medical terms, but rather in social and ethopolitical terms (Rose, 2001).

## Ethopolitical legitimation work: Guarding healthy family formation

During fieldwork, one of the regions had recently processed two 'full' cases concerning missing or deformed lower arms, and in both cases, the applicants were around 13 weeks along. In one of the cases, there was talk about a potentially shortened leg as well, which could be neither confirmed nor denied as a clear vision of the fetal body is not always technologically possible to obtain at that stage of pregnancy. Both cases were rejected because, as one committee member explained:

According to the Appeals Board's practice, missing extremities cannot in isolation give access to termination of pregnancy. What we would have wanted was that the pregnancy had been monitored over some time, or at least had been sent for a second-opinion to have specialists look as the sonograms, because it was very uncertain in the text from the hospital what the anomalies meant. So, we assessed that it was too uncertain. And with previous cases in mind, we completely agreed that we had to reject it. [...] It wasn't serious enough, based on the motto that everything operable with a good result, and a child missing a lower arm who will be disabled to some extent, we're not inclined to view that as a serious handicap.

After the committee had announced the rejection, the cases were appealed. In the case concerning possible deformities of both an arm and a leg, a letter was written to the Appeals Board in which the prospective couple emphasized two elements; one, that the

defect had been discovered during that nuchal translucency scan in gestational week 12 and therefore the pregnancy could not be terminated within the time limit of abortion-on-demand. Second, that they did *not* wish to terminate because of the "aesthetic" aspect of the malformed arm, but because having a physical malformation would not only influence the child's physical abilities but cause "social stigma". Thus, social imaginaries of potential stigmatization were mobilized to justify that anything but termination would cause suffering for the child-to-be (and implicitly for the couple). To the committees' astonishment, the Appeals Board overturned the case (as they did with the other) and allowed termination. The Board did so without demanding further testing or involvement of other clinical experts, in stark contrast to the Boards' own directives. In the decision letter, the Board concluded:

The parents see the best-case scenario being that the child will be born with a physical handicap, which will cause physical limitations but may also cause psychological effects. The Appeals Board finds that the character of the condition, where the child as a minimum will have malformations of the left arm, gives adequate ground for abortion also given that the time of the ultrasound scan was in gestational week 12 and the [applicant] is now in gestational week 13.

Wahlberg argues that selective reproductive practices form around not only biological "faulty modes of living", such as errors in cell division, but "the perceived impact a disease or condition has on a family's quality of life is a central element in deliberations about what constitutes a serious disease" (Wahlberg, 2009: 106). When referring to everything from Down's syndrome to missing or shortened legs, many committee members tended to speak of these abnormalities as constituting worst-case scenarios, rather than keeping within horizon the possibility that if born, the child could end up leading a high-quality life. As one psychiatrist said: "There are a few well-functioning mongols [sic], but they are very rare." In a case concerning a woman, who had been given permission to terminate in gestational week 21 because of an extremely shortened femur, the committee emphasized that such a defect "may give difficulties in establishing walking function, chronic pain, numerous treatments, considerable limitations in everyday life, and extraordinary burden for the family" (emphasis added). Yet, the Appeals Board's reversal of the decision in the case of a deformed lower arm not only begs the question of what exactly denotes severity, but also who is given the power to judge it?

When assessing seriousness, I learned that a "combination of factors" is taken into account, being gestational age, the weight of the defect and possibilities for operating or compensating the defect. If a defect can be fixed or corrected, for instance through maximum two surgeries with a good result, or a prosthesis or other assistive aid

technologies can create walking function or function of arms and hands, then it is not serious. However, as this case highlights, this combination of factors is surpassed by a different logic. The social imaginary of physical disability as propelling potential "social stigma" becomes part of the negotiations around what constitutes a life not worth living, which, together with low gestational age, are translated into a legitimate ground for termination. Interestingly, in the committees' interpretation of the case, gestational age made a precise diagnosis was unobtainable, meaning that gestational age was part of the reason why rejection was given. Yet, in the interpretation of the Appeals Board, gestational age was mobilized to justify approval. Thus, gestational age factors into decision-making in polymorphous ways with diverging results.

I argue that there are two key considerations underlying the Appeals Boards' reversal. First, the abortion law builds on a gradualist perception of fetal personhood (Petersen and Herrmann, 2021: 4). As all products of conception may be terminated without giving a reason for it within the first trimester of pregnancy, a fetus close to the threshold of free abortion is seen as less human than a more developed fetus. Second, implicit in the Appeals Board's rationale for approving the case is the notion of *parental choice*. One Board member said:

It's important to keep in mind that the entire prenatal diagnostic system is based on informed choice and if you detect something, they should have a real choice about diagnostics and what should happen with the pregnancy. And the moment they should be able to make their decision is not when the child has been born. It's during pregnancy.

This supports what Meskus refers to as "personalized ethics" (Meskus, 2012). Thus, justifications for termination for fetal anomaly are shaped not only by legal reasoning but also by emotional and moral incentives to enable such personalized ethics. As a gynecologist declared:

We also consider the fact that we're talking about a young couple who has looked forward to having a baby, and then it turns out that the baby is at risk of developing a handicap. And of course, we need to assess it, but we do think about the fact that the parents, who, after all, are those closest to the child, *they* have decided to opt out on the child. It's at least something I think about.

#### Another gynecologist said:

It won't do any good if you create a non-functioning life and destroy three well-functioning lives. That's forcing a family into accepting a child that's behind, against their wish. Because they have asked for an abortion. Forcing them to receive this child into their family, that's a huge responsibility. And still, it's them asking

for an abortion. I'm not forcing them. It's not the abortion committee forcing them. They've decided that this is too much of a burden.

In other words, when seriousness is disputed, parents' self-evaluation of a particular anomaly as constituting burden (or risk of social stigma) becomes a weight on the scale. One could argue that the accentuation of parental choice is puzzling, as the lack of free choice is why abortion committees exist in the first place. We might say, de facto, abortion provision is in conflict with the legal rules (lack of self-determination) that seek to regulate it (see also Lee, 2003). Yet, every member spoken with felt a strong ethical commitment towards extending parent's self-determination to the domain of secondtrimester abortion, both because parents are considered the only ones apt for making a decision about selective abortion and because choice is what the state-financed policy of prenatal screening has promised. The regime of routine prenatal screening and testing in Denmark was legitimated through a rhetoric of informed choice, built upon the norm of non-directiveness, which western clinical medicine adheres to, yet the heteronomy of second-trimester selective abortion is at odds with this ethical golden standard. I suggest that ethopolitics is the norm to which the juridical system subscribes to overcome this tension. It could be argued that the inclination toward authorizing termination for fetal anomaly in almost every case is a testament to reproductive medicine being once again on its way down the "slippery slope" to eugenics (Wahlberg 2008, 2009), yet it is not eugenics that drive the juridical system's practice. Rather, jurists and doctors feel great discomfort by the thought of standing in the way of prospective parents' autonomous choices, because they fervently believe these choices are being exercised as exactly that (See also Williams et al., 2002).

Helén (2004) argues that fundamental to high-tech antenatal health care is an "ethical split" between the prospective parents who are subjectivized as those who must take *ethical responsibility* for making choices about fetal testing and selective abortion, meanwhile the health care system carries the purely *technical responsibility* of identifying risks and abnormalities, based on which the pregnant woman and her partner are able to make such choices. Indeed, the ethopolitical imperative of enabling people to enact their freedom seems to extend to the juridical realm. What is at stake for committees and the Appeals Board is the "technical" *facilitation* of a personalized ethics and autonomous decision-making, which in effect enables the juridical system to distance itself from the moral questions pertaining to eliminating anomalous life. In this way, the legal administration of abortion circles less around the governing of life and death based on moral deliberations about what kinds of lives are worthy as future citizens and what lives

are expendable in the eyes of the state, as it revolves around safeguarding people's own wishes to procreate healthy offspring to ensure healthy families.

In her study of the interpretation and operation of the disability section of the British Abortion Act 1967, which states that abortion can be permitted if "two doctors have formed an opinion in good faith that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped" (Scott, 2006: 71), Scott argues that there is a good moral case to take parents' view on disability into account. She shows how guidelines issued by the Royal College of Obstetricians and Gynecologists (RCOG) require that assessments of danger and seriousness should be made by "informed persons with no personal involvement in the pregnancy and its outcome" (Scott, 2006: 74), yet one set of RCOG guidelines specify that "women vary in their reaction to being told that their fetus is, or may be, abnormal. Occasionally a woman feels strongly that she is unable to accept a probability of risk or a degree of handicap that her medical practitioners consider less than substantial or serious. Under such circumstances, and only when the gestation is less than 24 weeks, the practitioners may decide that abortion has become necessary to protect her mental health" (ibid. 75). The difference between the British and Danish regulation of selective abortion is that whereas RCOG guidelines make explicit that women's own perception of what constitutes seriousness is a legitimate ground for permitting termination until a certain gestational age, such transparency lacks in Denmark. Indeed, for committee members in Denmark, such transparency seems to be established after-the-fact of an appeal, yet for the broader public, the basis on which legal decisions are made is still highly opaque. Indeed, as the ethopolitical imperative of informed choice and self-determination became apparent, I was curious about in what ways this translated into the justifications for approving or rejecting abortion on social indication. Here, parental choice is not mobilized at all, as one legal specialist made clear:

It's not about your own experienced stress. It's about factual stress. It's about whether we see objectively that you are in an objectively difficult social situation. And you are not objectively in a difficult social situation if you have a good education, a good income, a good network, and good housing. You might feel that having a baby at this time is an enormous stress, but the law does not take that into account.

Rose argues that "ethopolitics is about the value of different forms of life, styles of life, ways of living, and how these should be judged and governed. Nowhere is this ethicalization of politics more evident than in the value-driven debates over scientific developments, whether these concern global warming or reproductive technologies. (Rose, 2007: 97). The ethopolitical imperative, as Rose notes, is precisely tied to the realm

of high-tech reproductive medicine. What is being safeguarded by committees is not free choice for all, but free choice for those at risk of procreating abnormal offspring. In other words, it is healthy family formation that is being safeguarded by approving termination even though, "objectively" speaking, the condition detected is not considered serious.

After the two cases concerning malformed lower arms had been overturned, the regional committees met with the Appeals Board to clarify the impact for future legal practice. Approx. three months after the meeting, the Appeals Board issued a briefing in which they informed: "In the Appeals Board's view, there was no doubt that there was a handicap. The degree of malformation must be held up against gestational age" (italics added). I wrote the committee member, who informed about the briefing asking; "Does that mean that in managing the abortion law, a handicap no longer has to be serious, but only has to be a deviation from the norm to be granted approval?" She replied: "I also read it like that. And yes, we will have to discuss how we relate to this from now on."

What is so compelling about the juridical world of abortion committees is the extent to which these justifications intertwine in ways that makes it difficult for those who work within the system to challenge legal practice. In lack of a better image, it appears like an endless loop. To my knowledge, what is being debated now is not whether or not a missing or deformed lower arm equals a legitimate ground for termination, or whether it constitutes a life not worth living. What is being debated is how to manage similar cases in the future to secure uniformity. There is no doubt that the reversal of the cases will create precedence, which makes me wonder; if *every* detectable abnormality is a legitimate ground for termination, why put pregnant women through the bureaucracy of application? Why use time, money and resources on management of cases that in almost every case end in sanctioning termination? As one committee member pondered: "What is really the purpose with these committees, because we're basically just delivering rubber stamps for people's wishes?"<sup>7</sup>

#### Conclusion

Through interviews with abortion committee and Abortion Appeals Board members, legal documents and annual reports, I explored the legitimation work enacted by committees to justify the authorization of selective abortion by asking: How do committee members negotiate and settle the criteria of "danger" and "seriousness"? For who and what purpose does the Danish state guard selective abortion when so rarely rejected, and what exactly is being guarded? Inspired by van Wichelen's notion of legitimation work

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<sup>&</sup>lt;sup>7</sup> I am still waiting the response from the Abortion Appeals Board for a follow-up interview.

as "ethics in the making", I identified three justificatory discourses, which I termed bureaucratic, collaborative and ethopolitical legitimation work. I showed how abortion committee members work with a very palpable sense of being under control of the Appeals Board's directives, to which they feel obliged to conform. This pervasive form of administrative legal reasoning, what I termed bureaucratic legitimation work, is mostly concerned with streamlining the kind of documentation seen as necessary to form an adequately illuminated case to ensure that it can be handled lawfully. Committees and hospitals working together to form sufficient case documentation is central to this streamlining, what I called collaborative legitimation work. By bringing boundary cases to the fore, I illustrated the contentiousness that surrounds the criteria of both danger and seriousness. Committee members must rely on the risk assessments of external medical and genetic experts while being aware of the limits of their expertise, as not everything is known nor predictable in the world of reproductive medicine, which brought affective dimensions such as discomfort to the fore. I further illustrated how the criterion of seriousness is under transformation, as the Appeals Board recently overturned decisions concerning lower arm malformations, which in the past have been rejected as not serious enough. Indeed, committee members turned to the ethos of informed choice as a way to reason that termination is legitimate even though the norm against which they measure seriousness is difficult to yield medico-legally. I delineated this relocation of the power to assess whether or not an anomaly is serious to prospective parents as a form of ethopolitical legitimation work. I argued that these forms of legitimation work in conjunction work to both justify current legal practice and explain the gaps, paradoxes and inconsistencies of that practice. Central to how abortion committees work is, on the one hand, a strong commitment to comply with established legal precedence brought about through interdisciplinary collaborate efforts, and on the other, a strong commitment to enable prospective parents to make autonomous choices, through which the juridical system configures itself as a technical bureaucracy, enabling it to distance itself from the ethical dimensions of sanctioning the elimination of anomalous unborn lives. Such commitments, I argued, are oriented towards safeguarding both the principle of the rule of law and healthy family formation, both of which are quintessential elements of welfare state Denmark.

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## **ARTICLE 2**

# Orchestrating Moral Bearability in the Clinical Management of Second-trimester Selective Abortion

Laura Louise Heinsen, Camilla Bruheim and Stine W. Adrian

#### Abstract

In present-day Denmark, second-trimester selective abortion has become a regular medical event, which has turned selective abortion care into a routinized task for health staff. In this article, we explore what forms of care practices abortion providers in Danish public hospitals engage in to make second-trimester selective termination emotionally and morally bearable. Using in-depth interviews, documents and social media data, we show how efforts to turn selective abortion into an emotionally and morally manageable medical event permeate both institutionally developed care practices as well as the relational work that predominately midwives and nurses carry out. We also unpack how material and visual aspects of abortion practices are entangled with the emergence of moral bearability and the normative effects of the care practices at stake. We mobilize the analytical concept of "moral bearability" to argue that care is orchestrated in particular ways to make the abortion—from the procedure, the decision to the handling of dead fetal bodies—simultaneously bearable for couples *and* health staff.

Keywords: [moral bearability, orchestration, selective abortion, death, Denmark]

#### Introduction

When we don't offer surgical termination here it is primarily because it's an unpleasant procedure to perform because the fetus is so large, so you have to pass [through the cervix] with a pincer and crush the skull. And a procedure like that, where you must mutilate the fetus, most doctors don't want to do that. So therefore, we've chosen that it takes place medically, because it's gentler on everyone.

[Bjarne, gynecologist]

You might meet someone saying "this wasn't a difficult choice" but then you sense that they still feel the need to, you know, explain why they've made the decision. You sense their guilt [...] And then I try mirroring, using the same words as them, nod, affirm, express an understanding. And if the couple is really tortured by the decision, then it's about talking about all the different emotions and rationales.

[Frederikke, midwife]

In present-day Denmark, the linkage between high uptake rates of routine prenatal screening (>95 %), high rates of couples opting for termination following the detection of a fetal anomaly (99 %) and an efficient medico-legal system authorizing nearly all applications for termination due to a fetal problem<sup>2</sup> has turned second-trimester selective abortion into a regular medical event (Lou et al., 2018; Petersen and Herrmann, 2021). In effect, selective abortion care provision has entered the public hospitals as a routinized task for healthcare staff to carry out. Nevertheless, what it entails, how it is done and what social and moral responses it provokes is seldom discussed outside clinic walls. Selective abortion care involves many tasks and concerns for healthcare professionals as they work to ensure the physical safety and well-being of the woman during the procedure. Yet, as we learned during fieldwork, given that abortion care is also highly morally charged, there is much more to selective abortion care than securing safe medical outcomes. This is likely so because selective abortion—theoretically as well as practically—balances at the border of life and death (Jensen, 2011), while also raising unresolved ethical questions about the value of anomalous or chromosomally different lives and who should decide what counts as a life un/worthy of living (Williams et al., 2002).

Since prenatal testing was at the cutting edge of becoming normalized, a growing social science literature has explored the social impact brought on by selective

<sup>&</sup>lt;sup>1</sup> According to the Danish Cytogenetic Central Registry (DCCR), 99 % of pregnant women choose to terminate a pregnancy when a chromosomal anomaly is detected (DCCR 2022), which has resulted in a reduction of the annual number of children born with Down's syndrome by more than 50 percent (Ekelund et al., 2009).

<sup>&</sup>lt;sup>2</sup> Statistics show that of the 600 annual applications for selective abortion in the second trimester, 94 % are granted approval by the committees (Abortion Appeals Board, 2020)

reproductive technologies (Wahlberg and Gammeltoft, 2017) from the vantage point of the "patients", exploring the excruciating emotional and moral struggles experienced by women when having to choose between keeping a disabled fetus or opting for abortion (Gammeltoft, 2014; Leichtentritt, 2011; Rapp, 1999; Risøy and Sirnes, 2015; Rothman, 1993a). In her pioneering study of amniocentesis in the United States in the 1980s and 1990s, Rayna Rapp (1999) for instance argued that the routinization of amniocentesis turned the women to whom it was offered into "moral pioneers". More recently, building on Rapp's work, Li-wen Shih shows how Taiwanese pregnant women take up on average 13-15 sessions of sonography in a single pregnancy out of concern for the health of their fetus, illustrating the anxiety carried by pregnant women of being a burden to society if having a disabled child (Shih, 2017). Shih theorizes this sense of obligation to the state conjoined with personal desires to have a normal child as "moral bearing". Similarly, Heinsen uses the term "moral adherers" to illustrate how prenatal screening has become habituated in Denmark to the extent that it is taken for granted as part and parcel of the experience of pregnancy, whereby the potential choice to terminate a disabled fetus is seen as implicitly being recommended by the state (Heinsen, 2017). In conjunction, these studies give important insights into the patient perspective across different historical and cultural junctures. However, we have yet to see studies that in a similar fashion explore the moral labor involved in caring for couples who go through disability-selective abortion and how selective abortion care delivery is orchestrated to manage the moral predicaments of health staff (for an important exception see Chiappetta-Swanson, 2001), not least in a Danish context.

Denmark is an interesting case-study, as it is often highlighted as the first Western country to establish both access and a right to free abortion in the first trimester of pregnancy. From the 12th weeks of pregnancy, permission for abortion must be obtained from a regional abortion committee. While the relationship between jurisprudence and ethics is contested, it could be argued that legal regulations mirror the ethical values of a society, thus reflecting a liberal attitude to the question of the morality of abortion, not least in cases of fetal anomaly. However, since 1989, it has been possible for hospital staff to reject performing abortion services for reasons of conscience (Herrmann, 2007). With the introduction of a conscientious objection clause, Danish lawmakers acknowledged an "ethical pluralism" to the question of abortion, while maintaining that the healthcare system is obliged to facilitate abortion without delay (ibid.).

Drawing on interviews with 11 healthcare professionals and an initiator of the National Organization of Infant Death, as well as on data drawn from medical guidelines, medical instructions, patient pamphlets and social media, this paper explores what forms of care health practitioners engage in to make second-trimester selective abortion

emotionally and morally bearable. To specify, we ask: In what ways does moral bearability emerge, how does it inform the ways in which care for women and their partners is orchestrated, and what normative implications do these care practices have? We mobilize the concept of "moral bearability" to capture how abortion care is done and why it is done in certain ways. According to Merriam-Webster online dictionary, bearing means "the way in which a person moves, stands or behaves" (URL 1), meanwhile, to bear signifies "to accept, tolerate or endure (especially something unpleasant) (URL 2. See also Shih, 2017). By following abortion practices from the perspective of health staff as what Dumit (2014) and Haraway (1997) describe as an "implosion", we show how efforts to turn abortion into an emotionally and morally manageable medical event permeate both institutionally developed care practices as well as the relational work that predominately midwives and nurses carry out. Furthermore, we unpack how material and visual aspects of selective abortion entangle with the emergence of moral bearability and the normative effects of the care practices at stake. Drawing on implosion methodology implies an ontological thinking where material, discursive, institutional, economic, social and symbolic elements all take part in the making of the world (Dumit, 2014), in this case in orchestrating moral bearability in the clinical management of selective abortion. Our use of the noun bearability (as opposed to the adjective form) connotes our argument's double meaning; we argue that in the very organization and on-the-ground, relational orchestration of second-trimester selective abortion care, what is strived for is to make the practical modality of abortion simultaneously bearable for couples and health staff. As we will show, the management of second-trimester abortion as medically induced birth is justified not only in medical but also in moral terms, which, in effect, has moved abortion care out of the hands of surgeons and into the hands of nurses and midwives, who on the one hand are highly committed to patient-centered care and, on the other, to follow particular care performativities, strongly believed as a prerequisite for steering women and their partners safely and assuredly through the abortion. In the following sections, we unfold the institutional, relational, ideological and material aspects of the orchestration of moral bearability with the hope of illuminating the normative underpinnings of this orchestration and to trouble the norms guiding existing care practices, showing that things could be otherwise (Adrian et al., 2018).

We begin by placing our study within existing literature on abortion provider's experiences and unpack the theoretical implications of the term moral bearability, followed by a description of our study. We then turn to analyzing how moral bearability has emerged through the development of clinical guidelines, face-to-face relational care and post-abortive care practices.

### Selective abortion: The providers' perspective

In recent years, several qualitative health studies have documented the experiences of doing abortion work in the global north (Becker and Hann, 2021; Chiappetta-Swanson, 2001, 2005; Cignacco, 2002; Garel et al., 2007; Harris, 2008, 2019; Lindström et al., 2007; Ludlow, 2008b; Mauri et al., 2015; Roe, 1989; Vinggaard Christensen et al., 2013) and the global south (Hằng, 2011; Mizuno, 2011), focusing especially on themes such as stigma, inadequacies in training to meet women's needs, and the emotional impact of being confronted with fetal remains (Harris, 2008; Ludlow, 2008b; O'Donnell et al., 2011). Sociologist Wendy Simonds' (1996) ethnography of American abortion clinics portrays the emotional toll of doing abortion work in a polarized political landscape, demonstrating the tension between abortion providers' personal pro-choice ideology and their discomfort with the bodily violence that is sometimes part of doing abortion work. Some studies have explored providers' experiences assisting in sex-selective abortion (Hằng, 2011; Kasstan and Unnithan, 2020), yet overall, there is a remarkable gap in the ethnographic literature investigating care work related to disability-selective abortion.

Catherine Chiappetta-Swanson's work on nurses' perspectives on caring for women who end pregnancies for fetal anomaly in Canada is an important exception. Using the analytical framework of "dirty work", she examines the working conditions on surgical-gynecological wards and the practices taken up to navigate providing care in a domain "shrouded in a veil of secrecy" (Chiappetta-Swanson, 2001: 124). Working at a time when few medical guidelines were in place, she shows how nurses built clinical routines, organized debriefings and developed post-abortive care practices, such as showing the dead fetus to the couples, which the nurses experienced as rewarding and meaningful. Building on Chiappetta-Swanson's groundbreaking insights, we aim to contribute to the ethnographic literature on abortion care by shedding light on the moral labor involved in selective terminations with data material generated in a place and a time when such care work has, to some extent, become "everyday". Because abortion work involves actions on the part of health staff that in a very literal sense produce and confront death, such work, we argue, involves making the production of death legitimate and justified to create such "meaningfulness".

### Orchestrating "moral bearability" in selective abortion care

Inspired by Jensen's work on organ donation (2011), we draw on the concept of orchestration to make the case that care practices are arranged in particular ways with the purpose of creating a morally bearable situation for all actors implied. The verb orchestrate comes from the world of music and means "to arrange or combine so as to achieve a desired or maximum effect" (Jensen, 2011: 13). The Cambridge dictionary

defines orchestrate as "to arrange something carefully, and sometimes unfairly, so as to achieve a wanted result" (URL 3). As such, central to the theoretical backdrop of orchestration is the understanding that that which is being orchestrated, in this case selective abortion care, has a wanted result or effect. Jensen suggests that the concept of orchestration "helps illuminate how families and staff play an active role in performing and creating an alternative environment or reality to make organ donation acceptable" (Jensen, 2011: 14). Yet, we suggest that in the context of selective abortion care, it is not only acceptability but also moral bearability that is strived for; by organizing abortion care as a medical procedure resembling involuntary pregnancy loss, the materiality of selective abortion and its "product" becomes emotionally and morally manageable; by supporting the couples' motivations for having opted for abortion by creating certain narratives, eg. about love and responsibility, health staff help make the abortion not just meaningful but also "right", and by undertaking certain material post-abortive care practices, such as encouraging couples to see, hold and attach to the dead fetus, which are seen as benefitting couples, health staff help couples on a good path of recovery, giving nurses and midwives a sense of reward. In conjunction, these practices (intend to) empower the couples to bear going through termination, and health providers to bear their bearing and bear being complicit in the event themselves.

With an emphasis on moral bearability, we shift analytical attention from "care" to "moral labor" in selective abortion work specifically, and work arrangements that balance at the margins of life and death more broadly. Caregiving in second-trimester abortion services takes on a particular moral urgency for at least two reasons; first, abortion as a body of practice involves assisting in ending the life of an unborn fetus, involving direct actions on the part of health staff to produce its death, as they are those who insert the labor-(and thus death)-inducing medication into the woman's vagina. Second, abortion care is a moral enterprise because it elicits deeply felt norms and values about good care and "proper" handling of the dead fetus, as well as how couples should respond to their "baby" and cope with the ordeal. In other words, in our "bio-age" (Bauer and Wahlberg, 2009), where bioscience, biotechnology and high-tech medicine are increasingly shaping beginnings and endings of life (Franklin and Lock, 2003; Kaufman and Morgan, 2005), care involves the moral labor of legitimizing and settling good and proper ways of managing such induced deaths. By suggesting moral bearability as a framework, we aim to take seriously that selective abortion work is challenging, and that health staff strive towards making these situations as considerate and caring as possible, ultimately in ways that support both couples and healthcare staff in coming to terms with selective termination as legitimate deaths.

#### Methodology

This article builds on a collaboration between the authors, which formed around a shared interest in the clinical management of selective abortion. Driven by our interest in how abortion procedures are "done" and why they have assembled in certain ways, we immersed ourselves into different sources. We draw on semi-structured interviews with three nurses, four midwives and three gynecologists undertaken by the first author in 2021, a semi-structured focus-group interview with four midwives undertaken by the second author in 2020, and an in-depth interview with an initiator of the National Organization of Infant Death undertaken by the third author in 2021. The recruitment of nurses and midwives took place via self-referral by responding to a call for participants circulated on listservs and a closed Facebook group for practitioners. The gynecologists were contacted directly due to their specialized knowledge about abortion procedures, and the initiator of the National Organization of Infant Death was recruited to shed light on the historically shifting approach to pregnancy loss care in Denmark. The goal of an in-depth interview is to give prominence to participants' narrative activity through openended "guided conversations" (Lofland and Lofland, 1995). Interview guides targeted at health staff were mainly used as a starting point, asking for example: "Can you tell me about the latest late abortion you assisted in?" and "what do you do when you meet a couple for the first time?" Additionally, we draw on medical guidelines and instructions and patient pamphlets from different hospitals, as well as a visit to a gynecological ward. In conjunction, these varied data were assembled to tease out how selective abortion care were discursively and materially exercised. All interviews were audio-recorded, transcribed, and analyzed using Nvivo. Coding categories followed a temporal frame of before (pre-meeting), during (labor-induction), and after (post-abortive care) the abortion procedure. While the process of coding took place separately, analysis took place through sharing and discussing research data, such as interview transcripts. The ethnographic approach taken in this study builds on the premise that data are created through the researchers' empirical interests, methodological preferences, the negotiated realities of particular field sites, and the researcher's interpretation (Madden, 2010). Ethical approval from the Research Ethics' Committee at Aalborg University was not required for this research, but we obtained approval from the Data Protection Unit to meet GDPR obligations. All names used are pseudonyms

## "A concern for the surgeon": Orchestrating moral bearability through clinical guidelines

Evidence says that surgical abortions have more complications than medical abortions. You risk doing damage to the uterus. You might meet someone in week

13 who begs for one [D&E], and then we explain to them that we don't think it's a good idea.

Interviewing a chief gynecologist working in one of the largest Danish hospitals, she gave evidence of physiological benefits as an explanation of why medically induced birth has become the standard procedure, and in most hospitals the only procedure offered to women ending a pregnancy in the second trimester. At some hospitals, terminations between gestational week 12-14 may be performed through D&E, however this depends on the presence of one of the few surgeons willing to do the procedure and no one performs them after gestational week 14. When women and their partners arrive at the hospital, health staff hand them a patient pamphlet that outlines the medical procedure and what to expect and be aware of. All pamphlets we have collected underscore that "After the 12th week of pregnancy, it is no longer possible to undertake an abortion through surgery. The abortion is now induced using medicine" and that "In some instances, you will be sent for curettage afterwards" (see figure 1). One pamphlet specifies that the woman will be handed a "pill of Mifegyne, which stops the pregnancy from developing further", that "bleeding and pain may occur", and that when the woman is admitted to hospital for induction, "the abortion is set in motion by inserting Cytotec tablets into the vagina", given "every three hours until the abortion is completed". The couple is also informed that "it is different from woman to woman how fast she aborts. In 90 % of cases, the abortion takes place within the first 24 hours".



Figure 1. Patient pamphlet

Although surgical abortion is considered a safe method provided the clinician is skilled and has access to specialized instruments (World Health Organization, 2012: 41), and comparative studies indicate that a surgical procedure is preferred by (some) women over medical termination and is associated with fewer post-abortion complications (Bryant et al., 2011; Westhoff, 2011), it is widely believed by Danish doctors, nurses and midwives that the process of giving birth to the dead fetus carries less clinical risks. Yet, as we began probing our interlocutors about the medical "evidence" behind the medical regime, it became clear that something more than a concern for the physiology of the woman is at stake. During an interview with two nurses, one of them told us that at her unit, only three doctors were willing to perform surgical abortion after 12 weeks of gestation: "I don't really know why. I guess, that's what I hear, that they speak about it as a very unpleasant procedure, because the fetal body parts are way bigger, so they might get stuck in the suction. It's just more complicated to do". During an interview with a gynecologist, who was part of standardizing medical terminations across the country, he explained that:

When we in the old days set the threshold for abortion at 12 weeks, it was because it was unproblematic to perform the abortion [up until this limit], because you could evacuate the fetus through suction. [...] At first, we did it with a curette, but a soon as we got suctions, we started using those, because for the one doing the procedure, using suction is much less confronting. And then obviously, if you do surgical abortion after 14 weeks, it demands a lot of practice. And most of my colleagues would say no. And that's because we're afraid of doing damage to the uterus, because it's a small, thin thing, and there are examples of accidents that have been very serious, where the uterus perforated, and the colon was damaged. It can be very dramatic. And in the 1980s and 1990s, in one case, a woman died because she lost so much of her colon. So, there's a history that's part of the reason why we don't think we should impose these risks on women. But I think we must be honest and say that it is just as much a concern for the surgeon. And that very few surgeons want to do late abortions. And on an everyday basis, it is typically the young doctors who perform the abortions, and therefore no one has that kind of routine.

This points to two interrelated reasons why Danish gynecologists promoted medical abortion as the preferred method; first and foremost, it is associated with profound discomfort on the part of the physician to do surgical termination because it involves dismembering the fetus and piecing the dismembered parts together after the abortion to secure that all pregnancy tissue has been evacuated, and second, it demands a high level of technical skills to dilate and evacuate the uterus neither achievable nor preferable within Danish public healthcare. According to Lisa Harris, second-trimester abortion was accomplished in the United States primarily by labor induction up until 1977, when David

Grimes and colleagues published a study documenting the safety of D&E (Harris, 2008). As D&E increasingly was accepted as a procedure superior to labor induction, the responsibility of doing abortions fell in the hands of doctors and staved there. According to different sources, between 70 % and 90 % of second-trimester abortions in the US continue to be surgical (Jones et al., 2017; Löwy, 2018), although increasing restrictions on abortion provision and the disturbing overturning of Roe v Wade by the American Supreme court will seriously impede women's access to this method and second-trimester abortion writ large (Andaya and Mishtal, 2017). In Denmark, the story is in many respects the opposite. Abortion has for decades, and continues to be, considered a reproductive right, and is politically backed by politicians and the Danish government as important for women's reproductive health and freedom (URL 4). Yet, at the same time, efforts have been made within the medical profession to turn abortion provision into an acceptable procedure for the medical institution to perform, as the above quote elicits. When RU 486, also known as the "abortion pill", developed and introduced initially into clinical practice in France in the 1980s (Gerber, 2002), was implemented in Denmark in 1997, it became possible not only to spare economic resources by reducing the number of surgical terminations but also for doctors to "incapacitate" themselves of the unpleasant work of performing these procedures and of being confronted with fetal body parts. Thus, while women and their partners are told that medical abortion is best because labor and birth is gentler on the woman's body, economic logics, institutional labor divisions, lack of technical skills, and moral drivers were all implicated in developing, cementing, and sustaining the medical procedure as "best practice". Indeed, the advocacy of "birthing is best" is reproduced during face-to-face encounters between couples and nurses or midwives, who must reassure couples about the benefits of the medical regimen. In these encounters, nurses and midwives often highlight both the physiological and psychological benefits of labor and birth. One nurse for instance explained:

You might think, it must be traumatic, why do I have to give birth? Many thinks like that, they don't want to, they cannot relate at all, because normally birth is associated with something good, not something painful where you don't get to bring anything home. But research says that the healing process is better, later on. By being part of the process rather than someone just removing it.

Still some health staff questioned the logic of birthing as best. One midwife for instance said:

I know it's because it's considered gentler on the woman's uterus and all that, but it's also because of some idealistic ideas about it being better psychologically. And to that I just want to say; we don't know anything about that. It might be gentler to be put to sleep, get it removed surgically, and never be confronted with the sight of

tiny fingers and toes and all that. I've no doubt at all that that would be better for some women. But they don't have a choice.

Couples who arrive at the hospital for second-trimester abortion are told that they must face the abortion as a bodily process demanding labor and birth for their own good. They are not informed about the reason why women do not have a choice regarding abortion method. That the practice also is due to the emotional and moral unease of physicians, and the demands of high levels of technical skills that are unobtainable in Denmark today.

## Orchestrating moral bearability through relational care

With the normalization of medical abortion followed a transfer of the responsibility for providing abortion care to the nursing and midwifery professions. The spatial organization of abortion care varies from hospital to hospital, but generally all early second-trimester terminations take place at gynecological units with attendance of nurses meanwhile later abortions take place at maternity wards employed by midwives. According to Danish medical instructions, health staff must follow a medical script (Timmermans, 1996), involving two steps; the administering of Mifepristone, and second, induction of labor 24-48 hours later when the woman or couple is admitted to hospital. The initial meeting where the pill of Mifepristone is handed out was referred to by our interlocutors as the "pre-meeting" and is typically handled by a nurse or a midwife. One medical instruction from one of the largest hospitals on Zealand outlines: "Before the treatment is initiated, the patient is informed about the course and, if any, side effects, as well as that the fetus in some cases may show signs of life and how this is handled" (URL 5), thus highlighting certain medical and procedural information, such as side effects, as vital information.

At the same time, caring for couples in this initial phase involves much more than such "factual" information. One midwife for instance said that she uses time before the pre-meeting reading up on the medical record to "be ready to greet exactly this couple, so you feel you've prepared yourself for *them*, so they are met with an attention to "we know why you are here and that it's a sensitive situation#, and that they don't have to explain." Frederikke, a midwife in her 30s also touched upon the importance of tuning in on the couple's specific emotional and psychological state as a way to make each couple feel safe and reassured:

There isn't a standard script I just turn on. Because the couple will go first and then I try to register where they are in all of this. Because they might say: "This wasn't a difficult decision, because the child wouldn't be viable outside the womb", or "we knew beforehand", for instance if they had already decided to terminate if the results came back positive, so it's with those things in mind that I talk with them [...] So

it's about making them feel safe and reassured. That's my most primary task. Off course there are also a bunch of practicalities, such as paperwork and formalities and that she is given the first pill, that they know what kind of procedure is in stall for them.

When women and their partners arrive at the hospital for induction, they are welcomed by the nurse or midwife in charge of their care. The practitioner follows the couple to a private room with an adjacent bathroom, offers them something to drink and hospital gowns, measures the woman's blood pressure, and orders blood testing for emergency blood transfusion in the case of excessive bleeding. As soon as the first Cytotec tablet has been inserted, the waiting begins as it can take hours before labor is induced and active birth begins. This waiting time is used to getting to know the couple (even more than achieved during the pre-meeting) and to figure out how to individualize care as best as possible. As part of this endeavor of getting to know the couple, it is standard to inquire how they relate to the event by asking: "what is this to you – an abortion or a birth, a fetus or a child?" Through such inquiring, conversations often circle around the decision to opt for termination, and the shame and guilt that haunt some couples (Heinsen 2022). Frederikke told how she approaches couples tortured by their decision by "mirroring" their emotions and language:

I try saying "I get it, I understand, and remember these and these things which are why you made this decision". [...] and I try to turn it into a more quotidian conversation about parent-child relations, because we feel love for our children, and we want to do good for our children. And we take on responsibility and we're struck by guilt and bad conscience as parents, one way or the other, so I try to weave it together with love.

In the *The Managed Heart. Commercialization of Human Feeling*, Hochschild ([1983] 2012) coined the term "emotional labor," which describes the attuning to and empathizing with the needs of another human being *and* the simultaneous management of one's own emotions in order to meet those needs. In selective abortion care, we suggest there is more to the relational labor being done by nurses and midwives than juggling the needs of couples and one's own emotional response to those needs. Getting to know each and single couple by listening to their story and to their moral anguish is pivotal not only to individualize care but to help couples feel they have chosen abortion for the "right" reasons. Reassuring couples of the legitimacy of the abortion are ways in which Frederikke and others seek to make the excruciating situation of what has already happened and what it about to take place more bearable. Weaving selective abortion together with "responsibility" and "love" through narrative strategies can be seen as moral

labor that re-orient the event from one that is experienced as an uncaring act of discarding of an unwanted fetus to an act of benevolence and care for a desired child too ill for this world. Through such moral labor, the couple and health practitioners who aid them in exercising their decision are turned into ethically responsible subjects, and into loving and caring mothers and fathers of a dead baby.

Apart from expressing emotional support for the decision to terminate, most health staff used the time during induction and labor to prepare the couples for confronting themselves with their dead "baby". Talking about how the fetus might look like at various gestational ages, how the fetal malformation might look like outside the womb, and how the fetal body could be handled and memorialized are considered important for the couples to be able to mentally prepare themselves for the grief work they will need to do after the abortion itself. Seeing the dead fetus is understood as pivotal for two ideological reasons. We return to the second in the next section, but the first ties closely together with our point raised above that moral bearability is orchestrated by supporting the justification for abortion. Several of our informants told us that they would encourage couples to see to reassure the couple of the reality of the fetal abnormality. One midwife for instance said:" If there are visible malformations, then yes, you have a greater tendency to verbalize that they've made the right decision". Marie, a nurse, explained:

If it's a case of acrania for instance, where the top of the skull is missing, for the parents sometimes it's a relief, like, okay, I can actually see it myself. Because sometimes they are like; "what does the sonogram picture mean? Why can't it live? So, it becomes a kind of confirmation that it's okay it's being ended, because you can see that the top of the head is missing.

In her work on Canadian nurses' practices in relation to termination for fetal anomaly, Chiappetta-Swanson notes:

Though they do it in subtle and non-directive ways, [nurses] feel it is their responsibility to counsel their patients and prepare them for the grief work they will need to do [...] They know how easy it is for their patients to look at the baby and to be plagued with lingering doubts about whether the procedure had in fact been necessary at all. The nurses want to spare them that anguish. (Chiappetta-Swanson, 2001: 154, 156)

Uncovering the malformed part or parts of the dead fetus slowly and inspecting these deficiencies together with the couple is exercised to confirm and reinforce that abortion was the *right* decision. Remarkably, the attenuation of the fetus' deformities is coupled with an attenuation of the fetus as a precious, human being or "baby", not as biological waste or a defected "product of conception" (Gerber, 2002). In the context of the Danish

nationalized health care system, enactment of fetal personhood and enactment of abortion justification go hand in hand. One midwife told us how she did great efforts to "tuck the baby" neatly because: "The child, when it's a wanted pregnancy, then it has been made out of love, and when they see two lines on the pregnancy test, you know, their whole life is unfolding in front of their eyes, and that's important to care about. So, it shouldn't just lie alone. I think it's important to take care of that life in spite of everything."

Moral bearability is accomplished through aiding couples in legitimizing the decision about termination as a responsible act of love, while simultaneously aiding the couple in confronting the abnormal baby's remains. This is more easily obtainable when the malformation is clearly visible and, not least, lethal, yet it is more challenging when the fetal abnormality is hidden beneath the skin. As Frederikke said: "some of the most difficult processes are those where something is wrong with the brain and the couple has been told about all these diffuse estimates, like it might lead to some level of developmental disorder, but you cannot predict to what extent".

Until now we have emphasized that a concern for the surgeon and a concern for the couples tormented by the decision to terminate are central to the ways in which selective abortion care has been put to form and is being performed in everyday clinical encounters. Next, we turn to the second reason seeing fetal bodies is perceived as good post-abortion care.

# "To say proper goodbye, you need to say hello": Orchestrating moral bearability through promotion of attachment and grief

Prior to the late 1970s, it was standard in most Western countries to encourage couples impacted by pregnancy loss to forget it happened and look to the future, which mirrored the then dominating grief model of "letting go" (Davies, 2004; Kofod and Brinkmann, 2017). Standard practice was to cover the woman's head with a veil during labor and birth, whisk the dead baby away immediately after birth, and dispose of the remains as biological waste without consulting the woman<sup>3</sup> (Bleyen, 2012; Hughes and Riches, 2003; Kjærgaard et al., 2001; Löwy, 2018). This shifted from mid-1980 onwards, when a the grass-root association Parents and Birth initiated a special group focusing on infant

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<sup>&</sup>lt;sup>3</sup> In an oral history study of Flemish retired and practicing gynecologists and midwives' management of pregnancy loss, Jan Bleyen (2012) describes how midwives would keep stillborn and malformed babies hidden from the women and her partner up until the 1990s, based on the assumption that confrontation with the loss and contact with the dead child would be harmful. Bleyen cites one retired midwife who recounted how things back then "was sorted in an ice-cold way" (ibid. 182). Similar oral history studies have, to our knowledge, not been undertaken in a Danish context, and much of the Danish clinical health literature that includes guidelines for best practice for how to manage these events seem to be based on anecdotal evidence and knowledge passed on from health provider to health provider.

loss, which later developed into The National Organization for Infant Death in 1992. As described by one of the initiators, the organization pushed for a shift because bereaved parents were:

desperate when they called because they had not received the necessary help. They had not been advised to see their child, no pictures had been taken, there were no one caring for making hand and footprints. It was not even considered. Even being allowed to see one's child was a struggle, because "you don't do this here."

About the same time as patient advocacy took hold, novel literature on grief and bereavement that stressed the importance of having contact with the dead child in order to facilitate the grieving process was published, which built on ideas about attachment to and "continuing bonds" with the deceased child (Hughes and Riches, 2003; Klass et al., 1996; Rådestad et al., 1996). In effect, it became common to promote contact with the dead fetus or child.

In the everyday care for couples opting for termination, we learned there is no difference between how health staff treat couples opting for termination from couples who go through involuntary pregnancy loss. Attachment is the powerful trope regardless of context. In a Facebook post posted by one hospital showing a picture of a health care worker holding two knitted Moses baskets, the caption reads:

When miscarriages and late abortions take place, it is important for us to give parents, who need it, good and concrete memories to take home. Memories to be shared with others who recognize the child who has been lost. On the birth ward, one of our amazing health care workers has therefore begun knitting Moses baskets for the small fetuses. [...] With the baskets, we can make a difference when it is most needed. The parents see a child they can touch and hold, not just a fetus. That means a lot for the grief process – and for the legitimation of the many difficult emotions that come along.



Figure 2: Picture of knitted "Moses baskets" made by health professional at a local hospital.

In a study of neonatal intensive care, Navne, Svendsen and Gammeltoft show how health staff enact extremely premature infants as morally valuable "maybe-lives" that parents are encouraged to relate and attach to despite the fact that health staff deem some of these lives not worth saving, pointing to how the philosophy of attachment is so pervasive that the enactment of "maybe-parents" is almost impossible (Navne et al., 2018). Indeed, the above caption not only speaks to the kind of conflation clinicians make between chosen and involuntary loss but also epitomize a broader ideology of parental-fetal bonding as fundamental to experiences of fetal and infant loss (Becker and Hann, 2021; Millar, 2016; Mitchell, 2016). During interviews, the ideology of attachment guided the beliefs of most health staff we met, represented in a mantra we heard several of our informants say. Birgit, a senior midwife, is one example: "Boiled down to one sentence, which we have learned to say since training is, 'you cannot say proper goodbye before you've said hello'. For me it's extremely important to find a way for these parents to embrace this child even though it's dead. And help them to integrate it into their life story."

Seeing and holding is widely seen as a prerequisite for good coping across professional divides. One gynecologist for instance said that he regarded the act of sitting with the dead fetus and "saying goodbye nice and quietly" to be the most "dignified" way to approach these situations and what gives the best "closure." Another gynecologist specified that it is better to see because "fantasy often haunts you more than reality". Though the routinised practice of fetal contact is contentious and subject to scientific debate (Hughes and Riches, 2003; Sloan et al., 2008), the health care providers we met largely depicted seeing and holding, aided through various personifying objects, such as knitted beanies, blankets and baskets, as a prerequisite for building a sense of attachment to the dead fetus, understood as vital for living on sanely and assuredly from the ordeal. Couples must "live with" their decision, and active steps are taken to help them come to terms with it and prepare them for the healing and grieving process they must go through. In an analysis of midwives' management of emotions during stillbirth and neonatal death in the UK, Carol Komaromy writes:

Cuddling a dressed and wrapped baby emphasizes how the actions of midwives might script the performance. For example, the reality is that dead babies do not need to be dressed, cuddled and kept warm—their need is an assumed one by practitioners on behalf of bereaved women and couples. [...] The important point here is that bereaved parents are encouraged to go along with a prescription of their own needs—regardless of how they might experience the events of stillbirth and neonatal death (Komaromy, 2012: 201).



Figure 3. Hospital cabinet stacked with knitted blankets and clothes offered to couples undergoing selective abortion on a routine basis. Photo taken by first author.

This suggests that the needs of women and the needs of health staff to provide care in a certain way understood as "good" might also be conflated. Indeed, not all couples who go through a second-trimester selective abortion want to see their dead fetus (Heinsen, 2022; Mitchell, 2016). When women and their partners do not adhere to the advice of seeing and holding, several of our informants mentioned that it caused great worry amongst health staff. One midwife repeatedly spoke about one couple who refused to see their dead fetus as "being in denial". Another midwife said: "I'm challenged when they don't want to see. And you try saying 'you can always change your mind and it's not something you have to decide right now'. Because you think it might not best on the long run." In these ways, orchestrating grieving practices can be seen as addressing both couples and healthcare practitioners' needs in the routinized provision of second-trimester selective termination.

### Conclusion

As has been the case in many other countries around the world, Denmark has experienced a tangible shift in the management of second-trimester abortion, from one of forgetting it happened to one imbued with deeply held beliefs in the benefits of labor and birth, and of bonding and grieving over the dead fetus. In this article, we have unearthed some of the "genealogies" behind this shift and shown the particular ways in which selective abortion

care has been put to form and is being exercised in the clinic. We have argued that the orchestration of selective abortion care can be understood as aiming towards making the morally difficult situation of selective abortion "right" through different approaches; through the management of abortion as medically induced birth, through legitimation of the decision in the clinical encounter between couple and staff, and through the promotion of attachment and grief, epitomized in the trope of "to say proper goodbye, you need to say hello", all of which we have proposed to conceptualize as orchestration of moral bearability. Care is done in certain ways to set couples on the right track of emotional healing as well as to lessen the burden on the health providers. The belief that abortion should be managed as medically induced birth because it is "gentler on everyone" combined with a pervasive subscription to the ideology of attachment as preconditions for "good" grief has brought the (dead) fetus to the center of these medical events as an entity to be confronted—visually, viscerally and relationally. Coming to terms not only with the decision but also with the loss—the actual fetus, not just the symbol of the fetus —is part of that. For health staff, it becomes less bearable to send couples home if they feel they have failed to set them on such a healing track, and they anticipate that the decision and loss will be less bearable for the couples on the long run if they have not faced the "reality" of their dead "baby." Thus, the accomplishment of moral bearability hinges on an alignment between constituencies; between health staff's guidance and performances, and couples wishes.

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## ARTICLE 3

Shouldering Death: Moral Tensions, Ambiguity, and the unintended Ramifications of State-sanctioned Second-trimester Selective Abortion in Denmark

#### Abstract

This article is based on an ethnographic study of pregnant couples' embodied, emotional and moral experiences of second-trimester selective abortion in Denmark. Drawing on 16 selective abortion stories, I unpack the intense, often highly accelerated days that follow from the moment a fetal aberration is detected to the moment of fetal disposal or burial. I show that although prenatal screening and diagnostics have come to occupy a routinized part of pregnancy in Denmark, when women and their partners opt for termination, they are faced with a series of bodily events and actions they are entirely unprepared for while at the same time feeling essentially alone in grappling with the moral confusion that ensues. I argue that despite widespread medico-legal sanctioning and social endorsement of selective abortion, the specificities of how such terminations are 'done' in Denmark in ambiguous and conflicted ways situate women and their partners in a series of *moral tensions* around how to relate to the abortion, the dead fetus, their grief and their entitlement to such mourning. By chronicling the core struggles that the process of termination catalyzes, I point to the social and moral ramifications of the embodied practices and medico-legal choreographing of selective abortion in Denmark.

Keywords: [Selective abortion; moral tensions; embodied practices; responsibility; death]

#### Introduction

It only took two pushes and then Lillebror was born at 2.30 PM. The midwife wrapped Lillebror in a blue blanket and placed him in the windowsill while managing my bleeding. Then I got to see the tiny boy. The most beautiful little boy with no visible sign of illness. It was incomprehensible to us that you could look this fine and hide such a big secret. An extra chromosome. We were devastated. OUCH how it hurts to see our own flesh and blood lying there dead because we had made a decision that was best for us all.



Figure 1: Camilla's photobook

I met Camilla and her husband Toke in their suburban home located on the Peninsula of Jutland, Denmark in the summer of 2020, three months after Camilla's second-trimester abortion. The abortion was set in motion at gestational week 14 after Camilla and Toke learned that the fetus had Down's syndrome. In congruence with Danish medical guidelines, it took place as a medically induced birth at a local hospital with the presence of a midwife and Toke. Camilla wrote the above words in a photobook called "Lillebror" [Little brother], which she made in the weeks following the abortion. She did so to gather her ambiguous emotions and thoughts about the decision to terminate and the events it set in motion. In images and text bits, the book details how, like most prospective parents in Denmark, Camilla and Toke took it as a matter of course to undergo prenatal screening, leading to a high-risk assessment followed by invasive diagnostics. Two days later, the doctor called to inform them about the positive diagnosis. To receive post-diagnostic counselling, pregnant women and their partners must return to the waiting room of the ultrasound clinic filled with expectant couples waiting their turn to have "baby's first picture" (Mitchell 2001). From there, they are escorted to a consultation room. When Camilla and Toke arrived at the hospital the day after receiving their diagnosis, they were asked what they wanted to do—continue or terminate the pregnancy? Camilla and Toke opted for abortion to spare their existing child from growing up in the shadow of a

disabled sibling, as well as from fear that having a chromosomally different child would threaten their marriage. As I asked Camilla to elaborate on her feelings about the abortion, she said: "The problem is that he was viable. That's what makes it so hard, that we've actually killed something that was viable."

When the Danish board of Health issued new guidelines for prenatal screening and diagnosis in 2004, the board replaced a former "paradigm of prevention" with a new criterion of success: The aim of "informed choice" (Danish Board of Health, 2004a-b). The idea was that by introducing an ethics of informed choice, any conflation of prenatal testing with past state-mandated eugenics would be obsolete. It became a question of parental choice, not state intervention. Since the roll out of the 2004 guidelines, offering all pregnant women a first-trimester prenatal risk assessment for chromosomal anomalies and a second-trimester malformation scan, regardless of age (Danish Board of Health. 2004a), selective abortion rates have been rising (URL 1). In spite of extensive rights and protections leveraged for people with disabilities in Denmark, such as access to health care, education and housing, the annual birth rate of children with Down's syndrome dropped markedly from an average of 65 before 2004 to an ensuing average of 33 annual births (ibid). According to the Danish Cytogenetic Central Register (DCCR), 99 percent of prospective couples opt for termination when Down's syndrome is detected in utero (DCCR)<sup>1</sup>. Contrary to, for instance, the American insurance-financed health care system, Denmark provides comprehensive tax-financed healthcare, including prenatal and abortion services, to all residents without charge. Pregnant women have a statutory right to first-trimester abortion, after which abortion must be approved by a regional abortion committee, consisting of a legal representative and two doctors. Second-trimester abortion may be granted on the ground that "there is a risk that the child will suffer a serious physical or mental illness due to hereditary predisposition, damage or disease in the fetal state" (Healthcare Act, consolidated Act no. 903 of 26/08/2019 § 94). Recent statistics show that 94 percent of the approximately 600 annual applications for abortion on foeto-medical grounds are granted approval by the abortion committees (Danish appeal court 2019). Grounds range from conditions deemed incompatible with life to conditions such as missing extremities and a cleft lip palate. As shown in a recent legal analysis of the Danish abortion committees, almost all cases of abortion due to fetal anomaly are granted approval through an "automatized" practice, while second-trimester

<sup>&</sup>lt;sup>1</sup> In 2019, 18 children were born with Down's syndrome, yet of these, only seven were the result of pregnancies carried to term by expecting couples who knew the fetus was affected by Down's syndrome. The remainder 11 cases were the result of either non-detection or false negatives (DCCR. See also Spalletta, 2021: 37).

abortion on social indication, where the fetus is healthy but unwanted, is more difficult to obtain (Herrmann and Petersen, 2021).

Indeed, in a prior research project on pregnant women's motivation for taking up routine prenatal screening, I asked the women I followed to reflect on the hypothetical scenario of ending the pregnancy in the event of a positive diagnosis. Here, abortion figured as a seemingly morally unproblematic "way out" of the pregnancy, largely depicting termination as a solution recommended by "the system." Yet when I began interviewing couples about their abortion experiences during 2020, I kept stumbling upon a completely different terminology. To my surprise, in nearly every interview, I heard my interlocutors speak of abortion as the detrimental loss of a "child" which they had chosen to "kill" and had to assume responsibility for. As Christina, who terminated her pregnancy due to a rare genetic disorder, said: "I signed the paper. I took the pill. I killed my baby. That's how it feels, because really, I was the one who had to do all these things."

It is these consistent depictions of selective<sup>2</sup> abortion that will be explored in what follows. Bearing in mind the politically and religiously vexed issue of abortion in the US (Ginsburg, 1998; Andaya and Mishtal, 2017), and elsewhere (Mishtal, 2009; De Zordo et al., 2016), I wonder why a language of "killing" shows up in a cultural context where selective abortion is overwhelmingly socially endorsed and medico-legally sanctioned. What produces the sense of individual responsibility that runs through the narratives of my interlocutors? And what is the signification of "all these things" Christina refers to? In short, I ask: what moral tensions and ambiguities emerge in the process of terminating a desired pregnancy within a moral-political landscape of state-sanctioned selective abortion?

Drawing on 16 selective abortion stories, I unravel the intense, often highly accelerated days that follow from the moment a fetal aberration is detected to the moment of fetal burial or disposal. I show that although prenatal screening and diagnostics have come to occupy an expected part of pregnancy in Denmark, when couples opt for termination, they are faced with a series of bodily events and actions they feel entirely unprepared for while at the same time feeling essentially alone in grappling with the moral confusion that ensues. I point to how the process of termination entails initially a dehumanization of the fetus in the medical encounter followed by a humanization of the dead fetus during the abortion procedure itself, propelled by the midwifery-driven tenor

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<sup>&</sup>lt;sup>2</sup> By the term "selective", I follow Wahlberg and Gammeltoft's (2017) definition of selective reproductive technologies as "technologies used to prevent or allow the birth of *certain kinds of children*" as opposed to the prevention of unwanted pregnancies. Selective abortion is thus my term for the act of selectively terminating a pregnancy, meanwhile my interlocutors used terms such as "abortion", "late abortion" or "birth".

of "to say proper goodbye, you need to say hello", and then followed by a lack of social recognition from the wider social milieu of the abortion as infant loss. I argue that these contradictory ways of managing and responding to second-trimester abortion within and beyond the clinical setting situate women and their partners in a series of moral tensions concerning how to relate to the abortion, the dead fetus and their responsibility and/or entitlement to grieve. By moral tensions, I mean social situations in which legally sanctioned decisions and actions (in this case to selectively terminate a pregnancy) remain ethically unresolved for those involved. Writing on transnational flows of people and goods, van Schendel and Abraham (2005) contrast what states define as legal and illegal with what is socially defined as licit or illicit in order to grasp how actions that are formally defined as illegal nevertheless come to be accepted as licit. Building on this distinction between social (il/licit) and political (il/legal) constructions of legitimacy, I suggest that from the perspective of some of the couples who experience selective abortion first-hand, the procedure comes to reside in an unsettled terrain between that which is legal and "right" on the one hand, and illicit and "wrong" on the other. Following this line of thought, I draw upon Cheryl Mattingly's neo-Aristotelian notion of moral selves as constituted relationally through "the doing of ordinary life" (Mattingly, 2013: 5), where what is considered the best course of action might be messy, muddled and difficult to judge. As Mattingly notes, "even if one is assiduous in trying to work on one's moral character, there is always the possibility of mistakes, unintended consequences, moral failure, or moral tragedy in which every choice and every action is somehow, morally, wrong" (ibid, 6).

The article is structured around three themes—responsibility, incongruity and "killing" —which crystalize the core struggles that the process of termination catalyzes. To be clear, I do not suggest that termination equals killing. In fact, my interlocutors explicitly expressed support for the availability of abortion as a health service and felt fortunate that they lived in a country where they had the possibility of making such a choice. Thus, what is at stake in the following analysis is how legal and medical management, as well as the undergirding medical regulations and care norms of present-day practices of selective abortion, impact the social and moral experiences of those who embody such terminations. Thus, abortion becomes morally complicated for some through its practical and normative itineraries and embodied undertakings. It follows from this line of argument that fetal personhood is not intrinsic nor universal (Morgan, 1997; Gerber, 2002) but evoked through these itineraries. But before I unfold my analysis, let me shortly situate my study in the field of research to which this article contributes, followed by a short description of my study.

## Accounting for selective abortion: Embodied experiences

Over the last decades, several pioneering ethnographies of 'selective reproductive technologies' (Gammeltoft and Wahlberg 2014; Wahlberg and Gammeltoft 2018) have been undertaken, covering technologies ranging from amniocentesis in the US (Rothman 1987; Rapp 1999), ultrasonography and sex-selective abortion in Vietnam (Gammeltoft 2014; Hằng 2011, 2018), and prenatal and genetic screening in Denmark as well as elsewhere (Schwennesen, 2010; Heinsen, 2017; Ivry, 2010; Thomas, 2016; Shih, 2017). This rich body of work has pointed to the excruciating dilemmas and troubling decisions placed on women and their partners by advancing prenatal diagnostic technologies. As American anthropologist Rayna Rapp writes in her groundbreaking ethnography of amniocentesis in the US, the normalization of this technology forces women to "judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community" (Rapp, 1999: 3). Yet such technologies also bring with them the concrete, embodied and moral work of bringing such choices into action as terminations are set in motion. In a qualitative study of selective abortion in Norway, Risøy and Sirnes (2015) show how decision-making following the detection of a fetal anomaly is experienced as a "state of emergency", arguing that to understand society's regulation of selective abortion, it is necessary to study the logic of such decisions. I suggest that to understand what selective abortion means and, not least, takes, we need to go beyond the realm of "the decision" and examine how such terminations are experienced, done and grappled with. The decision is part of that story, but not the whole story.

While social science scholars have been vocal in critiquing the proliferating medico-technical interventions into pregnancies through visualizing and diagnostic technology (Rothman, 1986; Petchesky, 1987; Duden, 1993), there is a paradoxical absence in the anthropological literature interrogating the embodied practices involved in selective abortion<sup>3</sup>. As historian Ilana Löwy writes, researchers who study prenatal diagnosis usually "stop short of asking what happened next to the women and the fetal remains" (Löwy, 2018: 25). This dearth in the literature is undoubtedly linked to the highly politicized and contested topic of abortion in many parts of the world (McCoyd, 2010; Millar, 2016), not least in the US where the abortion debate is characterized by what Ludlow terms an "unbridgeable discursive gap" (Ludlow, 2008: 28), and where the passing of new bills restricts access to abortion at a disturbingly unprecedented rate (Andaya and Mishtal, 2017). Nonetheless, bearing in mind that termination is the typical

<sup>&</sup>lt;sup>3</sup> See Gerber (2002) for an analysis of the embodied experience of medical termination of very early unwanted pregnancies and Purcell et al (2017) for an analysis of the embodied experiences of second-trimester abortion for non-medical reasons.

response to fetal abnormality amongst Danes, it is highly surprising that the social and moral impact of selective abortion in Denmark remains largely unexplored. This article aims to fill a corner of this knowledge gap<sup>4</sup>.

Hằng's study of sex-selective abortion in Vietnam is one of the few that portrays the on-the-ground abortion practices, demonstrating how these processes are "marked by pain, stress and, most notably, silence" as well as by the dismembering of fetal bodies through surgical abortion with body parts being pulled out in pieces (Hằng, 2011: 91-92). Through her interviews and participant observation, Hang shows how women "experience confusion as the cultural expectations that shape their decision-making clash with the potential sanctions against them, their maternal desires and duties, and the legal, moral and medical frameworks within which their decisions are made" (ibid. 88). In an article on practices of routinely offering aborting women in Canada contact with "fetal remains", Mitchell (2016) argues that these new visibility practices rest on professional care guidelines that tend to position women as needing contact with fetal remains as valued babies rather than as for instance biological waste, and that women's responses to this practice vary. This prompts her to ask how abortions are being framed today to create "particular spaces of visibility" (Mitchell, 2016: 171). Resembling new trends in Danish abortion care, where practices of seeing, holding and commemorating dead fetuses are gaining ground as a counter-response to the silencing of pregnancy loss of the past (Kjærgaard et al, 2001, see also Layne, 2003; Memmi, 2011), I follow Mitchell's train of thought that performativities, as these vary in different parts of the world, create different conditions for seeing and not seeing, as well as seeing in particular ways, as nurses and midwives work to "aestheticize" dead fetuses. Yet I disagree with the notion that what women give birth to can be depicted as merely representations that come to be given meaning as precious babies only via particular visibility "scripts". Such a rendering overlooks the fact that in places where second-trimester abortion is handled as medically induced birth, women go through labor and push out complete, fleshy, material fetal bodies. In Denmark, all abortions from gestational week 14 (but in many hospitals as early as in gestational week 12 and 13) are done according to a specific medical regime, combining a pill of mifepristone to block the production of pregnancy hormones, followed by 24-48 hours of waiting at home after which the couple is hospitalized for induction of labor with tablets of misoprostol inserted vaginally every three hours until the fetus has been birthed. While surgical abortion is performed much later in countries such as the UK and US, and though comparative studies of abortion methods show inconsistencies about which procedure is best (Lohr et al, 2008), medication followed by

<sup>&</sup>lt;sup>4</sup> Several psychosocial studies have explored how couples cope with termination for fetal anomaly. See for instance Statham (2002), McCoyd (2007) and Lafarge et al (2013).

induced birth is the only procedure offered in Denmark. Following Ludlow's argument that disregarding the embodied nature of abortion risks excluding the complexities of women's abortion experiences (Ludlow, 2008), I suggest that *embodied practices*, not only visibility, matters for the experience of these "chosen losses" (Rapp, 1999: 225).

## The study

This article builds from ethnographic research undertaken intermittently between 2020 and 2022 exploring how second-trimester selective abortion in Denmark is legitimated, practiced and experienced at the nexus of biomedicine, law, and everyday lives. The data I draw from more specifically come from 16 audio-recorded interviews with women and couples who had opted for termination due to fetal anomaly. In addition, my material consists of drawings made by my informants during the interview, as well as photos I have been given permission to use. Inspired by anthropologist Li-Wen Shih (2017, 2022), I asked my interlocutors to draw their abortion experience at the beginning of the interview to allow my interlocutors to guide my questions and probing. I interviewed 10 women, one man and five couples representing 22 persons in total. All identified as heterosexual, were primarily white and were from middle-to-high income backgrounds. The interviews lasted between two and six hours, with most lasting three to four hours. Most took place in the homes of my interlocutors. Three took place online. Three of the women had been through the abortion only three months before the interview, while others had been through it several years prior. All interviews were anonymized and transcribed verbatim and subsequently analyzed thematically. The recruitment of my interlocutors is based on self-selection, responding to a call for participation posted on pregnancy- and maternity websites, on my own Facebook page and on a closed Facebook group mediated by the Danish Association for Infant Death. What unites them is that they all felt motivated to speak about their experiences. In fact, while a great proportion had attended some kind of counselling or therapy, several disclosed that the interview was their first occasion of giving voice to their experiences in depth, not least for those for whom bereavement counselling was cut off due to the Covid-19 pandemic. While what I experienced as a palpable hunger for speaking about their experiences benefitted my research, it illustrates that my informants felt alone in dealing with the effects of the abortion.

## Making choices, (self-)imposing responsibility

The delivery of a positive prenatal diagnosis in Denmark inevitably forces a pregnant woman and her partner to make a decision about whether to continue or end the pregnancy. The trajectory from diagnosis to effectuated abortion is of course singular as each case is unique, each clinical encounter different, and each medically induced birth multifaceted, as well as experienced differently. What struck me while listening to the women and couples describe the entire process was the acceleration of the event. When Camilla learned that her fetus had tested positive for Down's syndrome, it only took four days until the abortion was effectuated. While she had waited at home for the test results, giving her and Toke more time to process and think about what to do in case of "bad news", others were told about the abnormality at the malformation scan, which propelled an even more hurried process. In these cases, post-diagnostic counselling, signing the application, getting legal approval, the abortion-preparatory talk and intake of the pill all happened within one or two days.

While a recent Danish study on the choice to opt for abortion due to Down's syndrome concluded that parents arrive at the clinic with a decision at hand (Lou et al 2018), my interlocutors generally spoke about not having considered carefully what to do in the event of a positive diagnosis. Most expected to be reassured that their unborn child was healthy and growing. In contrast to Lou and colleagues' conclusion that abortion decisions were shaped outside the realm of the clinical encounter, most of my interlocutors described vividly how doctors had prognosticated what life would be like if the affected fetus were brought to life. Peter told me that when he and his wife, Maj, showed up for their post-diagnostic consultation, Peter felt "the air was thick with expectations they would opt for abortion", with the conversation circling exclusively on the potential burdens of caring for a child with Down's syndrome:

So we say that we've decided that we would opt for abortion. And they are really supportive, like 'we understand and it's hard and difficult', and then Maj talks about our doubt and then they're like 'well, most have a really difficult life, and those stories you don't hear about in the news', so they are really supportive about the decision we've made.

Often, such foretelling transcended the mere medical horizons of a specific diagnosis. Frida and Lasse, who chose to terminate because of a severe heart malformation, recounted how their doctor had said that in his experience "parents of children with this condition often get divorced". But what seemed to influence their decision most was when the doctor associated going through with the pregnancy with "child neglect". In contrast to Vietnam, where decisions to opt for selective and sex-selective abortion are shaped by pervasive social pressure to reproduce healthy and preferably male offspring (Hang, 2011) - decisions that are made not individually but on the basis of wider family councils (Gammeltoft, 2014) - in my study, friends and family figured most often only either before a diagnosis had been made (for instance when waiting for test results) or after the

decision was made. The lack of involvement of relatives in the decision can be seen as an expression of the cultural depiction of these choices as inertly individual but also as an expression of the "structural directiveness" (Heinsen, 2017) of these choices, meaning that the choice to opt for termination is shaped by adherence to societal norms rather than by adherence to filial duties. It is also possible that the lack of familial consultation is due to a lack of time. For instance, when the doctors assessed that Christina's fetus might have a serious genetic condition, genetic testing that could confirm the diagnosis would take three weeks to process, and as Christina was soon approaching the "criteria of viability" in gestational week 22+6, the upper limit of access to later abortion in Denmark, she had to make a decision on the basis of diagnostic uncertainty under immense time pressure<sup>5</sup>. Despite the impact of prognostication, most often the couples I spoke to described decision-making as coming from themselves as autonomous, rational human beings, who took in and processed the "objective" medical facts they were presented with in order to reach *their* decision. For example, Sidsel, who terminated a twin pregnancy due to twinto-twin-transfusion-syndrome explained that:

She [the doctor] says that there are options but none are really good. Sometimes with these twins, you can do surgery to cut off some of the blood vessels in the uterus because the thing is that twin A gets too much blood and twin B actually gets too little. So, she says that sometimes you can burn those blood vessels, but because I had this hematoma and because I'm overweight, the chances that it will pan out well is very slim. So, they wouldn't offer to do that. [...] I can't remember exactly what she said, but she was very good at laying it all out. It was just a long list of "ifs", but the probability of things going well was so small. But she was really good at explaining the situation to us without like, and I really can't stress this enough, without putting *any* pressure on us. *We* asked [about abortion].

What Sidsel remembers most clearly from the situation in which the decision to terminate was made was that the doctor only delivered medical facts to act upon. What the above paragraph also highlights is that by *not* being offered the operation, the only trajectory leveraged for Sidsel was to either terminate or continue the pregnancy, knowing that the unborn twins were deemed so ill that they would likely never survive the pregnancy or birth without that exact surgery they were disallowed. Still, though the termination could be seen as the outcome of a much more complex trajectory of boundary making between

<sup>&</sup>lt;sup>5</sup> An upper threshold linked to fetal viability was amended to the Danish abortion law in 2000. At present, the criterion of viability is set at gestational week 22+6. The Danish model for regulation of abortion thus reflects a gradualist ethical view of the fetus as well as a balancing between, at times, competing concerns; the autonomy of the woman, the health professionals performing abortions and the increased ethical status of the embryo (Herrmann and Petersen 2021, 494).

eligibility or non-eligibility for surgery, and of medical probabilities through which the unborn twins were shaped into futile cases, Sidsel took complete responsibility for the decision. Others were caught off guard when learning the decision was theirs to make. As Henriette said:

They tell me the child is not viable, but then they tell me that I actually have to make a decision. I thought the decision was made. I didn't know I had to make the choice. It was only I who had to sign the paper. It hit me really hard. I don't know whether it was because we weren't married at the time or because it was my body but you know [wells up], sorry... em. I had to sign the paper.

Informed choice is not only an ethical principle guiding clinical practice. It has concrete implications for how responsibility is perceived and experienced by women (and their partners). This responsibility is exacerbated by the concrete embodied chain of events set in motion as soon as the words "we want to terminate" are spoken, and the concrete bodily acts women must take on themselves to effectuate the decision. This begins with a piece of paper.

## Moments of incongruity

As soon as a pregnant woman and her partner opt for termination, an application form must be signed by the abortion-seeking woman and subsequently by the fetal medicine specialist who sends the application electronically to the regional abortion committee. From there, a secretary prepares the case and contacts the three committee members on duty that specific day. My interlocutors responded differently to this moment of signing what some referred to as their child's "death sentence". Peter for instance remembers the moment as disconcertingly un-ceremonial, while others had difficulties recounting the details of the situation. In some weird way, the abortion committees and the legal dimension of second-trimester abortion figure as a small and insignificant "bump on the road", as no direct contact takes place between couples and committee members. I heard repeatedly that doctors had told them that the committee's case handling was a matter of "formality," yet despite the bureaucracy of the event, having to sign a piece of paper confirming a wish to end a pregnancy stands out as quite disturbing. Anja, who terminated a pregnancy due to a brain malformation, was unaccompanied by her husband at the time of signing the application. She said: "I think had my husband been there, I would have insisted that we draw a line for him to sign because I felt it was my responsibility, and I still do. I signed. I gave birth. I took the pill." Thus, abortion is both legally and bodily gendered. It falls on women to do the bodily labor of termination, beginning with picking up the pen and signing the application.

As soon as termination has been authorized, the gynecological or birth ward is informed that "a case" is under way. The responsible nurse or midwife then calls the pregnant woman and invites her and her partner for a preparatory talk at the hospital. In depicting her abortion experience, Rebecca, who ended a pregnancy in week 14 due to Down's syndrome, drew three female people, symbolizing the health staff, and above them a knife with a drop of blood dripping down from its sharp point, symbolizing the pill. This came to mind because she felt uncared for when her wish for surgical abortion was denied. She explained:

It felt SO bizarre to have it at home and having to take it by myself. It was strange that I had to kill the fetus. Because it's the pill that makes life stop inside of you. We didn't doubt the decision but yeah, it was like my responsibility to take the medicine.

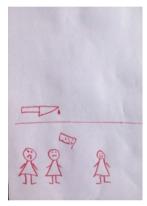


Figure 2: Rebecca's drawing of her abortion experience

## In a similar vein, Henriette described:

I'm sitting on the couch at my parents' house with these pills in my hand and realize that now there's no going back. Now I'm going to take them, and they were SO difficult to take. They weren't big, but incredibly large to swallow. Because you know, then it's definitely over. I haven't given birth yet, but that was the moment I killed her, you could say.

While the moment of taking the pill stands out vividly in most accounts, the wait for hospitalization was mostly described as playing out in a fog. Some used the days alone at home, lying on the sofa crying and sleeping. Others felt they had to "do something". This time span where little but waiting is happening was experienced as an unsettling state of existential disintegration. As Cecilie expressed it:

To know what you are carrying inside of you is SO physical. On Wednesday when I had taken the pill, it was horrible, I just sat on the edge of the bed and was paralyzed by this physical kind of grief I've never experienced before.

Signing the paper and taking the pill were two of the things that shaped Christina's and others' sense of responsibility not only for the decision but also for the production of fetal death and essentially their own loss. The bodily work of labor and birthing adds to this.

When a woman and her partner are admitted to hospital, they are appointed a private room equipped with two beds, TV and an adjacent bathroom. Couples who are admitted to the birth ward are often confronted with the noise from crying babies, the sight of new parents strolling down the corridors with their newborns, and other activity characteristic of a maternity floor. Immediately after arrival, the nurse or midwife inserts the first of a series of Cytotec (misoprostol) tablets to induce labor.



Figure 3: A pill of misoprostol, also known as Cytotec. In all but one Danish hospital, misoprostol is inserted vaginally every three hours to induce labor until the fetus has been birthed. The woman who took this photo was handed misoprostol for oral intake.

Typically, the couple is asked: "what is this to you—a child or a fetus?" and "have you considered a name?" The general belief held by health staff is that second-trimester abortion should be treated like involuntary pregnancy loss, accompanied by new ritualistic practices of seeing, holding and commemorating the dead fetus, such as taking photos and hand-and-foot prints. These practices are not done to dissuade women from obtaining an abortion. Rather, they are seen as proper and compassionate care. Health staff often nudge couples towards embracing the dead fetus as a lost child "for their own good", as one midwife said. Several of my interlocutors felt conflicted about the personification of the fetus through birth and these post-abortive performativities. When I asked how Peter and Maj responded to learning that Maj had to give birth, Peter said: "I think it gave like, okay, are we really able to execute this decision? Because the thing with birth is that you have to face it. It couldn't just be removed." Several of the women

I interviewed had a strong wish to see and hold the fetus and embraced birth as a prerequisite for this. While most expressed that they initially just wanted to be sedated to flee from the situation, this changed during hospitalization. Several mentioned that the health staff had swayed them of the importance of giving birth by emphasizing not only the physiological advantages but also the psychosocial benefits, as giving birth would enable the couple to process the abortion better and make it possible for the couple to see the dead fetus, which seemed to have transformative powers. Sara for instance said:

I think at first a lot think; "I'm not going through labor to deliver a dead child", but then I was like, I fought for you, like, I went through this because it meant something, that's how I feel anyway, that in spite of everything she [the fetus] was worth it. Like you were worth it, that you would fight for all your children even though it's painful as hell.

By adopting the logic of "birthing is best", Sara worked to legitimize her anomalous fetus as valuable and worthy of a good exit. Through this form of legitimation work, the painful work of birth comes to legitimate the act of termination, and to establish the parent as caring towards her fetus. Sometimes these births go "smoothly" and sometimes they turn complicated and even traumatic. Camilla, for instance, developed a fever, bled excessively, and had to be taken for curettage. Others developed nausea and hyperstimulation lasting for hours. Christina's birth is another extreme case in point:

I've been told that it doesn't have to hurt. So, I have an epidural but nothing happens. And I get a fever. A high fever and I'm like shaking. And then I'm having a second epidural and this one works. But I feel poorly and vomit. I haven't eaten for days. I'm totally exhausted. But I get some sleep during the night and when I wake up, I'm 10 cm dilated, but I don't feel anything. So, they give me oxytocin, but nothing's happening. They try to put pressure on my belly to push her [the fetus] down, and one inserts her arm [in the vagina] and they begin discussing if she's sensing an arm or a leg. It was like being at the gynecologist, you know, you just close off everything from the waist down, because it's so violent [begins to cry]. And then they go to get one of those ultrasound machines to see where she is. And she's still alive, she's moving [cries excessively]. And then they ask me to lie on my belly, on my knees, on a stool. I've just given up. She doesn't want to come out. And then they pull her by her legs. And then she's out.

When Christina's birth was finally over, the fetus was dead at arrival. The midwife wrapped it in a knitted blanket. Hand- and footprints were made and a series of photographs taken. Arriving home, Christina and her husband made arrangements for a private burial. Not all birth stories were as violent as Christina's. Indeed, most spoke about the birth itself as a "beautiful" experience with caring health professionals

validating their experience as the loss of a baby rather than as an abortion. All but two of my interlocutors saw their dead fetus, and almost all took some form of memento. What takes place in the birth ward is ontologically very different from what happens before in the ultrasound clinic. What is turned into a precious baby through these new standards of "good" abortion care is initially constituted as something futile through sonography and genetics. Couples meet a health care system that, to put it bluntly, first requires them to terminate, then bond and "make family" with what they chose to terminate. Anja explained:

It's all so clinical when you sit there with the doctors. They call it termination, they don't call it birth, they talk about it as a non-viable fetus, you know, all those words are all very rational, but it stops being rational when you birth the little child. Then rationality is like gone. When you see this little, tiny creature you think, my God, what have we done?



Figure 4: Hand- and footprint of aborted fetus

This, I contend, is at the heart of the matter in the emic mobilization of "killing". Postabortive performativities turn the abortion into something more than just the loss of a possible person; it becomes a voluntary loss of a concrete, material being that resembles a real "baby". These humanizing and personifying acts unsettle the procedure as a legitimate act. As Toke said: "When you call it a person, you commit a murder. When you call it a fetus, then it's an abortion."

# Socio-moral accounting: Legal abortion, illegitimate "killing" and the question of loss

Hằng writes that though sex-selective abortion in Vietnam was conditioned by external economic and social factors, most women felt ambivalent about going through with the procedure. They experienced confusion about the cultural expectation to terminate and the potential legal sanctions they could face (Hằng, 2011: 88). My interlocutors in

Denmark experienced confusion, but not in relation to the medico-legal legitimacy of their decision. Rather, they experienced a kind of socio-moral confusion, which emerged in the birth ward and was later exacerbated when they returned home. Indeed, the granting of fetal personhood in the birth ward was called into question as soon as the couples left the hospital. One informant said that her father-in-law had remarked that she "ought not turn her home into an altar." Another received a phone call four days after the abortion asking when she would resume her work duties. These social confrontations exacerbated the couples' already existing confusion by questioning whether their dead "babies" were babies at all. A central repercussion of the abortion is that it forces parents to negotiate with themselves and their social surroundings about what actions and emotions are legitimate. This entails weighing what feels right against what others might think is right (Franklin and Roberts, 2006), fearing that others might perceive one's response as "too much". As Cecilie's partner, Mikkel, put it: "It's your own choice so you're not entitled to be upset. What would others think of me if I told I was upset?" Under the surface of this sense of illegitimate grief lie guilt and shame. Even though termination is medicolegally permitted and socio-morally endorsed by the wider social fabric of society, its legitimacy is questioned by those who embody it. While many insisted that "we know we made the right choice," this insistence was always accompanied by a "but." This "but" was not necessarily directed at the decision itself but at the struggles they faced following the abortion, which were far more profound than many first imagined. Following Mattingly's argument that the moral is profoundly relational, I suggest that in the interstices of how selective abortion comes into being in the clinic, is handled in the ward and socially responded to in the wider social milieu, my interlocutors felt split between differing social expectations: the expectation of society that you abort, the expectation of health staff that you grieve, and lastly, the expectation of family and friends that you get quickly over it and resume your life as before. The simultaneity of structural directiveness towards termination and the lack of a collective space for acknowledgement of what termination entails, makes it difficult for the couples to come to terms with what took place and how to relate to oneself and what was lost. As Peter said, "I like the recognition of her [the dead fetus] as someone who is part of me if I call myself a father of two. But what's hard about it is that if I acknowledge that, then I've killed my own child."



Figure 5: Burial of fetus at a private ceremony

### Conclusion

Much anthropological attention has been paid to the social impact of the expanding array of prenatal technologies for post-diagnostic decision-making. Studies have shown how, against the backdrop of differing cultural formations, the moral burdens of these choices are carried, dispersed and divided differently. As I have attempted to show throughout this article, there is much more to selective abortion than choices. The decision-making that a positive diagnosis engenders is followed by a series of bodily events that is experienced as highly isolating and morally conflicted. Signing the application, taking the pill, giving birth, making mementos, and returning home "empty-handed" with the task of finding a way to live on in a cultural milieu that lacks a collective space for acknowledgement of the "chosen loss" that selective abortion embodies are as challenging as decision-making itself, at least in a society like Denmark where termination is almost a given. In the narratives of my interlocutors, it was the inescapable embodied undertakings as well as the after-the-fact moral self-reflection that stirred the most torment. Indeed, while a rhetoric of choice permeates the policy of fetal testing, women opting for selective abortion in Denmark are given no choices with regards to method of procedure. The legal bureaucracy of selective abortion and the management and performativity of abortion as birth have profound moral and existential ramifications for those involved. What is required of women (and their partners) physically, bodily, emotionally and materially matters for the experience of abortion as morally troubling. Selective abortion sticks with people as an event that remains ethically unresolved.

My findings further suggest a gap in Danish abortion care. Despite efforts to offer what health staff perceive as empathetic care, women and their partners still feel alone in grappling with the unexpected moral and emotional turbulence that arises in the days, months and years that follow. As Anja put it: "We thought it would be over as soon as I

had given birth, only to realize that, really, it had just begun." Women and couples confronted with selective abortion in a sense fall between chairs, not knowing who to reach out to for help and support. While contemporary abortion care is likely to fulfill many of the needs of abortion-seeking couples, the ways in which second-trimester abortion is managed, practiced, and responded to today is worthy of critical debate. More research on such terminations, and the social and moral implications of differing abortion procedures throughout the world has, I contend, great potential for raising critical discussion.

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## **APPENDIXES 1-4**

# Appendix 1.1: Information letter, recruitment of abortion committee members



### Vedr. forskningsprojekt om senaborter

Kære

Vi er to forskere, <u>Ph.d. studerende</u> og antropolog Laura Louise Heinsen og Postdoc og jurist Annika Frida Petersen, fra henholdsvis Aalborg Universitet og Københavns universitet, som er i gang med et forskningsprojekt om senaborter. Forskningsprojektet har som mål at bidrage til større viden om hvordan afgørelser om senabort træffes i praksis på et område som både er juridisk vanskeligt og etisk sårbart at navigere i.

Vi har som led i projektet fået tildelt aktindsigt i et antal afgørelser fra abortsamrådet. For at nuancere disse aktindsigter og tilvejebringe den nødvendige kontekst og forståelse for samrådets afgørelsespraksis og arbejdsprocesser, vil vi meget geme interviewe dig om dit arbejde i samrådet.

Interviewet har til hensigt at blive klogere på de rammer, samrådet arbejder under og de mulige juridiske og etiske problematikker, dilemmaer og overvejelser, samrådet møder i deres virke. Vi håber at den viden, der kommer ud af interviewet, kan bidrage til at skabe større transparens om afgørelsespraksisser på tværs af regionerne, så det blandt andet kan danne grundlag for tværgående læring.

Interviewet vil foregå når og hvor det er nemmest for dig, og vil forventeligt vare 1-2 timer.

Vi behandler alle oplysninger strengt fortroligt og sikrer alle, der deltager i forskningsprojektet fuld anonymitet.

Vi vil naturligvis meget geme fortælle nærmere om projektet, så du har mulighed for at stille spærgsmål til både forskningsprojektet og interviewet forinden.

Vi ser frem til at høre fra dig og håber at du har lyst til at deltage i projektet.

Med venlig hilsen Laura & Annika

Laura Louise Heinsen

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Annika, Frida, Petersen Griur, ku, dk





# Appendix 1.2: Information letter, recruitment of Abortion Appeals Board members



## Vedr. forskningsprojekt om senaborter

#### Kære Abortankenævn

Jeg er antropolog og <u>Ph.d. studerende</u> på Aalborg Universitet, og er i gang med et etnografisk forskningsprojekt om senaborter efter fosterdiagnostik. Som led i projektet har jeg fået tildelt aktindsigt i et antal afgørelser fra abortsamrådene og for at nuancere disse aktindsigter har jeg igennem det sidste år interviewet samrådsmedlemmer fra alle fem regioner. Med interviewene har jeg haft til hensigt at blive klogere på de rammer, samrådene arbejder under og de mulige juridiske og etiske problematikker, dilemmaer og overvejelser, medlemmerne møder i deres virke.

Igennem de interviews, har jeg opdaget, at Ankenævnet spiller en stor rolle i relation til nuværende praksis. Det står derfor klart, at Ankenævnet er en væsentlig aktør for at få et mere fyldestgørende billede af senabort-feltet.

Jeg vil derfor meget gerne interviewe en eller flere medlemmer af Ankenævnet om Ankenævnets afgørelsespraksis og hvordan denne har udviklet sig igennem årene. Interviewet har ikke fokus på konkrete sager, men snarere på hvordan Ankenævnet arbejder, hvad nævnets rolle er, og hvordan medlemmerne af nævnet oplever at arbejde som tilsynsførende/øverste instans og de juridiske og etiske udfordringer, der kan være forbundet hermed.

Jeg håber at den viden, der kommer ud af interviewet/yeg, kan bidrage til at skabe større transparens om gældende afgørelsespraksis og dens historiske udvikling.

Interviewet vil foregå når og hvor det er nemmest for jer, og vil forventeligt vare 1-2 timer. Jeg behandler alle oplysninger strengt fortroligt og sikrer alle, der deltager i forskningsprojektet fuld anonymitet.

Jeg vil meget gerne fortælle mere om mit projekt, hvis I har spørgsmål. Jeg ser frem til at høre fra jer og håber at en eller flere fra nævnet har lyst til at deltage.

Med venlig hilsen Laura

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## Appendix 1.3: Information letter, recruitment of nurses



## Sygeplejersker søges til antropologisk forskningsprojekt om selektive senaborter

Mit navn er Laura Louise Heinsen, jeg er Ph.d. studerende på Aalborg Universitet i København og er uddannet medicinsk antropolog. Jeg er i gang med et forskningsprojekt om senaborter efter fosterdiagnostik i Danmark, også betegnet selektive aborter.

Forskningsprojektet har som mål at bidrage til større viden om hvordan beslutninger og afgørelser om senabort grundet fostermisdannelser træffes i praksis, hvordan senaborter opleves både af de aborterende/fødende kvinder og af de sygeplejersker og jordemødre, som assisterer kvinden og hendes partner under og efter senaborten. Det vil sige mit projekt centrerer sig om de praksisser, der knytter sig både til ultralydsklinikken, abortsamrådet, GYN/OB, fødeafdelingen og kvindens private hjem/liv i og omkring selve aborthændelsen.

I den forbindelse søger jeg sygeplejersker, som har lyst til at blive interviewet om deres praksisser og erfaringer i forbindelse med senaborter grundet fostermisdannelser.

Jeg forventer at interviewet vil vare 1-2 timer afhængigt af hvor meget tid, du har, og det vil foregå enten på gynækologisk afdeling, online eller hvor det er mest belejligt for dig. Jeg behandler alle oplysninger strengt fortroligt og sikrer alle, der deltager i forskningsprojektet fuld anonymitet. Man kan til en hver tid trække sig ud af forskningsprojektet, hvis man senere fortryder.

Hvis du har lyst til at bidrage, eller hvis du blot har spørgsmål til projektet eller ønsker at høre mere, er du velkommen til at kontakte mig på lauralh@hum.aau.dk eller på 31711493.

#### Mange hilsner

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## Appendix 1.4: Information letter, recruitment of women, men and couples



### Personer søges til antropologisk forskningsprojekt om senaborter

Mit navn er Laura Louise Heinsen og jeg er Ph.d. studerende på Aalborg Universitet i København. Jeg er i gang med et forskningsprojekt om senaborter i Danmark.

Forskningsprojektet har som mål at bidrage til større viden om hvordan beslutninger om senabort træffes i praksis, hvordan senaborter opleves og hvad det siger om forståelser af leveværd og livskvalitet i en dansk sammenhæng.

Jeg har en baggrund som antropolog, hvilket betyder at jeg indsamler viden ved at følge og interviewe kvinder og deres partnere, abortsamrådsmedlemmer og sundhedsprofessionelle.

Jeg vil meget gerne i kontakt med personer, der har lyst til at fortælle om deres oplevelser af at gennemgå en senabort. Jeg hører meget gerne fra dig uanset om du står midt i det, om det er sket for nyligt eller for flere år siden. Eneste kriterium er, at senaborten er sket som følge af fund af misdannelser eller sygdom i fostret/barnet.

Jeg behandler alle oplysninger strengt fortroligt og sikrer alle, der deltager i forskningsprojektet fuld anonymitet. Man kan til en hver tid trække sig ud af forskningsprojektet, hvis man senere fortryder.

Hvis du har lyst til at bidrage, eller hvis du blot har spørgsmål til projektet eller ønsker at høre mere, er du velkommen til at kontakte mig på <u>lauralh@hum.aau.dk</u> eller på 31711493.

N.B. På grund af Corona epidemien vil interviewet foregå virtuelt eller på et nærmere oftalt sted, der er nemmest for dig, hvor vi kan sidde med god afstand.

#### Mange hilsner

#### Laura Louise Heinsen,

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## Appendix 2.1.: Interview guide, abortion committee members

## Interview guide - abortsamrådsmedlemmer

## Vejen til at arbejde som abortsamrådsmedlem

- Fortæl om din baggrund og hvad der fik dig til at arbejde i abortsamrådet?
- Hvordan er den typiske vej til at blive abortsamrådsrepræsentant?
- Hvor længe er man udpeget?
- Hvor mange sager tror du at du har sagsbehandlet i din tid som medlem?

## Veje til abortsamrådsansøgninger

- Fortæl hvordan en sag om abort havner hos dig?
- Hvad går der forud for at den lander hos dig?
- Hvor bliver den sendt fra og til?
- Hvordan ser en abortansøgning ud? Kommer den elektronisk eller med fysisk post?
- Hvorfor er det kun den gravide, der må/kan underskrive ansøgningen?

## Arbeidsprocessen

- Beskriv hvad der sker når en sag lander hos dig? Hvad gør du helt konkret? Hvem er du i kontakt med?
- Hvordan sagsbehandler I sagen?
- Hvilke elektroniske systemer arbejder I i/med?
- Er der nogen nedskrevne retningslinjer I arbejder ud fra?
- Har I en arbejdsgangsbeskrivelse, I arbejder ud fra?

## At træffe afgørelser

- Prøv at beskriv hvordan du griber det an at skulle vurdere en sag?
- Hvilken viden trækker du på?
- Hvordan spiller det medicinske ind?
- Hvordan spiller det juridiske ind?
- Hvordan spiller lovgivningens paragraffer ind i dit arbejde? Hvordan fortolker du paragrafferne?
- Hvilken vægt tillægger I levedygtighedskriteriet v. uge 22?
- I hvilke sager giver I tilladelse efter uge 22?

## Sager med klar godkendelse

- Prøv at beskriv en typisk sag som du hurtigt kan godkende
- Hvad er det der gør, at det er en no-brainer?
- Hvad gør du helt konkret for at vurdere sagen?
- Hvem taler du med?
- Hvor lang tid bruger du på det at sagsbehandle den?

## Sager der er svære at vurdere – grænsetilfældene

- Prøv at beskriv en sag, du har siddet med, hvor du fandt det svært at træffe en afgørelse
- Hvad gjorde det svær?
- Hvilke og hvis hensyn tager du med i betragtning, når du vurderer en sag?
- Hvad får vægt i afgørelsen når det bliver en godkendelse og hvorfor? Og det samme med et afslag og hvorfor?
- Hvor lang tid bruger du på at sagsbehandle grænsesagerne? Tager det længere tid end ved de klare sager?
- Gør du noget anderledes når du helt konkret skal håndtere de sager end ved de sager, du hurtigt kan afgøre?

## Sager med klart afslag

- Prøv at beskriv en sag, du har siddet med hvor I gav et afslag
- Hvilke og hvis hensyn tages i betragtning når man giver et afslag?
- Gør du noget anderledes når du skal håndtere sådan en sag? Konfererer du med nogen?

## Forskellen mellem de sociale og eugeniske aborter

- Hvordan vil du karakterisere forskellen på at træffe afgørelser i sager, som vedrører social indikation i forhold til de sager, vi lige har drøftet hvor det vedrører sygdom eller defekter i fostrene?
- Hvilke sager har du sværest/nemmest ved at arbejde med? Hvorfor?
- Hvad gør de sociale sager svære?
- Hvad gør de eugeniske sager svære?

## Efter sagerne - Opfølgning, kvalitetssikring og registrering

- Hvad gør du efter du har afgjort en sag?
- Hvordan registreres afgørelserne? Hvor registreres de? Af hvem?
- Man har hørt historier om forskellig afgørelsespraksis på tværs af rådene taler I sammen på tværs af abortrådene?
- Hvordan kvalitetssikrer I at I laver juridisk korrekte afgørelser?

## Oplevelser af at være samrådsmedlem

- Hvilke udfordringer oplever du at du har med dit arbejde som samrådsmedlem?
- Er der noget, der er svært ved den position du sidder med?
- Har du mulighed for at følge op på de sager, du har sagsbehandlet? Ved du hvordan det ender med sagerne?
- Er det en fordel/ulempe at man ikke er direkte involveret med de gravide og deres partnere?

## Synet på abortgrænsen, selvbestemmelsesretten og abortsamrådets mandat

- I hvor høj grad oplever du at det er problematisk eller et gode at vi har et abortsystem hvor beslutningen om senabort ikke ligger hos parrene?
- Hvilke positive/negative effekter har du erfaring med at den manglende selvbestemmelsesret efter 12. uge har for parrene?
- Hvilken betydning oplever du at det har for parrene at der er sat en øvre grænse for senabort ved 22 fulde uger?
- Har du erfaring med at I har givet tilladelse efter 22. uge? Hvilke sager drejer det sig om?
- Mener du at abortlovgivningen burde være strikket anderledes sammen?
   Hvorfor/hvorfor ikke?
- Er der noget du ville ønske blev gjort anderledes i abortsamrådene?

## Etiske og moralske refleksioner

- Der er jo medarbejdere i den kliniske praksis som kan frabede sig at udføre senaborter fordi de finder det etisk og moralsk problematisk – hvordan har du det med at dine afgørelser er med til at ende fostres liv?
- I hvor høj grad fylder de fostre og familier du støder på hos dig efterfølgende?
- Mange af de mænd, kvinder og par, vi har interviewet beskriver deres døde foster som et barn – det har fået navn, er begravet eller brændt og mange har billeder hængende af dem i deres hjem – i hvor høj grad influerer den viden at de fostre, der kunne være blevet til børn der enten var døde i armene på deres forældre eller havde levet et mere eller mindre sygdomsramt liv, bliver sørget over som børn på din oplevelse af at arbejde i samrådet?

# Appendix 2.2: Example of Interview guide with health care professionals (nurses and midwives)

## Kort introduktion af mig selv og forskningsprojektet

Konkretisering af, at jeg spørger ind til senaborter/sene provokerede aborter og hermed mener jeg aborter på eugenisk indikation, der kræver samrådstilladelse (gestationsalder 12+0-21+6).

## Jordemoderens baggrund

- Vil du kort beskrive dig selv, din alder og uddannelsesbaggrund (hvornår og hvor uddannet fra)?
- Vil du kort beskrive din nuværende samt tidligere ansættelser og ansættelsesforhold?

## **Oplæring**

- Kan du beskrive, hvad du har lært om sene provokerede aborter i løbet af din uddannelse?
- Den f\u00farste sene provokerede abort du assisterede ved, hvordan blev du forberedt til den?

## Organisering af senabort-området

- Kan du beskrive for mig, hvordan sene provokerede aborter er organiseret på hospitalet – hvilke afdelinger og professioner tager sig af dem?
- Hvilke juridiske retningslinjer og reguleringer gælder for området og hvordan spiller de ind på, hvordan man har organiseret området?
- På din arbejdsplads, hvad er så gestationsalder for de sager, du assisterer ved?
- Hvad er den tidligste og seneste gestationsalder et foster-barn havde ved en senabort, du assisterede ved?
- I hvor høj grad erfaringsudveksler I med sygeplejersker om håndtering af sene provokerede aborter?
- Har du kendskab til at der er store forskelle afhængigt af om sygeplejersker eller jordemødre er til stede ved senaborten/fødslen?

## Daglig praksis

- Vil du beskrive for mig, hvordan en typisk sen provokeret abort foregår på din arbejdsplads/når du har vagten?
- Vil du beskrive den sidste sene provokerede abort, du var med til?
- Kan du prøve at tale mig igennem en senaborts typiske faser?
- Hvordan bliver det meddelt på afdelingen af, at der er en sen provokeret abort på vej?
- Hvad sker der på afdelingen, når I får sådan en melding?
- Hvad ved du om kvinden inden du træder ind på fødestuen? Kender du årsagen til aborten?
- Hvad er det første du gør, når du træder ind på fødestuen?

- Hvad er det typiske syn, der møder dig når du træder ind på fødestuen?
- Er der noget særligt du gør og siger på sådan en vagt, som ikke nødvendigvis er almindelig praksis?
- Hvordan finder du ud af, hvorvidt kvinden og hendes partner forholder sig til hændelsen som en abort af et foster eller et mistet barn?
- Hvad gør du når parret ikke er helt enig?
- Hvad anser du som dine væsentligste opgaver når du assisterer ved en sen provokeret abort?

#### Fødestuen

- Hvordan ser en fødestue ud på din afdeling, hvor senaborter håndteres?
- Hvis det er en almindelig f\u00f8destue, g\u00far I s\u00e5 noget s\u00e8rligt ved rummet eller faciliteterne forinden?
- Hvor er fødestuen placeret i forhold til andre almindeligt fødende?
- Hvordan markerer man for de andre jordemødre eller ansatte, at der er en abort i gang – hvis man altså gør det?

## Medico-legal håndtering af det døde foster-barn

- Vil du beskrive hvad du gør lige så snart fostret eller barnet er født?
- Hvad er påkrævet at gøre?
- Hvad gør du derudover?
- Er der forskel fra gang til gang om fostret kommer på køl eller bliver hos forældrene?
- Hvis det fx skal obduceres, betyder det noget for håndteringen og opbevaringen af det?
- En senabort håndteres som en fødsel, men det døde foster registreres ikke som en paritet, vel? Hvorfor ikke?

## Om at se og holde og mindes

- Hvordan finder du ud af om en konkret kvinde og hendes partner skal se det døde foster?
- Hvad gør du hvis de ikke ønsker det?
- Hvordan finder du ud af om de forskellige mindeteknologier skal i brug eller ej?
- Hvorfor mener du at det er vigtigt at se og holde det døde foster-barn?

## De fødendes og deres partners reaktioner og jordemødrenes håndtering heraf

- Hvordan reagerer kvinden og hendes partner typisk når fostret-barnet er født?
- Hvad siger du typisk, når de ser fostret/barnet?
- Er der forskel på hvad du siger når fostret er synligt/usynligt misdannet?
- Hvilke forskellige materialer, ting og tilbud til at huske/minde fosteret-barnet har I på afdelingen?
- Hånd- og fodaftryk virker til at være blevet en fast bestanddel; hvordan er den praksis kommet ind i de her situationer?

#### Praksisser ift, bortskaffelse af døde fostre

- Hvad sker der med det døde foster efter aborten? Hvor kommer det hen?
- Når fostrene skal videre, hvis de ikke hentes af forældrene, som har valgt selv at stå for begravelse eller nedgravning, hvad sker der så med dem?
- Hvad er praksis på dit hospital ift. bortskaffelse?

## Vidensgrundlag ift. medicinsk induceret abort/provokeret fødsel

 Kan du sige lidt om hvorfor senaborter efter 12/13/14 uger typisk foregår som medicinsk induceret fødsel og ikke kirurgisk

#### Sammenligning mellem almindelig fødsel og senabortfødsel

 Kan du prøve at beskrive, hvordan en sen provokeret abort adskiller sig fra en almindelig fødsel (ud over at der er tale om fødsel af et dødt eller døende foster-barn)

## Sammenligning mellem aborter på eugenisk og social indikation

- Vil du fortælle lidt om, hvordan du oplever at forskellene er imellem de sene provokerede aborter, du assisterer ved i relation til om baggrunden er en fosterskade eller social indikation?
- Kan du sige noget mere om, hvordan du oplever at kvinderne og deres partnere agerer og reagerer ens og forskelligt i de to situationer

## Om skyld, skam og sorg

- Af de forskellige måder, man kan miste på, er den sene provokerede abort netop et resultat af kvindens eller parrets beslutning, på hvilken måde kommer det til udtryk hvis det overhovedet gør i forbindelse med selve fødslen?
- Er der noget særligt du siger eller lægger vægt på for at gøre senaborten mindre psykisk smertelig for kvinden og hendes partner?

## Jordemødrenes egne holdninger til sene provokerede aborter

- Er en senabort mere eller mindre acceptabel for dig afhængigt af hvilken indikation, den bliver udført på?
- Er din holdning til sene provokerede aborter forskellig alt efter hvilken gestationsalder fostret har?
- Har du været med en sen provokeret abort, som du syntes var svær at være i? Hvad gjorde den svær?

## Den gode senabort

- Hvad gør en senabort til en "succes" i din optik?
- Hvilke samtaler og overvejelser har I på afdelingen i forhold til hvordan man kan forbedre omsorgen for kvinderne og deres partnere?

## Appendix 2.3: Interview guide women/couples

## Introduktion af forskningsprojekt

Projekt med fokus på oplevelser af at gennemgå en provokeret senabort pga fund af misdannelse eller sygdom hos det ufødte barn til tiden efter at man har mistet, som er en del af et større projekt der handler om hvordan beslutninger om senabort træffes af gravide og deres partnere, hvordan abortsamrådene træffer afgørelser om senaborter og hvordan det foregår omkring selve den inducerede fødsel.

#### Introduktion til interviewform (anonymitet, optages på bånd).

Jeg er klar over at den historie du/I skal fortælle er fuld af minder om både gode og svære, sorgfulde oplevelser, og du/I skal endelig sige til undervejs hvis der er noget, du/I ikke har lyst til at komme ind på. Rummet er frit til at tale og at jeg lytter som en udefrakommende, der ikke har nogen aktier i feltet, hverken sundhedsfagligt, politisk eller etisk.

Hvis du/I har lyst til at dele fotos, dokumenter eller andet med mig, der sætter ord og billeder på det I har oplevet, så vil jeg meget gerne se det og tale med jer om de ting. Det er helt op til jer om vi blot taler om dem eller om I vil dele med dem, så jeg kan bruge dem i formidlingen af forskningsprojektet. I har altid ret til at trække jeres samtykke tilbage – så hvis I fortryder senere, vil jeg ikke bruge jeres historie/fotos/dokumenter.

## Jeg vil begynde med at spørge ind til din historie – der hvor du synes den begynder.

## Screening/Fosterdiagnostik

- Kan du fortælle om den dag, hvor I finder ud af, at der er noget i vejen med fostret/barnet?
- Hvad er der gået forud for den dag havde I været til nakkefoldsscreening og misdannelsesskanning?
- Hvordan bliver det fortalt at noget er i vejen med jeres barn? Kan I huske hvad samtalen handlede om?
- Forestillinger om fostrets fremtid/prognoser? Familielivet? Hvad satte det i gang af tanker?
- Hvornår falder samtalen på at afbryde graviditeten?
- Kan du huske hvordan samtalen om abort forløber? Hvad siger lægen/Hvad siger I?
- Hvordan har I det på det tidspunkt med at afbryde graviditeten?
- Er der noget særligt der gør indtryk på jer, som bliver afgørende for beslutningen om at afbryde graviditeten?

## Ansøgning om abort

 Hvordan foregår selve ansøgningen om abort? Skal I udfylde et papir? Hvem udfylder det? Får I en kopi? Hvem underskriver? Foregår det i hånden eller på computer? Hvem sender lægen det til?

- Hvad sker der i timerne/dagene efter I har ansøgt om senabort?
- Hvem taler I med/hvad laver I?
- Hvordan får I besked på om samrådet har godkendt ansøgningen?
- Hvordan reagerer I på svaret?

#### Senaborten/fødslen

- Prøv at fortæl om senaborten hvornår og hvordan starter den?
- Hvordan forbereder I jer på den? Taler I med nogen inden?
- Hvornår går det op for dig, at du skal føde dit døde barn?
- Kan du beskrive fødslen?
- Hvor føder du?
- Kan du beskrive hvordan fødslen sættes i gang?
- Får du smertelindring undervejs?
- Hvem er på fødestuen/GYN/OBS sammen med jer?
- Hvordan ser dit barn/foster ud?
- Hvordan f
  ølte du det, da du så hende/ham, hvilke tanker gik igennem hovedet?
- Hvad gjorde I eller jordemoderen/sygeplejerske med hans/hendes krop?
- Jeg har tænkt meget over, hvordan det opleves som forældre at føde et barn, der kommer sovende til verden – vil du prøve at sætte ord på hvordan det føles?

#### Efter senaborten

- Hvad sker der efter senaborten?
- Bliver jeres døde barn på hospitalet eller tager I hende/ham med hjem?
- Vælger I at lave en ceremoni, begravelse eller lignende?
- Prøv at beskriv dagene efter selve senaborten
- Hvordan fortalte I det til familie og venner?
- Hvordan reagerede jeres familie og venner på jeres tab?
- Søgte I hjælp hos nogen andre nogen at tale med om tabet?

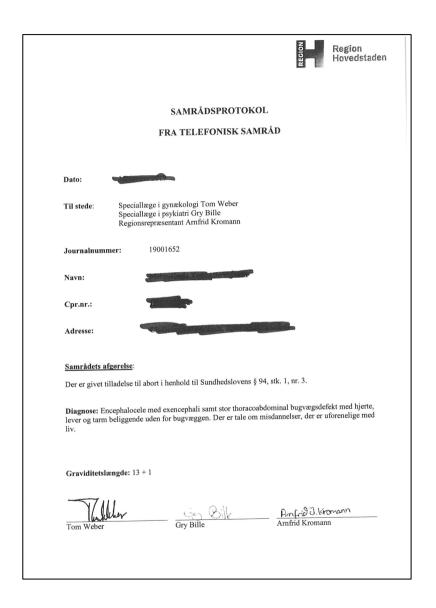
## I dag

- I hvor høj grad fylder senaborten i dit liv i dag? Hvordan præger det dit liv?
- Er der noget du ville have ønsket var forløbet anderledes?
- Er der noget du tænker tilbage på og især er glad for ved oplevelsen?

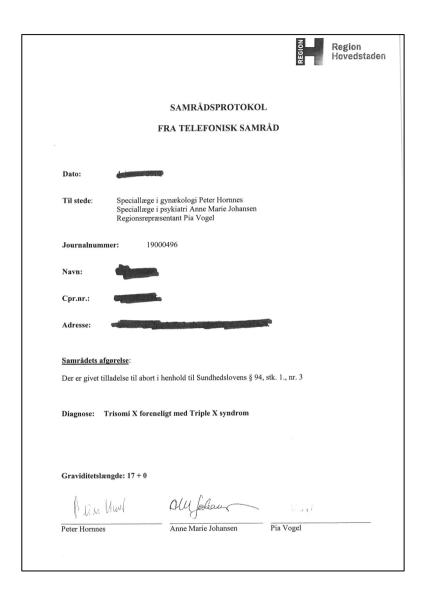
## Fotos/dokumenter

- Vil du beskrive for mig hvad det er for et dokument/fotos?
- Hvad er der på billedet? Vil du beskrive det med dine ord?
- Hvad betyder billedet for dig? Hvor har I det liggende (fremme/gemt væk)?
- Er der andre ting, du har gemt fra dengang?

# Appendix 3.1: Example of legal decision (1), in truncated form, from the Capital Region of Denmark



# Appendix 3.2: Example of legal decision (2), in truncated form, from the Capital Region of Denmark



Appendix 4.1: Excerpt from spreadsheet with legal cases from the Danish regions, used as data and preparation for interviews with committee members

Region	GA	Decision	Medico-legal assessment	LLH comments
Region omitted	16+0	Approval	Scanning revealed a slightly increased risk of Down's syndrome, which is why CVS was carried out. Down's syndrome was not diagnosed, but mosaicism was detected for chromosome 45X/46WY with a mosaicism rate of 40-60%. A further scan revealed male genitalia, making it more likely that this is a phenotypically normal boy. There is thus a 5% risk of varying degrees of pseudohermaphrodism or possibly Turner phenotype. Even if it is a phenotypically normal boy, there will probably still be an increased risk of the mosaicism having an impact on gender development. Client wants an abortion. Client stresses that she wishes to terminate due to the fact that she is very burdened by the uncertainty surrounding the child in relation to what the anomaly might mean.	Abnormality as kinds of living/potential burden = Seriousness
Region omitted	14+4	Approval	22q11 deletion syndrome characterized by developmental disorders, growth retardation, microcephaly, dysmorphia and congenital heart disease, although with great variation in expression.	
Region omitted	14+1	Approval	Trisomi 21	
Region omitted	15+6	Approval	Trisomi 21	
Region omitted	14+5	Approval	Microdeletion on chromosome 16 detected, which in 15% of cases causes mental retardation, mental developmental disorder, epilepsy and autism. The committee finds that a 15% risk of mental retardation must be said to constitute "danger" of serious malformation, although at present it is not possible to say anything about the extent to which the child will be affected.	Why is 15% a high risk? Who decides that 15% constitutes "danger"? Where do those percentages come from? Is 15 % part of the "list"?
Region omitted	15+6	Approval	Defect in the abdominal wall where intestinal contents lie outside the abdomen. On that basis, a placental biopsy was performed, which showed a deletion of 0.5 Mb on chromosome 16p12.2. This entails a risk of delayed development	
Region omitted	15+3	Approval	The fetus has been diagnosed with gastroschisis (abdominal wall defect) and the client wishes to terminate the pregnancy	Why is the woman's request foregrounded here?

## Appendix 4.2. Overview of paintings and photographs used in the dissertation

Image 1	Watercolor painting by Karen Ingversen, remade from photograph shared by interlocutor	P. 10
Image 2	Watercolor painting by Karen Ingversen, developed based on empirical data	p. 38
Image 3	Photograph of casket shared by interlocutor	p. 59
Image 4	Photograph of "birthday card" with hand-and-foot prints, which are made routinely at the maternity ward for women and couples experiencing pregnancy loss and termination of pregnancy in the second trimester. Shared by interlocutor	p. 90
Image 5	Watercolor painting by Karen Ingversen, depicting midwife making hand prints of dead fetus. Developed based on empirical data	p. 106
Image 6	Watercolor painting by Karen Ingversen, depicting doctor preparing to do an Achilles tendon biopsy on a dead fetus. Developed based on empirical data	p. 115

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