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Deviating from the Norm? The Pregnant Body in Scandinavian Health Law

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Abstract

This article explores how the political ideal of data interacts with the legal entitlement of autonomy in the care of pregnant people guided by feminist theory and critical approaches to data. Using Scandinavian legislation and administrative practice, it analyses how the presence or absence of data, namely scientific evidence, interacts with pregnant people's legal autonomy in healthcare. Data –particularly scientific evidence – is shown as something that is not neutral but open to interpretation and misappropriation. First, administrative complaints illustrate that not only a lack of scientific studies on pregnant people but also patriarchal attitudes have implications for care. Second, Scandinavian legislation authorizes the involuntary detention of pregnant drug users despite an absence of evidence supporting such drastic actions. Third, complaints bodies are found to frame injury to pregnant bodies as a natural consequence of birth, despite clear evidence as to the duties of healthcare professionals in preventing harm. A relational approach that sees the pregnant body and fetus as integrated though quintessentially unequal is needed. Evidence is not the only answer; an approach that recognizes the dignity of pregnant people must be central. This requires eliminating coercion, recognizing the pregnant patient as the decision maker in healthcare choices and prizing the birthing patient's voice as a valuable data source.

Keywords: health law; European comparative law; feminist legal studies; data feminism; pregnant patients; Scandinavian law; Danish law

A. Introduction

The health of pregnant people is a paradox: Medically neglected yet simultaneously of intense fascination for the modern welfare state.¹ Because of systematic exclusion of pregnant people from clinical trials, internationally there is an evidence gap regarding the effectiveness of many routine medications.² Pregnant people may be unable to make informed decisions regarding treatment options and medications due to clinical uncertainty concerning differences in their metabolism and risks posed to the fetus. As a result, pregnant people may avoid treatments or taking medications, or doctors may prescribe incorrect dosages to the detriment of their health.³ Improving

¹I use the term pregnant people interchangeably, as this is the language used in the Scandinavian health acts. See *infra* Part B.I.

²Vanessa Merton, *The Exclusion of Pregnant, Pregnable, and Once-Pregnable People (A.K.A. Women) from Biomedical Research*, 3 TEX. J. WOMEN & L. 307, 375 (1994).

³Carla Saenz, Phaik Yeong Cheah, Rieke van der Graaf, Leslie Meltzer Henry & Anna C. Mastroianni, *Ethics, Regulation, and Beyond: The Landscape of Research with Pregnant Women*, 14 REPROD. HEALTH 173, 173 (2017).

the health outcomes of pregnant people thereby appears to require gathering more data that can be used to create evidence on the safety and efficacy of treatments and medicines.

Part of this paradox is that politicians, industry, researchers and even healthcare workers seem to revere data as an answer to the welfare state's problems.⁴ A lack of data and moreover an absence of data sharing by public and private actors is seen as a problem, which nation states and the European Union seek to remedy through legislative proposals.⁵ By gathering increasing amounts of data, algorithms can analyze it and more accurately predict which treatments will be effective for specific groups of patients. Increased digitization will—so the story goes—lead to effectivization and slash healthcare costs in particular.⁶ Digitization and data are thereby political priorities. In theory, pregnant people as underrepresented in data stand to benefit from these promises.

However, the answer is not as simple as including more pregnant people in clinical trials. Most pregnant people are women and Western medicine has historically trivialized conditions pertaining to their bodies.⁷ This has contributed to gendered healthcare, which views women's bodies as “deviant,” while those of men are “normal and unproblematic.”⁸ As a result of such stereotypes, health professionals may be biased against women patients and, for example, neglect their reports of pain.⁹ Meanwhile, there is a knowledge gap regarding the health of pregnant transmen who may face stigma and barriers to care.¹⁰ Even in the fields entrusted with pregnant people's care—obstetrics and gynecology—patriarchal approaches endure.¹¹

In Europe, the “pregnant health data paradox” is situated in a social context that has traditionally viewed pregnant women with distrust. Since the Middle Ages, the nation state has used legislation to regulate pregnant women's behavior.¹² There is a long history of punishing women for their conduct while pregnant in, inter alia, Scandinavia.¹³ The basis for targeting pregnant women, in particular, unmarried women, has been linked to Judeo-Christian prescripts.¹⁴ While “irresponsible conduct” at birth, which places the infant in serious danger, remains criminalized,¹⁵ nowadays, with the decriminalization of abortion, criminal law's role in

⁴KLAUS HOEYER, DATA PARADOXES: THE POLITICS OF INTENSIFIED DATA SOURCING IN CONTEMPORARY HEALTHCARE 78 (2023).

⁵See, e.g., European Commission, *Communication From The Commission To The European Parliament, The Council, The European Economic And Social Committee And The Committee Of The Regions: A European Strategy For Data*, at 66, COM (2020) 66 final (Feb. 19, 2020).

⁶*Personalised Medicine for the Benefits of Patients: Clear Diagnosis Targeted Treatment Enhanced Research*, Danish Ministry of Health at 28 (2021), <https://eng.ngc.dk/Media/637614364621421665/Danish%20Strategy%20for%20personalised%20medicine%202021%202022.pdf>.

⁷Hilde Lindemann, *Feminist Bioethics: Where We've Come From*, in THE ROUTLEDGE HANDBOOK OF FEMINIST BIOETHICS 2 (Wendy A. Rogers, Jackie Leach Scully, Stacy M. Carter, Vikki A. Entwistle, Catherine Mills ed., 2022).

⁸*Id.* at 15.

⁹Britt-Marie Stålnacke, Inger Haukenes, Arja Lehti, Annacrine Fjellman Wiklund, Maria Wiklund, & Anne Hammarström, *Is There a Gender Bias in Recommendations for Further Rehabilitation in Primary Care of Patients with Chronic Pain After an Interdisciplinary Team Assessment?*, 47(4) J. REHAB. MED. 365, 370 (2015).

¹⁰Joshua D. Safer, *Research Gaps in Medical Treatment of Transgender/Nonbinary People*, 131 J. CLINICAL INVESTIGATION 1 (2021).

¹¹Stella Villarmea, *When a Uterus Enters the Room, Reason Goes out the Window*, in WOMEN'S BIRTHING BODIES AND THE LAW: UNAUTHORISED MEDICAL EXAMINATIONS, POWER AND VULNERABILITY 63–78 (Camilla Pickles & Jonathan Herring eds., 2020).

¹²Fiona Harris-Stoertz, *Pregnancy and Childbirth in Twelfth- and Thirteenth-Century French and English Law*, 21 J. HIST. SEXUALITY 263, 266 (2012).

¹³BETH GROTHE NIELSEN, LETFÆRDIGE QVINDFOLK (2d ed. 1999); MONA RAUTELIN, EN FÖRUTBESTÄMD SANNING: BARNAMORD OCH DELAKTIGHET I 1700-TALET'S FINLAND BELYSTA GENOM KÖN, KROPP OCH SOCIAL KONTROLL (2009).

¹⁴Inger Dübeck, *kvinders retlige stilling*, DEN STORE DANSKE (Apr. 23, 2021), https://denstoredanske.lex.dk/kvindere_tellige_stilling.

¹⁵§ 251 STRAFFELOVEN [CRIMINAL CODE] (Den).

regulating pregnant women has effectively been eliminated in Scandinavia.¹⁶ Yet, women can be punished indirectly, such as, through surveillance by social welfare authorities or by removing/threatening to remove their child at birth. In 2023, the Danish government adopted a new law allowing the decision for a newborn to be removed from its parents to be made in utero.¹⁷

The modern welfare state facilitates the monitoring of pregnant people by leveraging digitization to surveil the pregnant body. Through a process of “datafication”, fetal and maternal health is tracked from the earliest stages of pregnancy.¹⁸ The state has routinized technologies like ultrasound, which has transformed pregnancy from a biological to a medical phenomenon,¹⁹ through which the fetus becomes a separate patient.²⁰ Through medical birth registries,²¹ Scandinavian countries compel healthcare workers to transmit important snippets of data regarding the health of the fetus, pregnant person and future child.²² The state harnesses this data to espouse recommendations on achieving a healthy pregnancy,²³ furthering responsabilization and individualization of health. Clear expectations are thereby created for how a pregnant person should and should not behave, and failure to comply provides a justification for intervention by public authorities.

This Article explores how the political ideal of data interacts with the legal entitlement of autonomy in the care of pregnant people guided by feminist theory and critical approaches to data. Data—in particular scientific evidence—is not neutral in pregnant people’s healthcare but open to interpretation and misappropriation. In light of historical and enduring attitudes, patriarchal assumptions may fill the data gap. This can be the idea that pregnant people are a danger to the fetus or that they are incapable of making rational decisions due to their condition, in particular during childbirth. This Article will further reveal how fetal risk has been assumed where adequate data has not been gathered. Even where there is data available to guide healthcare options, legislatures and health professionals in practice limit pregnant patients’ self-determination. This is despite the fact that modern Scandinavian health law guarantees pregnant people the same autonomy-based rights as other competent patients.

Section B introduces the Article’s theoretical framework, the state of the art, methodology, terminology and limitations. The Article’s research question is then explored through three case studies. In Section C, the first case study is described, which focuses on pregnant patients receiving treatment in the context of a data gap. Section D introduces legislation that allows for the detention of pregnant people due to risks posed to their fetus by their drug or alcohol use. In

¹⁶Frank H Pedersen, Janne Rothmar Herrmann, & Laura TD Hansen, *The Factors Influencing the Trajectory of Danish Abortion Law: From Progressive to 50 Years of Stagnation*, 22(4) MED. L. INT’L 277 (2022).

¹⁷49 § Barnets lov [The Law of the Child], LOV nr 721 af 13/06/2023 (Den.).

¹⁸Alexis Paton, *The Surveillance of Pregnant Bodies in the Age of Digital Health: Ethical Dilemmas*, in THE ROUTLEDGE HANDBOOK OF FEMINIST BIOETHICS 476 (Wendy A. Rogers, Jackie Leach Scully, Stacy M. Carter, Vikki A. Entwistle, & Catherine Mills eds., 2022).

¹⁹ANN OAKLEY, *THE CAPTURED WOMB: A HISTORY OF THE MEDICAL CARE OF PREGNANT WOMEN* 5 (1984).

²⁰RAYNA RAPP, *TESTING WOMEN, TESTING THE FETUS: THE SOCIAL IMPACT OF AMNIOCENTESIS IN AMERICA: THE ANTHROPOLOGY OF EVERYDAY LIFE* 120 (1st ed. 2000).

²¹Jacqueline M. Cohen, Carolyn E. Cesta, Lars Kjerpeseth, Maarit K. Leinonen, Öskar Hálfðánarson, Øystein Karlstad, Pär Karlsson, Morten Andersen, Kari Furu, & Vidar Hjellvik., *A Common Data Model for Harmonization in the Nordic Pregnancy Drug Safety Studies (NorPreSS)*, 29 NORSK EPIDEMIOLOGI 117, 117 (2021).

²²Norway: Forskrift om innsamling og behandling av helseopplysninger i Medisinsk fødselsregister (Medisinsk fødselsregisterforskriften) (FOR-2021-11-19-3235) [Regulations on the Collection and Processing of Health Information in the Medical Birth Register (Medical Birth Register Regulations)]; Sweden: Förordning om ändring i förordningen (2001:708) om medicinskt födelserregister hos Socialstyrelsen [Ordinance Amending the Ordinance (2001:708) on the Medical Birth Register at the National Board of Health and Welfare]; Denmark: Bekendtgørelse om indberetning til godkendte kliniske kvalitetsdatabaser og videregivelse af data til Sundhedsdatastyrelsen nr. 585 of 28 May 2018 [Order on Reporting to Approved Clinical Quality Databases and Disclosure of Data to the Danish Health Data Agency].

²³E.g., SOSIAL—OG HELSEEDIREKTORATET, FAGLIG RETNINGSLINJE FOR SVANGERSKAPSOMSORGEN: KORTVERSJON—NBEFALINGER (2005), <https://www.dokter.no/PDF-filer/nasjonal-faglig-retningslinje-for-svangerskapsomsorgen-kortversjon.pdf>.

Section E, complaints regarding the lack of autonomy and dignity afforded to birthing patients are described. Section F further analyzes the three case studies and argues for greater recognition and protection of pregnant people's autonomy. It argues that their voices must be a guiding data source. In Section G, the Article's conclusions are presented.

B. Framework

The central questions that this Article seeks to answer are as follows. How does Scandinavian law govern pregnant people's autonomy in healthcare? In a modern welfare state that increasingly relies on data driven decision-making, how does the "pregnant health data paradox" play out in legislation, case law and administrative decisions?

1. Theory

The Article aims to contribute to the literature on feminist perspectives to health law by interpreting and explaining the rationales underlying Scandinavian law and practice. This body of scholarship exposes patriarchal structures and views that underwrite seemingly neutral systems like healthcare.²⁴ According to Fineman, concepts of power and injustice are seen as central to feminism, and the nature and operation of the explicitly coercive power of law is a concern.²⁵ Intersectionality is furthermore important; power does not operate in isolation but rather interacts with race, class and other forms of marginalization.²⁶ While women are increasingly involved in drafting and interpreting law, legislation and case law builds on what came before, which was a system created by men.

The position of pregnant people is particularly fraught as patriarchal notions can be triggered when fetal life is believed to be at stake. Laws and directives that deny women choice during pregnancy "subordinate women to their reproductive role."²⁷ Where a pregnant person's rights to control their conduct are removed, they are deprived of legal personhood.²⁸ Historically, the delivery room was a space where female midwives played a central role and their tense relations with male obstetricians tell part of the story of women's fight to control their bodies.²⁹ Childbirth has been described as a "socialcultural event in which multiple forms of power coalesce."³⁰ Yet, pregnant people's health is not confined to this space—it spans interactions with general practitioners, emergency rooms and social workers.

Meanwhile, data is a social and political force that negotiates power relations between citizen and state.³¹ The production of data engages power and knowledge.³² The Article draws on the concept of data feminism as developed by D'Ignazio and Klein. They ask, "what information needs to become data before it can be trusted . . . whose information needs to become data before it can be considered as fact and acted upon?"³³ Data feminism begins by "analyzing how power operates in the world".³⁴ The concept and role of data—and evidence as a product thereof— is thereby approached critically as a force that may be used to limit pregnant people's autonomy given

²⁴See generally, Seema Mohapatra & Lindsay Wiley, *Feminist Perspectives in Health Law*, 47(4_suppl) J. L. MED. & ETHICS 103 (2020).

²⁵Martha Albertson Fineman, *Feminist Theory in Law: The Difference it Makes*, 2 COLUM. J. GENDER & L. 1, 7 (2005).

²⁶RACHELLE CHADWICK, *BODIES THAT BIRTH: VITALIZING BIRTH POLITICS* 12 (2018).

²⁷*Rethinking (M)otherhood: Feminist Theory and State Regulation of Pregnancy*, 103 HARV. L. REV. 1325, 1340 (1990).

²⁸Dawn E Johnsen, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L. J. 599, 599 (1986).

²⁹OAKLEY, *supra* note 19.

³⁰CHADWICK, *supra* note 26, at 44.

³¹Evelyn Ruppert, Engin Isin & Didier Bigo, *Data Politics*, 4 BIG DATA & SOC'Y 1 (2017).

³²*Id.*

³³CATHERINE D'IGNAZIO & LAUREN F. KLEIN, *DATA FEMINISM* 10 (2020).

³⁴*Id.* at 129.

historical distrust of pregnant women. Furthermore, drawing on this theoretical approach, the Article recognizes that not all pregnant people are treated equally. Data may be used differently depending on the individual's race and social status. While privileged patients may benefit from the welfare state's use of digital surveillance, the same techniques can be harnessed against divergent sub-groups. Data feminism also acknowledges that certain knowledge has traditionally been privileged and regarded as objective, while "emotion and embodiment" are undervalued.³⁵ It asserts that data is not "neutral or objective but products of social relations" and that this context must be included.³⁶

The Article draws on feminist theory on relational autonomy, which views the pregnant patient as an embodied subject within social relations and institutions.³⁷ Law is recognized as a factor that can positively or negatively influence individual vulnerability in relation to these actors.³⁸ Crucially, data is not the only factor that guides pregnant people's decision making. For pregnant people, their health is naturally intertwined with that of the fetus. Meanwhile the views and behavior of any partner or co-parent may in practice, though not by law, influence and limit their choices. The social reality of a pregnant person may furthermore undermine the freedom of their choice. For example, a person with limited social and financial resources may have the same legal rights to sick leave during a difficult pregnancy but due to resources their decision to continue the pregnancy may be more limited. Thus, pregnant patients will not only be guided by data in making decisions regarding their health but also relational aspects.

Previous legal research has supported a relational approach and argued against seeing fetal and maternal rights and interests in conflict.³⁹ Thus, pregnancy's uniqueness should be recognized to support autonomy, not undermine it.⁴⁰ Law should instead "privilege" the pregnant person based on "[their] physical and psychological connection" to the fetus.⁴¹ As Herring reflects in the context of disputes over caesarean sections ("caesarean or C-sections" throughout), few pregnant people make decisions regarding pregnancy "without any consideration to their foetus".⁴² Viewing the fetus and the pregnant person as in conflict furthermore neglects the social pressures faced by pregnant people, such as an expectation to behave as the authorities believe a "good mother" should. Minority groups, such as non-gender conforming people, immigrants, and drug users may face heightened pressures due to stereotypes regarding their ability to parent. According to Laufer-Ukeles, a relational approach should, inter alia, be bias aware and combat stereotypes.⁴³

In this Article, I consider data feminism and relational feminism to be mutually reinforcing in that both theories underline a view of the individual as "embedded and embodied." The theories argue for acknowledging and analyzing the individual's social context and how this may impact their ability to exercise autonomy. My approach does not argue for replacing nor removing the legal guarantees of liberal autonomy afforded to patients under the relevant legislation—as

³⁵*Id.* at 37.

³⁶*Id.* at 109.

³⁷Natalie Stojlar & Catriona Mackenzie, *Relational Autonomy in Feminist Bioethics*, in THE ROUTLEDGE HANDBOOK OF FEMINIST BIOETHICS 71 (Wendy A. Rogers, Jackie Leach Scully, Stacy M. Carter, Vikki A. Entwistle, & Catherine Mills eds., 2022); Catriona Mackenzie, *The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability*, in VULNERABILITY: NEW ESSAYS IN ETHICS AND FEMINIST PHILOSOPHY 33, 43 (Catriona Mackenzie, Wendy Rogers, & Susan Dodds, eds.); Robin West, *Relational Feminism and Law*, in RESEARCH HANDBOOK ON FEMINIST JURISPRUDENCE 65, 72 (Robin West & Cynthia Grant Bowman, eds.).

³⁸Martha Albertson Fineman, *The Limits of Equality: Vulnerability and Inevitable Inequality*, in RESEARCH HANDBOOK ON FEMINIST JURISPRUDENCE 73, 73 (Robin West & Cynthia Grant Bowman eds., 2023).

³⁹SHEENA MEREDITH, *POLICING PREGNANCY: THE LAW AND ETHICS OF OBSTETRIC CONFLICT* 133 (2005).

⁴⁰Pamela Laufer-Ukeles, *Reproductive Choices and Informed Consent: Fetal Interests, Women's Identity, and Relational Autonomy*, 37 AM. J. L. & MED. 567, 609 (2011).

⁴¹*Rethinking (M)otherhood: Feminist Theory and State Regulation of Pregnancy*, *supra* note 27, at 1340.

⁴²Jonathan Herring, *The Caesarean Section Cases and the Supremacy of Autonomy*, in LAW AND MEDICINE: CURRENT LEGAL ISSUES VOLUME 3, at 269, 279 (Michael Freeman & Andrew Lewis eds., 2000; online ed., Oxford Academic).

⁴³Laufer-Ukeles, *supra* note 40, at 614.

described below. Instead, it views relational autonomy as a valuable way of understanding and supporting the realization of these rights in the context of pregnancy.

II. State of the Art

Scandinavian scholarship analyzing the legal status of pregnant people has primarily focused on access to abortion,⁴⁴ which will not be subject to detailed discussion in this Article. It is relevant to recall briefly that Scandinavian countries recognize an absolute right to terminate a pregnancy if the pregnant person's life is in danger. Otherwise, specific gestational limits apply. This ranges from 12 weeks in Denmark—after which an authorization by an administrative board is required until the pregnancy is viable,⁴⁵ 12 weeks in Norway—after which termination is allowed under more limited circumstances until viability,⁴⁶ and Sweden where a limit of 18 weeks is codified.⁴⁷ Thus, as the fetus develops, the pregnant person's right to terminate weakens where their life is not at risk. In summary, law only recognizes full autonomy for pregnant people in the earliest stages of pregnancy and where the life of the pregnant person is in danger.

Governance of the pregnant body beyond abortion has been studied in several comprehensive legal works, though these focus on common law jurisdictions. In *Policing Pregnancy: the Law and Ethics of Obstetric Conflict*, Sheena explores how UK and US case law has created conflict between the woman and the fetus.⁴⁸ She finds that pregnant women are “in a position of considerable disadvantage within health care systems that wield substantial power over them.”⁴⁹ Recently, Michelle Goodwin's book, *Policing the Womb*, masterfully explores the disturbing ways in which prosecutors and courts in the US have exploited statutes originally designed to protect pregnant people.⁵⁰ These works address common law jurisdictions where principles and conflicts are adjudicated through case law.⁵¹ How such questions play out in Scandinavian legal systems has not been studied. In the latter legal systems, legislation and administrative decisions play a greater juridical role, as outlined in the next section.

III. Legal and Welfare State Context, Methodology

In Scandinavian health law, patients' rights and entitlements are set out in legislation and regulations, not case law as in the common law tradition. The author therefore initially searched legal databases in the respective jurisdictions to identify legislation governing pregnant patients' autonomy and healthcare entitlements. Autonomy is a central principle of Scandinavian health law with choice and self-determination representing important values that healthcare workers should respect.⁵² The same rules pertaining to informed consent and information normally apply to pregnant and birthing patients.

⁴⁴Janne Rothmar Herrmann & Annika Frida Petersen, *Barriers to Abortion in the Autonomy-Based Danish Legal Model*, 28 EUR. J. HEALTH L. 490 (2021); KARI TOVE ELVBAKKEN, *ABORTSPØRGSMALETS POLITISKE HISTORIE 1900–2020* (2021); Elizabeth Kella, *Tidskrift för genusvetenskap: Abort och reproduktiva val*, 40(3-4) UPPSALA UNIV. 175 (2019).

⁴⁵92 § SUNDHEDSLOVEN [Health Act] (Den.).

⁴⁶2 § Lov om svangerskapsavbrudd [abortloven] [Abortion Act] LOV-1975-06-13-50 (Nor.).

⁴⁷*Id.* § 1.

⁴⁸See generally MEREDITH, *supra* note 39.

⁴⁹*Id.* at 31.

⁵⁰MICHELE GOODWIN, *POLICING THE WOMB: INVISIBLE WOMEN AND THE CRIMINALIZATION OF MOTHERHOOD* (2020).

⁵¹See JOHN SEYMOUR, *CHILDBIRTH AND THE LAW* (2000); Herring, *supra* note 42, at 269; *Rethinking (M)otherhood: Feminist Theory and State Regulation of Pregnancy*, *supra* note 27, at 1325.

⁵²E.g., 2 § SUNDHEDSLOVEN [Health Act] (Den.); 4 § Lov om pasient-og brukerrettigheter (pasient-og brukerrettighetsloven) [Act on Patient and Healthcare Users' Rights] (Nor.); § 4(1) PATIENTLAG [Patient's Act] (Svensk författningssamling [SFS] 2014:821) (Swed.).

To summarize briefly, patients have the right to information about their health and treatment options.⁵³ Healthcare professionals are normally not permitted to withhold pertinent information from the patient based on what they hold to be best. Danish law does not permit withholding information to protect the patient. This differs under Norwegian law, whereby it is permissible to withhold information if “urgently necessary to prevent danger to life or serious damage to the patient’s health.” Information may also be withheld if clearly inadvisable for the sake of those close to the patient.⁵⁴ Following Swedish law, confidential information may be withheld from the patient if “with regard to the purpose of the treatment it is of particular importance that the information is not provided.”⁵⁵ The Danish legislation on patients’ rights to information is thus the most autonomy and individual driven, whereas the neighboring jurisdictions impose paternalistic limitations on patients’ information rights.

Patients should normally give informed consent prior to any treatment being commenced.⁵⁶ Treatment may be given in the absence of consent where the patient is unable to give consent due to incapacity and a representative therefore steps in their place, or emergency situations where the patient is temporarily unconscious.⁵⁷ These exceptions do not encompass an authorization to use force. Outside of these exceptions, patients who are capable of understanding the nature and consequences of their treatment decisions are responsible for healthcare decisions. Healthcare workers should therefore not substitute their determination of what is best for the patient.

Normally, healthcare professionals must not share confidential patient information without patient consent unless the circumstances fall under an exception specified in law.⁵⁸ Protecting an unborn child is a valid exception. Following Swedish law, a public employee may break their duty of confidentiality regarding information about a pregnant person or someone close to them, if the information needs to be shared to protect the expected child.⁵⁹ Under Norwegian law, health personnel are obligated to inform municipal authorities if there is reason to believe that a pregnant woman is abusing drugs in such a way that it is overwhelmingly likely that the child will be born with damage.⁶⁰ Following Danish law, public employees—or employees carrying out public functions—must inform the municipal council if they become aware that a child may need special support immediately after birth due to the circumstances of the expectant parents.⁶¹ The Swedish and Norwegian provisions focus on averting harm to the fetus, whereas the Danish provision is aimed at supporting the child after birth. The Swedish and Danish measures apply to the conduct of either parent whereas the Norwegian is focused on the pregnant person’s conduct.

Although health legislation generally does not regulate pregnant people’s autonomy separately, one exception was identified, which forms the basis of Section D. This exception is legislation that allows for the involuntary detention of pregnant drug and alcohol users based on fetal indication. I draw on data feminism to question and interrogate the quality of the evidence put forward to justify far-reaching incursions on this patient group’s autonomy and liberty. I question why, in a data driven society, no evidence has been produced to justify the limitations on pregnant people’s

⁵³3 ch. PATIENTLAG (SFS 2014:821) (Swed.); 3 ch. Act on Patient and Healthcare Users’ Rights (Nor.); 16 § The Health Act (Den.).

⁵⁴3-2 § Act on Patient and Healthcare Users’ Rights (Nor.).

⁵⁵25 ch. 6 § OFFENTLIGHETS—OCH SEKRETESSLAG (Svensk författningssamling [SFS] 2009:400) (Swed.).

⁵⁶PATIENTLAG (SFS 2014:821) ch. 4 § 2 (Swed.); Act on Patient and Healthcare Users’ Rights § 4-1 (Nor.); Sundhedsloven [Health Act] § 15 (Den.).

⁵⁷4 ch. § 2 PATIENTLAG (SFS 2014:821) (Swed.); Act on Patient and Healthcare Users’ Rights § 4-6 (Nor.); Sundhedsloven [Health Act] §§ 18-19 (Den.).

⁵⁸25 ch. OFFENTLIGHETS- OCH SEKRETESSLAG (SFS 2009:400) (Swed.); 6 ch. 12 § PATIENTSÄKERHETSLAG (Svensk författningssamling [SFS] 2010:659) (Swed.); 3-6 § Lov om pasient- og brukerrettigheter (pasient- og brukerrettighetsloven) (Nor.); 5 ch. 21 § Lov om helsepersonell m.v. (helsepersonelloven) (Nor.). See generally 40 § & 9 ch. Sundhedsloven [Health Act] (Den.).

⁵⁹25 ch. OFFENTLIGHETS—OCH SEKRETESSLAG (SFS 2009:400) (Swed.).

⁶⁰6 ch. 32 § Lov om helsepersonell m.v. (helsepersonelloven) (Nor.).

⁶¹§133(1)(2) Bekendtgørelse af barnets lov, LBK nr 83 af 1/25/2024 (Den.).

fundamental rights. I suggest that the current legislation is not neutral and can be tied to patriarchal beliefs about pregnant people and their fetuses, as well as stigmatizing views of drug users.

Court decisions from the three countries were also searched with a view to identifying judgments on pregnant people's autonomy. Few decisions that revealed insights into patient autonomy were identified. For this reason, administrative decisions from patient complaints bodies and disciplinary authorities in Scandinavia provide the primary empirical foundation of Sections C and E.

To briefly contextualize, under Danish law, patients can complain to the healthcare disciplinary board regarding the conduct of an authorized healthcare worker. Another option is to lodge a system-orientated complaint against a hospital or region. All complaints from the patient complaints authority containing the keyword “pregnant” [gravid] were reviewed, while complaints to the disciplinary board were reviewed as far back as 2008 due to the large number of decisions in the latter instance. Complaints to the Norwegian Health Complaints Authority [*helseklage*] were also reviewed.⁶² Swedish complaints made to *Hälso—och sjukvårdens ansvarsnämnd* (“HSAN”) and the Inspectorate for Treatment and Care (“IVO”) were searched using JP Infonet.⁶³

Drawing on these administrative decisions, Section C explores how law protects pregnant patients' autonomy in response to the lack of clinical trials on the effectiveness of medications. The section draws on data feminism by asking questions about how data and which kinds of data is being used in determinations on pregnant people's autonomy rights. Furthermore, it exposes the patriarchal undertones of some of the decisions and draws attention to those patients particularly at risk in the process of datafication.

Section E explores complaints related to childbirth with a focus on exploring how autonomy and data are interpreted and drawn upon in available administrative decisions. This section draws on data feminism to question how scientific data and evidence is used. I expose how the voice of the patient is neglected as a data source, drawing on principle 3 of data feminism.⁶⁴

Section F has a normative focus. It argues for a relational approach that eliminates coercion and sees the pregnant body and fetus as integrated though quintessentially unequal. In this manner, more evidence is not the only answer; an approach that recognizes the dignity of pregnant people must be central. Legal guarantees, such as informed consent, are insufficient without a shift in attitudes towards pregnant people. This requires respecting pregnant people's rights to make decisions about their health even when it goes against what healthcare workers may determine is objectively best.

The pregnant person's experiences as described in this Article take place within the context of the welfare state. While liberal freedoms are enshrined in Scandinavian law, the welfare state setting adds a resource dimension to determinations regarding who survives and what treatment is provided. Svendsen describes how questions regarding the cost to the state of supporting, for example, a disabled child through its lifetime, play a role in decisions on providing active or palliative care to premature newborns.⁶⁵ In this manner, successful pregnancies are central to the future of the welfare state—forming thereby a reason to limit women's freedoms to ensure the safe delivery of future citizens—and “damaged” infants may pose a threat due to the high costs associated with their care. This may have an impact on decisions made in Section D.

The welfare state resource context also comes into play in the discussions of childbirth in Section E. Literature focuses on two salient themes. The first is “medicalization,” which views birth as a pathology that technology can resolve. Oakley, in her historical account of the pregnant body, describes the rise in misogynic obstetrics and gynecology that wields great power over women's lives and freedoms through medicalization, for example antenatal care.⁶⁶ The second is the “natural”

⁶²See *Nasjonalt klageorgan for helsetjenesten*, HELSEKLAGE, <https://www.helseklage.no/> (last visited Mar. 7, 2023).

⁶³For more information on these complaints bodies, see Sofia Åkerman, *Patientklagomål och ersättning*, in MEDICINSK RAETT 338–39, 340–41 (Kavod Zillen, Titti Mattsson & Santa Slockenberga eds., 2022).

⁶⁴D'IGNAZIO & KLEIN, *supra* note 33, at 37.

⁶⁵METTE N. SVENDSEN, *NEAR HUMAN: BORDER ZONES OF SPECIES, LIFE, AND BELONGING* 20 (2022).

⁶⁶OAKLEY, *supra* note 19, at 245–92.

argument that interventions should be avoided as much as possible, and that nature should take its course without medical involvement where possible.⁶⁷ In Scandinavian welfare state based healthcare, the method of treatment that is offered is a medical determination. Women do not normally have a choice regarding whether caesarean section is offered. The state's resources are limited, and as C-section is more costly than a vaginal birth, the state has an interest in preventing this form of delivery.⁶⁸

Also at a systematic level, women do not necessarily have a choice as to whether they give birth in a hospital, meaning that avoiding medical intrusion can be difficult. In Sweden, there is limited access to home birth, which until recently has only been available for persons with private insurance.⁶⁹ Only in Stockholm do public resources cover planned home birth, meaning that other Swedish women must have sufficient resources to enable choice.⁷⁰ While the cost of a midwife is covered by the Norwegian healthcare system, the woman must independently find a midwife to assist.⁷¹ In contrast, pregnant people in Denmark have a right to midwife assistance during home birth.⁷²

IV. Terminology

In *Data Feminism*, data is described as not numbers alone but also “words or stories, colors or sounds, or any type of information that is systematically collected, organized, and analyzed.” A wide view of data is important as a limited view of data can be used to exclude women or other groups and to devalue their knowledge and what they regard as important.⁷³ In this Article, scientific evidence is a type of data. For example, clinical trials use data to prove a hypothesis, such as, that a drug used at a particular dose will achieve a specific clinical result for more patients than the placebo. Armed with this knowledge, the data is then transformed into scientific evidence. However, scientific evidence requires that someone identifies a health concern as sufficiently important—and lucrative—to study, which is not always the case for illnesses affecting women. There may therefore be evidence gaps where data has not been used to test specific hypotheses.

In line with principle 4 of data feminism,⁷⁴ I use both the terms pregnant people and women to recognize that non-binary people or transmen can become pregnant. In fact, their health may be even more at risk due to them not conforming to the standard medical expectation of a pregnant person or the presence of added stereotypes and biases. At the same time, I do not wish to ignore that most men will never experience being pregnant, and thereby the health risks involved, while most women will.⁷⁵

⁶⁷E.g., CHADWICK, *supra* note 26, at 26–27, 34–35.

⁶⁸SUNDHEDSSTYRLESEN, KEJSERSNIT PÅ MODERS ØNSKE—EN MEDICINSK TEKNOLOGIVURDERING 50 (2005), <https://www.sst.dk/~media/029071F561B14C9F8964B85E05C93B7D.ashx>.

⁶⁹Maria Ahl & Ingela Lundgren, *Working with Home Birth—Swedish Midwives' Experiences*, 18 SEXUAL & REPROD. HEALTHCARE 24, 24 (2018).

⁷⁰Ingela Sjöblom, Ewa Idvall & Helena Lindgren, *Creating a Safe Haven—Women's Experiences of the Midwife's Professional Skills During Planned Home Birth in Four Nordic Countries*, 41 BIRTH 100, 101 (2014).

⁷¹Helena Lindgren, Hanne Kjaergaard, Olof Asta Olafsdottir & Ellen Blix, *Praxis and Guidelines for Planned Homebirths in the Nordic Countries—An Overview*, 5 SEXUAL & REPROD. HEALTHCARE 3, 4 (2014).

⁷²§ 83 SUNDHEDSLOVEN [Health Act] (Den.).

⁷³D'IGNAZIO & KLEIN, *supra* note 33, at 96.

⁷⁴*Id.* at 49.

⁷⁵Legal gender recognition in Scandinavian countries no longer uses a medical model but instead applies a declaration model. A person may be legally registered as male but have a womb and thereby become a pregnant man. In light of this, in 2014, the Danish parliament changed the Health Act to amend “the woman” to “the pregnant person” [*den gravide*]. Although a declaration model is now found in Norway and Sweden the term “woman” [*kvinna/kvinne*] is retained in the relevant provisions on pregnancy entitlements. LOV OM ENDRING AV JURIDISK KJØNN [Law on Legal Gender Change], LOV-2016-06-17-46 (Nor.); e.g., ABORTLAG [Abortion Act] (Svensk författningssamling [SFS] 1974:595) (Swed.); LOV OM SVANGERSKAPSAVBRUDD [abortionen] [Abortion Act], LOV-1975-06-13-50 (Nor.).

V. Limitations

While the complaints relied upon in this Article give a picture of the experiences of pregnant people, they are not representative. Most patients do not complain—or do not have the time, skills or emotional resources to do so. Others may complain informally to the hospital or patient ombudsperson. Furthermore, the available decisions only provide a brief summary of the complaint, the healthcare facility or health professional's response, the relevant law, followed by the decision. Nuances may be missing.

Furthermore, administrative decisions have limited precedential value. Oral arguments are normally not heard; instead, information from the patient's health record is often used as the basis for the facts of the case. According to the authorities, the patient record is given weight as it is recorded shortly after the event and before a complaint has been made.⁷⁶ In rare cases, the authority may find that, after a concrete balancing of evidence, the information in the health record cannot be correct with overwhelming likelihood.⁷⁷

Data feminism calls on us to examine the influence of racism and how it is baked into datasets. This has not been possible in this study as qualitative information is not systematically available about the complainant and conclusions cannot thereby be drawn about the gender/age/race/ethnicity of the individuals. Nevertheless, it can be mentioned that several complaints note use of an interpreter or that the complaint has been translated. Language barriers can lead to disadvantage for the patient, which may be a contributory factor in the women's negative experiences. For example, in her ethnographic work on amniocentesis, Rapp found that poor or non-native speaking patients received less scientific information.⁷⁸ Unless data is systematically collected, potential vulnerabilities will remain invisible.

The first case study explores how the historic neglect of pregnant people in clinical trials impacts pregnant health and autonomy through drawing on administrative complaints. The second analyzes how Scandinavian countries use legislation to varying degrees to allow for the detention of pregnant drug and alcohol users against their will without evidence to support this drastic approach. The final case study brings home the fragility of data in the face of paternalism, exposing violations of birthing patients' autonomy based on administrative complaints.

C. Making Healthcare Decisions amidst Data Gaps

In response to the thalidomide tragedy, internationally, pregnant people were excluded from clinical trials to protect the fetus. Ironically, thalidomide had not been tested on pregnant people or even pregnant animals—if it had been, its impacts may have been discovered much earlier. An indication of the extent of the patriarchal attitudes found in research ethics is that the enacted limitations were sometimes interpreted so broadly that all women were excluded from clinical trials for fear of harming their reproductive capabilities.⁷⁹ The impacts of such exclusions can be severe on the health of pregnant people.⁸⁰

In recognition thereof, steps have gradually been taken to promote more inclusive clinical trials. The most far-reaching policies have come from the US, where the NIH and FDA adopted legal

⁷⁶STYRELSEN FOR PATIENTKLAGER [PATIENT COMPLAINTS AUTHORITY], case no. 14POB085 (Nov. 24, 2014), <https://stpk.dk/afgoelser-og-domme/afgoelser-fra-styrelsen-for-patientklager/14pob085/> (Den.).

⁷⁷SUNDHEDSVÆSENETS DISCIPLINÆRNEVN [HEALTH SERVICE DISCIPLINARY BOARD], case no. 171401 (Apr. 7, 2017), <https://stpk.dk/afgoelser-og-domme/afgoelser-fra-sundhedsvaesens-disciplinaernaevn/171401/> (Den.).

⁷⁸RAPP, *supra* note 20, at 66.

⁷⁹Angela Ballantyne, *Women in Research: Historical Exclusion, Current Challenges and Future Trends*, in THE ROUTLEDGE HANDBOOK OF FEMINIST BIOETHICS 251, 253 (Wendy A. Rogers, Jackie Leach Scully, Stacy M. Carter, Vikki A. Entwistle, Catherine Mills eds., 2022).

⁸⁰Liberata Sportiello & Annalisa Capuano, *It Is the Time to Change the Paradigms of Pregnant and Breastfeeding Women in Clinical Research!*, 14 FRONTIERS PHARMACOLOGY 2 (Feb. 23, 2023).

rules encouraging the inclusion of women in clinical trials as far back as 1993.⁸¹ As of 2022, participation among white women has increased, but participation of pregnant women remains low.⁸² Internationally, the influential CIOMS guidelines were revised in 2016 to no longer frame pregnant people as vulnerable purely by virtue of their pregnancy.⁸³ Recently, the European Commission has tacitly highlighted that pregnant people face an unmet medical need, though it has not adopted proactive measures as in the US.⁸⁴ Meanwhile, researchers have called for further study of use of pain medications and chronic pain during pregnancy.⁸⁵ Despite this, important actors, like ethics committees, continue to view pregnant people as vulnerable and restrict their participation in clinical trials.⁸⁶

Where recruitment into clinical trials is difficult, registry data can be used to study side effects and benefits of routine medications and treatments. As described in the introduction, in Scandinavia, healthcare workers record large amounts of clinical data related to pregnant people, which is then stored in registries. This includes data on use of dietary supplements, medications, any special health conditions,⁸⁷ as well as information on smoking during pregnancy or on any complications during birth.⁸⁸ The data is then repurposed for quality control, clinical recommendations, and research purposes.⁸⁹ Hundreds of studies are published each year using data from these registries as per the Norwegian Public Health Authority's website.⁹⁰ From a review of the studies from 2021, the majority of the research focuses on the infant or future child, not the pregnant person's health. Studies examine the impact of exposure to breastfeeding,⁹¹ caffeine intake,⁹² alcohol,⁹³ use of antidepressants,⁹⁴ or "women's anxiety,"⁹⁵ maternal seafood intake⁹⁶ on

⁸¹STEVEN EPSTEIN, INCLUSION—THE POLITICS OF DIFFERENCE IN MEDICAL RESEARCH 80 (2007).

⁸²NAT'L ACADS. OF SCIS., ENG'G, & MED., IMPROVING REPRESENTATION IN CLINICAL TRIALS AND RESEARCH: BUILDING RESEARCH EQUITY FOR WOMEN AND UNDERREPRESENTED GROUPS 40 (2022).

⁸³Saenz et al., *supra* note 3, at 173.

⁸⁴*Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, Pharmaceutical Strategy for Europe*, at para 2.1, COM (2020) 761 final (Nov. 25, 2020).

⁸⁵Ann Z. Bauer, Shanna H. Swan, David Kriebel, Zeyan Liew, Hugh S. Taylor, Carl-Gustaf Bornehag, Anderson M. Andrade, Jørn Olsen, Rigmor H. Jensen, Rod T. Mitchell, Niels E. Skakkebaek, Bernard Jégou & David M. Kristensen, *Paracetamol Use During Pregnancy—A Call For Precautionary Action*, 17 NAT. REV. ENDOCRINOLOGY 757 (2021); NAT. REV. ENDOCRINOLOGY, *Caution Needed: Paracetamol Use in Pregnancy*, 17 NAT. REV. ENDOCRINOLOGY 699 (2021).

⁸⁶Saenz et al., *supra* note 3, at 175.

⁸⁷MEDICAL BIRTH REGISTER REGULATIONS, *supra* note 22 (Nor.).

⁸⁸KOORDINATIONSGRUPPEN FOR INDIVIDBASERT PATIENTREGISTRERING, SUNDHEDSDATASTYRELSEN, FÆLLESINDHOLD FOR BASISREGISTRERING AF SYGEHUSPATIENTER: VEJLEDNINGSDEL 6, 8, 107 (2019), https://sundhedsdatastyrelsen.dk/-/media/sds/filer/rammer-og-retningslinjer/patientregistrering/faellesindhold/fi_vejledning.pdf.

⁸⁹*Publications List for Medical Birth Registry of Norway*, NOR. INST. OF PUB. HEALTH, (May 13 2022), <https://www.fhi.no/en/ch/medical-birth-registry-of-norway/publications-list-for-mbrn/>.

⁹⁰*Id.*

⁹¹Elisa Baldin, Anne Kjersti Daltveit, Marianna Cortese, Trond Riise & Maura Pugliatti, *Exposure to Breastfeeding and Risk of Developing Multiple Sclerosis*, 50 INT'L J. EPIDEMIOLOGY 644, 645 (2021).

⁹²Sofia Berglundh, Margarete Vollrath, Anne Lise Brantsæter, Ragnhild Brandlistuen, Pol Sol è-Navais, Bo Jacobsson & Verena Sengpiel, *Maternal Caffeine Intake During Pregnancy and Child Neurodevelopment Up to Eight Years of Age—Results from the Norwegian Mother, Father and Child Cohort Study*, 60 EUR. J. NUTRITION 791, 792 (2021).

⁹³Elis Haan, Hannah M. Sallis, Eivind Ystrom, Pål Rasmus Njølstad, Ole A. Andreassen, Ted Reichborn-Kjennerud, Marcus R. Munafò, Alexandra Havdahl & Luisa Zuccolo, *Maternal and Offspring Genetic Risk Score Analyses of Fetal Alcohol Exposure and Attention-Deficit Hyperactivity Disorder Risk in Offspring*, 45 ALCOHOL, CLINICAL & EXPERIMENTAL RSCH. 2090, 2090 (2021).

⁹⁴A. Lupattelli, M. Mahic, M. Handal, E. Ystrom, T. Reichborn-Kjennerud & H. Norden, *Attention-Deficit/Hyperactivity Disorder in Children Following Prenatal Exposure to Antidepressants: Results from the Norwegian Mother, Father and Child Cohort Study*, 128 BJOG: INT'L J. OBSTETRICS & GYNAECOLOGY 1917, 1918 (2021).

⁹⁵Mona Bekkhus, Yunsung Lee, Ragnhild Eek Brandlistuen, Sven Ove Samuelsen & Per Magnus, *Maternal Anxiety and Infants Birthweight and Length of Gestation. A Sibling Design*, 21 BMC PSYCHIATRY 609, 610 (2021).

⁹⁶Eleni Papadopoulou, Jérémie Botton, Ida Henriette Caspersen, Jan Alexander, Merete Eggesbø, Margaretha Haugen, Nina Iszatt, Bo Jacobsson, Helle Katrine Knutsen, Helle Margrete Meltzer, Verena Sengpiel, Nikos Stratakis, Kristine Vejrup & Anne Lise Brantsæter, *Maternal Seafood Intake During Pregnancy, Prenatal Mercury Exposure and Child Body Mass Index Trajectories Up to 8 Years*, 50 INT'L J. EPIDEMIOLOGY 1134, 1134 (2021).

aspects of the child's health. Outliers include studies on maternal iron status and its associations,⁹⁷ perinatal depression in women with multiple sclerosis⁹⁸ and effect of cardiovascular disease on maternal deaths.⁹⁹ It seems that despite a high level of data being gathered during pregnancy, this is not filling the evidence gap on the effects of routine medicines and treatments left by women's exclusion from clinical trials.

Complaints to Scandinavian health bodies reveal the real-world consequences of the evidence gap for pregnant people's ability to make healthcare choices. Pregnant people are not necessarily healthy and most will use medications during their pregnancy.¹⁰⁰ Because of a lack of approved drugs, they often receive medications off-label. This is not necessarily clinically problematic,¹⁰¹ but it has implications for pregnant people's ability to give informed consent. Scandinavian complaints bodies have responded to this gap by requiring that patients be made aware that use is occurring off-label prior to giving consent. Several complaints suggest that this does not however systematically take place. In one instance, the patient complaints authority criticized a hospital for failing to inform a patient that a medicine used to induce birth was being administered off-label.¹⁰² In a different instance, a woman complained over the use of Cytotec—a brand name for misoprostol—off-label for induction, namely that she had not been informed of side effects or that its use was off-label.¹⁰³ The disciplinary board found that the doctor had not acted within the acceptable standard of information. The medicine in question—misoprostol—is subject to some controversy as there are examples of women dying and suffering uterine rupture.¹⁰⁴ A misoprostol drug was withdrawn from the French market in 2017.¹⁰⁵

Administering drugs off-label can raise questions as to the balance between maternal benefit and fetal harm. This is particularly tense where medicine is administered contrary to the patient's will. For example, in a first instance decision, the Psychiatric Patient Complaints Board criticized a doctor for giving a medication in a dose that was too high and found that the medicine “should not be given to pregnant people.” The decision was reversed on appeal, with the appeals body finding that the drugs in question—Trilafon and Serenase—were not associated with significant adverse effects.¹⁰⁶ Ultimately, it determined that the risk of not treating the patient's psychosis exceeded the potential damage to the fetus. According to medicin.dk, Trilafon and Serenase should not be given to pregnant people due to lack of data¹⁰⁷ and there are examples of neonatal withdrawal

⁹⁷Ida Henriette Caspersen, Lucía Iglesias-Vázquez, Marianne Hope Abel, Anne Lise Brantsæter, Victoria Arija, Iris Erlund, Helle Margrete Meltzer, *Iron Status in Mid-Pregnancy and Associations with Interpregnancy Interval, Hormonal Contraceptives, Dietary Factors and Supplement Use*, 126 BRIT. J. NUTRITION 1270, 1270 (2021).

⁹⁸Karine Eid, Øivind Fredvik Torkildsen, Jan Aarseth, Heidi Øyen Flemmen, Trygve Holmøy, Åslaug Rudjord Lorentzen, Kjell-Morten Myhr, Trond Riise, Cecilia Simonsen, Cecilie Fredvik Torkildsen, Stig Wergeland, Johannes Sverre Willumsen, Nina Øksendal, Nils Erik Gilhus & Marte-Helene Bjørk, *Perinatal Depression and Anxiety in Women With Multiple Sclerosis: A Population-Based Cohort Study*, 96 NEUROLOGY 2789, 2789 (2021).

⁹⁹Lill T. Nyfløt, Marianne Johansen, Ajlana Mulic-Lutvica, Mika Gissler, Birgit Bødker, Katarina Bremme, Liv Ellingsen & Siri Vangen, *The Impact of Cardiovascular Diseases on Maternal Deaths in the Nordic Countries*, 100 ACTA OBSTETRICIA ET GYNECOLOGICA SCANDINAVICA 1273, 1273 (2021).

¹⁰⁰See, e.g., Merton, *supra* note 2, at 408.

¹⁰¹Andrew D. Weeks, Christian Fiala & Peter Safar, *Misoprostol and the Debate Over Off-Label Drug Use*, 112 BJOG: INT'L J. OBSTETRICS & GYNAECOLOGY 269 (2005).

¹⁰²PATIENT COMPLAINTS AUTHORITY, case no. 14POB085 (Nov. 24, 2014) (Den.).

¹⁰³Klage Over Manglende Information I Forbindelse Med Behandling Med Cytotec (Igangsættelse Af Fødsel), case no. 1441103, SUNDHEDSVÆSENETS DISCIPLINÆRÆVN (July 17, 2015), <https://stpk.dk/afgorelser-og-domme/afgorelser-fra-sundhedsvaesnets-disciplinaernaevn/144103/>.

¹⁰⁴Sarantis Michalopoulos, *Dangerous Off-Label Drug Use to Induce Labour Raises Eyebrows in Europe*, EURACTIV (May 13, 2020), <https://www.euractiv.com/section/health-consumers/news/eu-medicines-agency-silent-over-dangerous-off-label-drug-use-to-induce-labour/> (last visited Mar 7, 2023); Marsden Wagner, *Off-Label Use of Misoprostol in Obstetrics: A Cautionary Tale*, 112 BJOG: INT'L J. OBSTETRICS & GYNAECOLOGY 266 (2005).

¹⁰⁵Barbara Casassus, *Misoprostol Drug to Be Withdrawn From French Market*, 390 THE LANCET e42 (2017).

¹⁰⁶SUNDHEDSVÆSENETS PATIENTKLAGEÆVN, case no. 0978208, June 18 2010, <https://stpk.dk/afgorelser-og-domme/afgorelser-fra-sundhedsvaesnets-disciplinaernaevn/0978208/>.

¹⁰⁷Serenase®, MEDICIN.DK, <https://pro.medicin.dk/Medicin/Praeparater/68#a150> (last visited Mar. 7, 2023).

symptoms.¹⁰⁸ More clarity on how to balance fetal and maternal health and autonomy in cases of forced medication is needed.

Other complaints illustrate however, that it is not only lack of data that can limit pregnant people's access to safe medications, but also paternalistic approaches. Patriarchal attitudes can lead healthcare workers to attempt to protect pregnant people or their fetus from the pregnant person's choices even when safe and effective treatment is available. In one example, the obstetrician had underlined that it was important for both the woman and the fetus that the former received adequate pain relief in the form of morphine after surgery.¹⁰⁹ The doctor stipulated that morphine should be limited shortly before delivery as it can affect the infant's breathing. The woman complained that despite these orders, the discharging nurse advised her to generally limit use of morphine due to her pregnancy. The complaint illustrates that paternalistic concern for the fetus can eclipse pain management for pregnant patients, contrary to medical evidence. In a separate instance, a general practitioner did not disclose to a pregnant patient that she had melanoma for three months. His reasoning was that as she had suffered from depression after her last pregnancy, it was better to wait until her six-week post-partum check-up. He did not wish to upset the patient and cause a new depressive episode while she was pregnant.¹¹⁰ By denying the patient's agency and controlling her access to information about her health, the patient's personhood is undermined. Autonomy—though central to the relevant health acts—becomes reserved for those who are deemed capable of responsibly handling information about their health. Pregnant people are assumed to be fragile and thereby incapable of exercising judgment.

Furthermore, pregnant people with chronic conditions may feel pressured to stop taking their regular medications due to the lack of clinical trials. This may result in motherhood and mental illness being deemed incompatible. For example, a patient complained about a declaration given by a general practitioner regarding her health, which was used—together with other information—in child removal proceedings.¹¹¹ The doctor's intimations carry a paternalistic tone. He wrote that the patient suffered from paranoid schizophrenia and, at the time of conception, was taking three different types of anti-psychotic medications. He added that she had indicated that she wanted to continue the pregnancy, even though he had informed her that the medication could possibly harm the fetus. The doctor also stated that he had made the pregnant person aware of the “risky and inappropriate nature” of having a severe psychiatric disorder and at the same time being a single mother with a small child. Expressing this moral objection to her becoming a parent constitutes an attack on the patient's autonomy, a concern that the decision fails to acknowledge. Shortly after the consultation, the patient decided to stop taking the medications. Stopping anti-psychotic medications while pregnant may be more harmful than continuing them and fetal harm is not well established in most cases.¹¹²

For patients with mental health diagnoses, the stakes are heightened, as unmanaged psychiatric diagnoses can be grounds for removing a child at birth. Patients who do not comply with medical advice risk being flagged by healthcare workers as problematic and in need of surveillance. For example, the doctor told the gynecological department in June that the patient was “severely psychotic” because she was no longer taking anti-psychotic medicines and had refused a health nurse access to her home. The doctor did not seem to consider that on the nurse's last visit in March, the patient had reported feeling well and to not be experiencing hallucinations. Crucially, the decision makes no reference to the doctor's earlier comments regarding the dangers of taking

¹⁰⁸Trilafon® Dekanoat, MEDICIN.DK, <https://pro.medicin.dk/Medicin/Praeparater/997#a150> (last visited Mar. 7, 2023).

¹⁰⁹SOCIALSTYRELSEN, Dnr 9.2-33554/2011, Oct. 30, 2012.

¹¹⁰HELSEKLAGE, case no. N2018/6414, June 13 2019, <https://helseklage.no/media/3568/n2018-6414.pdf>.

¹¹¹SUNDHEDSVÆSENETS DISCIPLINÆRNEVN, case no. 0017013, May 19 2000, <https://stpk.dk/afgorelser-og-domme/afgorelser-fra-sundhedsvaesenets-disciplinaevn/0017013/>.

¹¹²Hannah K. Betcher, Catalina Montiel & Crystal T. Clark, *Use of Antipsychotic Drugs During Pregnancy*, 6 CURRENT TREATMENT OPTIONS PSYCHIATRY 17, 17 (2019).

anti-psychotic medications while pregnant, which may have influenced the patient's decision to stop taking the medicines. In this regard, drawing the conclusion that the decision was irrational and thereby a sign of pathology lacks foundation, as the patient was possibly acting on what she understood to be medical advice. Patients are furthermore not obligated to allow healthcare workers access to their home, and it is perplexing that the doctor flagged failure to do so as a sign of risk or pathology. The right to private and family life, including determining access to one's home, is fundamental in European law.¹¹³

A final complaint can be mentioned for taking a different, and in my view, less patriarchal tone. The patient lodged a complaint about her midwife reporting her behavior to the municipality. The midwife had reported that the patient was underweight and that the fetus was below average weight. Furthermore, she claimed that the patient was speaking rapidly and behaving frantically. She also shared somewhat banal information such as that the complainant had stated that she did not want to breastfeed but might do so for the first 24 hours after birth and that she wanted to deliver via elective caesarean section. The Board found that the midwife had breached her obligation of confidentiality in that these pieces of information did not signal danger to the fetus.¹¹⁴ The woman's admission of smoking cannabis while pregnant could pose a danger to the fetus and was therefore reportable. The decision illustrates healthcare workers' own biases as to who is an appropriate mother. Pregnant patients should be able to deviate from recommendations and the "normal expectations" of a parent without attracting increased scrutiny. The complaint also underscores the risk that scientific evidence is weaponized against pregnant people. Data should not replace but instead inform patient autonomy. Healthcare workers are required to provide evidence of risk to pregnant people to assist them in making decisions about their health or treatment in a neutral manner and not use deviations from these recommendations as evidence of their unsuitability as future parents. How an individual intends to parent may differ from the reality of parenthood.

This section has discussed several complaints that centered on pregnant patients' autonomy in the context of decisions regarding use of prescription medicines. Because of limited clinical trials on pregnant patients, there remains uncertainty regarding the efficacy and safety of drugs, even those used routinely. This has implications for the patient's ability to consent to treatment on an informed basis. The law's response is to place heightened information requirements on clinicians, though these requirements do not always seem to be met. Furthermore, even where evidence is clearer, paternalistic beliefs seem to sometimes influence healthcare workers who limit pregnant people's autonomy or view their choices with suspicion. The same choices by patients who are not pregnant would not illicit the same response.

D. Pregnant Alcohol and Drug Users

Moving to the second case, under Scandinavian legislation, pregnant drug and alcohol users can be subject to involuntary detention to protect their fetus.¹¹⁵ This is the only instance beyond abortion where Scandinavian legislation specifically authorizes limiting the pregnant person's autonomy based on their status as pregnant. Such laws have been described as taking the fetus into "protective custody" until delivery.¹¹⁶ It is a manifestation of near complete responsibilization of pregnant women for fetal health.¹¹⁷

¹¹³Convention for the Protection of Human Rights and Fundamental Freedoms art. 8, Nov. 4, 1950, 213 U.N.T.S. 221.

¹¹⁴SUNDHEDSVÆSENETS DISCIPLINÆRNÆVN, case no. 145003, Aug. 21 2015, <https://stpk.dk/afgoreselser-og-domme/afgoreselser-fra-sundhedsvaesnets-disciplinaernaevn/145003/>.

¹¹⁵The same is possible in three US states. See GOODWIN, *supra* note 50, at 31.

¹¹⁶*Id.* at 137.

¹¹⁷RAPP, *supra* note 20, at 88–89.

As in the US,¹¹⁸ Scandinavian laws targeting pregnant drug and alcohol users were proposed from the 1990's onwards and adopted without a strong scientific basis. In the case of Norway, which has the most far-reaching provision, a statement by a single pediatrician was “a central premise” for amending the law to allow detention based on fetal indication.¹¹⁹ Per the doctor, although the impact of drugs on the future child could not be quantified, any misuse could potentially lead to permanent damage. Meanwhile, in 2009, the Swedish Ministry of Social Affairs proposed a similar measure, even though the amendment seemed “meaningless” as pregnant people could already be detained to protect their own health.¹²⁰ The Parliamentary Ombudsperson criticized the proposal for inadequate evidence of causation and it has thus far not been adopted.¹²¹ There is thereby some political appetite for involuntary detention based on fetal indication in Sweden, but lack of available data has halted its adoption.

In Norway, legislation authorizes admitting a pregnant user of drugs or alcohol to an institution against their will and detaining them for the duration of the pregnancy if their using is such that it is overwhelmingly likely that the child will be born with injury and that other measures are insufficient.¹²² Despite the existence of copious medical registries—as described in the last section—there remains no national registry on infants damaged by alcohol or drugs, or on the health status of previously detained pregnant people or their children.¹²³ They are invisible in the process of datafication. In a data driven society, this allows for speculation: Maybe the problem is worse than we think; maybe detention is the only way to protect the innocent?

Meanwhile, Swedish law does not have a specific fetal indication, but each year an estimated ten to twelve pregnant users are involuntarily detained based on their own health indication.¹²⁴ The social authorities may assess that the mental damage caused to the mother should the fetus be injured is sufficient to justify intervention.¹²⁵ Detention can also be ordered to protect relatives from the user, though the fetus does not fall under that provision. Swedish law has thereby not awarded the fetus a form of personhood as under Norwegian law and it remains an extension of the pregnant person.

Under Danish law, municipalities must offer a pregnant drug or alcohol user a contract whereby she can agree to be detained at a later point should she seek to leave a treatment center—that she has entered voluntarily—and where leaving would place her health or that of the fetus at risk.¹²⁶ Use of physical force is permitted to stop the pregnant alcohol user from leaving the place of treatment—though neither isolation nor restraints. The legislation does not authorize forced treatment.¹²⁷ In Denmark, some social workers believe that the Norwegian model should be adopted to allow for more detention.¹²⁸

¹¹⁸GOODWIN, *supra* note 50, at 31.

¹¹⁹KARL HARALD SØVIG, TVANG OVERFOR RUSMIDDELAVHENGIGE 77 (2008).

¹²⁰Weddig Runquist, *Sverige—Om Konsten Att Sila Mygg Och Svälja Kameler*, 26 NORDISK ALKOHOL—& NARKOTIDSKRIFT 304 (2009).

¹²¹Karl Harald Søvig, *Detention of Pregnant Women to Protect the Foetus—Nordic Perspectives*, in NORDIC HEALTH LAW IN A EUROPEAN CONTEXT 158, 170 (Elisabeth Rynning & Mette Hartlev eds., 2011).

¹²²10(3) § 91 Prop. L Lov om kommunale helse—og omsorgstjenester m.m. (helse—og omsorgstjenesteloven) (2010–2011), <https://www.regjeringen.no/no/dokumenter/prop-91-l-20102011/id638731/?q=rusmiddel&ch=7> (Nor.). Rule transferred from the *sosialtjenesteloven* kapittel 4A om bruk av tvang og makt overfor personer med psykisk utviklingshemning.

¹²³Søvig, *supra* note 121, at 179.

¹²⁴Runquist, *supra* note 120, at 305.

¹²⁵SOCIALSTYRELSEN, LVM I HÄLSO OCH SJUKVÅRDEN: HANDBOK FÖR HÄLSO OCH SJUKVÅRDENS TILLÄMPNING AV LAGEN OM VÅRD AV MISSBRUKARE I VISSA FALL 18 (2022), <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/handbocker/2022-6-7917.pdf>.

¹²⁶Bekendtgørelse af lov om tilbageholdelse af stofmisbrugere i behandling [Law on the Detention of Drug Addicts in Treatment], consolidated no. 972, Aug. 8 2017; 141b § SUNDHEDSLOVEN [Health Act] (Den.).

¹²⁷INGRID RINDAL LUNDEBERG, KRISTIAN MJÅLAND, & KARL HARALD SØVIG, TVANG I RUSFELTET: REGELVERK, PRAKSIS OG ERFARINGER MED TVANG 41 (2014).

¹²⁸SUNDHEDSSTYRELSEN, EVALUERING. KORTLÆGNING AF OMRÅDET FOR BEHANDLING AF GRAVIDE MED ALKOHOL—OG/ELLER STOFPROBLEMER 25 (2019), <https://www.sst.dk/-/media/Udgivelser/2019/Kortlaegning-af-omraadet-for-behandling-af-gravide-med-alkohol-og-eller-stofproblemer.ashx>.

Statistics show that the Norwegian provision is applied more frequently than the Danish. For example, in 2013 the Norwegian provision was invoked 159 times, while from March 2008 to October 2014, three women in the whole of Denmark entered into a contract agreeing to future involuntary detention.¹²⁹ This is in line with Scandinavian drug policy, whereby the Norwegian model has been dubbed “repressive” and the Danish the most liberal and pragmatic.¹³⁰ It should be noted that involuntary admissions—estimated at around 350 a year in Norway—are much lower than the circa 14,000 voluntary admittances a year.¹³¹

There is no solid evidence that involuntary detention improves fetal or maternal health.¹³² There is some evidence that the longer the woman is admitted, the more the baby will weigh at birth¹³³ but this could also be due to other factors like diet or stress. For the pregnant person, involuntary treatment may be seen positively in that it allows them to access treatment faster.¹³⁴ This is an example of citizens feeling compelled to enter into a coercive relationship with the state in order to access health entitlements due to lack of state investment. An opposite concern is that pregnant drug or alcohol users may avoid seeking help for fear of being detained.¹³⁵ In the US, prenatal child abuse laws that penalize pregnant people for opioid use have been shown to cause pregnant women to avoid accessing treatment.¹³⁶

Lundeberg and Mjåland interviewed seventeen Norwegian women who had been subject to detention during their pregnancy. Their results show a variety of opinions among the women. Around half of the informants felt that the use of coercion had saved their lives or prevented harm.¹³⁷ Yet, other former patients reported experiencing boredom and a feeling of being placed in a holding pattern, instead of accessing effective treatment.¹³⁸ A common problem was lack of aftercare; the women returned to the same situations that they were in before, such as debt, which limited their opportunities even if their addiction was brought “under control.”¹³⁹ Thereby, the underlying conditions and social risk factors remained unaddressed by their removal from society. Likewise, all of Knight’s pregnant, drug using informants in the San Francisco area who received drug treatment following arrest, returned to drug use without custody of their children.¹⁴⁰

Finally, although alcohol abuse is more prevalent than use of narcotics and evidence of fetal harm is better established, less coercion is used in relation to the former. This may be linked to societal attitudes around alcohol. Alcohol users are also less likely to be in contact with the social authorities.¹⁴¹ In Denmark and Norway in the 1990s, as in the US in the same time period, there was particular concern about “narco mothers” and “narco babies”.¹⁴² Goodwin eloquently exposes that there was little evidence for these fears and the moral panic that appears to have manifested on both sides of the Atlantic. In fact, leading US medical journals, as well as the New York Times,

¹²⁹*Id.* at 9.

¹³⁰Lau Laursen, *Scandinavia’s Tug of War on Drugs*, in *DISCUSSING DRUGS AND CONTROL POLICY: COMPARATIVE STUDIES ON FOUR NORDIC COUNTRIES* 49–50 (Pekka Hakkarainen, Lau Laursen & Christoffer Tigerstedt eds., 1996).

¹³¹LUNDEBERG, MJÅLAND, & SØVIG, *supra* note 127, at 18.

¹³²*Id.* at 219.

¹³³*Id.* at 227.

¹³⁴*Id.* at 194.

¹³⁵See also, KELLY RAY KNIGHT, *ADDICTED. PREGNANT. POOR*, 53 (2015) (providing Knight’s ethnography on addicted pregnant women who avoided prenatal care).

¹³⁶Cara Angelotta, Carol J Weiss, John W Angelotta & Richard A Friedman, *A Moral or Medical Problem? The Relationship between Legal Penalties and Treatment Practices for Opioid Use Disorders in Pregnant Women*, 26 *WOMEN’S HEALTH ISSUES* 595 (2016).

¹³⁷Lundeberg et al., *supra* note 127, at 222.

¹³⁸*Id.* at 203–07.

¹³⁹*Id.* at 226.

¹⁴⁰KNIGHT, *supra* note 135.

¹⁴¹Pekka Hakkarainen, Timo Jetsu, & Astrid Skretting, *Arguing Drug Policies in Nordic Parliaments*, in *DISCUSSING DRUGS AND CONTROL POLICY: COMPARATIVE STUDIES ON FOUR NORDIC COUNTRIES*, 84–85 (1996).

¹⁴²*Id.* at 86–87, 91.

have retracted previous claims regarding the evidence on “crack babies.”¹⁴³ Use of narcotics is often combined with drugs and alcohol, rendering it difficult to isolate the impact of one substance.¹⁴⁴ In summary, coercive laws and their enforcement focus on illegal drugs, even though evidence of fetal harm from alcohol is better established. The applicable laws seem to be thereby driven by societal attitudes or politics, not evidence.

E. Evidence and Data in the Delivery Room

Pregnancy is a liminal state,¹⁴⁵ which ceases through miscarriage, abortion or birth. The complaints studied in this section reveal lack of self-determination while giving birth as a frequent theme, as well as, routinization of extreme pain and injury by healthcare workers. This—and the attitudes of complaints bodies in some instances—neglects well-established evidence on the role that healthcare workers play in minimizing pain and injury during childbirth. Women must be the ultimate decision makers, while healthcare professionals should be guided by scientific evidence when deciding which treatment options to offer the patient. The complaints illustrate that even when evidence is available, it can prove insufficient in a patriarchal system. Women’s voices are neglected as important data sources.

As described in Section B.III, following the principle of self-determination, the patient should be the decision maker regarding any intervention in line with her priorities and values. Still, the woman’s power to avail of these entitlements is contingent on the state ensuring adequate conditions, such as resources. At a structural level, conditions in maternity wards in Scandinavia have been subject to sustained criticism,¹⁴⁶ including the risk that understaffing poses to patient safety.¹⁴⁷ The actions of individual professionals must be viewed within this context, given that pressurized conditions will limit how much time a healthcare worker can devote to a patient’s care, as well as their energy and patience.

Women’s frustrations in this system and desire for greater self-determination are clear from numerous complaints. In one complaint, the woman, whose baby died following mistakes by healthcare workers, called on medical professionals to listen to patients’ wishes regarding their own bodies. She specifically called for personnel to be more accepting of C-sections after a long labor.¹⁴⁸ The remarks were translated from English to Swedish, implying that the patient was an immigrant. In another complaint, IVO criticized the hospital for failing to take the pregnant patient’s fears and worries seriously. According to the patient, due to this anxiety, her condition deteriorated into a depression. The hospital failed to conduct a risk assessment of her level of fear of childbirth. During the delivery, the patient felt that the risks to her and her baby were not taken seriously, such as, a request for a C-section.¹⁴⁹ A further immigrant couple complained of not having access to a C-section; instead, repeated attempts to use a suction cup resulted in injury to the infant.¹⁵⁰ Other women report feeling uninvolved in their birth plans¹⁵¹ and “abandoned” during delivery.¹⁵² It seems in many cases that healthcare workers are not living up to the expectations of self-determination promised in the health acts.

¹⁴³GOODWIN, *supra* note 50, at 21.

¹⁴⁴KNIGHT, *supra* note 135, at 162.

¹⁴⁵RAPP, *supra* note 20, at 105.

¹⁴⁶VÅRDANALYS, OLIK ELLER OJÄMLIK? EN ANALYS AV REGIONALA SKILLNADER I GRAVIDITETSVÅRDKEDJAN, <https://www.vardanalys.se/rapporter/olik-eller-ojamlik/> (last visited Mar 7, 2023).

¹⁴⁷REGERINGEN, SVERIGES KOMMUNER, LANDSTING & SKL, MILJARDSÄTSNING FÖR TRYGGHET FÖRE, UNDER OCH EFTER GRAVIDITET (2018).

¹⁴⁸IVO, Dnr 3.4.1-43094/2019-30, Aug. 19, 2020 (Swed.).

¹⁴⁹IVO, Dnr 8.2.1-32718/2019, June 4, 2021 (Swed.).

¹⁵⁰HSAN 2009-05-12 2008/1839:B2 (Swed.).

¹⁵¹IVO, Dnr 8.2-17670/2014-18, Sept. 6, 2016 (Swed.).

¹⁵²IVO, Dnr 8.2-20387/2015-16, Mar. 29 2016 (Swed.).

Furthermore, decisions do not seem to be led by data, or data is used haphazardly to justify non-intervention. In one complaint, the patient “pleaded” for a C-section, which the midwife and doctor on call supported. Despite this, on arrival, the consultant obstetrician wanted to attempt a forceps delivery. The complainant reported feeling that she “was not allowed to say anything.” According to the doctor, the C-section posed a greater risk at this point in the delivery. The Patient Complaints Authority found that as the situation was not acute, the woman should have been thoroughly informed prior to consent, including of alternative methods, like suction cup and C-section, as well as the option of not intervening. This is in line with findings from international research, which highlight that women should be informed of the increased risks of anal sphincter tearing posed by forceps delivery.¹⁵³ While this decision upholds the basic patient entitlements to informed consent and information, in a different complaint, the board found that the consent given to the use of a suction cup was sufficient, even though the woman complained that she had not been given other options.¹⁵⁴ Furthermore, the consultant in the previous complaint had noted in the patient record that the forceps delivery was performed “on maternal request.” The disciplinary board also criticized the doctor for this given the previous finding that woman had not been adequately informed.¹⁵⁵ The focus on procedural aspects—whether specific information was recorded in the patient record—may fail to give adequate credence to the loss of integrity and autonomy felt by the woman.

Alarmingly, some decisions seem to question whether informed consent belongs in the delivery room contrary to women’s legal entitlements. In one complaint, the patient stated that she did not receive adequate information or give informed consent to a caesarean section.¹⁵⁶ The patient complaints board noted that:

[M]any of the things that happen in a delivery room happen urgently for the sake of progress in the birth process and for the sake of the health of the mother and the child, e.g., there will rarely be time to explain in more detail the effects of installing a suction cup, if the reason for the installation is a threatening lack of oxygen inside the uterus.¹⁵⁷

Under the Danish Health Act, information entitlements are described in more absolutist terms. Nowhere is the fetus given a legal status that justifies setting aside the pregnant persons’ rights. The disciplinary board went further in another complaint. It stated that it is “extremely difficult to handle the concept [of informed consent] . . . [d]uring the most painful and hectic minutes of birth.”¹⁵⁸ It found that it is normal for a woman in labor to express a desire not to continue. Revoking consent in such cases should therefore be clear and unequivocal. The doctor had thereby not erred in continuing to apply a suction cup despite protest from the patient. This statement places responsibility on the birthing person to be clear, instead of the health professional to listen and respect. It seems to convolute distress with the exercise of will. Ultimately, fetal health again trumps the autonomy of the mother despite there being no legal basis for this. Emergency situations may limit the amount of information that can be given but patients must, according to

¹⁵³Maria Gyhagen, Marie Ellström Engh, Heinrich Husslein, Heinz Koelbl, Ida E K Nilsson, Jane Schulz, Adrian Wagg & Ian Milsom, *Temporal Trends in Obstetric Anal Sphincter Injury from the First Vaginal Delivery in Austria, Canada, Norway, and Sweden*, 100 ACTA OBSTETRICIA ET GYNECOLOGICA SCANDINAVICA 1969 (2021).

¹⁵⁴SUNDHEDSVÆSENETS DISCIPLINÆRNÆVN, case no. 20DNU38, Oct. 16, 2020 (Den.), <https://stpk.dk/afgorelser-og-domme/afgorelser-fra-sundhedsvaesenets-disciplinaernaevn/20dnu38/>.

¹⁵⁵SUNDHEDSVÆSENETS DISCIPLINÆRNÆVN, case no. 21DNM105, Dec., 1, 2021 (Den.) (on file with author).

¹⁵⁶PATIENTKLAGENÆVNET [Patient Complaints Authority], case no. 0233313, Nov. 20, 2002 (Den.), <https://stpk.dk/afgorelser-og-domme/afgorelser-fra-sundhedsvaesenets-disciplinaernaevn/0233313/>.

¹⁵⁷*Id.*

¹⁵⁸SUNDHEDSVÆSENETS DISCIPLINÆRNÆVN, case no. 20DNU38.

the relevant legislation, give informed consent unless they are incapacitated.¹⁵⁹ In my view, these decisions are not in line with the legal entitlements provided for by the health act.

Another example of ignoring women's voices is found in a complaint regarding conduct shortly after birth. The new mother complained that her healthcare record stated that her newborn was breastfeeding well. Yet, the woman's evidence was that the baby was not feeding—only sucking without milk coming out. She therefore paid out of pocket to go to a private birth “hotel” for new parents.¹⁶⁰ It is difficult to imagine that a new mother would misremember whether their baby had fed for the first time, but the formulaic nature of the complaint does not allow for such reasonable conclusions. Instead, the mother's recollection must give way to that of the “experts” even where this is illogical in light of the facts presented.

The routinization of pregnant people's pain—as though it is not something that healthcare workers play a role in—is evident in several complaints. In one complaint, the patient suffered stage 4 tears during childbirth, whereby her sphincter tore and her perineum ruptured. The disciplinary board announced that this was a “completely normal birth” but criticized the midwife for failing to record the rupture in the woman's medical record. The failure to recognize the likely emotionally but also physically traumatic experience, even if the doctors' conduct was not criticizable, sidesteps her humanity while the bureaucratic focus on documentation does little to redress the harm. Meanwhile, the Norwegian Supreme Court, as well as the no-fault patient injury compensation fund, has also found that incontinence following sphincter rupture is not an injury that can be awarded compensation. According to the court, the birth—not the treatment—was the cause of the injury.¹⁶¹ Yet, research suggests that introducing a perineal protection program—which Norway did in 2004—can reduce the instance of obstetric anal sphincter injury, thereby undermining the idea of severe tears as a “normal” part of motherhood that doctors/midwives cannot combat.¹⁶² Evidence shows that factors like supporting the perineum can help to avoid tearing.¹⁶³ Ultimately, what counts as a normal birth is contested and unclear.¹⁶⁴

F. Discussion

This Article has analyzed examples of how health legislation and administrative decisions govern the autonomy of pregnant bodies through a lens of data feminism. I reflected on how “missing” data influences access to safe and effective healthcare for pregnant people. Data invisibility means that physicians fill evidence gaps when treating pregnant people. This is not always problematic but can be where patriarchal approaches dominate. For lawmakers and authorities, data gaps can also be viewed with suspicion and form a justification for state intrusion, as in the case of “deviant” groups, like pregnant drug and alcohol users. Data invisibility may be harnessed by patriarchal healthcare that routinely disregards “expression of pain and wishes for treatment.”¹⁶⁵ Even when evidence is available, patriarchal attitudes can mean that healthcare workers ignore it and instead substitute their views regarding what is best. Psychiatric patients may be particularly impacted by the pregnant health data paradox due to stigma around their suitability as parents.

Section C explored pregnant patients' autonomy through analyzing the pregnant health data paradox in the context of prescription medicines. For pregnant people to exercise their autonomy when making treatment decisions there is a need to facilitate clinical trials that include them.

¹⁵⁹See for example §§ 15, 16 & 19 of the Danish Health Act.

¹⁶⁰STYRELSEN FOR PATIENTKLAGE, case no. 14POB085.

¹⁶¹Supreme Court (Nor.), HR-1998-56-B—Rt-1998-1336.

¹⁶²Gyhaugen et al., *supra* note 153.

¹⁶³Vasilios Pergialiotis, Ioannis Bellas, Maria Fanaki, Nikolaos Vrachnis & Stergios K Doumouchtsis, *Risk Factors for Severe Perineal Trauma During Childbirth: An Updated Meta-Analysis*, 247 EUR. J. OBSTETRICS & GYNECOLOGY & REPROD. BIOLOGY 94 (2020).

¹⁶⁴CHADWICK, *supra* note 26, at 35.

¹⁶⁵*Id.* at 46.

Given the level of data gathered by Scandinavian welfare states during pregnancy and beyond, registry data could be harnessed to a greater degree to provide a better evidence basis for the impacts of routine medicines. This would support the interests and autonomy of pregnant people. At present, many published registry studies focus on the impact of pre-natal choices on the future child's health, which risks furthering responsibilization and neglecting pregnant health. Still, registry studies are not a substitute for clinical trials. For example, a registry study found an association between treatment with *carbimazole* for hyperthyroidism and increased risk of preterm birth.¹⁶⁶ Such a finding is concerning but if no other drug is available, it is difficult to act upon where the woman—and maybe the fetus'—health is at risk from lack of treatment. Pregnant patients are entitled to be informed that medications are being given off-label and of the potential associated uncertainties. However, this information may be of limited use to pregnant patients that require medications where there is no available authorized drug.

Off-label use of medications raises particularly tense questions in the case of involuntary psychiatric treatment of pregnant patients. On the one hand, it is important from a liberal autonomy standpoint that the pregnant person's health is at the center of any such determination. Pregnancy should not become a barrier to obtaining necessary care. On the other hand, ignoring the unique relational aspects is out of step with the pregnant patient's reality in my view. Where the pregnant person is concerned with the impact of the medication on the health of their fetus, this should be taken seriously in decision-making. Clearer guidelines are needed on how these treatments decisions should be approached.

Furthermore, it must be genuinely possible for pregnant people to act on the information they are given without risking secondary consequences. Although criminal sanction is rarely used to regulate the conduct of pregnant women in Scandinavia, women who do not comply with medical advice risk being reported to social services for endangering their future child. This can undermine the freeness of the woman's consent to treatment in that she fears losing her child if she does not comply.¹⁶⁷ Given that many medications have not been adequately tested on pregnant bodies, coupled with stigma around mental health conditions, pregnant people with mental health disorders are particularly vulnerable. Healthcare workers and complaints bodies should be cognizant of these dynamics. Pregnant people experiencing psychiatric ill health should be offered extra support but this information should not be used in later determinations on their fitness to parent. To do otherwise assigns the fetus a status of personhood that puts it in conflict with the pregnant person. For pregnant patients who rely on anti-psychotic medicines, failure to continue to take medicines off-label should be approached with an understanding of the relational aspects. Exercising one's autonomy by refusing medications should not be used to judge suitability as a future parent. The interplay between who is a "good" and "bad" mother with a psychiatric illness should not be narrowed to compliance or non-compliance with medical advice. Medical recommendations should remain just that and not be transformed into prescripts. For a pregnant person to be a truly autonomous patient, their health decisions prior to the birth cannot have been subject to legal censure. The criminal provision on irresponsible conduct during birth noted in the Introduction should be repealed as it is out of line with the ethos of modern healthcare. The new legislation permitting removal of infants at birth for conduct during pregnancy should also be repealed for the reasons described in this section.

Beyond better data, an approach to anti-natal healthcare that goes beyond gathering data and respects the inherent dignity of pregnant patients is needed. The Article described several

¹⁶⁶El Khalil Nebghouha, Angela Lupattelli & Hedvig Nordeng, *Antithyroid Drug Treatment and Pregnancy Outcomes Among Women with Hyperthyroidism In Pregnancy: A Norwegian Population-Based Registry-Linkage Study*, 29 *NORSK EPIDEMIOLOGI* 71 (2021), <https://www.ntnu.no/ojs/index.php/norepid/article/view/4048> (last visited Mar 7, 2023).

¹⁶⁷Rebecca Brione, *Non-Consented Vaginal Examinations: The Birthrights and ALMS Perspective*, in *WOMEN'S BIRTHING BODIES AND THE LAW: UNAUTHORISED INTIMATE EXAMINATIONS, POWER, AND VULNERABILITY* 30 (Camilla Pickles & Jonathan Herring eds., 2020).

examples where health personnel substitute their assessment of what is best for the patient despite available evidence. In this manner, a data gap does not remain empty but is filled by other types of knowledge or belief, some of which appear to be patriarchal. As with any other patient, the pregnant patient must make decisions about their own health with support from healthcare professionals. Healthcare workers should avoid assumptions regarding their conduct that are rooted in stigmatizing or patriarchal attitudes.

Section D explored the pregnant health data paradox and autonomy through examining legislation that is not supported by scientific evidence but instead by fears and a compulsion to control women's bodies to protect fetal life. For some, the urgency of protecting the fetus from drugs and alcohol may justify denying pregnant persons their liberty.¹⁶⁸ Law seems to rationalize that the pregnant person is so impaired by addiction that they cannot make decisions in their best interests. But for the individual's impairment, would they enter a treatment facility to safeguard the fetus? This reasoning may sound convincing, yet ultimately the law-making processes in each of the Scandinavian countries have failed to put forward any data to support this claim. In the years since the adoption of the laws, this gap has not been addressed, meaning that it remains unproven that detention benefits fetal health. The fetus may, for example, already have been injured prior to the detention. When the welfare state is engaged with collecting all sorts of fetal and maternal data, it seems peculiar that no effort has been made to fill this data gap. Fetal protection laws that do little to promote fetal health can be accused of being intended to measure "women's obedience."¹⁶⁹

Ultimately, detaining a person contrary to their will for the duration of their pregnancy in the interest of a future person ascribes a lower value to the former's freedoms than the latter's potential for good health. It devalues and subordinates a woman's existence by legitimating coercion without having justified the necessity of such through, for example, evidence that the pregnant person's health is improved. It stands in stark contrast to the deference that is usually shown to patient decision-making, where even irrational decisions, such as a fifteen year old's refusal of a lifesaving blood transfusion, is respected.¹⁷⁰ In contrast to psychiatric treatment, the law does not require an assessment of competency to give or refuse consent, which means that a refusal based on a "rational" decision, such as, involuntary care not being in line with one's values or wishes, can be ignored for the hypothetical good of the fetus. By framing protecting the fetus from harm as a social good, the woman's conception of what is good for her body can be overruled. By elevating the status of the fetus to that which can justify overruling the women's self-determination, fetal interests—despite lacking personhood—outweigh the rights of the woman.

In my view, a relational approach does not support the adoption of legislation that authorizes fetal indications. Instead, relationality assumes that the pregnant individual makes decisions not with a view to harming the fetus but in the context of their social reality, such as poverty, unemployment and violence. The Norwegian legislation justifies governing pregnant bodies based on the state's interest in the fetus, instead of forging a collaborative relationship between patient and social worker. Fetal indications should be removed from the Norwegian and Danish statutes. Harm-reduction approaches are instead more in line with the dignity of the patient. Providing pregnant drug users with increased prenatal care has been shown to increase drug abstinence and decrease relapse postpartum.¹⁷¹ Yet in Sweden, harm reduction programs have been regarded as controversial with their availability limited.¹⁷² Furthermore, parents must be provided with

¹⁶⁸E.g., SØVIG, *supra* note 119.

¹⁶⁹GOODWIN, *supra* note 50, at 82.

¹⁷⁰24 § SUNDHEDSLOVEN [Health Act] (Den.).

¹⁷¹Tricia Wright, Renee Schuetter, Eric Fombonne, Jessica Stephenson & William F Haning III, *Implementation and Evaluation of a Harm-Reduction Model for Clinical Care of Substance Using Pregnant Women*, 9 HARM REDUCTION J. 7 (2012).

¹⁷²Julie Holeksa, *Dealing with Low Access to Harm Reduction: A Qualitative Study of the Strategies and Risk Environments of People Who Use Drugs in a Small Swedish City*, 19 HARM REDUCTION J. 2 (2022).

support after the birth if the conditions that led to the drug or alcohol use are to be effectively addressed.

The “voluntary” detention contract systems found in Norwegian and Danish legislation should also be repealed. To suggest that a pregnant drug or alcohol user can autonomously enter into such an agreement obscures their social reality. The person may do so to access treatment or in a bid to keep custody of the future child. As described above, women report that involuntary detention provides a means of accessing treatment faster than through consenting to voluntary treatment. It seems clear that better access to voluntary treatment options specifically aimed at this patient group would benefit more patients than the small group against whom involuntary treatment is currently used.¹⁷³

One could ultimately question why the law does not provide for forced treatment for any other person based on a fetus’ hypothetical health. Why is the focus not on detention of drug using partners who pose risks to a fetus or the pregnant person? The answer in some cases may be that coercing and detaining pregnant bodies is seen as legitimate as they are ultimately still regarded as vessels, whereas the autonomous—male—body is inviolable. The control of pregnant bodies to protect the fetus is a slippery slope in that almost anything a pregnant person does could ultimately be harmful to the fetus. Still, law does not provide for detaining pregnant people who smoke or consume high quantities of sugar, which can lead to fetal injury. Furthermore, data suggests that detention is rarely used against alcohol users, despite stronger evidence of harm. This suggests that drug addiction amongst pregnant women continues to be seen as particularly abhorrent, despite many of the claims made in the 1990s being disproven. It also illustrates that contrary to the political promises of the data driven Scandinavian welfare state, scientific evidence is not the driving force in this case but perhaps societal attitudes.

Section E explored administrative practice related to informed consent during birth. Birth is a time of unique bodily vulnerability.¹⁷⁴ Previous research has argued that health rights, such as autonomy, disappear in pregnancy, labor, and birth.¹⁷⁵ Women are often not listened to despite formal legal protections.¹⁷⁶ This is confirmed in several complaints, where women repeatedly put forth claims of their wishes being ignored. To fully respect the birthing person’s rights, health personnel must also respect the patient’s voice as a valuable data source.¹⁷⁷

Contestation between vaginal and caesarean birth is present, with several women sharing that their request for a C-section was denied. Ultimately, this is a manifestation of a lack of autonomy during birth. Brown and Mulligan have argued for caesarean sections to be routinely offered alongside vaginal birth. They claim that framing the latter as “natural” or default” is a normative judgment that is “unhelpful and inappropriate.” The authors also argue that vaginal birth is less cost effective than assumed when side effects like urinary incontinence are factored in.¹⁷⁸

Furthermore, viewing pain as something that just happens to birthing people—instead of something that can be managed—is unacceptable and ignores the evidence. The expectation of female suffering and physician knows best during birth is an expression of paternalistic misogyny. While none of the complainants claimed to have been exposed to overt violence, some of their experiences echoed the idea of gentle violence, in other words, where their laboring was constrained by an inability to exercise choice in the manner that the autonomy focused legal system promises women can.¹⁷⁹ This further reflects how certain scientific evidence is not

¹⁷³Rebecca Stone, *Pregnant Women and Substance Use: Fear, Stigma, and Barriers to Care*, 3 HEALTH & JUST. 13 (2015).

¹⁷⁴CHADWICK, *supra* note 26, at 82.

¹⁷⁵*Id.* at 37.

¹⁷⁶Villarmea, *supra* note 11, at 67.

¹⁷⁷Elizabeth Kukura, *Contested Care: The Limitations of Evidence-Based Maternity Care Reform*, 31 BERKELEY J. GENDER L. & JUSTICE 241, 287 (2016).

¹⁷⁸Rebecca CH Brown & Andrea Mulligan, “Maternal Request” Caesarean Sections and Medical Necessity, 18 CLINICAL ETHICS 313–14 (2023).

¹⁷⁹CHADWICK, *supra* note 26, at 109–13.

transformed into knowledge that is acted upon, thereby reflecting the power underlying data. Acting on evidence or data—at least in the current configuration of birth care—is not mandatory and healthcare workers may be driven by other beliefs. While it is important that scientific evidence does not become a new form of paternalism that obscures the voice of the birthing person,¹⁸⁰ Section V has detailed instances where the woman *and* science are rejected. It seems that professional paternalism, at least in these examples, continues to dominate.

Some decisions even suggest that a birthing person is unable to consent due to pain. Herring's reflections in relation to similar statements by a British justice are relevant. He wonders whether the logical implication is that “any pregnant woman in labor is automatically incompetent” due to the pain and emotional stress.¹⁸¹ Agency is not a binary concept¹⁸² and should such a view be followed, autonomy should be denied to a great many patients. Murray argues in favor of going beyond binaries—capable/incapable—by recognizing that pain affects decision making but does not necessarily render a patient incompetent.¹⁸³ Childbirth is not the only space where patients suffer pain yet surely one of the few where it is viewed as natural. Similar findings of women's pain being ignored have been made in relation to painful sex and pelvic pain during menstruation.¹⁸⁴ In contrast, it is difficult to imagine that a complaints body would suggest that a cancer patient's treatment wishes should be denied due to their pain.

The actors discussed in this Article—law-makers, healthcare workers and complaints bodies—should understand the pregnant person as exercising autonomy in a social context. This requires healthcare workers to eschew stereotypes regarding pregnant people during and prior to birth. Such stereotypes can be the idea of women as in conflict with their fetus but also the concept of women as vessels who will willingly sacrifice their body and autonomy at all costs. To see severe, potentially life-changing tearing as a natural part of childbirth is contrary to evidence that healthcare workers can limit such an injury through adequate training.

A corollary finding is that the complaints systems come across as ill-equipped to remedy the harms suffered by pregnant patients. The reliance on the data in the patient healthcare journal means that the information recorded by the healthcare workers generally provides the basis for the facts of the complaint. Data contained in the healthcare record is generally regarded as “objective” even where this seems unreasonable. By privileging the information written in the patient record, the patient's voice can easily be eclipsed. Similar findings have been reported in the UK with “little regard being paid to the woman's testimony when compared with official notes.”¹⁸⁵ In this manner, legal practice may be viewed as privileging the doctor's “detached view”¹⁸⁶ as an objective source of correct information, while the mother is seen as too emotional or impaired by pain to be a source of truth. This finding echoes that of Laufer-Ukeles who called for the need to recognize dignitary harms instead of merely physical; otherwise doctors will focus on avoiding the former and not the latter.¹⁸⁷ This is not to say that courts are better placed merely because they hear oral arguments. Unlike how Sheena describes the situation in UK courts,¹⁸⁸ the complaints authorities, particularly in Sweden, do not merely accept medical knowledge as fact. In several instances,

¹⁸⁰Kukura, *supra* note 177, at 292.

¹⁸¹Herring, *supra* note 42, at 276.

¹⁸²Agomoni Ganguli-Mitra, *Power and Feminist Bioethics*, in *THE ROUTLEDGE HANDBOOK OF FEMINIST BIOETHICS* 68 (2022).

¹⁸³Claire Murray, *Troubling Consent: Pain and Pressure in Labour and Childbirth*, in *WOMEN'S BIRTHING BODIES AND THE LAW: UNAUTHORISED INTIMATE EXAMINATIONS, POWER AND VULNERABILITY* 155 (Camilla Pickles & Jonathan Herring eds., 2020).

¹⁸⁴Nicky Hudson, *The Missed Disease? Endometriosis as an Example Of “Undone Science”*, 14 *REPROD. BIOMEDICINE & SOC'Y ONLINE* 9 (2022).

¹⁸⁵Brione, *supra* note 167, at 36.

¹⁸⁶*Rethinking (M)otherhood*, *supra* note 27, at 1339.

¹⁸⁷Laufer-Ukeles, *supra* note 40, at 622.

¹⁸⁸MEREDITH, *supra* note 39, at 6.

complaints bodies engage with available scientific evidence that contradicts the healthcare worker or hospital's defense.

This Article, in line with the principles of data feminism, posits that the birthing person's voice should also be given credence as a data source. Child birth is a unique experience and the birthing person's account should be given weight unless it would be unreasonable to do so. Furthermore, the manner in which complaints' decisions are written should be reconsidered. The decisions could recognize the harm experienced by the individual in a more compassionate manner, even if they ultimately do not regard the hospital or healthcare worker as having breached its legal duties. Complaints bodies should furthermore avoid drawing on normative terms like "normal" to characterize experiences that the patient has experienced as abnormal and distressing.

G. Conclusion

This Article explored the regulation of pregnant people's autonomy in Scandinavian health law through a lens of data feminism. Data has been shown to have many faces. Inadequate evidence can mean that pregnant people must give informed consent in an uncertain treatment environment. At the same time, available complaints reveal that pregnant people's autonomy may be limited irrespective of the evidence base.

Three case studies were used to illustrate how data interacts with the legal entitlement of autonomy in the care of pregnant people. The first examples reveal how a lack of evidence on the effectiveness of medicines can lead to sub-optimal treatment of pregnant patients. Yet, reliable data is insufficient as even where scientific evidence was available, cases were found where patriarchal attitudes limited pregnant patients' autonomy. Pregnant patients with mental health conditions were identified as particularly vulnerable due to their reliance on medicines and prevailing stigmas regarding their appropriateness as parents. The second case study showed how in the absence of data, Scandinavian states adopted coercive laws that allow for involuntary detention of pregnant drug and alcohol users. It was argued that such incursions into autonomy are viewed as justified due to a willingness to see pregnant people as secondary to their fetus. This can be attributed to patriarchal beliefs concerning pregnant people as well as beliefs stemming from faulty evidence regarding narcotics. The third example looked to complaints made by pregnant people which revealed powerlessness and absence of autonomy during birth. Some decisions demonstrate a view of pain and damage as unavoidable despite evidence on the healthcare worker's important role in prevention. Finally, it was found that the complaints systems appear ill suited to remedy the harms suffered and instead focused on bureaucratic requirements, thus obscuring the woman's humanity.

The Article has argued for a shift in how pregnant people are governed by health law and practice. While gathering better scientific evidence is needed to improve pregnant people's health, this alone will prove insufficient without respect for pregnant people's full and equal rights. This calls for a recognition on the part of lawmakers, social workers, and healthcare professionals of pregnant people's dignity. Pregnant people's autonomy should be respected on an equal footing with other patients as recognized by law. This involves fully informing patients of available evidence and the gaps therein, and not limiting patient choices based on the doctor's view of what is best for the fetus. Pregnant people's health and interests should furthermore not be necessarily seen as in conflict with the fetus. Instead, the relational aspects of pregnant healthcare should be factored into the information that is provided to patients. The value that the pregnant person attributes to the health of the fetus versus their own is their decision, and should not be assumed. In childbirth, the birthing person's voice should be acknowledged as an important data source that should guide treatment decisions. Finally, recognizing pregnant people as equal citizens necessitates removing statutes that legitimize involuntary detention of pregnant people for the protection of their fetus.

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