



Guardians of ableist family formation: the legitimization work of Danish abortion committees in cases of termination for fetal anomaly

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Accepted: 10 November 2023
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Abstract

In Denmark, pregnant persons 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 and 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 arrive at and legitimate the authorization of disability-selective abortion. Building on van Wichelen’s (Legitimizing life: adoption in the age of globalization and biotechnology, Rutgers University Press, New Brunswick, 2019) concept of ‘legitimation work,’ I show how abortion committees make legal decisions by dividing and distributing the task of—and moral responsibility for—making life-ending decisions by leaning on established legal practice, what I refer to as *bureaucratic legitimization work*; risk estimates made by external medical experts, what I refer to as *collaborative legitimization work*; and the ethical panacea of individual autonomy and informed choice, what I refer to as *ethopolitical legitimization work*. I argue that in conjunction, these forms of legitimization work turn termination of almost every non-conforming fetus into legitimate acts, hereby safeguarding ableist family formation.

Keywords Disability-selective abortion · Abortion committees · Legitimation work · Ethopolitics · Denmark

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Introduction

You focus on what the concrete diagnosis and prognosis are for the fetus and then you're able to make a decision very quickly [...] And occasionally it does come up; what are we really going to do with these committees, because people are given permission anyway, and we're pretty much just blue stamping? [...] But, 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. [...] And, they've decided that this is too much of a burden.

- Jens, gynecologist and abortion committee member

In Denmark, pregnant persons have a statutory right to abortion on-demand in the first trimester of pregnancy, after which what is now termed a 'late abortion' must be sanctioned by one of five regional abortion committees, comprised of a legal specialist and two doctors (Herrmann 2008). Late abortions may be authorized based on six criteria, one of which reads when there is "danger that the fetus will suffer a serious mental or physical disability," what I will refer to as disability-selective abortion, drawing on what Wahlberg and Gammeltoft coin as 'selective reproductive technologies' (SRTs) as technologies used to "prevent or allow the birth of certain *kinds of children*" as opposed to the prevention of unwanted pregnancies (Healthcare Act, Consolidated Act LBK nr 210 of 27/01/2022, n.d.; Wahlberg and Gammeltoft 2018). However, the letter of the law does not spell out what exactly constitutes 'danger' nor what fetal aberrations fall under the category of 'serious,' nor are there any written legal guidelines that specify how to assess these ambiguous concepts. In effect, it is up to abortion committee members to decide upon these matters. Overseeing the regional abortion committees is a cross-national Abortion Appeals Board, which holds the power to overturn regional decisions, hereby setting precedence for what counts as legal grounds for late termination.

Statistics show that among the approx. 6–700 annual applications for disability-selective abortion, approval rates exceed 95%, ranging from conditions incompatible with life to missing or shortened limbs (Lou, et al. 2018; Abortankenævnet 2019; Petersen and Herrmann 2021). In a recent analysis of the legal practices of the abortion committees, legal scholars Petersen and Herrmann argue that the juridical system has developed "an automatized practice for approval on a number of diagnoses, which have come to constitute an unofficial positive list" (Petersen and Herrmann 2021, p. 198). Among the conditions that are given permission 'carte blanche' are Down's syndrome, sex-chromosome anomalies, neural tube defects, as well as a vast array of genetic diseases and malformations to the vital organs (ibid.). This makes me wonder: if the vast majority of selective terminations are approved by the committees, and many as a matter of automaticity, what purpose do abortion committees serve?

Building on fieldwork among abortion committee and Appeals Board members, this article asks: how are legal decisions to approve disability-selective



abortion arrived at and legitimated? Drawing on the work of anthropologist Sonja van Wichelen, who has proposed the concept of ‘legitimation work’ regarding “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, p. 8), I argue that abortion committees make legal decisions by dividing and distributing the task of—and moral responsibility for—making life-ending decisions by leaning on: (1) legal precedence, what I refer to as *bureaucratic legitimization work*; (2) external medical experts, what I refer to as *collaborative legitimization work*; and (3) the ethical panacea of individual autonomy and informed choice, what I refer to as *ethopolitical legitimization work*. According to the Meriam Webster dictionary, legitimization 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 regard legitimization work as an empirical phenomenon that cuts across legal, ethical, biomedical, social and affective realms. Echoing van Wichelen’s definition of legitimization work as a form of socio-ethical engineering, I define legitimization work as *practices of legitimizing and stabilizing potentially ambiguous and unsettling decisions*. As will be expanded upon later, these legitimization forms differ from each other with respect to their ‘logics.’ Whereas bureaucratic legitimization work is based on the principle of administering the law in a uniform way to secure lawfulness, and collaborative legitimization work is a methodological approach to secure such lawfulness as well as to corroborate that an abnormality in fact constitutes danger and seriousness, ethopolitical legitimization work encompasses a bioethical ethos that is mobilized to legitimate the permissibility of approving late abortion. We might say that an ethopolitical rationality takes over when legality (such as when a condition’s severity is contested) falls short. What these legitimization forms share is that they enable committee members to distance themselves from the moral burden of sanctioning abortion by distributing responsibility; to legal precedence, medical experts and prospective parents themselves. My overall contention is that in conjunction, these three forms of legitimacies turn termination of almost every anomalous fetus into legitimate acts, hereby perpetuating ableist family formation.

To substantiate this argument, in the analytical sections that follow, I make occasional detours to the management of late abortion on ‘social indication,’ or as the law reads, “when it can be assumed that pregnancy, childbirth, or care of a child constitute a serious burden to the woman, which cannot otherwise be averted” (Healthcare Act, Consolidated Act LBK nr 210 of 27/01/2022, n.d.). I do so as the boundaries drawn between what is considered “pathological” versus “social” reveals how future citizens deemed “normal” are considered less “expendable” than the “abnormal.” Furthermore, I zoom in on what could be considered boundary cases, meaning cases that have not yet come to figure under the umbrella of legal precedence. Whereas those conditions for which abortion is granted approval automatically and hence for which abortion *has already been made legitimate*, 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 bring “ethics in the making” (van Wichelen 2019) to the forefront. Lastly, I draw on Nikolas Rose’s term ‘ethopolitics’ (Rose 2001) to specify how the legitimation work of the abortion committees takes a particular political form. In an 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. 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., p. 6). As I hope to show, ethopolitical reasoning seeps into the operation of the juridical system to enable personal choices. However, before I expand on these matters, let me situate the article within existing scholarship, historically and methodologically.

The legitimation of selective reproduction: a review of the literature

In recent years, several qualitative studies have shed light on the reasons why fetal testing and disability-selective abortion has settled as the norm in Denmark (Schwennesen 2010; Lou 2014; Heinsen 2018), 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 reached, and the socio-legal logics underpinning such legal work. An exception is the work of Rimón-Zarfaty and Raz (2010), who have explored how Israeli 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 pervasively favored (see also Hashiloni-Dolev 2007; Rimón-Zarfaty and Jotkowitz 2012). In a sociological analysis of public hospital ethics committees in Argentina, Irrazábal shows how religious agents appointed to sit on 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 (Irrazábal 2015). Only a handful of 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).

While abortion committees have not been the object of much anthropological scrutiny, several studies have, nonetheless, focused on how selective reproductive practices have been justified in other ways and realms. For instance, using written information material aimed at parents about to undergo carrier testing, preimplantation genetic diagnosis and prenatal diagnosis in the UK, Wahlberg (2009) shows how social rather than biological norms are invoked in defining the “seriousness” of a prenatally diagnosed condition, pointing to how social imaginaries around disabilities as certain ‘kinds of living’ are central to how selective practices are justified. In a similar vein, Meskus shows 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 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, pp. 380–381). And, Williams and colleagues (2002) have demonstrated how British health practitioners involved in prenatal screening and testing elicited a strong commitment to women’s individual autonomous choices.

As such, this is the first study that examines how legal experts and doctors working on Danish abortion committees and with the Abortion Appeals Board operate. This dearth in the literature is astonishing considering that the Danish abortion law has been in place for the last 50 years with technological capacities for detecting fetal differences constantly expanding, making not only parental reproductive decision making but also the legal governing of life and death more complex. As an effect of this lack of scientific scrutiny, the differences between how disability-selective abortion and social abortion are governed, and the medico-legal and moral work done to establish the severity of a fetal condition lack transparency, making it impossible for applicants to pre-calculate their chance at getting access to late abortion. As Petersen and Herrmann note, the legal practices of the committees and Appeals Board constitute a “black box”¹ (Petersen and Herrmann 2021).

By uncovering the practices of these juridical institutions, my aim is to contribute to medical anthropology and disability studies by unearthing the underlying dominant normative ideas around dis/ability and health in contemporary Denmark. As I hope to show, legal decisions, and the way they come about, are part of perpetuating disability-selective abortion as a reasonable remedy to reproduction gone ‘awry,’ as well as part of continuing negative stereotypes around disability as the cause of human tragedy and familial suffering, as the quotation with Jens in the beginning of the article eloquently illustrates. However, this does not mean that committee members do not struggle emotionally and morally with the task they have been entrusted. To account for some of the moral contours of the committees’ work, in the next section, I take a short historic diversion into the politically shifting strategies to curb the birth of children with handicap in Denmark.

¹ While the Appeals Board previously published annual reports in which they accounted for the legal practice of the regions, following an event in 2011 when the Danish Data Protection Agency pointed out that guidelines for proper anonymization had not been fulfilled, the Appeals Board decided to remove all former reports from the internet, in effect shrouding the legal practice of the committees and Appeals Board in complete secrecy (Petersen and Herrmann (2021). See also Herrmann and Petersen (2021).



Selective abortion in Denmark past and present

The Danish welfare state, known for its publicly funded general healthcare, prenatal care, maternity leave, day care, public education, old age pension and elder care offered to all citizens, was founded on the pillars of a comprehensive set 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). These reformist laws were put forth by Karl Kristian Steincke, the minister of Justice in the then newly elected Social Democratic government, 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 (Svendson 2022, p. 118). Of the two hundred pages that constituted his book, Steincke devoted 28 to eugenics (Hansen 2005, p. 28). He 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. Thus, eugenic thinking merged with the political vision of a strong welfare state when a test act was tried in 1929, offering voluntary sterilization to the “feeble-minded” (sic) (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. Steincke justified the sterilization laws by stating that “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” (cited in Koch 2000, pp. 24–25). As such, Steincke launched the welfare state as a power that regulated citizens’ reproductive lives and, in return, providing them with free care and social benefits (Vallgård 2013).

This kind of thinking reverberated in the first abortion law from 1937 that would grant legal access to abortion on the so-called ‘eugenic indication.’ In her comprehensive comparative analysis of the political debates on abortion in the 1930s and 1970s, historian Sniff Andersen Nexø argues that in the 1930s, reproductive issues were tied to securing a population that consisted of enough and sufficiently biologically “*fit*” citizens. Politicians across political divides approached eugenic abortion as “natural” and “responsible,” and the majority of the parliament was of the belief that while eugenic abortion could not be directly enforced upon women, with time “a sense of duty may arise in the woman herself” (Andersen Nexø 2005, p. 102). The political debates around abortion shifted in the 1970s towards an understanding of both pregnancy and abortion as private matters, alongside a vision for making sure that childbearing consisted of planned pregnancies and the birth of wished-for children to secure that those born into society would develop into *well-functioning social citizens*, culminating in the liberalization of first-trimester abortion in 1973. What is striking about these two political periods is that, despite differences in the outlook on reproduction and the 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 left largely untouched.

Parallel to these shifts, politicians became occupied with the rolling out of 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 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, p. 7).

Fast forward to the twenty-first century, and political attitudes towards selective abortion have shifted. 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. The working group 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 they argued belonged to a "paradigm of prevention," since 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 new principles of "informed choice" and "self-determination" which were seen as more aligned with current legislation on patient rights and contemporary ethical principles of patient autonomy and integrity (Schwennessen et al. 2008). In the hopes of silencing any speculation about the economic incentives behind the expansion of the program, the working group asked for a clear statement from the Danish Parliament about what it considered to be the primary aim of prenatal testing: prevention or choice? The Danish parliament then issued a statement that stressed: "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, May 15, 2003). As such, the new guidelines not only launched choice as the answer to a problematic former arrangement but also rhetorically dismissed any conflation of prenatal screening with state-mandated eugenics of the past.

It is within this thorny moral-political terrain that abortion committee members do their job today, one that is bioethically committed to individual choice yet



historically haunted by a not-that-distant eugenic past. Didier Fassin argues that when exploring different state institutions, such as 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, p. 2). Assuming a position of what Svendsen (2009) has coined as “critically engaged science,” meaning taking solidarity with the field as the ground from where to make visible and problematize logics, values and norms of state officials, I aim to critically question juridical work while acknowledging that their position and the work they undertake are ethically delicate and emotionally troubling. 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).

The study

This article draws on an ethnographic study undertaken intermittently between October 2020 and February 2022. It builds on four types of data, some of which I bring to the forefront of the analysis and others more tacitly. I draw on 200 anonymized legal decisions on applications for termination for fetal anomaly accessed through 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.² In other cases, approval 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 scholar. Some of these interviews took place online, while others took place at the home or workplace of my interlocutors. During the interviews, it became clear that the Abortion Appeals Board plays an important role in how committee members think and operate. To get a better understanding of the entire 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 and 2020, as well as on four anonymized full cases, which one region was kind to share with me. All interviews were anonymized and transcribed verbatim and subsequently analyzed thematically.

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

² For instance, cases concerning Down’s syndrome only include a short note such as “Trisomi 21.”



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 she made such assessments, 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; a legal specialist with whom I conducted interviews, 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 which 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, pp. 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 state institutions need to be accessible to scrutiny from outsiders. Yet, the reference to the legal method also made me realize that 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 (Blumer 1954) took shape.

While I did not begin my fieldwork with the heuristic of legitimation work in mind, I was, however, more or less consciously paying attention to the grammar of justification for abortion, which naturally shaped the subsequent process of coding and analysis. It was, for instance, the patterns of repeated mentioning of "legal practice" that shaped my conceptualization of bureaucracy as vital to decision making, and it was the various ways in which my interlocutors referred to experts and parental choice as important factors in the work of authorizing disability-selective abortion that got me on the track of collaboration and ethopolitics as guiding concepts. These terms did of course not arrive immediately but through tacking back and forth between the transcripts, theories, new ethnographic encounters and my analytical endeavors. In this way, the overall analytical approach might best be described as 'abductive.' 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 (Timmermans and Tavory 2012, p. 181).

In line with a number of anthropologists working with interview-based data material as primary source, I regard ethnography to be "a mode of engagement" (Hockey and Forsey 2012) rather than limited to a matter of method. As Hockey and Forsey argue, "The vast majority of papers and monographs that are called 'ethnographies' these days flow from some form of engagement with the people



portrayed—engaged listening, engaged observation, both are forms of participant engagement, and both reflect the important sense of ‘being there’ and ‘being with’ research participants, notions that are fundamental to a field-based study” (Hockey and Forsey 2012, p. 75. See also Rubow 2003). Let me now turn to my analysis.

Bureaucratic legitimation work: toward a uniform practice

When an application for termination following the 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,’ typically consisting in sonographic or diagnostic test results, prognostic assessments as well as information about gestational age. The secretary then contacts the committee members on duty and sends the documentation via secure mail. In all regions, cases concerning a fetal anomaly are handled on an ad hoc basis through either email correspondence or telephone conferences. Only in the very rare event of disagreement do the members consult each other. During my engagement with my interlocutors, I heard repeatedly that when a case lands on their desk, they *always* assess it case-by-case based on an “individual assessment.” Yet, as I probed them about how they distinguished different types of malformations in terms of assessing their severity, it became evident that the vast majority of these cases is easily and quickly agreed upon, because they are, in the words of one gynecologist, managed as “mere expediting cases.” Asking a legal specialist, who had recently been appointed to sit on one of the abortion committees, why she thought abortion for conditions like Down’s syndrome are managed as mere expediting, she responded:

I don’t know. I’ve actually also thought about it a bit myself, because it’s not mental retardation in the same way as some of the other [more severe chromosomal differences]. And you’re not spastically paralyzed. It’s a...I don’t know how to say it, slightly milder disease to a certain extent, but it’s, it’s just practice. It’s a permission without even blinking.

Such a quotation illustrates that central to the juridical work done in these committees is securing a uniform practice. When asking one legal specialist where current legal practice “comes from,” she answered: “From the Abortion Appeals Board. Three months a year, we must send every single decision over to the Appeals Board. Then they go through them to see if we follow practice, and then they might announce something like, ‘here, you have to be aware of this and that.’ And then we align.” This attention towards alignment illustrates that when legal practice has been settled, termination is by the same token indexed as not only legal but also as ethically legitimate. As one judge from the Appeals Board said in a rather brusque tone: “We don’t manage ethics. We manage the law.” When asking the Appeals Board members how they experienced having the responsibility of establishing legal precedence, one judge said:



I haven't 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.

This sense was shared by many legal experts and doctors working on the committees, namely that ethics is built into the law; thus, what is right and wrong has been established by lawmakers, not those who implement the law into practice. Especially legal specialists see their role not as one of judging the morality of the current legal practice but one of upholding it in a lawful manner. One legal expert who had served on one committee for well over 10 years explained: "I'm very meticulous with my role because I see myself as a civil servant and only as a civil servant; as someone who has to make sure that the legislation is respected, that legal practice is implemented as it should be."

To ensure that all applicants had their case handled based on the most comprehensive groundwork possible, the Appeals Board set up clear directives for what should be included as necessary case material, such as diagnostic results that could confirm suspicion of a fetal defect. Agreement on what adequate and comprehensive case material implies, obviously makes legal decision making more efficient, but it also gave committee members a sense of delivering high quality decisions. As one jurist said: "It's super seldom that the Appeals Board overturns our decision, so on some level we're pretty well aligned with the legal position [retsstillingen in Danish]." Within this pervasive legal rationality of alignment and uniformity, it is difficult to challenge what has become legitimate grounds for selective abortion, even though some of the committee members I spoke to questioned the severity of some of the fetal conditions in question, such as sex-chromosome anomalies like Klinefelter's and Turner's disease. In the words of one gynecologist:

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, [but] 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.

Thus, one thing that is safeguarded by the juridical system is ensuring applicants an equal legal position, which is foundational to the constitutional principle of the rule of law, while also safeguarding committee members against criticism from the Appeals Board. Especially those legal specialists responsible for writing decision letters to applicants felt great responsibility for living up to established practice, as failing to do so would jeopardize their reputation as skilled jurists.

When I began inquiring how committees managed cases on social indication, I learned that while the juridical system is adamant in ensuring an equal legal position for applicants who seek abortion due to a fetal problem, pregnant persons who wish to terminate an unwanted pregnancy because of social issues are, from



the outset, on unequal terrain. This is due to the different ways in which such cases are deemed sufficiently “informed.” Pregnant persons seeking termination on social grounds must show up for an interview with a caseworker, which entails being asked several private and invasive questions—from conditions of upbringing, current socio-economic conditions to social relations. In some regions, the case worker visits the applicant at her home to check whether her living conditions are as poor as she had indicated. In these ways, applicants who wish to terminate the pregnancy because the pregnancy rather than the specific fetus is unwanted must *convince* the juridical system that her situation merits approval. Convincing the system in this case means being credible, as one legal specialist told me when I asked how the committee for instance assessed whether a pregnancy was the result of rape: “The word ‘credible’ could well be included as part of the overall impression, but not specifically directed at whether she has been raped or not. It’s more whether they are coherent and answer openly to the questions asked [...] But we tend to believe what people tell us.” Conversely, when you apply for late abortion due to a fetal anomaly, you are not required to give a reason for your wish to terminate. In the legal cases I got access to, the diagnosis and prognosis described by the fetal medicine specialist were followed by a short sentence like “the couple wishes to terminate.” The necessity of the abortion is, thus, seen as encompassed in the medical documentation in itself. 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 unproblematic as presented here. In conventions regarding adequate case documentation, a foundation for legality is crafted in particular normative ways. The distinction rests on a notion of biomedical knowledge as credible “objective facts,” as many committee members underscored. Such facts about the fetus renders a *specific* couple’s *specific* reason for wanting the abortion obsolete. Indeed, the wish to terminate a pregnancy due to a fetal anomaly is seen as self-explicatory, as the mere existence of the abnormality is expected to trigger human tragedy. As one gynecologist said when our conversation circled on Down’s syndrome:

You mustn’t get me hung up on the percentages, but at least 10–15% die early, some need surgery, some develop leukemia, you become demented earlier, some, when they reach puberty, become really externalizing. If you were given the choice whether to expose your otherwise well-functioning family to this trauma, what personal risk would you take? It may well be that you are 1 in 100 who will get a really well-functioning mongol (sic). Sorry, you mustn’t say that. Person with Down syndrome. But personally, I would never take that risk.



As illustrated here, the abnormal fetus is indexed as lacking the capacity for making happy (dis/abled) families, regardless of the likelihood that the affected fetus could in fact develop into a child with a high quality of life, and regardless of the potential wealth and social resources its parents might have. Wealth that could support the child's physical, mental and social thriving.

In contrast, I learned how (presumed) 'normal' fetuses were regarded as more "sacred." When I asked how committee members considered the implications of being born into an existence where you were unwanted and the socio-economic resources of the parent/s were scarce, all committee members agreed that such normal unborn lives could blossom through municipal interventions and aid, such as housing assistance. Some replied that such children could even bring joy to others through adoption. Thus, while the unwanted yet healthy fetus was deemed prosperous, the fetus diagnosed as "pathological" and "abnormal" was generally cataloged as futile, unless the abnormality could be "compensated," as I return to later. And not a single committee or Appeals Board member mentioned the probability that a couple would even consider adopting an "abnormal" child. In these ways, Danish abortion committees exercise and reproduce a disability model that locates suffering in the biology of the affected individual rather than focusing attention onto social oppression, cultural discourse, and environmental barriers that disability scholars for decades have argued are the main cause of suffering and exclusion of disabled people (Shakespeare 2013, p. 214).

Collaborative legitimization work: settling legality through predictive risk estimates

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, learning difficulties, the establishment of danger is inextricably linked to the medical concept of risk (Herrmann 2008, p. 138). This means that risk assessments have become central in the work of ensuring legality. In January 2005—the same time when routine prenatal screening was being rolled out nationally—the Appeals Board issued a briefing:

The Appeals Board predicts an increasing pressure on 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". As a minimum, 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 3% 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, p. 32), approval should not have been granted. However, the 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” (sic) to 90 percent or more. When probing how everything within this spectrum could qualify as ‘danger,’ the most frequent answer I got was that such qualifications take place outside the committees, which the gynecologist in the committees 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 (Hoffman-Andrews 2017), which challenges 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’s a considerable risk that the child will be mentally disabled, then we of course consider that. It has actually happened a few times that we’ve been dealing with statements from a neuropediatrician or the like, and they have written something we really can’t 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 that 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 that 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.

The risk estimates made by doctors outside the realm of the committees, thus, forms the very basis for legal decision making by transfiguring dangers into calculable objects that committee members can act upon (Helén 2004, p. 32). 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.” 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, p. 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 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. 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. Questioning why she was denied access, the response from all but one committee member was that the threshold of viability is definitive; 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, however, 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, 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, legal experts and doctors alike declared the uncertainties of such knowledge, which were distressing to some. During an interview with a middle-aged gynecologist, he explained:

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. [...] 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?

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). One psychiatrist for instance 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’s 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.

Such quotations elicit, I suggest, the affective responses to committee work. This is where legal precedence and the collaborative effort to yield danger and seriousness come in handy. As several committee members mentioned repeatedly, it was considered a "strength" that three people are sitting in the committees making decisions jointly, and it was regarded a strength that doctors outside the committees provided the members with clear prognoses they could lean on. We might say that it is by dividing and distributing the moral responsibility for the approval to various "others; legal practice and risk estimates made by external experts, that the sanctioning of selective abortion becomes not only legally but morally and emotionally manageable, and the uncertainties of medico-legal assessments tamed.

It is, however, not only the ambiguity of danger and severity that constitutes a struggle for committee members. I learned that the material reality of late abortion infused especially gynecological members with a sense of emotional and moral discomfort. One member for instance said: "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 afterward at all. But the one lying in the tin bowl gasping does." Echoing this sense of unease invoked by the materiality of dead embryos and fetuses, several committee members argued that while the abortion committees almost always grant approval in cases of fetal disability, the committees' existence is still important. As one committee member phrased it:

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".

Thus, we might say that performing committee work serves to make bearable the involvement in the making of death on both committee members and other state agents, such as abortion providers. The juridical system, thus, both distributes and takes on moral responsibility. Indeed, as we shall see in the last analytical section, moral responsibility for the decision to terminate is ultimately placed with prospective parents.

Ethopolitical legitimization work: guarding parental choice

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. As a legal specialist 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 at 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 principle that everything operable with a good result isn't, 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 "aesthetics" 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 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 its own directives. In the Appeals Board's decision letter, they 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, p. 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. 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*” (italics 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?

I learned that a “combination of factors” is taken into account when seriousness is assessed, such as gestational age and the 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 ensure 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, low gestational age made a precise diagnosis unobtainable, meaning that gestational age was part of the reason why rejection was given. Yet, in the interpretation of the Appeals Board, low gestational age was mobilized to justify approval. Thus, gestational age factors into decision making in polymorphous ways with diverging results.

There are two key considerations underlying the Appeals Boards’ reversal. First, abortion law in Denmark builds on a gradualist perception of fetal personhood (Petersen and Herrmann 2021, p. 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 board’s rationale for approving the case is the notion of *parental choice*. As one Appeals 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). 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.



One could argue that the accentuation of parental choice is puzzling, as the expiration of the right to self-determination is why abortion committees exist in the first place. We might say, *de facto*, abortion provision is in conflict with the legal rules that seek to regulate it (see also Lee 2003). Yet, every member spoken with felt a strong ethical commitment towards extending parents' self-determination to the domain of late abortion, both because parents are considered the only ones apt for making a decision about disability-selective abortion and because *choice is what the state-financed policy of prenatal screening has promised*. Yet, the heteronomy of late 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 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).

As the ethos of informed choice and self-determination became apparent to me, I was curious about how this translated into the justifications for approving or rejecting abortion on social grounds. Here, parental choice was 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, p. 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.

Conclusion: guarding ableist family formation

After the two cases concerning malformed lower arms had been overturned, the regional committees met with the board to clarify the impact for future legal practice. Some three months after the meeting, the 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.”

In the juridical world of abortion committees, such justifications intertwine in ways that make it difficult for those who work within the system to challenge legal practice. For lack of a better allegory, they appear as endless loops. To my knowledge, what is being debated now is not whether a missing or deformed lower arm is a legitimate ground for termination but how to manage similar cases in the future. This makes me reiterate my initial question; if *every* detectable abnormality is a legitimate ground for termination, why put pregnant women through the bureaucracy of application? What is gained by performing committee work?

In this article, I have tried to unravel some of the logics that shape how committees operate and reason. I have shown how committee members work with a very palpable sense of being under the control of Appeals Board directives, to which they are obliged to conform. This form of legitimation work is oriented towards streamlining the kind of documentation seen as necessary to form an adequately illuminated case to ensure that it can be handled lawfully, meanwhile collaborative legitimation work centers on forming sufficient case documentation that verifies that a condition constitutes danger and seriousness that is, in turn, central to the work of securing legality. However, by bringing boundary cases 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. Here, 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 argue that these three forms of legitimation work in conjunction work to both justify current legal practice and explain the inconsistencies of that practice. To sum up, I contend that bureaucratic legitimation work works to configure all fetuses with a prenatally detected anomaly or difference as futile and burdensome, regardless of the particular conditions and resources of the parents, family and welfare system it would be born into. Collaborative legitimation work configures all non-conforming fetuses as ‘defected’ even though the severity of the particular condition varies from child to child, and despite some of these “defects” being of unknown significance. And lastly, ethopolitical legitimation work configures the wish to selectively terminate a pregnancy as a legitimate personal choice best left in the hands of prospective parents.

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, while the health care system carries the ‘purely’ *technical responsibility* of identifying risks and abnormalities, as a basis 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 into the juridical realm. What is at stake for committees and the Appeals Board is the ‘technical’ *facilitation* of a personalized ethics, which in effect enables the juridical system to distance itself from the moral questions pertaining to discarding non-conforming life. In other words, 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 both the principle of the rule of law and people’s own wishes to procreate ‘normal’ offspring.

Yet, affective responses influence jurists and doctors’ sense of doing important societal work, as they take on the moral burden of sanctioning the termination of a fetus that other professionals must then effectuate. In conclusion, the legitimacies I have pointed to work to preserve ableist family formation while mitigating the moral unease associated with making death. Perhaps because moral responsibility is divided in these ways, hardly any questioning or resistance is made against this kind of systematic discarding of non-conforming life—neither within the juridical world nor in the wider Danish society.

Acknowledgements I would like to extend my gratitude to the abortion committee members and Abortion Appeals Board members who agreed to take part in this research. I also want to extend my gratitude to Prof. Ayo Wahlberg and Associate Prof. Stine W. Adrian for their untiring support and for their comments and suggestions, all of which have helped to shape this article.

Funding Open access funding provided by Aalborg University. This research was made possible by the Independent Research Fund Denmark grant Technologies of Death and Dying at the Beginning of Life [Grant Number: 9037-00118B].

Data availability The data that support the findings of this study are available on request from the corresponding author, [LLH]. The data are not publicly available due to sensitive nature of the topic and to the privacy of research participants

Declarations

Competing interests There are no competing interests—intellectual or financial—in the research detailed in the manuscript.

Ethical approval I hereby confirm that the manuscript is comprised of original material that is not under review elsewhere, and that the study on which the research is based has been subject to appropriate ethical review.

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