Cesarean section on maternal request in Norway

A qualitative and normative study of birth counseling and decision-making

Kristiane Tislevoll Eide

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
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Scientific environment

This work originates from the multi-disciplinary environment of the Global Health Priorities Research Group at Department of Global Public Health and Primary Care at the University of Bergen. My membership in this research group started in 2009 as a medical student. I joined the Research Track (Forskerlinjen) after an interesting talk with Ole Frithjof Norheim in the break between his engaging ethics lectures. The research group's broad and global interests have been truly inspiring and motivating throughout the years of my membership. During this time, I had many interesting discussions about ethical issues with Kristine Bærøe, resulting in the early ideas of this PhD project.

In October 2018, I was a visiting student at the Ethox Centre at University of Oxford, where I enjoyed a similar research environment. It provided me with the perfect combination of inspiring lectures, low-key coffee-break discussions, and a quiet working place for thinking and writing. I am grateful for the opportunity to have met and worked among so many recognized ethicists at Ethox.

This PhD was supervised by associate professor and ethicist Kristine Bærøe (main supervisor), professor and gynecologist Nils-Halvdan Morken (co-supervisor) and PhD and cardiologist Margrethe Aase Schaufel (co-supervisor).

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Abstract

Background

Cesarean section (CS) is a common and life-saving intervention. While lack of access is a severe problem in some parts of the world, excessive use has become a growing concern recently. In light of this, a debate has emerged concerning the acceptability of providing CSs in low-risk pregnancies conducted on the request of the mother. The literature shows that attitudes toward the phenomenon vary between healthcare professionals and across countries. Maternally requested CSs challenge such modern ethical concepts as patient autonomy, professional autonomy, shared decision-making, trust, and power. Thus, countries have developed different practices and guidelines on the matter.

Objective

The overall objective of this thesis was to develop research that can contribute to good-quality decisions for CSs on maternal request in absence of obstetric indications. This objective was achieved by establishing in-depth knowledge about i) why women request CSs in Norway and ii) how the counseling and decision-making processes were handled, and by conducting iii) a normative analysis of the premises for ethically justified decision-making in the care for women requesting CSs.

Methods

Two qualitative studies were conducted, including 17 semi-structured in-depth interviews with women requesting planned CSs at a University Hospital in Norway and six focus-group discussions with 20 healthcare professionals (nine midwives and 11 obstetricians) working in the same hospital. Interviews were taped, transcribed, and analyzed according to systematic-text condensation, which is a method for cross-case analysis of qualitative data.

A normative analysis was carried out based on knowledge gained from the qualitative studies and reading of the scientific literature. We drew upon theories about autonomy, power, trust, and risk in the professional-patient relationship in order to

explore how to promote ethically justified decisions for planned CSs in absence of obstetric indications.

Results

The first study revealed that women had individual and nuanced reasons for wanting a planned CS. Their previous birth and postnatal experiences, self-perceived risks for an emergency CS, or deep-seated fear of giving birth all influenced their decision. Rarely, obstetricians claimed to also experience requests that in their opinion lacked significant fear or well-grounded reasons. This indicates a need for an individually targeted counseling approach.

The second study found a prominent culture advocating for vaginal delivery among healthcare professionals and also among women, even though they requested a planned CS for different reasons. There were differing attitudes and approaches among healthcare professionals toward CS on maternal request. Women were also divided in their views on maternal decision-making entitlements, but the majority did not support complete maternal choice and opted for a shared decision-making process. Midwife-led counseling resulted in high satisfaction among the women.

The normative analysis revealed that although a woman may not be entitled to demand a planned CS, she should take part, and be heard, in the decision-making process. Due to the structural inferiority of women in terms of power and knowledge, as compared to healthcare professionals, initiatives to limit this power through shared processes of decision-making are needed in order to make these processes trustworthy for women.

Conclusion

Although most of the women in this study had nuanced and well-grounded reasons to request CSs, women and their healthcare professionals had differing attitudes toward the decision-making process. This highlights the need for an individual counseling approach as well as for standardized guidelines justifying the use of power among healthcare professionals in order to assure that women who need a planned CS can experience a truly shared, honest, and transparent decision-making process.

List of Publications

I. Eide KT, Morken NH, Baeroe K: Maternal reasons for requesting planned cesarean section in Norway: a qualitative study. *BMC Pregnancy Childbirth* 2019, 19(1):102. *

II. Eide KT, Morken NH, Baeroe K: Tensions and interplay: A qualitative study of access to patient-centered birth counseling of maternal cesarean requests in Norway. *Midwifery* 2020, 88:102764. **

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Abbreviations and terms

CS – cesarean section

CSMR – cesarean section on maternal request

Nulliparous/primiparous woman – a woman giving birth for the first time

Multiparous woman – a woman who has given birth before

SDM – shared decision-making

EB – empirical bioethics

STC – systematic text condensation

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1. Introduction

1.1 Cesarean sections (CSs) in the world

Cesarean section (CS) is a maternal-fetal life-saving intervention when medically required [1]. Lack of access and underuse can have devastating consequences, while overuse and weak clinical indications have become a growing worldwide concern in recent years [2]. The world's CS rates increased from 12.1 to 21.1% between 2000 and 2015. There are striking disparities within and between countries, with the highest prevalence in Latin America and the Caribbean (44.4%) and lowest in Central and West Africa (4.4%). Under and overuse can co-exist within one country, as, for example, in China, where the CS rates ranges from 4 to 62% between provinces (ibid.). The use of CS is socioeconomically concentrated, especially in low- and middle-income countries. In Brazil and China, high CS rates were observed especially among low-risk women, who had more education and delivered at private facilities [2]. In Norway, in contrast, CSs was most prevalent among lower socioeconomic groups [3].

To prevent severe maternal and neonatal morbidity and mortality, an overall CS coverage of 10% is suggested to be necessary for safe delivery care to be provided [1]. According to the WHO, higher rates than 15% have not been proven to benefit mothers and newborns and may even cause harm (ibid.). Other researchers have found national CS rates of up to 19% to be associated with the lowest maternal and newborn mortality [4]. About 6.2 million CSs were conducted in 2008 without medical indication, with Brazil and China accounting for 50% [5]. Overuse is thought to be driven by an intertwined combination of maternal, health professional, and health system related factors [6]. Although most women do not prefer CS in absence of previous and/or current delivery complications, maternal request is thought to contribute to the rise in CS rates [6-8]. Fear of pain and pelvic complications, previous negative birth experiences, and misconceptions about safety have contributed to such requests [6]. Health professionals are influenced by medicolegal as well as convenience incentives for providing CS as professional protection in some

countries [9, 10]. Factors at the health system level that contribute to CS overuse are economic incentives in private care as well as lack of training in assisted vaginal delivery [6].

Hence, interventions proven to reduce CS overuse include external cephalic versions of breech deliveries, breech deliveries for selected women, vaginal births after CS (VBAC), and midwife-led continuity of care [6]. Suggested non-clinical interventions for reducing CS rates include relaxation and psychoeducation programs, meaningful dialogue, and emotional support. System targeted interventions should strive to eliminate financial incentives and reduce fear of litigation (ibid.). The International Federation for Gynecology and Obstetrics (FIGO) has stated that the medical profession cannot turn the increasing CS trend on its own and has called upon further cooperation between women's groups, professional organizations, the UN, and governmental bodies [11].

1.2 Risks and benefits of a planned CS

Although CS is a safe and common surgical procedure in many countries today, it represents an intervention within the physiological process of giving birth, which, in general, entails an increased risk of unfavorable short- and long-term consequences for both the mothers and their children [12]. Complications occur in a dose-response manner, increasing with each repeated CS. Thus, decisions about CSs (especially primary CS) should consider the procedure's implications for future pregnancies and the possible consequences for the woman's whole reproductive lifespan [13-15]. Most research and reviews do not distinguish between emergency and planned CSs [12, 16]. Complication rates are generally lower for a planned CS, as compared to an emergency CS [17, 18]. Consequently, decisions about planning a CS should consider the individual woman's anticipated risk of experiencing an emergency CS during labor.

There are no randomized controlled trials comparing outcomes for mothers and children of a planned CS versus a planned vaginal delivery for low-risk pregnancies

lacking obstetric indications [19]. Thus, recommendations are based on and limited to the best available evidence from previous observational studies [20].

1.2.1 Maternal consequences

A Swedish registry-based, case-control study found an increased risk of bleeding and infections with planned CSs as compared to planned vaginal deliveries [21]. Likewise, a multi-country study in Asia, Latin America, and Africa found an increased risk of severe maternal short-term outcomes following CS, such as maternal death, ICU admissions, blood transfusion, and hysterectomy, as compared to spontaneous vaginal delivery [22]. However, the study did not incorporate the risk of an emergency CS with vaginal delivery. A Chinese cohort study found no significant differences for nulliparous women undergoing a planned CS on maternal request (CSMR) compared to planned vaginal delivery in terms of maternal intensive care unit admissions, infection, severe hemorrhage, thromboembolic disorders, and organ injuries [23]. A Danish registry-based study comparing planned CSs and planned vaginal deliveries among nulliparous women found no increased risk of major morbidity outcomes (death, cardiac arrest, hysterectomy, and thromboembolic disease) but a slightly higher risk of wound infection following a planned CS. Women planning a vaginal delivery had a 5% risk of anal sphincter injuries [24]. A review comparing planned CSs at term with planned vaginal deliveries concluded that both have similarly low short-term maternal morbidity [25]. Moreover, the study found that planned CSs were associated with higher rates of infection, while planned vaginal deliveries were associated with higher rates of bleeding (ibid.). However, most morbidity following a planned vaginal delivery was attributed to an emergency CS and operative delivery (forceps) (ibid.).

Although the short-term consequences of CS may be low, a primary CS effects subsequent pregnancies with an increased risk of complications, such as abnormal placentation (placenta previa, accreta and abruption), unexplained fetal death from week 34, and uterine rupture [13, 20]. A Nordic registry-based study found an increased risk of having an abnormally invasive placenta, uterine rupture, and postpartum hemorrhage at second delivery if the first delivery was a CS. The risk was

higher if the first delivery was a planned CS compared to an emergency CS [26]. A review of the literature suggests that a planned CS may have benefits regarding urinary incontinence, though of unclear duration, whereas no clear benefit was found for pelvic organ prolapse, fecal incontinence, and sexual function [27].

1.2.2 Consequences for the child

A registry-based study from Iceland found no correlation between CS rates and perinatal mortality for children with birthweight >2500 g in the period 1987-2006 [28]. A Swedish study found that children born by CSMR had an increased risk for breastfeeding complications and respiratory distress compared to children born by spontaneous onset of labor ending in emergency CS [21]. A Norwegian survey comparing neonatal outcomes for planned vaginal deliveries and planned CSs at term found increased transfer rates to neonatal intensive care units and risk of pulmonary disorders in the latter group but found no difference in Apgar scores and neurologic symptoms between the groups [29]. A study from China confirmed the increased risk of respiratory distress following CS on maternal request among primiparas, but the study also showed an increased risk for birth trauma, neonatal infection, hypoxia, and meconium aspiration following planned vaginal delivery (including emergency CS) [23].

Research increasingly suggests that a caesarean birth negatively affects the development of the child's immune system [30]. Several studies have identified associations between CSs and the development of asthma, allergies, diabetes mellitus type 1, and celiac disease [31, 32]. For one of the few studies stratifying between planned and emergency CS, the risk was only present for planned CSs, not emergency ones, implying that unstratified research may underreport the association for planned CSs [33]. A planned CS is anticipated to bypass the vaginal delivery's favorable exposition to the maternal bacterial flora, which serves to establish an immune response in the child's gut and to avoid the natural stress response in the child undergoing a vaginal delivery. These two factors may alter epigenetic regulations and gene expression in the child, which will have consequences for the development of the immune system [31].

1.2.3 Considerations of the mental issues of a planned CS

One systematic review has investigated the mental effects of a planned CS on maternal peripartum anxiety and depression and found only three relevant studies to include [34]. A Norwegian cohort study investigated emotional distress at 30 weeks of gestation and six months postpartum across delivery modes. Women delivering by a planned CS had higher scores on distress ante- and postpartum compared to other delivery groups (vaginal, instrumental, and emergency cesarean deliveries). Women with a planned CS showed a greater decline in distress scores after birth compared to women in other delivery groups, but no significant association was found between a planned CS and decline in distress for women wishing a planned CS [35]. Thus, emotional distress before delivery had the strongest association with distress after delivery. Another cohort study from Norway found that women with a preference for CSs who delivered vaginally had higher symptoms of posttraumatic stress after birth compared to women with no such preference who delivered vaginally. Such an effect could be partly explained by a psychological vulnerability among these women in terms of fear of birth, anxiety, and depression [36]. This is the only study to investigate such a mismatch between preference and mode of delivery. Unpublished data showed that women who preferred but did not in fact have a CS also had higher postpartum depression scores, whereas for women who had a planned CS, their postpartum depression scores normalized [34]. Within both groups, anxiety levels normalized after delivery. A smaller Swedish cohort study found no difference in postpartum depression among women requesting and receiving a CS and women planning a vaginal delivery [37].

Increasing evidence suggests that negative stress in pregnancy has an unfortunate impact on the fetus and future development of the child. Epidemiological studies have found social and emotional problems in children exposed to perinatal anxiety and depression [38-41]. Neuroimaging studies show altered brain structure and functioning after exposure to prenatal maternal anxiety [42], and animal models have found altered endocrine secretion and behavioral disturbances [43-45]. The complex mechanisms of fetal programming that may explain these alterations are still poorly understood and are thought to involve the hyperactivation of the hypothalamic-

pituitary-adrenocortical axis, cortisol, epigenetic changes in fetal DNA, and the postnatal environment [46]. If the reassurance of a planned CS can serve to lower prenatal anxiety among women with concerns about delivery, this may benefit the unborn child as well as the wellbeing of the mother. Distress reduction through counseling and therapy would be beneficial to women and their fetuses.

1.3 CS indications

There are multiple indications for a CS. A CS is usually considered when the probability of a better outcome for the mother and/or the child is assumed to be greater for a CS than for a vaginal delivery [47]. The CS is either planned (i.e., the decision is made more than eight hours before delivery) or is an acute, emergency CS (i.e., conducted during trial of labor) (ibid.).

CSs can also be distinguished according to absolute (life-threatening) and none-absolute (relative) indications. Absolute indications include severe maternal bleedings (e.g., due to placenta previa, abruptio placenta, and postpartum hemorrhage), abnormal presentation (including brow and transverse lie), major cephalopelvic disproportion, and (pre)rupture of the uterus [48]. Relative indications may include protracted labor, fetal distress, and having had (a) previous CS [49].

General risk factors for CS include having had a previous CS (or other surgery on the uterus), having had a previous traumatic birth experience, breech presentation, diabetes mellitus, obesity, induction of labor (especially among primiparas), mental health issues, fear of birth, and older age [47].

A Norwegian study for the period 1998-99 found that 85% of CSs were conducted on indication of fetal distress, failure to progress/protracted labor, having had a previous CS, breech presentation, maternal request, preeclampsia, failed induction, abruptio placenta, having had a previous complicated delivery, or placenta previa [50]. The overall CS rate during this period of study was 13.6%, with 64% emergency and 36% planned cesareans. Maternal request accounted for 7.6% of all the cesarean deliveries (ibid.). A more recent study from Finland found indications to be also dominated by

fetal distress, failure to progress, and breech presentation [18]. Fear of childbirth accounted for 9.2% of the CSs.

In Norway, attempted vaginal delivery is usually recommended for women who have had one previous CS and for breech and twin pregnancies when fulfilling certain criteria [51].

1.4 Cesarean section on maternal request (CSMR)

1.4.1 Definition

A CSMR has been defined as a planned (primary) CS conducted on request of the mother in the absence of medical or obstetric, maternal, and/or fetal indications [14, 20, 52]. Alternatively, a CSMR has also been defined as a planned CS on maternal request when there are no obstetric contraindications for vaginal delivery, assuming vaginal delivery to be the primary way of birth [53]. The lack of an explicit definition about what counts as a "medical indication" (e.g., is mental indication included?), as well as ambiguity surrounding indications and secondary diagnoses (such as having had a previous CS and breech presentations), make definitions, estimates, and discussions of CSMRs difficult [7].

1.4.2 Prevalence

Many scholars have critiqued the influence maternal requests have on increasing CS rates. Gamble et al. emphasize that few women request CS without previous or current obstetric complications, suggesting a prevalence of less than 1% for all deliveries [54]. This finding is in line with Norwegian studies of CSMRs, although these two studies are limited to old or self-reported numbers [50, 55]. American estimates have suggested around 2.5% of all American deliveries are conducted as a CSMR [14]. A multi-country study of countries in Africa, North America, and Asia found 1% of all deliveries to be CSs that lack medical indications (either unregistered indication or maternal request) [22]. A Swedish registry-based study between 1997 and 2006 found a threefold increase in CSMRs (from 1.3 to 3.6%), accounting for 2.3% of all the births and 14.7% of all the CSs. However, the rise in CSMRs was a

minor contributor to the general increase in CSs during the study period [7]. A similar increase in CSMRs has been found in the UK [8]. A Danish study estimated a prevalence of 3.6% among multiparous and 1.3% among nulliparous women, suggesting parity to be a crucial factor affecting maternal requests [56].

Reported preference for a CS among pregnant women is, however, higher than the number of women actually requesting and receiving one. A Norwegian study found that 5% of pregnant women in week thirty reported a preference for CSs, with a higher prevalence (6.6%) among multiparous compared to nulliparous women (3.5%). However, the majority of women (85%) stated a preference for vaginal delivery [55]. A similar investigation across six European countries found a cesarean preference of 3.5% among primiparous and 8.7% among multiparous women [57].

1.4.3 Maternal characteristics

A European study (including Belgium, Iceland, Denmark, Estonia, Norway, and Sweden) found that a preference for CS was associated with a fear of birth, previous negative birth experiences (among multiparas), at least one previous CS (among multiparas), a history of abuse and depressive symptoms (among primiparas), as well as social characteristics, such as older age, low education, and being non-native [57].

Results from a Norwegian cohort study showed that the 5% of pregnant women in week thirty who prefer to give birth by CS have an increased probability of giving birth by both an emergency and a planned CS [55]. A preference for a CS was more common among multiparas compared to primiparas and was further associated with characteristics, such as older age, lower education, unemployment, and smoking. The strongest predictors of a CS preference was a fear of giving birth, having had a prior CS, and negative birth experience [58]. Although a fear of childbirth has been shown to be a strong predictor of preference for a planned CS, most of the women (85%) who feared childbirth delivered vaginally, and a few of the women without a previous negative birth experience requested a planned CS in a Norwegian cohort study [59]. A negative birth experience in subjective terms does not necessarily correlate to objective complications [60, 61].

The women requesting a CS constitute a heterogeneous group, in which parity and previous birth experience are likely to be important. Some researchers have focused on first-time mothers requesting a planned CS in absence of a previous birth experience [62, 63].

Swedish primiparous women who give birth by a CSMR appear to suffer more from psychiatric illness (e.g., neurotic, stress-related, and mood disorders) than primiparas not giving birth by CSMR; they are also older, and they tend to, more often, be smokers, have less education, to be married and unemployed, and to be second generation immigrants [64]. Another study on primiparous women from Sweden found that women giving birth by a CSMR had more negative expectations of vaginal delivery; they also tended to be older and born outside Sweden. Only 43% of these women had a significant fear of childbirth (defined as a W-DEQ questionnaire score of above 84 points) [65]. A prospective Swedish cohort study comparing 91 women planning a CSMR with women planning a vaginal delivery found that primiparas planning a CSMR experienced their health as less good and were more often immigrants; they were also planning to have one child only and felt more often anxious because of a lack of support, a loss of control, and worries over possible fetal injury or death during vaginal delivery [37]. Women delivering by CSMR, in contrast, had better birth experiences, and had no increased risk of postpartum depression, but they breastfed to a lower extent. The women's requests stemmed from their fear of birth and/or pain, concerns over their own or their child's health, as well as whether they had relatives with complicated births and whether they had a history of sexual violence (ibid.).

1.4.4 Guidelines and maternal choice

Juridical and clinical guidelines regarding the practice of CSMR vary between countries and healthcare systems. The mode of delivery (a planned CS) is not officially regarded as an option for patient choice in Norway and Sweden, which both have publicly financed single-payer health systems [7, 47]. In the UK, which has a comparable healthcare system, the 2011 NICE guidelines state the following: "For women requesting a CS, if after discussion and offer of support … a vaginal delivery

is still not an acceptable option, offer a planned CS" [66, p. 8]. Thus, further on, it says: "An obstetrician unwilling to perform a CS should refer the woman to an obstetrician who will carry out the CS" [66, p. 8]. Danish guidelines state that an obstetrician can refuse to conduct a CS in a given situation, but should offer the woman a "second opinion" from another colleague [67, p. 2].

In other parts of the world, practices and attitudes are different and are often related to the arrangement of the health system. In Brazil, where 25% of births occur in private hospitals, the overall CS rate was 53% in the Southeast region in 2011-2012, but the percentage was significantly higher in the private sector (85%) than in the public one (43%) [9]. In the private sector in Brazil, women may not be offered a vaginal birth due to the inconvenience it could cause the staff (ibid.). And as a consequence, experience in performing a vaginal operative delivery may be significantly reduced among professionals.

1.5 Research context: Norwegian delivery care

Norway has a publicly financed single-payer healthcare system, which offers pregnancy care, delivery, and children's care free of charge [68]. Antenatal care is provided by primary care midwives and general practitioners (GPs), and private alternatives for antenatal care offered by midwives and obstetricians exist to some extent. Delivery and direct follow-up of the mother and child are provided at public hospitals. Private practicing midwives also offer home births in some areas of the country [69]. Planned home births are relatively rare, representing only 98 births in 2019 [70].There are otherwise no private hospitals in Norway offering alternative delivery care. In Norway, like in other Scandinavian countries, delivery care is primarily midwife-led, with assistance provided from obstetricians during complicated events [71]. Postnatal care is to a growing extent delegated to primary care midwives, who conduct home visits when possible. A postpartum checkup is offered by GPs six weeks after birth.

Norway, like other countries in the world, has seen an increase in the use of CSs since the practice became a life-saving option for delivery care, but its prevalence has been stable at around 16% over the last 20 years. The first CS succeeding to save maternal life in Norway in 1890, and was for a long time considered "a last despairingly resort" [72, 73]. The overall CS rate in Norway was 1.8% in 1967, when it was only undertaken to save the mother's life [72]. The rate further increased to 12% in 1980, 14.9% in 2001, 16.1% in 2005, and has been stable since toward 15.9 % in 2019 [70]. Emergency CSs account for 66.5 %, while planned CSs comprise 33.5 %. In 2019, there were regional differences between 12.1 and 19.3 % across the country (ibid.). The CS rate was lowest in the western region, where obstetricians have more restrictive attitudes toward providing a CSMR [74]. CS rates also vary according to Robson groups; the rate was 7.5% among primiparous women with a spontaneous onset of labor (group 1), 1.6% among multiparous women with a previous CS and had a spontaneous onset of labor (group 3), and 47.5% among multiparous women who have had a previous CS [70, statistics from 2019].

The Norwegian Patient's Rights Act aims at providing citizens with equal access to healthcare services of good quality in primary as well as specialized care [75]. There are two pathways into specialized care in Norway: 1) in need of immediate care and 2) in need of planned necessary care. In the latter scenario (which is relevant for women requesting a planned CS), a referral sent from a GP in primary care will be evaluated by a specialist in specialized care within a certain timeframe (§ 2-2). During this evaluation of whether a patient has a right to planned necessary healthcare, priorities are set after given criteria in the Priority Regulation [76]. The regulation aims at providing equal access by treating the same conditions in equivalent ways. First, whether a patient has a right to specialized care is evaluated based on the two criteria of "anticipated gain from healthcare" and when the "cost matches the anticipated effect" (§ 2). Second, priorities are set between patients who have a right to healthcare according to the two former criteria by evaluating a third criterion: severity and urgency. This criterion determines which conditions or patients should be considered first. Thereby, the system aims at delivering equal access to

health services of good quality by treating all referrals based on the same criteria of priority.

According to the Patient's Rights Act, patients have a right to participate in decision-making concerning accessible and justifiable treatment options [75]. However, it is the physician in charge that determines which treatment options are justifiable in each case. Norwegian physicians are rarely held economically responsible for patient complaints and are rarely targeted by law suits because of the public system of Patient Injury Compensation [77]. This arrangement aims to prevent financial and medio-legal motivations from interfering with clinical judgements, in contrast to what has been reported from other European countries [10].

The clinical guidelines for the Norwegian Society of Gynecology and Obstetrics state that maternal requests for CS may be due to mental illness, unprocessed life events, dissatisfactory care, or lack of trust in healthcare [47]. Delivery wards should provide counseling and support for these women and offer them the opportunity to make a birth plan. Nevertheless, a CSMR in absence of medical indication is not recommended [47]. The Patient's Rights Act is interpreted and understood as to provide women with a right to codetermination but not a right to determine mode of delivery (ibid.). If disagreement arises about the planned mode of delivery, the women shall be offered a second opinion by a colleague or another delivery unit (ibid.)

2. Theoretical perspectives

2.1 Autonomy

The role of autonomy has received much attention in the debate about CSMRs [78-83]. In Beauchamp and Childress' influential book from 1979, the authors propose that autonomy is one of four (equally important) principles guiding biomedical ethics [84]. Since the book's publication, autonomy has received a great amount of attention in debates over modern bioethics [85, p. 34]. The remaining three principles—beneficence (doing good for patients), non-maleficence (avoiding harm) and justice (providing fair and equal care for every citizen)—have also been much debated, including the redundancy of beneficence and non-maleficence (do they not entail the same?) and how to weigh and handle conflicting principles. The increased attention toward autonomy, contrary to the remaining three principles though, could be caused by its complexity and many interpretations. Respect for autonomy has received great support, but the role of autonomy in healthcare has also been subjected to critical scrutiny.

Over the past five decades, medical practices have moved away from a paternalistic tradition, which understood physicians to judge what was in the patient's best interest, toward a more regulated profession that emphasizes individual patient rights and autonomy. Attempts have been made to equalize the professional-patient relationship. Moreover, patients have become more knowledgeable and are less dependent on their physician's judgment.

2.1.1 Individual (personal) autonomy

What does autonomy actually mean? And why do we endorse it? According to O'Neill, Gerald Dworkin once suggested several understandings of the concept, which includes such notions as liberty, dignity, integrity, and independence [85, p. 21]. O'Neill herself adds self-control and self-determination to the idea of autonomy. In bioethics, autonomy is often understood as the ability of an individual to make independent decisions and to take independent actions [85, p. 23].

Although John Stuart Mill never uses the word “autonomy” itself, much of the contemporary admiration for individual autonomy derives from his naturalistic account of human action. In his account, civil and social liberty are important for the development and flourishing of “persons individuality and character” (as individual autonomy) [85, p. 31]. In this respect, people need protection from mechanisms of control imposed by the majority or by society. Mill sees individual autonomy as taking charge of and acting on one’s own desires; it reflects an individual’s true nature. Liberty, thus, should only be restricted when it can harm others [85, p. 45]. If we apply his account on women requesting a CS, they should perhaps be free to choose themselves as long as it does not harm the unborn child. A psychotic patient is an example of when restricted autonomy in healthcare is appropriate in order to protect the patient as well as others. Another, perhaps more controversial, example includes forced cesareans on women who refuse surgery in situations in which their unborn child’s life is in danger [86-88].

2.1.2 Procedural accounts of autonomy

Procedural accounts of individual autonomy evaluate the process or procedure of how autonomy is exercised rather than the content of the action or decision [89]. Gerald Dworkins definition of autonomy requires an agent to have the capacity to identify and critically reflect upon one’s basic (first-order) desires through one’s higher level (second-order) desires and to make choices based on the latter ones [84, p. 102]. Imagine an alcoholic person with a first-order desire to drink and a second-order desire to stop drinking. Actions based on first-order desires are, according to Dworkins definition, non-autonomous, unless they are endorsed by the second-order desires. Accordingly, a woman requesting a CS can only exercise an autonomous choice if this is a second-order desire. If a woman actually desires a vaginal delivery but requests a CS for some first-order reason (e.g., having a previous traumatic delivery), her choice is not an autonomous choice. Dworkins theory of autonomy results in few choices qualifying as autonomous, thus providing little guidance for medical practice [84, p. 104]. It also fails to provide any moral argument for why we should respect autonomy [89].

Beauchamp and Childress' theory of autonomy builds on three conditions for autonomous decisions (rather than persons): intentionality, understanding, and non-control (being free from controlling factors) [84, p. 105]. For an action to be autonomous, it has to be intentional (deliberate); the actor needs to understand the relevant information and facts and be free from internal (e.g., mental states) and external (e.g., coercion and manipulation) controlling factors. While the first component is a binary one (present or non-present), the two latter are scalar and demand a certain threshold. Decisions and decision-makers can, therefore, hold various degrees of autonomy [84, p. 105]. The three outlined conditions are requirements for autonomous decisions, not persons, primarily. While autonomy is often referred to as a property of decisions in the medical ethics literature, moral philosophical literature also sees it as a property of persons [89]. This theory of the autonomy of decisions may fail to address some actors or decisions as non-autonomous, and, like Dworkin's account, it also lacks a moral argument for respecting autonomy, which is practically carried out by obtaining informed consent. But the theory does not provide any guidance of how to respect persons who are not able to give informed consent. Some philosophers have argued that health professionals providing extensive amounts of information may not be beneficial for patients [89]. Complete and specific consent may be unrealistic to obtain in practice; thus, O'Neill argues for a genuine consent, in which patients can control the amount of information received [90].

Some medical sociologists have suggested that appeals to individual autonomy in medicine represent an illusion of patient empowerment, which leaves professional authority intact [85, p. 26]. The power of professionals persists, as they control the agenda in consultations and determine treatment options. Respecting autonomy in medical care is often reduced to only obtaining informed consent.

2.1.3 Principled (substantive) autonomy

O'Neill is unconvinced by the individualized (and procedural) understanding of autonomy as a sufficient standard for bioethics. Instead, she argues for a broader and more substantive view of what she calls "principled autonomy" [85]. She appeals to

an older and quite different view of autonomy provided by Kant [85, p. 74]. She states that there cannot be individual rights (e.g., autonomy) if they are not grounded in obligations toward others. A right to basic healthcare can only be guaranteed through other peoples' corresponding obligation to provide it; thus, there is a relationship between obligation bearers and right holders. For this relationship to be true, we need a convincing argument for the centrality of human obligations. According to O'Neil, Kant never speaks about autonomous individuals, independence, or individual preferences. He rather writes about the autonomy of reason (or principles) [85, p. 83]. Kantian autonomy is based on someone acting on principles (of obligation). His formula of the "autonomy of the will," one of the many versions of the categorical imperative, is expressed as follows: "Never to choose except in such a way that in the same volition the maxims of your choice are also present as a universal law" [91, p. 108]. That is, our autonomous will, as rational human beings, must be universally representative for everyone. Because (or if) we are rational beings, we are autonomous (self-legislating), and this provides the basis for respect (as opposed to individualistic autonomy often being based on respect for persons). It is this ability to reason that justifies treating other people, not as means, but as ends in themselves. The imperative, thereby, provides a basis for universal rights and obligations. How Kant's autonomy as self-legislation specifically applies to CSMR is beyond the scope of this thesis; however, following O'Neill's interpretation, Kant's concept of autonomy can be used to rethink the debate around CSMR in a broader normative setting beyond informed consent and individual choice.

Substantive, perfectionist accounts of autonomy generally incorporate a notion of normative competence, which refers to an individual's ability to critically reflect on and evaluate the different options available [89]. Raz's three elements of autonomy are appropriate mental ability, an adequate range of options, and independence (referred to as freedom from coercion and undue manipulation) [89]. The normative competence represents a neo-Kantian notion of identifying norms and deciding upon whether to apply them in a decision. For a choice to be autonomous, it has to reflect

the person's self and will. Hence, it is necessary to know the content of the decision as well as the person's goals and values that are relevant for the decision. The fact that a person holds a normative competence to self-rule gives them a capacity for morality (acting as a moral agent), and this provides the normative justification for respecting autonomous persons' choices [89]. This implies that a decision for CSMR can only be autonomous after an active and self-initiated deliberative process identifying the woman's situation, norms, and preferences.

2.1.4 Relational autonomy

Individual accounts of autonomy have been subject to considerable feminist critiques for their individualistic focus [92, ch. 1]. The Kantian position of understanding people to be rational self-legislating human beings has also been heavily challenged by Nietzsche, Freud, and their followers, who argue that such self-mastery is illusory and persons fundamentally exist in societies of micropractices of power [92, p. 10-11]. Relational accounts call for understanding how the social context influences individuals' autonomous capacities. One such context is the patient-physician relationship, with its impact of power and communication [89]. Family relationships may be another relevant influencer on medical decision-making. People fundamentally exist in social relations, which influence how they make decisions in the healthcare system and beyond it [89]. The relationship between the patient and their family members or healthcare professional can both enhance and undermine their autonomous capacity. Respect for autonomy means respecting people's normative authority over decisions in their lives (i.e., "as I do not know what it is like to be in your situation, I am obliged to respect your normative authority to decide"). However, such normative authority is both personal and relational. Mackenzie argues that respect for autonomy also involves a positive obligation to promote the autonomous capacity of agents, even in situations where autonomy is (partly) impaired [93]. She underscores that autonomy is not an either-or capability, as it presents itself in various degrees (ibid.). Thus, healthcare professionals working in delivery care should be obliged to include women in discussions about delivery mode and promote women's ability to reason and take part in the decision.

2.1.5 Professional autonomy

Pellegrino argues that the autonomy of the physician is often neglected in moral debates about autonomy [94]. In the physician-patient relationship, the physician also has the right to make choices in line with their own conscience about what constitutes good practice of medicine. The physician's autonomy emerges from three dimensions: i) their autonomy as an individual person, to be allowed to live and make personal choices based on their own conscience and values; ii) their autonomy as a professional physician, with the corresponding obligation to use their medical knowledge wisely; and iii) the autonomy of the entire profession (professional autonomy) and its members, who have collective obligations [94, p. 51-52].

The first dimension comprises the same grounds as the autonomy of the patient. A physician as an individual will hold their own personal beliefs and values, but they are obliged not to impose these on their patients and their decisions [94]. The respect for moral integrity is, thus, a common argument in ethical conflicts concerning conscientious objections among healthcare workers. Within liberal democracies, though, entering the profession of medicine involves voluntarily taking on the responsibility for delegating a public good that requires obligations, which, in fact, will limit a physician's autonomy at work [95].

The second dimension, the autonomy of the physician as a professional (professional autonomy on the individual level), is grounded in the expert knowledge one holds, which is needed to treat sick people [94]. The power of possessing such knowledge requires the physician to use it with their best judgement. Physicians are required to use their knowledge to help people, but in order to fulfil this obligation, they must be given sufficient discretionary space (and power). When entering a profession like medicine, the physician accepts a contract with society, which provides certain privileges and obligations that come with the profession's knowledge and skills [94]. This contract is based on trust. Violation of trust happens when the physician acts incompetent, out of their self-interest, and their own values. A physician holds no expertise on human social values and, thus, has no obligation to make value-based judgements on behalf of the society [94, p. 53].

The third dimension of physician's autonomy, professional autonomy at the group level, is the collective autonomy of the entire profession. Grimen refers to Friedson's definition of professional autonomy as "control over the technical aspects of work" [96, p. 19]. Professional autonomy in this view persists even without economic, administrative, and educational control. Technical control provides power and considerable space for medical judgement and discretion. Delegated authority to provide healthcare can be perceived as given to the medical profession through a social contract, which allows its members to provide their special competency through discretion [97]. In return, society expects to receive the trustworthy provision of healthcare.

According to Pellegrino, the physician-patient relationship is a moral relationship of mutual respect, rights, and obligations. The large emphasis placed on patient autonomy has in some cases been interpreted as an entitlement to demand treatment despite the physician's recommendation and medical judgement. This position challenges the physician's moral integrity as a physician, as well as the physician's expertise and discretionary space, by reducing their position to a mere technical instrument [94, p. 59]. Discretionary space is necessary in medicine because applying knowledge case by case is often required in order for treatment to be effective.

Concluding remarks on autonomy

Autonomy has gained considerable importance in modern bioethics. Still, the concept comes with numerous interpretations and understandings. There is no consensus on how to understand and interpret the concept beyond the general value of self-determination. Women requesting a CS as well as healthcare professionals can usually be assumed to be autonomous actors. Both autonomous and non-autonomous individuals deserve protection from unjustified and deleterious decisions made during the provision of healthcare. I will now discuss other central notions to the maternal-professional relationship, before looking at different CSMR decision-making models.

2.2 Power, trust, and risk

Although the maternal-professional relationship consists of mutual rights of respect and autonomy, it is highly asymmetric in other elements, such as power, knowledge, and vulnerability. I will start with a brief conceptualization of power and trust before I outline the nature of the relationship between them, which Harald Grimen calls "the nexus of power, trust, and risk" in healthcare [96].

Power

According to an overview paper in the *Stanford Encyclopedia of Philosophy*, power is a multifaceted concept that may apply to several aspects of the professional-maternal relationship in decisions for CSMR [98]. Several definitions of power involve the understanding that "A exercises power over B when A affects B in a manner contrary to B's interests" [98, 99]. Power can be understood as relational (power-over others) or as actional (power-to) [98]. The latter conception of power merely involves being able to. Thus, power can be defined as a potentiality (i.e., an ability that may not be used). Some regard power as the ability to impose one's will on others and, hence, regard power-over as a derivate of power-to. Others view the two as completely separate concepts. Some feminists understand power as a positive social good, a resource (ibid.).

A suitable framework of power in the context of healthcare is proposed by Steven Lukes. According to Lukes' original description of power, power may involve i) coercion (e.g., physical force of action), ii) control over agendas and interactions, and iii) control over worldviews [99]. In modern healthcare, force is strictly regulated (with few exemptions in, for example, psychiatry). But in spite of common simplifications, power is more complex than just force. Professional autonomy also holds significant space for discretion, which provides healthcare professions with extensive power to control their own worldview in terms of identifying healthcare needs and entitlements of their patients [96].

Trust

According to another overview paper in the *Stanford Encyclopedia*, trust is an important concept for healthcare and society, but trust is also risky [100]. Trust enables us to depend on others and form relationships with them, but trust is also unsafe in the sense that we may lose something we value. For trust to take place between two people, both parties need to be trustworthy [100]. Conditions for trustworthiness include being competent and committed to the trusted task. Generally, trust requires people to a) be vulnerable to other people (i.e., accept the risk involved in trusting), b) think well of others, and c) be optimistic concerning the competence of others. If one cannot be optimistic about others and if they are suspicious and assume the worst in others, then trust is inhibited, resulting in distrust [100].

Mark Warren defines trust as "a judgement, however implicit, to accept vulnerability to the potential ill will of others by granting them discretionary power over some good. When one trusts, one accepts some amount of risk for potential harm in exchange for the benefits of cooperation"[101, p. 1]. Grimen argues that trust can occur voluntarily or be forced due to lack of options [96], while some literature exclude the form of forced trust emerging from situations of dependency [102, 103].

The nexus of power, trust, and risk

Health professionals are socialized to be not only beneficial helpers but also gatekeepers and controllers of access to healthcare. Possessing specialized knowledge and control is inherent to being a professional, and modern society would not function without such a division of labor and epistemic power [96]. Grimen explains how power cannot be eliminated unless we opt to radically change the structures of modern healthcare, which is a solution that he does not believe will benefit patients. He rather argues for professionals to become more conscious about power operates and to develop more humane institutional forms in which power can be beneficial (i.e., used merely to promote something good) [96].Thus, power, trust, and risk are closely connected, as Grimen describes:

"If A trusts B, then:

1. A leaves or has something, X, in B's custody for a period of time.
2. A transfers—always de facto, sometimes de jure—discretionary powers over X to B for this period of time or is in a situation where B has such powers.
3. A values X.
4. A expects that
    a. B is not going to do something that harms A's interests.
    b. B is competent to take care of X according to A's interests.
    c. B has the necessary means to take appropriate care of X.
5. A takes few precautions against B's misuse or careless use of his discretionary powers over X." [96].

Thus, to trust someone is to transfer power over some goods to someone else. Hence, to trust is to take a risk that the trusted person will not misuse their powerbase. This makes the trustier vulnerable. When patients use healthcare services, they are dependent on healthcare professionals for help. Patients need to take the risk of trusting healthcare professionals for help; they are leaving their health in custody of healthcare professionals with the expectation that they will use their power in the patient's interests beneficially. Trust is needed for beneficial power to exist in healthcare and to facilitate provision of care. But the powerbase that the professionals hold need not be beneficial. *Beneficial power*, as conceptualized in Paper III, encompasses a capacity "to promote patient treatment without suppressing patients' experiences or points of views."

Trust is important and can be facilitated by lack of options (forced trust), respect for authority-delegated discretion, and a belief in a forecasted efficacy (e.g., experiences of how healthcare benefits people) [96]. Similarly, trust can be lost when institutions lose legitimacy (e.g., due to their mixed motives, such as saving public resources while providing public goods) or when people no longer believe in their efficacy (e.g., after bad experiences in healthcare, negative media publicity, or rumors) (ibid.). For women requesting a CS, knowing that a CS costs more and may be valued less by professionals, as well as their previous birth experiences, may all be factors that can challenge their trust in healthcare professionals.

Patients are generally situated in a position of structural inferiority in terms of the gap of knowledge between themselves and professionals as well as lack of options they have, which force them to trust whatever they receive. Also, the professionals' gatekeeping role may conflict with the interests of patients, and an illness may make patients more vulnerable to manipulation than healthy people. Patients are dependent on professionals, and there are limits to what degree patients can be dialogue partners, as professional-patient dialogues do not occur between equals when it comes to the knowledge they possess [96]. As Grimen claims, we have to accept that power exists and be conscious about it when we improve the structural forms of modern healthcare (ibid.). There are good reasons to avoid deepening the structural inferiority of patients or broadening professionals' space for nonaccountable discretion and power. Instead, we should find more humane institutions that can foster trust and beneficial power (ibid.). Ethical quality and shared decision-making (SDM) are examples of such initiatives [104]. Trust can be promoted by professional behavior through, for example, investing time in patients or being sensitive in consultations [105].

2.3 Shared decision-making

SDM has become an important concept in bioethical literature as well as in political debates in recent decades. Although the concept has been criticized as slightly vague and difficult to explicitly implement in practice [106, 107], it has changed the ethical foundation of modern healthcare decisions.

In the early research on SDM, Charles et al. outlined key characteristic that should characterize SDM in practice: i) including more than one participant in the decision, ii) mutually revealing information, iii) building consensus on a decision by both parties, and iv) reaching agreement [106]. Later, Charles et al. called for more flexibility in the dynamic decision-making process [108]. Moreover, decision-making can exist on a gradual axis, ranging from paternalistic to more informed models, with SDM appearing in the middle [109].

Emanuel and Emanuel originally outlined four main decision-making models [110]. In the paternalistic model (1), the professional acts as a guardian, makes decisions on patients' behalf, and provides them with no autonomous rights. Except for emergency situations, this model is rarely recommended today. In the informative model (2), healthcare professionals serve as technical experts; they inform patients in order to help them make choices on their own and provide them with full autonomous rights, while professionals have none. This model may be more common in private institutions offering planned CSs (e.g., in Brazil).

The deliberative model (3) advocates for a process in which healthcare professionals help patients explore and endorse the best possible health-related values. The model leaves healthcare professionals with a double superiority in terms of medical knowledge as well as moral values, which is problematic. In the interpretive model (4), however, healthcare professionals are expected to act as advisers, initiating deliberation on the patient's own health-related values and help the patient realize these through the decision alternatives. In this model, patient autonomy is helped by the professional relation, in line with relational views on autonomy. Model (3) and (4) are suggested as models for SDM [110].

Grimen claims that some of the discussion of the professional-patient relationship represent wishful thinking, especially for those who argue that professionals and patients should be equal dialogue partners [96]. SDM has sought to empower patients and foster patient autonomy, and has provided many good initiatives in research and practice. However, power does persist through SDM, and according to Grimen, is often neglected in the debate. Decisions cannot be equally shared in a relation of such asymmetric knowledge, but the process leading up to a decision can be shared, and based on patients' preferences and values. This may not be contradictory to the SDM concept. But power needs to be addressed in the debate about and practice of SDM. Pål Gulbrandsen, is a researcher that has argued for a broad understanding of SDM that captures the existential aspects of falling ill, such as power, dependency, trust, and vulnerability [111].

As I have outlined earlier, women requesting a CS are often vulnerable in terms of psychosocial characteristics (Section 1.4.3). In counseling, they are also vulnerable in terms of knowledge inferiority and being subjected to the power of others. They cannot order a planned CS in Norway, and there is no private option for giving birth by a planned CS. Hence, obstetricians in Norway possess a great deal of power over the counseling and decision-making process. Women take a risk when seeking medical help, depending on the professional(s) they will meet. Thus, trust is crucial to the entire counseling and decision-making process.

3. Objectives

Overall objective

To promote research that can contribute to good-quality decision-making for women requesting CS in absence of obstetric indication.

Specific objectives

1. To explore why some women ask for a planned CS in the absence of obstetric indication.
2. To explore the counseling and decision-making process for CSMR among women and healthcare professionals
    a. To evaluate access to patient-centered care.
3. To provide a normative analysis of how to promote ethically justified decisions about CSMRs based upon:
    a. discussions of the impact of power, trust, and risk on decision-making; and
    b. a proposed framework for operationalizing SDM processes in the case of CSMR.

4. Methods

4.1 Rationale for this thesis

Women who request CS in the absence of obstetric indication was a phenomenon I first became aware of during my rotations in obstetrics and gynecology in medical school. Since then, I have observed media publicity on this subject several times. Inspired by this clinical issue, the overall aim of this PhD project has been to integrate empirical findings with normative reasoning in order to reach conclusions that could be relevant and helpful for practice. Since CSMR is a complex phenomenon embedded in cultural norms and involving many psychosocial factors, it was natural to start out with qualitative interviews (Papers I and II) with relevant stakeholders to answer objectives one and two. Qualitative methods based on a constructivist understanding of how meaning is shaped by social contexts are well-suited to studying a less understood phenomenon and gain deep knowledge [112]. Hence, qualitative inquiries can allow for a broader understanding of medical issues, decisions, and care [113]. Based on the knowledge gained from the existing literature and qualitative studies, we conducted a normative analysis (Paper III) of the premises for clinical decisions for CSMRs to seek answer to the third objective. The overall methodology of this thesis seeks to build a bridge between ethical theory and practice, according to translational ethics. Translation between theory and practice in ethics requires a careful justification of each bridging movement [114]. I will detail the ideas of such a methodology in the following sections.

4.2 Translational ethics

Along with the emergence of bioethics as a field of medicine striving to improve the ethical standards of healthcare, there is also a need to bridge the gap between theoretical and practical approaches to medical ethics [114]. A vast philosophical literature exists on the ethics of medical practice, yet real ethical decision-making is done in the real-world circumstances of medical practice. Introducing clinical ethics support services has been one way to enhance ethical competence in healthcare

institutions, but theoretical and clinical ethicists still sometimes appear to work in two different worlds [115].

The term “translational ethics” was somehow playfully associated with the process of translational medical research by Alan Cribb [116]. Just as laboratory translational research strives at making their scientific discoveries from the laboratory relevant for medical care, translational ethics similarly seeks to describe the transition of ethical arguments into medical policy-making and care. The main challenge of this mission is, however, to maintain both argumentative rigor and practical relevance without the one sacrificing the other [116]. The concept of translational ethics may be relevant for academic work on normative questions in bioethics, which can impact and shape norms, institutions, and politics in real-world practice. Such a translation calls for researchers who carefully justify how to integrate theoretical perspectives and practical challenges on a case-to-case basis [117]. Pertaining to this aim, there is a need to clarify the opportunities and limitations of translational work in the interdisciplinary field of medical ethics [114].

The translation of ethics from practice to theory can occur in several ways [114]. First, researchers can engage in practice themselves by supporting practitioners through the ethical deliberation of practices. Together, they can articulate and identify new ethical issues for philosophical reflection, which are grounded in real-world practice. The translation from practice to theory may also be initiated by practitioners themselves by seeking external advice or attention (e.g. by contacting philosophical researchers, clinical ethics support services, or the media) (ibid.). CSMR is an issue that has received much attention in recent years, both in the Norwegian public press and in academic debate. Professionals have engaged in local press and academic literature to warn about increasing CS rates beyond medical indications [11, 118]. Ethicists and obstetricians have discussed the ethics of CSMR and the boundaries of maternal autonomy [78-81].

For a translational bridging to be complete, several phases of translation must be addressed. First, an ethical challenge needs to be identified, development of a

justifiable normative approach should be undertaken, testing of the approach in a setting, implementation of the results in practice, evaluation of the implementation, and adjustments in case of suboptimal result (if the ethical challenge persists) [114]. Researchers should be self-reflective about how they impact these various phases of translation, as some practical decisions should be primarily shaped by affected stakeholders (and not external researchers) (ibid.).

Empirical bioethics (EB) aims to explore how ethics is embedded in real-world practice [116]. Bioethicists can have different approaches to the use of empirical data in their normative research, with varying degree of integration. Integrated empirical ethics refers to research in which ethicists and descriptive scientists work together to integrate moral theory and empirical data to reach normative conclusions about social practices [119]. Recently, European researchers within the field have started the preliminary work toward developing broad consensus on what should be the standards of assessing EB research [120]. The group proposes several requirements. First, EB research should seek to address normative issues oriented toward practice, where "normative issues" refer to ethical uncertainties or disagreements. Empirical methods should be integrated with ethical arguments to address the normative issue. The theoretical position on integration as well as the method of integration should be accounted for, and the conduction and reporting of integration should be transparent and consistent, and rigorous. The empirical work should facilitate data collection that meets the research aim and critically reflect upon the appropriateness of the chosen empirical method and the implicit ethical assumptions involved in it. The normative work should thoroughly delineate the ethical issue and make an explicit and robust ethical argument (e.g., "convince X to adopt position Y with the use of reasons") [120]. The research team should be competent in ethical, empirical (including clinical, when relevant), and integrational work.

Overall composition of this thesis

This PhD project originated from a clinical ethical problem, which had been voiced by clinicians and the public press. Its overall composition can be viewed as an example of translational and empirical bioethics study. The main objective was to

promote research that can contribute to good-quality decision for CSs on maternal request lacking obstetric indications. The three different papers each explore distinct steps that together allow for translation between theory and practice. The first paper explores the women's own reasons for demanding a CS. The second paper draws upon the conceptual lens of 'having one's healthcare need met' to shed light on women and healthcare professionals' experiences and attitudes across the decision-making process during pregnancy. The third paper discusses decisions for CSMR against normative conceptualizations of autonomy, SDM, power, risk, and trust in order to arrive at a justified, normative framework on how to promote good-quality care for women demanding a CS without obstetric indications. Anchoring this project in interviews with the affected parties hopefully have constrained the impact of our subjective normative reasoning and made this research project more relevant to practice. Still, our normative impact is present in how we have understood and interpreted the results and the choices of theory across the three papers, which have resulted in our recommendations.

The research team:

The research team behind this PhD project is composed of researchers with background in medicine, philosophy, qualitative, quantitative, normative, and translational bioethical research. As a newly educated medical doctor with interest in ethics, I did not have any formal philosophical training when approaching this project. The usefulness of working with an experienced philosopher as my main supervisor has therefore been significant. The two of us had no work experience from delivery care. Thus, working together with my co-supervisor, who is an experienced obstetrician, was necessary to keep footing in real-world practice. My second co-supervisor is an experienced qualitative researcher.

The translation of this project from practice to theory and back again to practice has been facilitated but not fulfilled. For this to be realized, our concluding framework resulting from Paper III will need to be found useful by practitioners, implemented in practice, and, subsequently, evaluated and perhaps revised. The attempted

translational movement of this project was carried out by integrating empirical and normative approaches [120] as described in the following sections.

Theoretical position on the integration of empirical and normative approaches:

The theoretical position for this project is the assumption that CSMR is a phenomenon constructed within the social frames of people's lives, norms, and cultural perceptions. [121]. Thus, we assume that the empirical knowledge and the normative questions following its presence in society go hand in hand and should be integrated. Moreover, we acknowledge that we, as researchers, also represent perspectives that are embedded in social contexts and shaped by social interactions. For this reason, we were careful not to let the data collection be driven by theoretical preconceptions (Section 4.3.4).

The method of integrating the empirical and normative approaches:

Papers I and II are descriptive qualitative papers seeking answers to objectives one and two. They draw upon different degrees of theoretical framing, which I will elaborate more on in Section 4.3.4. Paper III is a prescriptive paper drawing upon ethical conceptualizations (Section 4.4), which enabled us to reach a normative conclusion on the third objective of this thesis. The premise for the normative analysis in Paper III was the evidence generated by the interviews with the relevant stakeholders in Papers I and II, in addition to the existing literature about the phenomenon. This was the basis for enabling the translation from practice to theory, which hopefully can be translated back again to practice if the results are found useful by the stakeholders.

Reporting on the integration of empirical and normative approaches:

First, the empirical evidence from the qualitative studies was generated to facilitate a better understanding of the ethical issue of investigation. Based on the interviews, the conditions constituting the ethics of these decision-making processes were identified based on the normative theories and concepts the team was familiar with. Thus, the normative analysis of the question "how should decisions about CSMR be carried

out?" (objective three) relies on both the empirical data as well as theoretically and conceptually informed reflection. Hence, the empirical and theoretical approach was consecutively integrated, as the former informed and laid the ground for the choices of the latter. In section 6.1.5, I discuss the choices of the concepts for Paper III.

4.3 Qualitative methods (Papers I and II)

4.3.1 Study context

The qualitative studies were conducted at a university hospital in Norway within a region with a somewhat lower frequency of CSs (about 12%) compared to the overall country (about 16%) [70, statistics from 2019]. The hospital held around 5,000 births annually (ibid.). Birth counseling for women was primarily provided by midwives at a counseling out-patient clinic. The final decision about scheduling a planned CS was taken by a specialist in obstetrics, either by agreement with the midwife or by direct consultation between the woman and obstetrician after consultations with midwives. Women were referred to birth counseling by primary care midwives and GPs or by healthcare professionals at the hospital when the need was revealed in relation to consultations for other issues. Obstetricians had previously been in charge of counseling women about cesarean requests, and this practice was rearranged and delegated to dedicated midwives several years ago.

4.3.2 Data collection and participants

In-depth interviews with women

Semi-structured in-depth interviews were used to gather information about women's reasons for requesting CSs and their experiences with counseling. Individual interviewing is a suitable method for exploring people's lived experiences and worldviews [122, p. 9]. In order to obtain new knowledge about personal (and potentially sensitive) issues, the interviewer needs to create a safe climate for the interviewee to share their personal stories [112, p. 131, 122, p. 8].

Women requesting CSs were recruited for semi-structured in-depth interviews consecutively by midwives responsible for birth counseling. A written invitation to

participate in the study provided with an information scheme was given to women who were above 16 years of age, who had a normal pregnancy with no excess medical risks or obstetric need for a planned CS, and who made an oral request of a CS during counseling. Recruitment started out by information schemes were handed out by midwives to potential participants who individually contacted the interviewer (me) to schedule an interview, if they wanted to participate. Six women were recruited this way. Initially, we planned to bypass the midwives to ensure confidentiality and avoid feelings of pressure to participate that might have arisen if the healthcare professionals had collected the informed consents. However, the procedure turned out to be too time-consuming and probably would have resulted in a selection of women who had a strong wish to participate in the study. To achieve a more heterogeneous sample and to speed up the recruitment process, the midwives recruited the informed consent from women to participate directly, gathering women's contact information on the consent form, which was provided to me in person. I then contacted the women who had consented to participate by phone or e-mail to schedule an interview.

Individual interviews were carried out between June 2016 and August 2017 and lasted from 51 to 79 minutes. Women were again provided general information about the study and the right to withdraw at the beginning of the interview, which usually was scheduled late in pregnancy (usually around week 34-37). But some were interviewed after birth. (The time of interview ranged from week 20 in pregnancy to eight months postpartum). We preferred to schedule interviews late in pregnancy when women were likely to have received a decision about the delivery mode and when they were thought to be more available than they would be after giving birth. The interviews took place at my office or at the woman's home if preferable to her. One woman was interviewed both late in pregnancy and after birth because of relevant information to the study questions emerging late in pregnancy. All of the participants were contacted by SMS, e-mail, or a short phone call after birth to get their overall impression of the birth experience and satisfaction with the final choice of delivery.

The interviews were guided by an interview guide (Appendix VI), with open-ended questions and probes, which was flexibly followed as necessary. The interviews usually took a narrative style and were opened with the question "Would you like to tell me your story about why you want a CS in this pregnancy?" The women usually talked vividly and freely, providing thorough explanations for their rationales. Their previous birth experience was often described in detail. Additional questions and probes were then added toward the end of the interview to check that all of the issues had been covered. Sporadically, I summarized my understanding of their rationales and stories, or I asked them to confirm what I had understood to check if my interpretation was correct. However, this was not done in all interviews, and the quality of the interviews improved as my own skills as interviewer also improved. The quality of each interview was also dependent on the dynamic between me and the informant, which was overall perceived as very good but varied with the woman's personality, comfortability, and fluency in the language we spoke. Three women were first generation immigrants born outside Norway (and Europe) and did not speak fluent Norwegian. Two of them were interviewed in Norwegian, and one preferred to be interviewed in English. They were obviously constrained by not being able to express themselves in their mother tongue. Still, they managed to express their experiences and attitudes well and brought the very relevant perspective of immigrants into the data material.

Characteristics of the women

A total of 17 women were interviewed; 14 were multiparous women who had previously experienced a delivery. Three women had been referred for birth counseling in their first pregnancy because of a cesarean request, but two of these women were interviewed at the end of their second pregnancy. They were asked to explain their rational for requesting a CS and their experience with counseling in both pregnancies. The women were between 27 to 42 years old at the interview; all except one woman were married or a cohabitant. There was a large variety in their educational background; four women had completed high school, seven had completed education at the bachelor's level and six had completed education at the

master's level or higher. The same variety was seen in their occupational backgrounds.

Eleven women were finally scheduled for a planned CS toward the end of their pregnancy, whereas four women changed their mind and agreed to have a vaginal birth plan, often involving a planned induction of labor. Two women had their requests declined and were planning a vaginal delivery more or less unwillingly.

Focus group discussions with midwives and obstetricians

Healthcare professionals were purposively sampled for focus group discussions and comprised a favorable heterogeneous sample of informants who had experience with the patient group from different professions and working areas. Focus groups are a well-suited method to obtain qualitative data about experiences and opinions among people who work within a setting of collaboration [123, p. 22]. It was, therefore, a natural approach to answer our research questions. The focus groups were homogeneously composed, after profession, as recommended by Malterud [123], in order to strengthen the group dynamic and facilitate dialogue and participation among all members of each group. Mixing professions and hierarchy could have also provided interesting conversations, but due to the risk of strategic communication and power dynamics, this was avoided [123, p. 44]. Focus groups were, therefore, arranged as three groups of obstetricians (one consisting of consultants only, one of residents only, and one mixed), and three groups of midwives (one group of midwives working in counseling, one working in delivery care, and one working in a combined unit of delivery and postnatal care). Stratification by sex could have been beneficial to avoid the "peacock effect," which is when men tend to dominate the conversations [123, p. 44]. However, few men worked at the clinic, and only four men were included in the sample. They were, therefore, spread across groups. Homogeneity should also be balanced against variation within the groups to allow for nuances and diversity to develop in the material. We regard the lively and self-driven discussions that arrived in the focus groups to be an indicator of successfully composed groups. The groups consisted of three to four participants, which is slightly lower than is usually recommended (five to eight participants) [123, p. 39]. We

experienced this to be an advantage because it allowed for more participation among all of the informants and because there was a considerable time constraint due to pragmatic reasons in the arrangement, giving us a maximum of one-hour sessions (with the exception of one group that was able to allocate more time from their working schedule).

The focus group interviews were carried out in March and April 2017 and lasted between 40 and 70 minutes. All of the participants were invited to participate by e-mail and were provided with an information letter about the study (Appendix V). The focus groups started with a presentation about the study, including the handling and confidentiality of the data as well as right to withdraw. Consent to participate was obtained through active participation in the focus groups. Questions from the interview guide (Appendix VI) guided the discussions but allowed for flexibility to enable more spontaneous conversations. I functioned as the moderator, and my co-supervisor (NHM) functioned as the support moderator during the first focus group with the obstetricians (consultants). Due to the small focus groups, we felt that two moderators took too much place and could inhibit discussion among the participant. We, therefore, refrained from having a support moderator in the subsequent groups, although some observations and impressions of non-verbal communication might have been lost. During the data collection and preliminary analysis (step 1), we evaluated the sample size and saturation. We regarded the information power to be satisfactory to illuminate the research questions after 12 interviews with women and six focus group discussions with healthcare professionals [124]. Recruitment stopped, and the last interviews with the women already enrolled were conducted. Further elaboration on the sample size and saturation is provided in section 6.1.2 of the discussion.

Characteristics of the healthcare professionals

Nine midwives were recruited to participate and had experience from counselling, delivery and/or postnatal care. Several midwives also had experience in primary care midwifery (i.e., pregnancy follow-up). Eleven obstetricians, consisting of six consultants and five residents, all with varying length of experience, participated. The

age of the healthcare professionals at the time of the focus groups ranged from 29 to 63. Healthcare professionals reported having between less than a year and 40 years of experience. Four participants were men, and 16 were females.

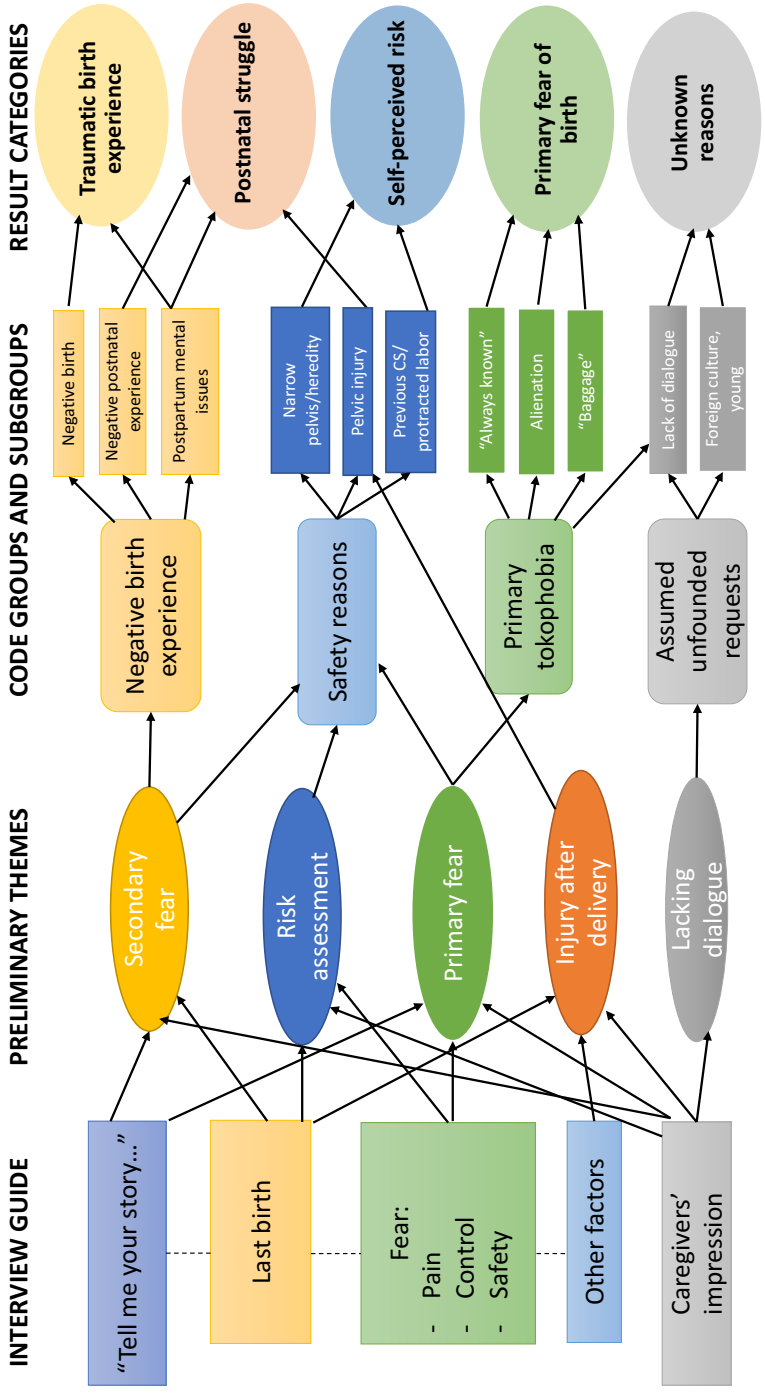
4.3.3 Analysis

All of the interviews and focus groups were carried out, audio recorded, and transcribed verbatim by myself. The length of the transcripts varied from 12 to 28 pages (single line-spaced and written in Times New Roman pt. 12) for the in-depth interviews and 13 to 19 pages for the focus group discussions. The transcripts were arranged and coded in NVivo Software version 11. We analyzed the data according to systematic text condensation (STC), which is a thematic method for cross-case analysis of qualitative data in medical research [112, ch. 9, 125]. This method shares certain similarities and differences with other cross-case methodologies, such as qualitative content analysis [126] and thematic analysis [127]. We chose to use STC because it is well known, and its specific and pragmatic approach to qualitative data seemed like an advantage for a beginner using qualitative methods. STC is conducted in four main steps: obtaining the total impression of the data, coding, condensing, and synthesizing. The first step involves reading whole transcripts stepwise (two to three transcripts at a time) during data collection to obtain an overall impression of the data and allow for flexibility and adjustment of the aim, interview guide, recruitment strategy, and saturation. One seeks to obtain a total impression of the growing material by identifying main themes for further analysis. During the second step, the researcher decontextualizes the text by identifying meaning units in the transcripts and coding them systematically into main code groups. In the third analytical step, the researcher condenses the text from the main code groups by splitting them into subgroups (as a top-down procedure). The content of a subgroup is then summarized into a condensate written in first-person (artificial quotation), which helps the researcher to evaluate the content of the code group and make changes (uncode or recode) if necessary. The researcher then identifies especially well-phrased quotes in the material to illustrate the main content. Finally, in step four, the researcher recontextualizes and reconceptualizes the material by synthesizing the condensates into new descriptions of the interpretations and concepts. The analytical process was

systematic but also flexible, as the themes, codes, and categories were revised continuously during all steps of the analysis. The analytical process developed over time and between the co-authors.

Step one was conducted during data collection by me and my main supervisor, while steps two and three were conducted mainly by me after data collection had ended. Step four was done in collaboration between me and my two supervisors, allowing for cross-check between our understandings of the material and the development of the main categories. Figure 1 (reprint from Paper I, modified with permission [112]) shows the analytical process with the development of the preliminary themes, coding groups, and subgroups as well as the development of the main result categories for Paper I. The preliminary themes, codes, and categories were changed and reorganized during the analytical process, and Figure 1 presents the final version of the analysis. It seeks to illustrate the flexibility and complexity in the analytical process and development during the analysis from left to right.

Figure 1: Illustration of the analytical process for Paper I



4.3.4 Application of theory

Whether the qualitative analysis is supported by a theory or not, the nature of qualitative research is influenced by the "glasses" through which the researcher observes the data. These glasses are influenced by the researcher's background as well as the existing knowledge (empirical as well as theoretical) they have obtained [112, p. 42]. I will elaborate more on my reflexivity in section 6.1.2.

The analysis of qualitative data can take three different styles with regards to the use of theory [128]. Crystallization style develops categories founded purely in the empirical data, in which the researcher immerses themselves in the text and sorts out the essential points. This technique is rather noncommittal and involves the risk of producing insufficient documentation and transparency between the data and the development of the results [112, p. 95]. Template analysis style is a theory-driven approach in which the data are coded according to predefined categories obtained from an existing theory. While this approach contains a certain risk of reproducing existing knowledge, it is also well-suited for development of new insights [112, p. 95]. Editing analysis style (often called data driven) is an approach that lies in between these two styles; the researcher's theoretical position is reflected upon but is used more flexibly in the data analysis. This analytical approach is suitable for developing new concepts [112, p. 95].

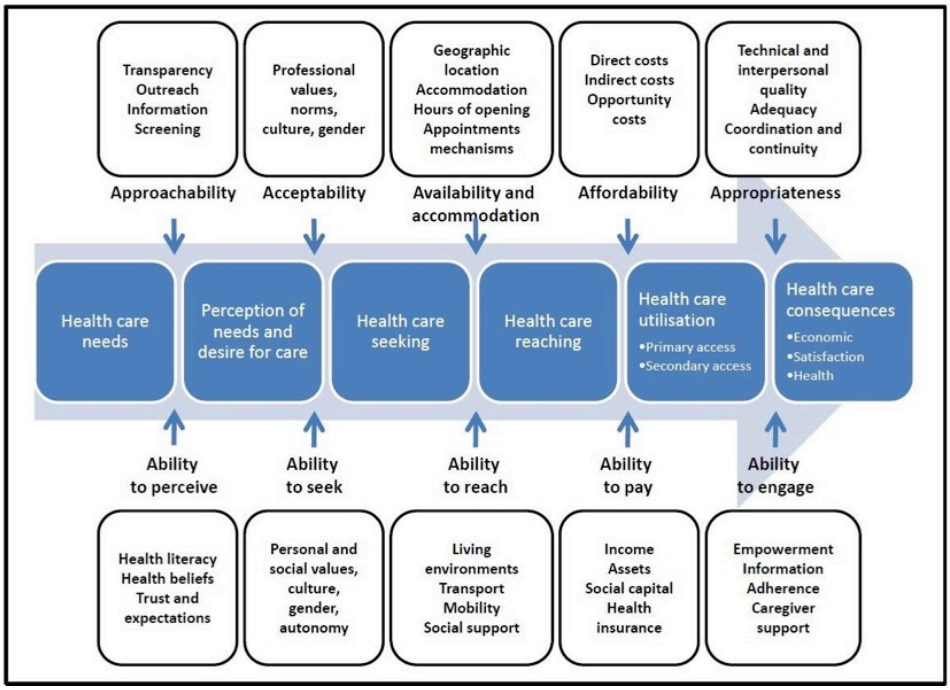
The analysis in Paper I was descriptive (data driven), without the application of a specific theory during the analytical process, although the analysis was influenced by existing empirical knowledge of the field in line with the editing analysis style [128]. During the analysis for Paper II, we applied a theory during step four, when moving from the third to fourth column of Figure 1 (with different code groups and result categories developed for this analysis). We started out by coding the data according to the editing analysis style, but the results were finally structured according to predefined categories from a distinct framework (theory), which is similar to the template analysis style. This enabled us to explore the findings of the interviews independently of a predefined theory and then to illustrate them by a framework we found relevant and useful.

Hence, the three approaches offer different ways of organizing data and developing new knowledge, and the choice of design was based on our research questions and the relevance of the findings within the existing literature. When seeking answers to the objective of Paper I, we wanted to approach the material as open mindedly as possible in order to develop new understandings of the phenomenon primarily based on the data material. This is why we chose to not apply a specific theory during this analysis. During the analysis of Paper II, we found a specific framework of access to healthcare to be useful to present the material in a way that would be relevant to the existing literature as well as to medical practice.

4.3.5 Theory used in Paper II: A framework of access to healthcare

Women asking for a CS that professionals may argue they do not need are, nevertheless, in need of equal access to good-quality healthcare, independent of their final mode of delivery. The existing literature on the concept of "access to healthcare" is complex, and there are many interpretations. Several frameworks of access have previously been proposed, but one of them stands out as the most nuanced and useful [129]. Levesque and colleagues developed a systematic framework based on a synthesis of published literature on the subject. They outline a definition of access as "the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care" [129, p. 4]. Access to healthcare results from the interface between the features of persons, households, physical, and social environments on the demand side of care and the features of healthcare system, organizations and providers on the supply side. Facilitators and barriers to access can, thus, occur on both sides of this interface. For access to be realized (through the blue arrows of Figure 2), a person will need to take certain steps to obtain healthcare, which represent crucial transitions where facilitators and barriers can be revealed.

Figure 2: A conceptual framework of access to healthcare, licensed from [129] http://creativecommons.org/licenses/by/2.0



Consequently, Levesque et al. present five dimensions of access on the supply side of healthcare, and corresponding five abilities of care-seekers on the demand side. These dimensions are important for the five crucial steps on the way to approach access to healthcare (across the blue arrow).

The first dimension of access includes the approachability of a service, which relates to whether people with a healthcare need can identify that such a service exists. Approachability can be facilitated by, for example, transparency, outreach, information sharing, and screening in order to increase awareness of the service among people who may need it. For a service to be approachable, a patient must have the ability to perceive a need for such a service, which is dependent on the literacy, knowledge, and beliefs of the patient.

The second dimension, acceptability of a healthcare service, depends on the values, norms, and culture of the healthcare professionals. The ability to seek care is also dependent on the patient's personal and social values and their capacity and autonomy to choose to seek care and knowledge about their options and rights.

The third dimension, availability and accommodation, refers to practical arrangements and how healthcare services can be reached physical and timely. The corresponding ability to reach depends on the care-seekers' living environments, transport mobility, and occupational flexibility.

Forth, the affordability of a health service refers to the cost of the service (including direct and opportunity costs) on the supply side. On the demand side, it refers to the ability to pay for care (including income and health insurance).

Finally, the fifth dimension, the *appropriateness* of care, indicate the fit between the service offered and the care-seeker's need. The adequacy of care depends on the appropriateness (type of care) and quality (how care is provided) of care. The care-seekers' *ability to engage* in the offered care is the corresponding dimension of appropriateness on the demand side, and it refers to participation and involvement in decision-making and treatment.

This framework of access to healthcare appears to be comprehensive and dynamic; access is highly dependent on personal characteristics, cultural context, and the organizational structure of healthcare systems. This comprehensive understanding of access makes the framework relevant and useful for exploring the barriers and facilitators of healthcare for other specific issues and in different contexts [129].

4.3.6 Ethical approval

The study comprising both interviews with women and focus group discussions with healthcare professionals was approved by the regional committee for medical and health research ethics in Norway (7 Dec 2015 Ref: 2015/2029 REK vest, see Appendix IV). The focus group discussions were approved by the Norwegian Social Science Data Service (20 Nov 2015 Ref: 45158/3/MSS). The information letters provided to the informants prior to their interviews and focus groups, along with the informed consent scheme for in-depth interviews, can additionally be found in Appendix V.

4.4 Normative analysis (Paper III)

Paper III seeks to explore how to promote ethically justifiable decision-making processes for CSMRs. We draw upon the empirical findings of Paper I and II, in addition to other relevant empirical literature, to make an integrated normative analysis of the research questions. We used Grimen's nexus of power, trust, and risk (described in Section 2.2), which underlines the maternal-professional relationship in modern healthcare, to conceptualize the ethical issues surrounding CSMRs. We further drew upon Lukes' definition of power (Section 2.2) to conceptualize beneficial power and how to reach justifiable decisions for CSMRs in an asymmetric relationship between women and healthcare professionals.

5. Results

5.1 Paper I: Maternal reasons for cesarean requests

The findings from Paper I explores the maternal reasons for cesarean requests and revealed complex and nuanced explanations among women embedded in various life experiences. Five principal categories emerged from the analysis.

For most women, a previous negative birth experience was the dominant reason for their reluctance toward another vaginal delivery. The birth experience, commonly described as traumatic, could initiate a secondary fear of birth. Having a planned CS was a way of protecting themselves from experiencing a new trauma.

For several women, the time following their last delivery, which included the postnatal ward experience and the extended puerperium, dominated their negative experience, leading to their request for a planned CS. For many of these women, they perceived surgical birth to provide them with better mental health, although, they expected a more physically challenging recovery as compared to vaginal delivery.

Some women requested a planned CS due to safety reasons based on the perceived risks of an emergency CS. They commonly did not believe that they were able to succeed with a vaginal delivery and sought to avoid an emergency CS by having a planned one instead. Such perceptions were based on e.g. history of delivery among their female relatives, their perception of having a narrow pelvis, their expectation of having a big baby, and their own previous birthing experiences.

A few women requested a CS in their first pregnancy based on a deeply held fear of, or a feeling off alienation toward, vaginal delivery, which they had carried since their early teens.

Sometimes, though rarely, obstetricians encountered women requesting a CS without what they regarded as well-grounded reasons or fear, and where there were considerable difficulties of establishing a sufficient dialogue with the women.

5.2 Paper II: Access to counseling and decision-making

Paper II, which explores the counseling and decision-making process for women requesting CSs, revealed considerable tensions as well as fruitful interactions among women and healthcare professionals involved in counseling for CSMRs:

Both women and healthcare professionals advocated for vaginal deliveries. Women were highly aware that a vaginal delivery was the best option for their child. Most of the women would have delivered vaginally, had it not been for their reasons for requesting a CS. Healthcare professionals usually endorsed empowering women to have a vaginal delivery, although they admit a CS in some situations was recommendable.

Many women had low expectations prior to counseling and feared not to be understood or taken seriously. Although most were very pleased with the counseling process, especially when they were led by midwives, many complained about a long and exhausting process as well as postponed decisions, which led to uncertainty and increased stress. Midwives invested their time in creating a safe dialogue with the women, which aimed to (re)establish trust.

Healthcare professionals, especially obstetricians, had diverging attitudes toward refusing a woman a CS when they regarded it as inappropriate. Some healthcare professionals emphasized professional autonomy and responsibility, while others did not feel comfortable with forcing a woman to have a vaginal delivery and emphasized informed choice. Several obstetricians delegated the decision to the woman as a strategy of facilitating trust and dialogue. Midwives were concerned about the mental costs of a forced delivery as well as the consequences for the attachment between mother and child.

Women also held diverging attitudes toward maternal autonomy, as the majority did not support a complete maternal choice for a CSMR. They rather endorsed a good, shared dialogue and counseling process. Counseling primarily led by midwives was highly appreciated among both women and healthcare professionals.

5.3 Paper III: Trustworthy decisions for CSMRs

The normative analysis of the conflict between maternal wishes for CSs and the general medical recommendation of a vaginal delivery revealed the need for trust.

A closer discussion of the entitlements of women and obstetricians revealed that women may not claim a planned CS without a presumed benefit of the intervention. Nevertheless, they should be respected for their deliberative capacity. The obstetricians are, likewise, entitled to provide what they regard as acceptable and good-quality care. Thus, they may object to providing potentially harmful surgery without prospective benefit. The result is a situation of opposed autonomous claims.

Inspired by Grimen, we demonstrate that the maternal-professional relationship is rooted in a nexus of power, trust, and risk, in which women depend on healthcare professionals for help. This places women in a position of structural inferiority to healthcare professionals when it comes to power, knowledge, options, and general vulnerability. Trust is necessary for beneficial power to exist in healthcare and for communication and cooperation to take place. If women are to benefit from counseling and decision-making, structural initiatives are needed to control and limit the use of power so that women can find the processes trustworthy and rely on the recommendations of healthcare professionals.

Inspired by Lukes' three-dimensional notion of power, we developed a framework seeking to facilitate trust and make room for beneficial power in decisions regarding CSMRs. First, we argue for a SDM process, involving both parties share information. Second, healthcare professionals should never resort to coercion. Third, women should be involved in the agenda setting and planning. Fourth, women should be presented with neutral and accurate information, avoiding phrases such as "normal," "best," and "right or "wrong." Fifth, information should be made publicly available. Sixth, healthcare professionals should be made conscious about the ethical use of power in education programs and through ethical guidelines. Finally, holding healthcare professionals accountable for their use of power should be regulated in a way that allows for women to make appeals in the case of any breach of that power.

6. Discussion

Before I discuss the relevance of our main findings in light of other literature, I will consider some of the methodological challenges that are relevant for interpreting the results.

6.1 Methodological considerations

All research should be evaluated with regards to its rigor (trustworthiness). Quantitative research traditions describe the rigor of findings with concepts such as validity, reliability, and generalizability. These concepts are commonly referred to within qualitative research as well, although many researchers encourage and use the corresponding concepts of credibility, dependability, and transferability in order to distinguish between the different research traditions [126]. Other researchers, however, claim that the essence of validity and reliability persists regardless of the research tradition, and mixing labels may just cause more confusion [130, 131]. I will, therefore, refer to the universal concepts of validity and reliability in this thesis. First, I will reflect on my own role as researcher in this context, which is specifically important for validating qualitative research [131].

6.1.1 Reflexivity

When considering qualitative findings, it is important to also incorporate the subjectivity of the researcher on the validity of findings [130]. The researcher's background will always affect the choices made (e.g. the research questions asked and the angle of the investigation and analysis) [131]. Identifying the preconceptions a researcher brings into a research project is also an important part of reflexivity [131]. Looking back at when the idea of this research project emerged, when I first was made aware of the phenomenon of women requesting a planned CS toward the end of my medical education, I imagined a modern, resource-rich woman in need of control, or, perhaps, she had concerns about bodily effects of a vaginal delivery. But first and foremost, I believe I visualized a primiparous woman requesting a CS. When

I started reading the literature and interviewing women about their reasons for requesting a CS, I was surprised by their answers.

When I planned and conducted this fieldwork, I was a newly educated medical doctor, with limited clinical experience. I had not worked in obstetrics and gynecology but had, with great interest, attended births with midwives and physicians during clinical rotation in my medical education. This made me approach the project with some professional insight; as well, I had the advantage of being an "outsider," who had no role to play in clinical follow-ups of the women I interviewed. I found this detachment to be advantageous, especially during the in-depth interviews with women, which facilitated honest dialogue about their experience with delivery and counseling. During the focus groups, however, a clinician might have had an advantage of probing deeper and more specifically as well as possessing more background information about the issue beforehand. Still, I was not free from my medical presumptions and perceptions as an interviewer, and I, perhaps, did not question all aspects of the phenomena as open-mindedly as, for example, an anthropologist could have done.

I am also a young woman, and mother, like the women I interviewed, which was helpful for establishing a good dialogue with them. However, I found my own personal preference for, and experiences of, giving birth as quite different from the women I interviewed. My preference for vaginal delivery (in low-risk pregnancies) is also a consequence of the medical knowledge and Norwegian culture I possess. This provided me some distance toward the study subject, which might have been beneficial, but it might have also affected my interviewing and my interpretation of the results. Having a different experience and preference of giving birth did, however, not prevent me from understanding their rationales. As the interviews progressed, I rapidly gained an understanding of how important a previous birth experience (which in my case was completely uncomplicated) could be for preferring CSs.

Many of the same assumptions were also valid for the focus groups. Having a medical background and participating in delivery care during my education, perhaps,

allowed the informants to talk freely while using medical terminology because they assumed I understood their work. However, there was a large age gap among healthcare professionals, as well as in clinical experience, making my own age and lack of experience quite inferior to my informants. I found the discussions to be lively and self-driven, often obtaining a high tempo (especially among the group of consultants only), making the moderator (leader) role a little difficult to abide to. I did not find this as a disadvantage, as the questions from the interview guide was well covered by all of the groups.

I read and discussed all of the interviews with my main supervisor, who is an ethicist. Furthermore, we read and discussed coded and condensed material together with my co-supervisor, who is an obstetrician. Working together in planning and analyzing the qualitative studies, allowed us to analyze and ask questions from different angles throughout the process.

6.1.2 Reliability

The reliability (and the corresponding term “dependability”) of the results refers to the stability of the data collection measures [130]. The researcher seeks to describe potential instability and changes in data and alterations made over time during the studies [126]. When data collection is comprehensive and is collected over a long period of time, there is a larger risk of inconsistency in the data gathered. It is then important that the same topics have been addressed among all of the informants [126].

The in-depth interviews were collected over a large time interval (two years), which brings a risk of inconsistency in the data collection. However, all of the participants were asked about the same main themes in the interview guide, which was modified and changed somewhat but was kept quite constant, especially after the first interviews. Also, the women did not have any possibility to interact with one another to influence the data collection or results. The most important factor to consider regarding reliability was that some of the women were interviewed late in pregnancy (13 out of 17 women, usually around week 37) and some after birth (four women,

usually one to two months postpartum), which might have influenced their story. One woman requesting a CS was interviewed in week 21 of her second pregnancy, and one woman was interviewed eight months postpartum because of late recruitment. All (except one) of the women, however, had received a decision on delivery mode at the time of interview, except one woman who was, therefore, interviewed twice. My own impression of consistency in the data gathering was that knowing the final mode of delivery was of great importance for cross-analyzing the content of the interviews, thus becoming an important factor for scheduling the interviews. It was pragmatically difficult to assure a higher consistency in the scheduling of interviews with the women, as the process was already quite rigid and time consuming. We prioritized scheduling the interviews at a time when we assumed the woman had received a decision regarding their delivery method, and we hoped to be able to meet them before birth, as we thought the risk of dropout would be higher after delivery. Surprisingly, the postpartum interviews showed to be quite easily accessible for the women (and their newborns), and they often included an additional rich description of how the final delivery was experienced. Overall, we believe the reliability of the findings are satisfactory; the findings have illuminated the research questions from a broad angle, giving us a chance to capture a large variety of experiences.

The focus group discussions were conducted over a six week period, with an interview guide that changed very little (adding a few probes only). The group discussions developed individually and differently, but the main themes from the interview guide were covered for all of the groups. Participants might have been able to discuss with one another between the group sessions. However, the healthcare professionals talked spontaneously and freely about the management of a controversial patient group that had obviously evoked difficult feelings and equivocal attitudes among them. The richness of the discussions varied with how much experience the healthcare professionals had with these women. Midwives, for example, working in postnatal care felt less experienced with the patient group, and, although this group provided valuable insights and experiences, it appeared to be less rich in data than the other groups.

6.1.3 Internal validity

The validity (or credibility) of qualitative research findings seeks to question whether the analysis describes what it was intended to describe, explain, or theorize [130]. In other words, whether we were able to answer the intended research questions with the data gathered.

Sample, sample size, saturation, and information power

Central to validity is selection of the setting, informants, and approach to data collection. Gathering data from people with various backgrounds and experiences will help shed light on the research questions from a broad angle [126]. Source triangulation is conducted when several techniques are used for gathering data, or when informants are recruited from different positions shedding light on the research questions from different perspectives [112, p. 191]. We combined both in-depth interviews and focus group discussions, with women and healthcare professionals (midwives and obstetricians), in this study to illuminate the research questions from as many perspectives as possible. The background characteristics of the informants also show a favorable heterogeneous sample, increasing the validity of the material by having captured many aspects of the phenomenon under study. We did not do any observational research, which would have undoubtedly contributed to this study. It would, however, have been difficult to implement in a clinical setting addressing sensitive topics and where confidentially issues would have needed to be addressed.

An appropriate sample size is important for ensuring the internal validity of the study [124]. Too much data material may lead to superficial and insufficient qualitative analysis, while too little may not answer the study questions [112, p. 60]. After approximately 12 interviews, we found the material to reach a sense of saturation, in which the typical rationales and birth stories began to reoccur. The same was experienced after six focus group discussions. Still, new experiences and descriptions emerged with every interview and focus group, as every story was unique. The wide inclusion of all women requesting a CS, in addition to the healthcare professionals, also made the recruited sample heterogeneous and, perhaps, more difficult to completely saturate. Saturation is a concept founded in grounded theory and is

supposed to be continuously evaluated during data collection and analysis [124]. Saturation is said to occur when further data gathering does not seem to add any new contribution to the theory developed from the data analysis. However, saturation has been criticized as representing a theoretical ideal targeting a total amount of facts, which seems inappropriate for research within a constructivist tradition that regards knowledge as partial and dependent on the situated view of the researcher [112, p. 61, 124]. Malterud et al. suggest that the sample size should be guided by an evaluation of information power during data collection [124]. Information power is dependent on the broadness of the aim and sample specificity, use of theory, dialogue quality, and analysis strategy. We held a specific aim for Paper I and a wider one for Paper II; hence, the analysis of Paper I was descriptive and paper II was more theory-driven. We allowed for a quite wide inclusion of informants, including all women requesting a CS for non-obstetric reasons (primiparous and multiparous), midwives, and obstetricians. The dialogue was perceived as good for the individual interviews as well as for the focus groups; both provided rich material. We regarded the sample as sufficiently rich to illuminate the research questions after 12 individual interviews and six focus group discussions and ceased the recruitment process. Women who had already been recruited were interviewed, resulting in a sample size of 17 interviews with women and six focus groups with healthcare professionals (20 healthcare professionals in total).

Validity of the analysis

Another aspect of the validity (credibility) of a study depends on how well the developed codes and categories cover the data, which can be strengthened by sharing representative quotations form the material as well as seeking agreement between the co-authors [126]. We included several authors with different backgrounds in the research team and analysis as a way of increasing the validity of the analysis and findings; two of us read all transcripts, and three of us agreed on the development and interpretation of the main results from the coded material. Rich quotations were provided in the final published manuscripts, and even more quotations were used during the analytical process. The goal should not be to ensure that the data are coded and labeled exactly the same way by each researcher (which is not a goal in

qualitative research) but to agree about how the data have been sorted through conversations between several co-researchers [126].

Some researchers also provide member checks, in which participants evaluate the transcripts and/or the results. This does not necessarily provide more "truth" to the material and results, as it is the researcher's responsibility to interpret the material, but member checks may contribute to confirmability [126]. Especially, for cross-case analysis (analysis across different cases), in which we seek answers based on broader material, participants may not feel represented in all aspects of the results section [112, p. 183]. We did not provide member checks, but I sporadically summarized what the informants had told me and asked if I had understood them correctly. However, in retrospect, I realize that I should have done this to a larger and more systematic extent to ensure the internal validity of the interviews.

The fact that all interviewing, transcribing, and coding was done by myself hopefully strengthens the validity of the analysis, as I have maintained a comprehensive overview of every informant and recalled much of the non-verbal dialogue that occurred in the interviews during transcription. This has probably increased the likelihood of correct transcription and understanding of the quotes in the analysis. However, involving the research team to a larger extent in the line-by-line transcription and the subsequent analysis could have led to a more critical examination of the interviews as well as some of my presuppositions. The interviews were conducted in Norwegian for all participants, except one, who was interviewed in English (see section 4.1.4). The analysis of the transcript was undertaken in Norwegian as was the development of codes and categories, which were then translated into an English results section with quotes. The translation of quotes and analysis from Norwegian to English represents a risk of misleading translation and misinterpretation. To avoid this as much as possible, the quotes were translated from Norwegian to English, and the language was cleaned by a professional language editor and translator, who was fluent in both English and Norwegian. The manuscripts were then back-checked by the research team.

6.1.4 External validity

The transferability of qualitative finding refers to the extent to which the findings are transferable to other groups or settings [126]. Ideally, the study and context are described in a transparent way so that every reader can evaluate the transferability of the results to their specific setting. Therefore, a rich description of the culture and context in which the findings have arisen, as well as an explicit description of the recruitment, data collection, and analysis, is important to enhance the reader's ability to transfer knowledge [126]. Based on a critical and reflexive evaluation of the above, researchers may, thus, make suggestions about the transferability of their own findings.

In the recent sections as well as in the methods section, I have elaborated on the recruitment, data collection, analysis, and the validity of the findings. I have outlined the cultural context of these findings in section 1.1.5 and 4.1.1. Our sample of informants showed large variation in background characteristics, which strengthens the external validity of the study [131]. However, women were recruited from specialized care only, and women with either a strong interest in sharing their story or having more justifiable reasons for requesting a CS might have been more likely to participate in the study. The midwives responsible for the counseling care suggested that about 70% of the women coming with a cesarean request change their mind and give birth by a vaginal birth plan. However, as many as 10 (out of 17) women who participated in the study gave birth by a planned CS, which may indicate a selection of women toward either more severe fear or well-grounded requests. Therefore, we may assume that other reasons and experiences of requesting a CS may arise among women who never approach specialized care but hold a preference for a CS and perhaps request a CS in primary care but change their mind earlier on. This research, thus, presents the reasons and experiences of women entering counseling for a cesarean request in specialized care, which to a high degree persisted in their requests and was accepted for surgery. When it comes to the sample of healthcare professionals, we recruited almost all available and relevant healthcare personnel at the hospital. They comprised a large variety of professions, fields of competence, years of experience, and age. As a result, we believe that we have been able to

investigate the experiences and attitudes toward women requesting a CS from a broad and varied perspective. It should be mentioned, though, that all of the healthcare professionals worked at the same hospital, where the CS rate is relatively low compared to other hospitals, which may be influenced by cultural attitudes supporting a more restrictive use of CSs in general.

Our findings are obviously embedded in the cultural and organizational context from which they have emerged, and regarding maternal preferences for delivery, there is likely to be large cultural differences between Norway and other countries. Cultural differences concerning the preference of mode of delivery are also likely to be present within Norway. Still, we believe that some of our findings are of a universal character and relevance. For example, some maternal reasons for requesting a CS outlined by Paper I relate to fundamental human conditions, such as birth experiences, fear, and trauma. Traumatic birth experiences might have existed at all times and in all cultural contexts, and it is an important reason for why women would want to protect themselves as far as possible from re-experiencing such trauma. Exploring the mechanism behind the creation of such trauma is, thus, important and may be context dependent and prevent unnecessary CSs in the future. In section 6.2, I will consider our results in light of other literature and elaborate more on how the Norwegian context may differ from other countries and cultures.

The findings of Paper II are highly dependent on the Norwegian context as well as the local healthcare system regarding access to patient-centered counseling for cesarean requests. Still, some of these findings also correlate well with the broad international literature, which emphasizes the controversy and variation in attitudes among healthcare professionals, and may, thus, be assumed applicable in several other settings. Paper II also illustrates a methodological approach by the use of Levesques and colleagues' framework of access to care to investigate the provision of a controversial procedure, which may serve as an example to be transferred and applied in other healthcare settings.

6.1.5 Consideration of the normative analysis

Many of the previously mentioned considerations of the qualitative studies indirectly apply to the normative analysis, which was partly based on the empirical findings of Paper I and II. In assessing the normative analysis, one can challenge either the choice of the theory applied or the development of the argument.

The first concerns the choice of the lens through which one has chosen to investigate a phenomenon. One may agree on the development of the argument along the text but disagree on the basic premise for the analysis. Even if one does not completely disagree on the choice of theory or position as a relevant starting point, the choice considerably affects the outcome, and choosing another path to go would naturally lead to other results and implications, not implying, though, that any of the approaches are necessarily more right or wrong. It is quite similar to choosing the lens through which the researcher views their qualitative data and whether that is descriptive or theory driven. Explaining why a particular choice was made, as well as the consequences of that choice, is therefore important.

We made several important research choices in our third paper. First, we chose to narrow our scope of analysis to concentrate on the professional-maternal conflict concerning interest and autonomy. We could have chosen to discuss other issues, such as resource allocation and priority setting issues in a public healthcare system. We chose to analyze an aspect that we believe lies at the core of ethical issues surrounding CSMRs, as important issues are at stake for both parties regarding their ability to make decisions. Additionally, the analysis provides a universally relevant contribution to the existing literature for all healthcare system and settings.

Second, we chose to analyze this conflict between the interests of women and healthcare professionals through the concepts of power, trust, and risk in healthcare and how SDM has influenced the importance of these concepts. We could have approached the issue from a range of different ways and positions, but we made a pragmatic choice about what we found to be a valuable contribution not only to the existing literature but also to the real-world provision of care in all kinds of

healthcare systems. SMD has become a recommended decision-making model in modern healthcare, which is tightly linked to the emphasis of autonomy that has emerged in the development in modern bioethics [111]. Power imbalance is a crucial element of the professional-patient relationship, which patient autonomy and SDM have tried to address over the past decades. Accordingly, we hope our analysis can make a valuable contribution to existing literature and debates.

When it comes to the development of our arguments, we have restricted the scope of our aim to narrow down the relevant discussion to the specific objective. Still, there may be considerations we have overseen and assumptions to be further challenged. We highly welcome further debate to challenge our paper's findings in the future.

Although we find our empirical analysis and implications to be quite universally relevant and applicable, we believe it should be up to every individual reader to evaluate the transferability of our analysis to different settings [126]. Our paper's findings concerning the clinical implications of CSMRs may be transferable to other settings; moreover, our paper illustrates a methodological example that may be applicable to other settings and issues (e.g., other controversial requests for treatment).

6.2 Discussion of main findings

Nuanced reasons calling for individual judgement

Paper I showed that nuanced reasons lie behind maternal requests for a planned CS, which was often influenced by their previous birth and postnatal experiences, mental health concerns, and risk considerations.

A synthesis of other qualitative studies has similarly shown that emotional and personal experiences, particularly previous births, were important reasons for requesting a planned CS [132]. One study among first-time mothers in Sweden also found an impact of personal negative experiences with healthcare earlier in life [62].

Fear of childbirth is a common reason among women requesting a planned CS [57-59, 133, 134]. Fear commonly emerges as a consequence of previous traumatic birth experiences [132, 135, 136], like for most of the women in our study. The increased prevalence of CSMRs among multiparous women seems to be caused by previous birth experiences (e.g., a previous emergency CS), rather than parity per se [58], which correlated well with the rationales of the women in our study. Even though others have shown that objective measures poorly predict a subjective traumatic birth experience [60, 61], many multiparous women in our study had experienced either operative deliveries and/or an emergency CS. A previous CS has also shown to be associated with a cesarean request [55, 57, 59], but our study suggests that cesarean requests in light of a previous CS are often due to a negative birth and/or postnatal experience or a self-perceived risk for a repeat emergency CS. If previous birth experience is a major driver of a CSMR, it may be partly regarded as an iatrogenic problem with potential for prevention by proper midwifery and mental health support [137]. The women as well as the healthcare professionals in our study called for postnatal debriefing as a preventive initiative. The effects of such an intervention on the development of traumatic stress reactions are currently unclear [138], but women and midwives experience it as beneficial [139]. It would be interesting to know more about debriefing's impact on subsequent cesarean requests among women.

Some women experience a primary fear of birth emerging prior to or within their first pregnancy, which often involve concerns about safety and control [62, 63, 134, 140]. This correlates well with the descriptions made by the two first-time mothers included in our fieldwork, in addition to the findings from a Swedish study indicating deep-seated fear carried since early youth [141]. Our study indicates that primary fear of birth can be accompanied with an alienation towards vaginal delivery, which may serve to explain the misconceptions about safety among primiparous women.

Despite the current evidence, a planned CS is often perceived as safer than a vaginal delivery among women requesting a CS [62, 63, 133, 134]. Several women in our study requested a CS based on a self-perceived risk of an emergency CS. This may explain why many women perceive a planned CS to be a safer alternative and, thus,

why some women request a CS in the absence of clinical anxiety. A planned CS is safer than an emergency CS (as outlined in section 1.2). However, healthcare professionals did not always agree that an emergency CS posed a high risk for these women. The reasons for a perceived increased risk for an emergency CS include previous obstetric history (including protracted labor or an emergency CS), expecting a large baby, perceptions of having a narrow pelvic outlet, and a history of CSs in the family. Others have claimed that CSMRs rarely appear in absence of previous or current obstetric complications, which underscores the relevance of maternal concerns about risk [54, 133, 142]. What constitutes significant obstetric or medical indication for CS seems to represent a large gray area with considerable room for clinical discretion and the need for individual case-by-case judgement.

The obstetricians talked about experiences with some women presenting without clinical fear of childbirth and who lacked willingness to establish a dialogue or accept counseling. Other studies have similarly found that about a third of women who fear childbirth do not accept treatment and demand a CS without deliberation and counseling [135, 143-145]. Another study has shown that only 43% of first-time mothers requesting a CS have a significant fear of childbirth [65]. The reasons and arguments behind these requests remain unclear. Why some women do not accept recommended counseling needs to be better understood. This could, for example, be due to lack of trust in healthcare professionals and/or the healthcare system. If that is the case, efforts to enhance the trustworthiness of the providers and/or the system are called for.

Cultural norms and acceptability

Paper II showed a prominent culture for vaginal delivery in Norway, which is in line with other Scandinavian studies [71, 146]. Most women in Norway do prefer a vaginal delivery [55, 58]. Swedish women requesting a CS often felt stigmatized in society and preferred not to talk to other people about their experience [62]. Such cultural favoring of vaginal delivery may be a reflection of the central and highly valued role of midwives in delivery care in Scandinavia, which may, partly, explain the low CS prevalence compared to other high-income countries [71]. This situation

stands in contrast to other settings where CS is perceived as culturally favorable. In countries with a high prevalence of CSMRs, such as Brazil and China, CSs are typically accessed through private delivery care [2], an option that is not present in Norway. Among women in Iran, a CS was perceived as a modern, fashionable, and high-class delivery mode [147], and Iranian women appeared to have more trust in obstetricians than in midwives [63]. While some women in Iran were encouraged to undergo a cesarean delivery by their husbands [119], Austrian women were encouraged by their gynecologists [134]. Another study from Australia demonstrated that women perceived a planned CS as easier, quicker, and more controlled [148]. This finding stands in contrast to descriptions made by women in Paper II, as they understood a planned CS not to be an easier mode of delivery, and the women claimed to want to deliver vaginally had it not been for their reasons for requesting a CS.

Appropriate counseling and decision-making

Midwives invested time in (re)establishing trust among women in counseling for maternal cesarean requests. Trust was often lost due to a previous negative birth or postnatal experience. Women often expected not to be understood or taken seriously prior to counseling, reflecting their lack of trust in the support they were seeking. Nevertheless, most women were generally relieved and satisfied with the counseling they received by midwives.

Even though fear of birth is an important reason and predictor of a CSMR, CSs were generally not regarded as a treatment for anxiety by healthcare professionals in our study. Fear of childbirth can be treated with psychoeducation and cognitive therapy, as more than half of women withdraw their CS requests after treatment [135, 149]. Several studies have shown that intensive therapy, group psychoeducation, and relaxation can reduce anxiety and depression in and after pregnancy and can have a positive effect on delivery in terms of lower CS rates, reduced labor time, and better birth experiences [143, 150-152]. Like in our study, poor information and delays in decisions about CSs have been identified also among women requesting CSs in the UK [153]. Investing time and effort in proper counseling for women requesting a CS

may, thus, improve maternal and child mental health and reduce costs through preventing surgical deliveries and limiting postpartum mental health problems. Nulliparous women with a severe fear of childbirth generate considerably more costs than women with a low fear of childbirth [154].

Counseling provided by midwives, rather than obstetricians, for low-risk women requesting a CS may also be beneficial and was highly valued by the women as well as the healthcare professionals interviewed in our study. It may, perhaps, serve to increase satisfaction among women and reduce CS rates as seen with midwife-led continuity of care models in delivery care [6, 155]. Midwives have a highly valued role in Scandinavian delivery care, which may partly explain the high preference for vaginal deliveries among women and the low prevalence of CSs and CSMRs [55, 58, 71].

There were considerable differences between the obstetricians' willingness to decline a cesarean request when regarded as clinically unjustifiable. Some obstetricians saw it as their professional duty of providing adequate care, while others regarded it as wrong to force an informed woman into a vaginal delivery and did not see it as worth the emotional burden of dealing with patient complaints. Discrepancies in attitudes among healthcare professionals have been found between obstetricians from several European countries, in which obstetricians in the UK are the most willing to comply with a CS request, and Spanish obstetricians are the least willing [10]. The willingness to comply was significantly associated with the country origin, fear of litigation, and working in a university hospital, whereas female physicians with children were less likely to comply. Norwegian physicians are protected against financial and medicolegal consequences of patient complaints and litigation through the Patient Inquiry and Compensation System [77]. Even in a setting of medicolegal protection, we have found that, like for other European countries [10], fear of litigation is relevant factor in clinical judgements. This finding is supported by a Norwegian study that found a wide variance in judgements about CSs in ambiguous cases, which were affected by the perceived risk of litigation and malpractice complaints but not by risk attitude [156].

A Norwegian study among obstetricians showed that the majority (62%) of obstetricians regarded CSMRs as clinically problematic [74]. Older, male obstetricians and obstetricians working in the western region of the country were less likely to regard CSMRs as problematic. However, obstetricians working in the western region were less likely to perform a CSMR. This finding points to regional differences in practice and attitudes in Norway in addition to the intrainstitutional variance found by our study.

Obstetricians cited professional autonomy as a reason for declining maternal requests lacking medical indication. Respecting maternal choice in the provision of a CSMR also varied considerably between obstetricians in different European countries; Spanish physicians were the most frequent in totally refraining from providing a CSMR [10]. Healthcare professionals, just as women, are autonomous agents, both as individuals and as professionals. They are entitled to act in line with good professional standards and provide good-quality healthcare in line with professional guidelines and recommendations. Objecting against providing harmful treatment is an act of conscience [94]. Thus, rights and obligations are bilaterally present within both parties of the professional-maternal relationship when shared decisions for a CSMR are to be made.

Neither a majority of women nor of healthcare professionals in our study favored total maternal choice. Both parties highlighted the benefits and importance of establishing a shared dialogue. Another study from the UK confirms that women do not claim autonomous choice for CSMRs [157]. Theoretical literature is less conclusive on (maternal) autonomy, providing various understandings and interpretations of the concept (Section 2.2). However, the common implementation of patient autonomy in liberal healthcare systems is the right to refrain from medical treatment and to take part in decisions about relevant treatment options but not to demand treatment that is not regarded as necessary (usually defined by physicians and/or clinical guidelines) [85, p. 37]. Women requesting a CS in pregnancy seem, in general, to be autonomous agents, as they are able to (and with the right to) deliberate over their own delivery options with healthcare professionals. As with the healthcare

professionals interviewed in our study, UK obstetricians emphasized taking time to talk to women requesting CSs about their fears [133]. This calls for a shared process of decision-making as an appropriate approach to deliver good-quality care during pregnancy for this group of women.

A call for bilateral trust to facilitate shared decisions

The findings from Paper II call for a SDM process between healthcare professionals and women with caesarean requests. This call is in line with the general shift in healthcare practices from the former paternalistic practice toward emphasizing patient rights, patient-centered care, and SDM [158]. There are both practical and theoretical arguments for SDM. The empirical literature suggests the benefits of SDM, such as improved health outcomes, attending to patient values, fewer invasive treatment choices, and increased patient knowledge [159]. Theoretically, shared decisions are often grounded in respect for patient autonomy and for fostering relational autonomy in the professional-patient relationship [111].

In Paper III, we showed that inherent to the maternal-professional relationship, which is composed of bilateral rights and obligations, there is a power structure that depends on risk and trust. Power can be beneficial when used in line with appropriate ethical standards, but it can make patients vulnerable toward harmful care. Trust is necessary to facilitate beneficial power [96, 160]. The shift in patient care from paternalism toward patient-centered care has, thus, established a new ground for trust. Important facilitators of trust include conferred legitimacy and forecasted efficacy of the health service. If many women who request a CS have had previous negative experiences with healthcare, trust is naturally threatened [161]. Likewise, the Norwegian regulative guidelines provide limited rights and guarantee for these women, and the delegated authority for delivery care may be perceived as less trustworthy if there is uncertainty about what kind of support these women will get when they approach the healthcare system.

Relational trust is dynamic and depends on personal and professional characteristics [162]. Midwives working in counseling used many strategies identified in the

literature as conditions facilitating trust in the nurse-patient relationship, e.g. investing sufficient time, obtaining continuity of care over several appointments in pregnancy and meeting the women as a whole person and getting to know her properly [162]. When women felt understood, and provided with honest advice and information, trust enabled beneficial power to exist. When trust is sufficiently gained between midwives and women, it can promote self-trust and empowerment in preparation for delivery [163].

Trust in the healthcare system, in contrast, is presented as more strongly linked to fairness and the legitimacy of the organizational structure [103]. If the decision-making process is regarded as fair, people may accept decisions independently of the outcomes. Fair decision-making for CSMRs is, thus, important to establish trust among women and in society, and such decision-making would assumingly lie somewhere in the middle on the spectrum between consumerism and paternalism [110]. While consumerism is widely present in private delivery care (e.g., in Brazil [9]), the Norwegian model lies closer to borderline paternalism, as it provides healthcare professionals with most of the power over the decision-making [164].

SDM is a pragmatic compromise that delegates responsibilities and obligations among both decision-making parties. It can serve to facilitate trust [160] and to increase the likelihood of reaching bilateral understanding, consensus, and agreement [106]. Public reassurance of a practice and an acknowledged right to SDM may, thus, serve to avoid conflicts of opposed autonomous claims when healthcare professionals object against providing CS. The SDM concept does not solve such conflicts [109]. In Paper III, we suggested that some protection of the least powerful party is needed, especially in situations where consensus is not reached.

If trust can allow beneficial power to exist in counseling for CSMRs, the general conditions for interaction between healthcare professionals and women will be improved. Healthcare professionals can get the opportunity to inform women properly about their obstetric recommendations; they will be allowed to clear up any misconceptions and achieve a bilateral dialogue with a vulnerable group of women.

More specifically, if the system is set so that the women do not fear being forced into a vaginal delivery, this can accommodate more dialogue and shared deliberation over alternatives. This may serve to benefit not only healthcare professionals as well as society (by reducing costs) but also the women themselves through providing more support and offering better care for their pregnancy concerns.

7. Conclusion

There are nuanced reasons and well-grounded rationales behind maternal requests for a planned CS. A previous birth and/or postnatal experiences are impactful incidents for many women and can greatly affect their choice of delivery mode. Some women report a primary fear of giving birth, and obstetricians sometimes experience requests in which the women express no willingness to establish proper dialogue with them. Consequently, there is a need for individualized and targeted counseling and prevention.

Overall, most of the women experienced the counseling and decision-making process for CSMR as supportive, especially if provided by midwives. The process was, however, long lasting, leading to a postponed decision for many women and varying involvement in the decision, which contributed to increased distress in pregnancy. Healthcare professionals endorsed an empowered vaginal delivery and sought to follow the minds of women requesting CSs through the counseling process. Some obstetricians gave women the choice as an attempt to enhance trust. Otherwise, obstetricians had various thresholds for declining a cesarean request in absence of any perceived benefits. Neither the majority of the women nor the healthcare professionals favored complete maternal choice, illustrating the relevance of communication and deliberation.

From a theoretical perspective, women are not entitled to demand a planned CS in absence of any presumed benefits. Still, they have the right as well as the autonomous capacity to take part in deliberations and decisions regarding their own life and health. Obstetricians are morally entitled to object to providing harmful care, in line with their professional knowledge. There is an asymmetric power structure inherent to the maternal-professional relationship, making women vulnerable to the misuse of power. Power, risk, and trust are intrinsically intertwined in the maternal-professional relationship. Structural initiatives to protect women against such a misuse of power may serve to facilitate trust and allow for beneficial power to exist in counseling.

8. Future perspectives

8.1 Clinical implications

- Nuanced reasons and obstetric histories among women call for targeted counseling and recommendations.
- The importance of previous negative birth and postnatal experiences underscores a partly iatrogenic problem, with potential for preventive initiatives.
- Mental health concerns should be weighed in the risk-benefit analysis with regards to mode of delivery.
- Healthcare professionals may facilitate beneficial dialogue through a SDM process and midwife-led counseling.
- Women are not entitled to make individual choices about cesarean delivery that is not medically indicated, but they have a right to be heard and take part in deliberation and decision-making.
- Professionals are entitled to object to providing potentially harmful surgery in absence of any perceived benefits.
- The structural inferiority of women in the power relationship with their healthcare professionals calls for structural initiatives to protect women against the misuse of power (e.g., by implementing the proposed framework resulting from Paper III).
    - Empirical and normative evaluation and adjustment of such implementation should be subsequently followed up by exploring its legitimacy and usefulness in practice

8.2 Research implications

Although there are medical reasons to believe that a vaginal delivery is safer than a cesarean also for low-risk women lacking obstetric indication, current evidence on low-risk women is insufficient and needs to be improved to secure recommendations for these women. More research is also needed on the mental risks and benefits of a

surgical delivery on women who are already vulnerable in terms of psychosocial characteristics and how a decision or reassurance about CSs affect the maternal level of distress among women in pregnancy. More knowledge on other interventions seeking to lower maternal distress among women requesting a CS in pregnancy as well as on the long-term impact for the mother's and child's wellbeing and development is also called for to improve maternal mental health.

There is a lack of consensus about the philosophical understanding of autonomy and how to interpret the concept in healthcare. Also, professional autonomy is sometimes neglected in bioethical debates. More discussion is needed on how to bridge the gap between more sophisticated philosophical discussion about patient and professional autonomy as well as the practical incorporation of these concepts in healthcare systems. SDM is a popular term in contemporary healthcare debates, often grounded in respect for autonomy. However, increased attention to the vital concepts of power and trust is required. More empirical and normative research into the presence of, and balance between, power and trust in other specific and contextualized medical practices can lead to a broader understanding of the conditions for high quality decision-making in the healthcare system.

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Maternal reasons for requesting planned cesarean section in Norway: a qualitative study

Kristiane Tislevoll Eide[1*], Nils-Halvdan Morken[2,3] and Kristine Bærøe[1]

Abstract

Background: Pregnant women who request a cesarean section in the absence of obstetric indication have become a highly debated issue in academic as well as popular literature. In order to find adequate, targeted treatment and preventive strategies, we need a better understanding of this phenomenon. The aim of this study is to provide a qualitative exploration of maternal requests for a planned cesarean section in Norway, in the absence of obstetric indications.

Methods: A descriptive qualitative study was conducted consisting of 17 semi-structured, in-depth interviews with women requesting cesarean section and six focus group discussions with 20 caregivers (nine midwives, 11 obstetricians) working at a university hospital in Norway. Data were analyzed with Systematic Text Condensation, a method for thematic cross-case analysis.

Results: Fear of birth emerged most commonly as a result of a previous traumatic birth experience that prompted a preference for a planned cesarean to avoid a repetition of the trauma. For some women in our study, postnatal care and the puerperal period were their crucial past experiences, and giving birth by planned cesarean was seen as a way to ensure mental rather than physical capability to care for the expected child after birth. Others were under the impression of being at high risk for an emergency C-section, and requesting a planned one was based on their perceived risk. Such perceptions included having a narrow pelvis, hereditary factors or previous birth outcomes. Some primiparas requested a planned cesarean based on a deep-seated fear since their early teens, accompanied by alienation towards the idea of giving birth. Some obstetricians participating in our study also experienced requests that lacked what they regarded as any well-grounded reason or significant fear.

Conclusions: Behind a maternal request for a planned cesarean section are various rationales and life experiences needing carefully targeted attention and health care. Previous births are an important driver; thus, maternally requested cesareans should be regarded partly as an iatrogenic problem.

Keywords: Cesarean section, Maternal request, Qualitative methods, Fear of birth, Traumatic birth experience

* Correspondence: kristiane.eide@uib.no
[1]Department of Global Public Health and Primary Care, University of Bergen, Kalfarveien 31, 5018 Bergen, Norway
Full list of author information is available at the end of the article

Background

Rising cesarean section (CS) rates in high and middle income countries over recent decades have initiated concern about the overuse of CS [1]. Nordic countries have made a remarkable effort in keeping rates low [2]. Nevertheless, maternally requested surgery remains a controversial issue in academic and public debate.

CS on maternal request (CSMR) is defined as a planned CS conducted on maternal request when there is no obstetric contraindication for vaginal delivery [3]. There is a lack of explicit medical classification and secondary diagnoses are frequent, creating uncertainty of prevalence estimates [4]. A study from Norway found that 10% of CSs undertaken in its study period (1998–99) were conducted on maternal request, representing less than 1% of all births in Norway at that time [5]. This coincides with self-reported numbers (0.8%) by Fuglenes et al. [6]. Estimates for Sweden lie around 2% [4], whereas the prevalence in Denmark is twice as high for multiparous (3.6%) as for primiparous women (1.3%) [7]. A Swedish registry-based study showed that although caesarean section on maternal request (CSMR) increased three-fold over a 10-year period, it was a minor contribution to the overall rise in CSs [4].

Cesarean preference is strongly associated with fear of birth, previous CS and previous negative birth experience compared to women with preference for vaginal delivery [8, 9]. Women who prefer CS more often have characteristics such as higher age, low education level, unemployed, non-native origin, smoking, symptoms of depression and history of abuse [8–10]. Moreover, a cesarean preference is predictive of both planned and emergency CS outcomes [6, 8]. First-time women requesting planned CS do not always present with a clinically significant fear of childbirth, but have more negative expectations of vaginal delivery compared to women planning for vaginal delivery [11]. A qualitative study from Sweden showed that primiparous women requesting cesarean section often expressed deeply rooted emotions about natural birth since early adulthood [12]. Reasons reported among 91 Swedish women requesting CS in first pregnancy were fear of birth, safety issues, birth history of relatives, fear of pain and history of sexual abuse [13]. Parity may be crucial for understanding maternal requests, but few studies have shown stratified results for multiparous women. A higher prevalence among multiparas seems to be due to factors like previous cesarean or fear of birth rather than parity per se [9]. Understanding how and why the fear of giving birth increases with parity among some women is important for developing future care.

In contrast to a lively debate about maternal autonomy, there has been little discussion about reasons for CS requests and possible prevention and treatment strategies [14, 15]. Researchers have called for qualitative research on the subject to facilitate better understanding of cultural and psychosocial factors influencing maternal requests for CS in order to improve care for these women [16, 17]. Many qualitative studies have focused so far on primiparous women [18–20]. Women requesting CS is a diverse group of women for whom factors relating to parity may be important for understanding its sociocultural drivers. As the first purely qualitative study in Europe to include multiparous and primiparous women and their caregivers, our aim is to provide an in-depth exploration of women's reasons for requesting a planned CS in Norway, in the absence of obstetric indications.

Norwegian birth context

Primary care midwives and general practitioners (GPs) have the main responsibility for follow-up and care during pregnancy in Norway, while births and postnatal care are provided at public hospitals. There is no private delivery option, and all care during pregnancy is provided free of charge. Delivery care is primarily midwife-led, assisted by obstetricians in the event of complication. If a woman requests a planned CS, she must be referred for counseling at the hospital where she plans to give birth. Birth counseling at each individual delivery unit may be provided by a midwife or an obstetrician. Planned CS is officially not available on request, and considered only as indicated by an obstetrician [21]. For non-Norwegian and English-speaking women, interpreting services are provided if possible. The Norwegian CS rate was 16% in 2017 [22], a low rate as compared to other high-income countries. The county variance in CS rates in Norway ranged from 11.5–21.0% [22].

Methods

A descriptive qualitative design was chosen to explore the research question in depth and to facilitate new understanding and knowledge. The study was undertaken at a university hospital in Norway with 5000 annual deliveries and a regional CS rate of 12.6% [22]. Women requesting CS were referred for birth counseling by their general practitioner or primary care midwife, and were seen at a midwife-led counseling center at the hospital. Internal referrals by obstetricians and midwives within the hospital also occurred. The final decision on a planned CS after the counseling process was taken by direct consultation with an obstetrician or by the midwife in charge of counseling after agreement with an obstetrician.

Recruitment and data collection

Women were recruited consecutively for semi-structured in-depth interviews by midwives responsible for birth

counseling at the hospital. Written information and an invitation to participate in the study were provided by the midwife if a woman was above 16 years of age, had presented an oral request for CS and had a normal pregnancy with no significant medical risk (interpreted as no obstetric indications for a planned CS). Informed consent was obtained prior to the study interview by the recruiting midwife or the first author. The women were interviewed late in their pregnancy or after birth. The interviews took place in the first author's office or in the informant's home if preferred. One woman was interviewed twice due to subsequent relevant information acquired late in her pregnancy. In-depth interviews were chosen to facilitate dialogue about this personal and sensitive issue. The interviews often took a narrative style and were opened with, "Would you like to tell me your story about why you want a planned C-section?", followed by questions and probes from the interview-guide when needed (Additional file 1). Interviews usually appeared to be lively and self-driven reflecting that the women wanted to tell their story. Three informants were immigrants, born outside Norway, and were somewhat constrained by not being able to explain themselves in their mother tongue. Two of these women were interviewed in Norwegian and one in English.

A purposive sample of midwives (working in counseling, delivery and postnatal care) and obstetricians was selected to participate in focus group discussions consisting of three to four participants grouped by profession. Groups of three to four participants were chosen for primarily pragmatic reasons, but eventually experienced as a favorable size to facilitate discussion and allow participation by all informants. The focus groups were held at the hospital and selected to allow interaction and sharing of experiences and opinions between colleagues. In all focus groups, the conversations were lively and driven mainly by the participants, sharing positive and negative experiences and conflicting opinions. Questions from the interview guide for the focus groups are provided in the Additional file 2.

All interviews were carried out by the first author between June 2016 and August 2017. Focus groups were conducted during March and April 2017. An interview guide with open-ended questions was developed by the research team and modified during the process. Individual interviews lasted from 51 to 79 min; focus groups from 40 to 70 min. All material was audio recorded and transcribed verbatim by the interviewer. After 12 individual interviews and six focus groups, the material was evaluated as being sufficiently rich to illuminate the research question. Scheduled interviews were conducted and further recruitment ceased.

Analysis

The transcripts were organized with the coding software NVivo, version 11. Data were analyzed using Systematic Text Condensation [23, 24], a method for cross-case thematic analysis conducted in four steps: 1) Reading the transcripts stepwise during data collection to adjust the interview guide, evaluate saturation and identify main themes for further analysis. 2) Identifying meaning units in the text and coding into main groups. 3) Condensation by splitting into subgroups. 4) Synthesizing condensates into re-conceptualized descriptions. The first step was conducted by the first and last authors, steps 2–3 by the first author and step 4 by collaboration among all authors in a step-by-step process of discussion and reflection. The transcripts were analyzed using editing analysis style, drawing categories upon the empirical data rather than a theory-driven template analysis, although the analysis was influenced by existing empirical knowledge ([23], 95, p.). Data from women and caregivers were synthesized to inform the analysis, with findings among women supported and complemented by the experiences and impressions stated by caregivers. Figure 1 shows the analytic process, illustrating keywords and flexibility in the development of themes and coding of data into code groups and categories. Norwegian quotes have been translated into English by a Norwegian and English-speaking professional language editor and translator and back checked by the research team. Informants were coded numerically starting with W for woman, M for midwife and O for obstetrician.

Results

Participants

Seventeen women referred to the delivery unit for birth counseling with a cesarean request were interviewed. Women's ages at the time of the interview ranged from 27 to 42 years. Fourteen women were multiparous women who had not requested a cesarean section in a previous pregnancy. Two women were second-time pregnancies and had been referred for birth counseling due to a cesarean request in both the current and a previous pregnancy. These women were interviewed about their rationale for cesarean preference during both pregnancies. One woman was pregnant for the first time and referred due to a cesarean request. Toward the end of pregnancy, 10 women were scheduled for a planned CS, while seven women planned for a vaginal delivery. Nine midwives and 11 obstetricians (six consultants, five residents) with varying lengths of experience were also interviewed in the focus groups. Their experience with and impression of the maternal group supported and complemented the findings from the women. Additional characteristics of the informants are presented in

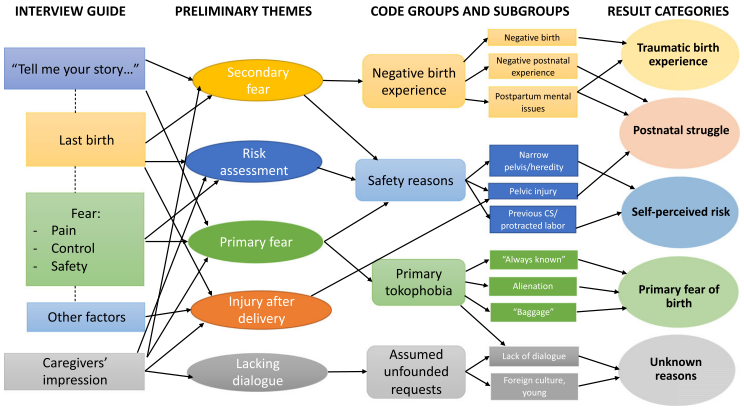

Fig. 1 Illustration of the flexible analytic process with development of the main result categories (to the right). Figure modified with permission from Malterud [23]

Tables 1 and 2 and indicate a favorably heterogeneous sample.

Main categories

Five principal categories emerged from the analysis of women's rationales for requesting CS (Fig. 1). For some, fear of birth emerged as a consequence of a previous traumatic birth, and resulted in a preference for a planned CS as a way of avoiding repeated trauma. For others, negative experiences in postnatal care and the puerperal period led to a request for planned CS in order to ensure mental rather than physical capacity to care for the expected child. Some women were under the impression that they were at high risk of emergency CS, and requested a planned CS on the basis of self-perceived risk. Requests for planned CS in first pregnancies were based on deeply held fear accompanied by alienation towards the idea of giving birth. Additionally, obstetricians reported on experiencing requests without what they regarded as well-grounded reasons or significant fear.

Table 1 Women's characteristics

Characteristics	Number
N=	17
Age	
27–42	17
Relationship status	
Married	11
Cohabitating	5
Single	1
Education completed	
High school level	4
Bachelor's level	7
Master's level	6

Previous traumatic birth experience: 'Back on that butcher's bench'

A previous traumatic birth experience typically encompassed multiple dimensions. A secondary fear of giving birth may arise shortly after delivery or during the next pregnancy. An important dimension of the previous birth experience was having experienced extreme fear during delivery, often involving a woman's conviction

Table 2 Caregivers' characteristics

Characteristics	Number
N=	20
Profession	
Midwife	9
Obstetrician	11
Gender	
Female	16
Male	4
Age	
29–39	7
40–49	6
≥ 50	7
Years of experience	
≤ 5	5
6–10	6
11–20	5
> 20	4

that her own or the baby's life was at risk. This could be due to dramatic events or insufficient information and support during or after delivery. Language barriers were a particular source of fear for immigrants, like the case of this woman born outside Norway:

> "And I was so scared that I just understood the pulses [fetal heart rate] were going down, and I was scared like if my baby will come out alive, or it will be dead. And then I was just asking them, will she be alive? And nobody bothered to answer me." W9 Multiparous woman

Midwives acknowledged the difficult balance of providing enough information without creating unnecessary fear. Communication between caregivers was also described as giving rise to fear and misunderstanding:

> "They can retell almost verbatim how a conversation has occurred between two parties in a delivery room, and was almost perceived as warfare. Disagreement between midwife and doctor, which is perceived as enormous, creates a terrible insecurity for the woman." M1 Midwife

Recalling extreme pain and lack of control was important in reluctance toward another attempt of a vaginal delivery, the one leading to the other:

> "So in a way it's the pain that was the reason. But then it wasn't. Because the pain made me lose control … And when I lost control I panicked. And the panic made me go completely irrational. Then there was no way back … Then I remember I told him [partner] I am fainting now, you will just have to get that baby out." W16 Multiparous woman

Operative delivery was a significant contributor to lack of control for some. Several women had experienced multiple vacuum and/or forceps attempts provided with either too much or too little analgesia (according to the women), the former leading to lack of control and the latter leading to extreme pain and shock, as in the case of this woman who explained that she failed to receive a pudendal block:

> "They made it on the 4th [forceps] attempt. But by then I thought I was dead a long time ago. I had no clue what happened… They didn't have time to pay any attention to me when she [the baby] was in bad shape, I get that. But one of the two [caregivers] present had had time to give me that [pudendal] analgesia… And I am a bit scared that even though it is all normal now. When the baby comes, I will go straight back. In my head I'm back on that butcher's bench." W13 Multiparous woman

A negative birth experience may result in distrust of the clinic. Some women were left with the impression of being subjected to mistakes, inadequate care or pain relief, experimental medicine, poor communication or being turned into a teaching case. One woman felt like a scientific case presented to a broad collegium in the delivery room. For some, an emergency CS felt like a relief when caregivers verbally summarized what they were about to do. A woman born outside Norway explained how lack of information and predictability left her with the impression of delivery care as "floating" and based on experiment rather than medical judgment:

> "Like no one was sure what are they doing. Everyone, like how the situation is in villages in my home country, like ok now we will try this thing now we will try this thing, it was not like medically." W9 Multiparous woman

Several women described being reluctant to become pregnant again after the last birth experience, delaying a new pregnancy for many years, becoming pregnant unwillingly or having received assurance of a planned CS prior to getting pregnant.

Many women expressed a need for, as well as an expectation of, some follow-up by the clinic after birth, especially after operative deliveries. All women in Norway receive a check-up free of charge with their GP 6 weeks postpartum, but there is no official provision of follow-up at the delivery clinics after discharge. Caregivers working at the hospital, however, provided targeted follow up in special cases, especially after obstetrician-assisted deliveries, consisting of either an in-house talk at the postnatal ward before discharge or by calling them in several weeks postpartum for a debriefing in the out-patient clinic. Most women had received a visit from the obstetrician responsible for their birth before discharge, but a few had not had that opportunity. The optimal timing suggested by the women for a postpartum talk was between three and 6 weeks postpartum; by that time the mother would have had time to adjust to her new situation and reflect on what had actually happened. Women preferred the postpartum talk to take place within a specialized care setting, rather than in primary care, and with caregivers who had insight into the clinic's routines and delivery care.

> "And if I had been sent to the right people straight after the birth the last time, then I wouldn't necessarily have, first, refused to have [more] children,

and second, when I finally had got it [pregnant], to be so scared of a potential birth. I feel that there is a lot that could have been avoided. If they would just have followed up properly… The baby survived, the mother survived. That's good. But it's not good enough." W13 Multiparous woman

Caregivers also emphasized the importance of a postpartum follow-up appointment after birth. This would be an opportunity for debriefing, answering questions and clearing up misunderstandings. This was practiced to some extent by several of the caregivers, but not established as a routine. The main challenge was to identify the women that needed such follow-up. There were routines for a short in-house postpartum visit soon after all obstetrician-attended deliveries. The timing of this was regarded as suboptimal, providing the women with too little time to process the event and reflect on any questions she might have.

"... where I worked before I always had postpartum talks with these (women), I always saw them in the out-patient clinic after six weeks for a talk. And I believe I prevented a lot of fear of birth." O6 Obstetrician

Postnatal struggle: 'I'd rather be present in my head than in my body'

The time following delivery was the crucial part of previous birth experiences for some women. Several women (and some partners, according to the women) had experienced difficulties processing the event, including shock, repression, depressive or anxious symptoms, but few had sought professional support. The experience of feeling mentally incapable of caring for the child due to difficulties with processing the birth experience was especially challenging. Some midwives emphasized how a negative birth experience can be exacerbated by negative experiences in the puerperium, such as feeling a lack of support, feeling incapable of caring for their child, and other difficult emotions following birth:

"I agree that a lot of what we see is that trauma often comes after delivery. The trauma comes from bad experiences in postnatal care… Several, we can see in hindsight, have been through a postpartum depression without receiving care. And it is a black hole. And it creates fear, for some a fear of dying." M1 Midwife

Several women complained about lack of staff and support in the postnatal ward. They often felt too sick to care for their newborn properly after the birth experience, especially if their partner was sent home. Feelings of a lack of safety and being left on their own at the clinic made some demand early discharge against the clinic's advice:

"I have never felt so unsafe and helpless as I was at the clinic… It took all my effort to pretend that I was well so that I got out of that madhouse." W8 Multiparous woman

These women usually had experienced a protracted labor, emergency CS or operative delivery, and a planned CS was perceived to provide better health and an easier time after birth as compared to a complicated vaginal delivery.

Some women had experienced pelvic complications (urinary/anal tract damage, chronic pain) followed by handicap, social stigma and frustration in getting help. While afraid of aggravating the present injury by another vaginal delivery, these women also regarded a planned CS as a way of avoiding recurrence of a difficult time following birth, as in the case of this woman who had experienced a pelvic floor injury with urinary incontinence leading to a difficult time after delivery, both emotionally and socially.

"Some are just a bit unlucky, and things happen during the birth. And unfortunately, I was one of them. And that's why I'm thinking that I don't want to (give birth). I am terrified of it happening again." W5 Multiparous woman

Overall, many women in this category regarded a planned CS as a predictable and calm birth experience that in turn would facilitate a mentally stable puerperal period. The anticipated mental benefit after a planned CS was worth the longer recovery time in physical terms, as described by this mother expecting her second child:

"Because now I have two small children to think of. Then I'd rather be present in my head than in my body." W1 Multiparous woman

Fear due to safety reasons based on self-perceived risk: 'I can't give birth normally, I'm convinced'

Several women based their request on what they personally considered medical risk factors. They were concerned about complicated births running in their families, previous protracted labor/emergency CS, perception of having a narrow pelvis or expecting a big baby. While some were afraid of experiencing stillbirth, others simply wanted to avoid a stressful emergency

situation. The conviction of not being able to deliver vaginally was recurring:

> "I hear from my family that my great-grandmother and great-great-grandmother had lots of stillbirths because they [the unborn child] got stuck… And my maternal grandmother had a C-section with my mum, and my mum had a C-section with me… So, I can't give birth normally, I am convinced of it." W8 Multiparous woman

Caregivers were aware of these requests, although they might disagree about the medical significance of the upcoming birth. The women's rationale was to avoid an emergency CS by having a planned one, as in this case of a woman who had reviewed the academic literature on her own:

> "I checked the guidelines of the Royal College of Obstetricians and Gynecologists… They concluded in the end that [for women with previous CS] the overall risk of a vaginal birth was quite small, but still safer with a C-section… And if you have a big baby, the risk of having a C-section is already 50%… It's the emergency in this I want to avoid." – W17 Multiparous woman

Primary fear of birth: 'It's just an anxiety that I have'

Some women presented with deeply rooted fear they had carried since their early teens, making them feel different from other people. It was experienced as an encompassing primary phobia that had accelerated with pregnancy. They had typically delayed becoming pregnant. One of the women based her fear on a traumatic experience in her early youth giving rise to a fear of death during delivery.

> "I've been frightened. I thought it might change, go away some of the time during the pregnancy, but it didn't go. The closer I got the more scared I was… Death and pain, they were the only things in my head." W3 Primiparous woman

Another woman was not able to describe properly what her fear was about; it was a deeply rooted feeling of birth being completely unnatural to her:

> "I cannot understand what makes me so different from others. And that has perhaps been partly what's been the most unpleasant, to feel that it is experienced as different. Because it is in a way something all women are supposed to feel as a natural part of life. But I don't believe it is anymore natural than for a man, without that making me different. It's just an anxiety that I have." W6 Multiparous woman, requesting CS in her first and the current pregnancy

According to caregivers, these women could sometimes be extremely scared and difficult to convince about a vaginal delivery. They emphasized how some were particularly vulnerable and carried "excess baggage" from earlier life. Some had experienced sexual assaults or other traumatic life events that, one midwife underscored, would not always be revealed during counseling. They often carried a sense of alienation toward giving birth and having children in the first place:

> "Some have a psychological baggage from earlier in life, and have perhaps delayed becoming pregnant, are scared of being so and of having a child at all. Birth is very strange to them… They don't believe they will cope with it." O11 Obstetrician

Requests based on unknown reasons – lack of dialogue

Obstetricians were especially concerned with a minority of women requesting CS who presented without well-grounded reasons or significant anxiety. Willingness to comply with such requests was lower, and willingness to spend time and effort on them varied. Such requests were rare, and it was difficult to obtain a good dialogue. These women could be very determined about their choice of delivery; they were sometimes very young and possibly without understanding about the implications of surgery.

> "And there is something about those who you absolutely do not get into dialogue with, who just sit there and say no no no. Won't have a story, won't have a background… And sometimes they are very young. Who absolutely do not understand this. Who just think it is much easier with surgery and then finished" O1 Obstetrician

Sometimes these were women immigrated from countries with high C-section rates:

> "Those cases that are not anxiety for birth are those who have seen in the media, heard from friends, read and think, 'Oh what an easy solution to have C-section'… You have the normal birth which most people have to accept, and you have the Hollywood version where you're admitted to the hospital and get a planned C-section, free from perineal tears, baby comes out newly washed. That's not a medical indication. I had one patient

from abroad with that kind of argument. From a country with a very high C-section rate." O5 Obstetrician

Discussion

Although previous birth experiences are central to many, there are nuanced reasons and various rationales behind a cesarean request. Traumatic birth or postnatal experiences were important for some women, whereas others based their request on self-perceived risk. Primary fear of birth in first pregnancies also appeared, as did 'requests based on unknown reasons', according to obstetricians. This multifactorial complexity behind maternal requests is in accordance with the findings of other qualitative studies [25].

Background characteristics of women requesting C-sections suggest a population susceptible to mental illness [8, 10, 26]. The rationale for many women was to avoid mental health problems following a traumatic birth experience. However, little is known about the impact of a planned CS on mental health after birth. Provision of a planned CS does not seem to lower antepartum anxiety or depressive symptoms, but to compel a vaginal delivery may lead to post-traumatic stress and depression [27]. To be able to give proper recommendations during birth counseling for women with a fear of birth, mental health has to be addressed in the trade-off between risk and benefits with regard to delivery mode.

Fear of birth due to previous birth experience was the dominant reason for cesarean requests among the women in this study. Twelve out of 14 multiparous women had experienced either operative delivery and/or emergency CS. Other studies have shown strong associations between cesarean preference and previous negative birth experience, previous CS and fear of birth [6, 8, 26]. Our findings suggest that it is not the previous CS but rather the negative aspects of the birth experiences, which are crucial in their justification of a cesarean request. This is in line with a systematic review of qualitative literature also reporting previous birth experiences as an important reason for requesting CS [25]. Størksen et al. found that 8% of pregnant women in Norway had significant fear of birth, which was highly predictive of a cesarean preference. Presence of a previous negative birth experience was the strongest predictor of fear, followed by impaired mental health and lack of social support. Only 13% of women with fear received a CS, and very few requested CS in the absence of a previous negative birth experience [26]. If various traumas from a previous birth experience are the major causes of CSMR, we should acknowledge the phenomenon as partly an iatrogenic problem. Fear of birth due to previous traumatic birth experience can be prevented through proper midwifery and perinatal mental health care [28]. Women and caregivers interviewed in this study suggested postpartum follow-up after birth as a way of avoiding cesarean requests in subsequent pregnancies. A challenge described by caregivers was how to capture the subjective trauma. A subjective negative birth experience is not necessarily determined by an obstetric event, but rather by lack of support and poor-quality care during childbirth [29, 30]. Prevention and follow up must therefore be targeted. Whether postnatal debriefing improves postpartum mental health and avoids development of post-traumatic stress is currently uncertain [31]. Women seem to appreciate such services and midwives regard it as beneficial for women [32].

Several women (including one woman who had requested CS in her first pregnancy) based their request on safety reasons due to self-perceived risk for, and as a means of avoiding, an emergency CS. Previous birth experience, if present, was not necessarily described as negative or traumatic. This may partly explain why clinical anxiety is not present in all women requesting CS [11]. Several researchers have highlighted the association between CSMR and previous or current obstetric complications, bringing maternal perception of risk into account [33–35]. These requests may call for a different healthcare response than the more trauma-based requests. Over all, adequate healthcare toward this patient population seems to necessitate targeted approaches.

A study among primiparous women from Sweden revealed how deeply rooted emotions beyond fear of birth dominated their requests for a planned CS [19]. As for two out of three women having requested cesarean section in their first pregnancy in our study, these women described that they had always known they would not wish to give birth the natural way. According to caregivers, primiparous requests of this kind were not usual. Others have indicated that several women with fear of childbirth do not accept psychological counseling and demand a CS without further discussion [36–38]. Obstetricians were especially concerned with the rare but present women who gave no well-grounded reasons for their request and had a lack of willingness to establish a dialogue. Midwives did not discuss these women and may have achieved a better dialogue and understanding of these requests. Nevertheless, we were not able to probe specifically on this issue during data collection since the midwives working in counseling care were the first focus group interviewed.

Strengths and limitations

The majority of women interviewed in this study gave birth by a planned CS at a hospital with a low CS rate compared to the overall country. Midwives at the counseling center suggested that approximately 70% of

women withdrew their request during birth counseling. This may imply that the women in this study already had a strong motivation for planned CS, and may partly explain why requests based on unknown reasons were not represented among these women. The female interviewer had no direct relation to the clinic. This opened up an honest dialogue and promotes the credibility of the findings. The majority of women were multiparous women with a previous experience of attempted vaginal delivery. Inclusion of only three women having requested CS in their first pregnancy may question the credibility of findings regarding first-pregnancy requests. However, our findings from the focus groups with caregivers and existing literature support these results. Most women were interviewed late in their current pregnancy, and some women were interviewed after giving birth. Two second pregnancy women requesting CS in both their current and the previous pregnancy were interviewed regarding their rationale for requesting CS in both pregnancies. Recalling prenatal fear and other factors influencing their wish may have been affected by the birth experience and memory at the time of the interview, which may have influenced the results. However, postpartum interviews also provided the advantage of illuminating the phenomena from a comprehensive pre- and postpartum perspective, and all women provided spontaneous and rich descriptions about their reasons and rationales for wanting a planned CS. There was an overall strong interview dialogue with lively and self-driven discussion pointing toward high information power [39]. The heterogeneous characteristics of informants (Tables 1 and 2) and the complementation of women's and caregivers' perspectives add credibility to the study. As a multidisciplinary research team (i.e., a newly educated medical doctor, an experienced obstetrician and a philosopher), we were able to approach and discuss the research question and findings from different angles and ensure consistency in the analysis. Even though the study is constrained by the setting, birth and fear relate fundamentally to the human condition, permitting transferability to other settings as well.

Conclusion

Cesarean requests are based on varying rationales and life experiences. Previous birth experience occurs as a major driver of subsequent fear of birth. Thus, CSMR should be regarded partly as an iatrogenic problem with potential for improvement and prevention both during and after deliveries. Some women based their requests on concerns about a perceived high risk of emergency CS, which may call for a different counseling approach. Over all, prevention and healthcare should be carefully targeted according to such findings.

Additional files

Additional file 1: Interview guide for in-depth interviews with women. Questions and probes used in interviews with women. (DOCX 15 kb)

Additional file 2: Interview guide for focus group discussions with caregivers. Questions and probes used in focus group discussions with caregivers. (DOCX 14 kb)

Abbreviations

CS: Cesarean section; CSMR: Cesarean section on maternal request

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Availability of data and materials

Original data cannot be made available due to restrictions in the ethical approval of the study. Additional quotes may be provided upon request to the corresponding author up to 5 years after the ended study period, when data shall be deleted.

Authors' contributions

All authors designed the study. KTE had the primary responsibility for data collection and analysis. All authors participated in analysis, interpretation and drafting of the results. All authors have read and approved the final draft.

Ethics approval and consent to participate

Approval was obtained from the regional committee for medical and health research ethics in Norway (REK) on December 7, 2015 (Ref. 2015/2029REK vest) and the Norwegian Social Science Data Services (NSD) on November 20, 2015 (ref 45,158/3/MSS). All participants were provided information sheets about the study and all women signed written consent prior to the interviews. Caregivers consented by active participation in the focus groups as approved by both REK and NSD.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Author details

[1]Department of Global Public Health and Primary Care, University of Bergen, Kalfarveien 31, 5018 Bergen, Norway. [2]Department of Obstetrics and Gynecology, Haukeland University Hospital, Jonas Lies veg 87, 5021 Bergen, Norway. [3]Department of Clinical Science, University of Bergen, Jonas Lies veg 87, 5021 Bergen, Norway.

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Tensions and interplay: A qualitative study of access to patient-centered birth counseling of maternal cesarean requests in Norway

Kristiane Tislevoll Eide[a,*], Nils-Halvdan Morken[b,c], Kristine Bærøe[a]

[a] Department of Global Public Health and Primary Care, University of Bergen, Kalfarveien 31, 5018 Bergen, Norway
[b] Department of Clinical Science, University of Bergen, Bergen, Jonas Lies veg 87, 5021 Bergen, Norway
[c] Department of Obstetrics and Gynecology, Haukeland University Hospital, Jonas Lies veg 87, 5021 Bergen, Norway

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ABSTRACT

Objective: This study aimed to explore women's *access* to patient-centered counseling for concerns initiating cesarean requests in absence of obstetric indications in pregnancy, and to identify tensions, barriers and facilitators affecting such care.

Design, setting and informants: This qualitative study (June 2016 to August 2017) obtained data through semi-structured in-depth interviews with 17 women requesting planned C-section during birth counseling at a university hospital in Norway and focus group discussions with 20 caregivers (9 midwives and 11 obstetricians) employed at the same hospital. Analysis was carried out by systematic text condensation, a method for thematic analysis in medical research, presented within the frames of Levesque and colleagues' conceptual framework of access to patient-centered care.

Findings: The analysis revealed that there were considerable tensions in care seeking and provision of counseling for maternal requests for C-section. There was a prominent culture of vaginal delivery among caregivers and women. The appropriateness of CS on maternal request was debated and caregivers revealed diverging attitudes and practices when agreement with women was not reached. Women's views on their entitlement to choose were divided, but the majority of women did not support complete maternal choice. Midwife-led counseling were highly appreciated among woman as well as obstetricians.

Implications for practice: Tensions and barriers in care seeking and provision of counseling for women requesting C-section for non-obstetric reasons, call for standardized counseling in order for equal and adequate care to be provided across health care institutions and providers. Dialogue-based decision-making and midwife-led care may improve satisfaction of care, enhance spontaneous vaginal deliveries and avoid future conflicts.

Introduction

Cesarean section on maternal request (CSMR) is a CS conducted at the request of the mother in the absence of obstetric contraindications of vaginal delivery (VD) (D'Souza, 2013). The subject has received attention in public as well as academic debate, and appears to be controversial (D'Souza and Arulkumaran, 2013). Along with the physician-driven rise in CS, there has been an increase in maternally requested CS in many countries (Boerma et al., 2018). Meanwhile, there has been a shift in medical care from paternalistic practices towards patient-centered care and shared decision-making (Barry and Edgman-Levitan, 2012). There is growing concern about the world-wide increase in CS rates, with elevated maternal and newborn morbidity (Boerma et al., 2018; Sandall et al., 2018).

Fear of birth, previous traumatic birth experience and previous CS are important predictors of CSMR (Fuglenes et al., 2011; Ryding et al., 2016). A subjective traumatic birth experience is not, however, predictable by objective complicative events (Nilsson and Lundgren, 2009; Storksen et al., 2013). Over all, women requesting

* Corresponding author.
E-mail addresses: Kristiane.eide@uib.no (K.T. Eide), nils-halvdan.morken@uib.no (N.-H. Morken), Kristine.baroe@uib.no (K. Bærøe).

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Abbreviations

CS	cesarean section
MR	maternal requests
CSMR	cesarean section on maternal requests
VD	vaginal delivery
FGD	focus group discussion

CSMR carry an overrepresentation of vulnerable psychosocial characteristics (Fuglenes et al., 2011; Ryding et al., 2016; Storksen et al., 2015; Sydsjo et al., 2015). Most Norwegian women with fear of childbirth deliver vaginally, but a previous traumatic birth experience is highly predictive of CSMR (Storksen et al., 2015). However, first time mothers requesting CSMR do not necessarily have clinically significant anxiety (Wiklund et al., 2008).

Attitudes towards providing CSMR vary widely among obstetricians across European countries (Habiba et al., 2006). The majority of Norwegian obstetricians consider CSMR as clinically problematic (Fuglenes et al., 2010). Although about half of the respondents were willing to perform CSMR in the absence of medical indications, just as many thought the physician should make the final decision. There are, to the best of our knowledge, no qualitative studies exploring both women and caregivers experience of such counseling in light of access to *appropriate* care. This study aimed to explore caregivers' provision of and women's access to patient-centered birth counseling for maternally requested CS in Norway.

Norwegian birth context

Norway has a publicly financed health care system where delivery care is free of charge. Primary care midwives and general practitioners (GPs) provide care during pregnancy, while birth and direct follow-up after birth is taken care of in public hospitals. A woman who requests a CS is referred for birth counseling at the hospital where she plans to give birth. Birth counseling is provided by obstetricians or midwives and the final decision about CS is made by a consultant in obstetrics. There is no established private alternative, and CSMR in the absence of a medical indications is not recommended according to obstetric guidelines (Norsk Gynekologisk Forening (Norwegian Society for Gynecology and Obstetrics), 2014). Whether fear of birth is to be regarded as a medical indication should be evaluated individually. The Norwegian Patients' Rights Act ensures patients the right to participate in decision-making concerning accessible and justifiable treatment options (Lovdata, 1999). Physicians in Norway are protected against economic responsibility for patient complaints and lawsuits through the Norwegian System of Patient Injury Compensation (Norsk Pasientskadeerstatning (The Norwegian System of Patient Injury Compensation) 2016).

Methods

In order to gain new understanding and insight into a complex subject we chose a qualitative explorative design. The study was conducted at a university hospital in Norway with approximately 5000 deliveries annually. The regional CS rate was 12.6%, representing one of the lowest CS rates in the country (The Norwegian Institute of Public Halth (Folkehelseinstituttet) 2020). Requests for planned CS were handled by midwives providing birth counseling at the hospital. Referrals came from primary care midwives or GPs, or from midwives and obstetricians working at the hospital. According to midwives working in counselling 70% of women changed their mind and opted for a vaginal delivery plan during counseling. If they persisted on a cesarean request, midwives would either make an agreement for CS with a consultant in obstetrics themselves, or refer the woman for final consultation(s) and decision by a consultant.

Table 1
Women's characteristics.

Characteristics	Number
Age	
27–32	6
33–37	6
38–42	5
Civil status	
Married	11
Cohabitant	5
Single	1
Education	
High school	4
Bachelor level	7
Master level	6
Immigrants	3
Parity	
Nullipara	1
Multipara, with previous nulliparous request	2
Multipara	14
Final delivery mode	
Planned cesarean section	10
Attempted vaginal delivery	7
N=	17

Data collection

Data were collected from semi-structured in-depth interviews with 17 women referred for birth counseling and 6 focus group discussions (FGDs) with caregivers, including 9 midwives and 11 residents or consultants in obstetrics (Tables 1 and 2). Women were recruited by midwives at the counseling center after provision of oral and written information about the study and if the woman was above 16 years, had presented an oral request for CS and had a normal pregnancy. Informed consent was gathered by the recruiting midwife or the first author before the interview took place and women were usually interviewed late in pregnancy (week 21–38). Four women were interviewed (2 weeks to 8 months) after birth due to practical difficulties. The interviews took place at the first author's office or at the informant's home according to preferences. One woman was interviewed before and after labor because of consecutive information relevant to the study question. The interviews were usually opened with the

Table 2
Caregivers characteristics.

Characteristics	Number
Profession	
Midwife	9
Physician	11
Resident	5
Consultant	6
Sex	
Women	16
Men	4
Age	
29–39	7
40–49	6
>50	7
Years of experience	
<5	5
6–10	6
11–20	5
>20	4
N=	**20**

Table 3
Interview guide for in-depth interviews with women.

No.	Question	Probes
1.	Would you like to tell me your story about why you are requesting a C-section?	
2.	What is the reason for your wish for a C-section?	

		• What was it about the last birth?
		• What do you fear?
		  ○ Pain?
		  ○ Control?
		  ○ Injury towards yourself or the child?
		• Is there anything or anyone who has influenced your choice and your attitudes towards this?

3	How has it been to talk to other people about this?	
		• Who have you talked to about this?
4	What information have you gotten or searched for?	
5	How did you proceed to get help for this?	
6	Tell me about your experience with counseling.	
		• Expectations, information, communication
7	Is there anything that could have been improved for you or others in your situation?	
8	Who do you believe should make the final choice of delivery mode?	
9	Is there something else you think I should know?	

encouragement of, "Would you like to tell me your story about why you want a planned C-section?". Three informants were immigrants interviewed in either Norwegian or English, neither of which was their first language. Ten of the women gave birth by planned CS, while seven planned a vaginal delivery where three of them had an emergency CS.

Caregivers were chosen to facilitate a purposive heterogeneous sample of midwives working in counseling, delivery and postnatal care as well as obstetricians with varying length of experience. Caregivers were sent an invitation to participate by mail together with information about the study. Active participation was regarded as consent to participate. Short information about the study aim, confidentiality and right to withdraw was given prior to the FGDs. The FGDs were held at the hospital and comprised of 3–4 informants grouped by profession. All interviews were undertaken by the first author between June 2016 and August 2017. The transcripts and interview guides (Tables 3 and 4) were evaluated and revised and sample size (saturation) evaluated continuously by the first (a medical doctor) and last author (a bioethicist) during the interview process. Interviews lasted from 40 to 79 min, were audio recorded and transcribed verbatim by the interviewer. After 12 interviews with women and six FGDs with caregivers, we regarded the material as sufficient to illuminate the research question(s), in terms of information power (Malterud et al., 2015). Malterud recommends evaluating the information power of a sample rather than saturation, which is a concept originally applied in grounded theory (Malterud et al., 2015). Information power depends on a narrow aim, specific and relevant sample, support of established theory and good quality of dialogue and analysis (Malterud et al., 2015). A sample should be large enough to provide in-depth information on a research question, and should not be larger than necessary in order to prevent a superficial analysis. The interviews gathered data for two studies with separate research aims. Data derived from question 1–2 in the interview guide with women and question 1 in the focus groups with caregivers, have been analyzed separately and previously published elsewhere (Eide et al., 2019). This study's aim was covered by discussion emerging from the remaining questions in the interview guides.

The interviewer was a female with no direct relation to the hospital. This facilitated an open dialogue about women's help-seeking processes. The research team was multidisciplinary and consisted of a newly educated medical doctor and PhD student (the interviewer), an experienced obstetrician and a bioethicist. This influenced our preconception, approach towards and interpretations of

Table 4
Interview guide for focus group discussions with caregivers.

No.	Question	Probes
1	What is your impression of women who request cesarean?	
		• Who are they? • Why do they want C-section?
2	How is it to work with these patients?	
		• What kind of emotions do they evoke? • Do you experience any ethical challenges facing them?
3	Would you like to tell me about how you handle these patients?	
		• Strategies? Improvements?
4	How do you think the decision should be made? Who should make the final choice?	
		• Shared, doctor, midwife, the woman?

the subject of study, but enabled us to approach the research question and findings from multiple perspectives enhancing the credibility of our analysis.

Ethical approval

This study was approved by the regional committee for medical and health research ethics in Norway December 7th 2015 (Ref. 2015/2029REK vest) and the Norwegian Social Science Data Services November 20th 2015 (ref 45158/3/MSS).

Analysis

NVivo software version 11 (1999–2017 QSR International Pty Ltd.) was used to organize text and conduct coding. We used systematic text condensation, a cross-case thematic analysis for qualitative data to approach the material through four systematic steps (Malterud, 2011; 2012): (1) reading transcripts during data collection to obtain an overall impression and identify main themes, (2) coding of meaning units into main categories, (3) condensation of content in the categories by coding into subgroups, and (4) synthesizing the condensates into new descriptions and concepts. The first and last author collaborated on step 1 of identifying themes for further analysis, the first author subsequently had the main responsibility of coding and analysis, while the whole research team collaborated on the last step of analysis of data during discussions and reflection in a stepwise, flexible process. Levesque et al.'s conceptual framework of patient-centered access to health care was used during step 4 of the analysis to organize, structure and describe the content, according to distinctive dimensions of access. Hence, the analysis was originally data-driven, but eventually used a conceptual framework of access to illustrate and actualize the findings in line with an editing analysis style (Malterud, 2016). This enabled us to explore the material before choosing a relevant framework to complement the analysis, by adding flexibility to the process.

Framework: Patient-centered access to health care

Access to health care is a complex term with varying interpretations. Based on existing frameworks, Levesque and colleagues have developed a systematic framework of patient-centered access to health care, where access is defined as "the opportunity to reach and obtain *appropriate* health care services in situations of perceived need for care" (Levesque et al., 2013). Access is regarded as a result of the interface between characteristics of individuals demanding care, and characteristics of the health care providers. Relevant facilitators and barriers to such access are present from the supply side as well as the demand side of care in addition to factors in the process by which access is realized (as illustrated by the blue arrow in Fig. 1).

Levesque et al. presents five dimensions of accessibility of services with five corresponding abilities of individuals or populations seeking health care: 1) *Approachability* relates to whether people can identify that a certain service exists and a corresponding ability of individuals to perceive a need for care. 2) *Acceptability* relates to cultural and social acceptance of certain health services and the corresponding ability to seek care. 3) *Availability and accommodation* imply that health services can be reached in physical terms and in a timely manner and implies a corresponding ability of individuals to reach health services. 4) *Affordability*, and the ability to pay for care represent the economic capacity people have to spend time and resources on accessing care. Finally, 5) *Appropriateness* represents the fit between clients' need and services offered. Adequacy of the care given is dependent on appropriateness of the service provided, its quality, and individuals' ability to engage and participate in health care decisions. Consequently, Levesque and colleagues describe a comprehensive and dynamic model of access, where the abilities of individuals interact with dimensions of the health care services along the cumulative line of help-seeking and fulfillment of health care needs.

Results

Tensions and interplay were observed between and within the supply and demand sides of access to counseling for requested planned CS. Women requested planned CS based on a large variety of life experiences and rationales, but previous birth experience was very important to many of them (Eide et al., 2019). Many women experienced the accessibility of counseling for their cesarean request to be challenged by late referrals to counseling, a strong ideal of vaginal delivery, a long-lasting process of and late decision-making. Caregivers struggled between the responsibility for the individual woman and the responsibility towards the profession and society. Obstetricians revealed different opinions on the appropriateness of CSMR and thus to different degree involved women in the actual decision. The findings are structured according to Levesque's five dimensions of access in the following.

Approachability & the ability to perceive a health care need

Caregivers were concerned about how media and trends in society influenced women's perception of need for CS. While some midwives thought fear of birth had become an increasing problem over past decades, several obstetricians mentioned a shift and a positive trend over the last few years after bloggers and celebrities had advocated for own vaginal birth experiences in media. Many caregivers were concerned about the free access to unfiltered information on the internet, which was particularly unfortunate reading for women who were prone to anxiety.

> "It may be a trend in society, that we decide more how we want things. And we read up a lot more on our own. And that's great really. But there is something about where we get that information from." L1 Obstetrician

Several caregivers pointed out the importance of primary care midwives in preparing women for their births. They called for better access to and earlier appointments with midwives in pregnancy. Midwives believed that early exploration of thoughts about birth could help pregnant women normalize fear and avoid medicalization. Early processing of previous delivery was perceived as important for multiparous women.

> "They only get an appointment with a midwife in week 24 of pregnancy. Many of them are locked into specific thoughts by then. You're almost 6 months pregnant and you've heard all the stories." J6 Midwife

Most women had initiated the help-seeking process themselves. One of the women questioned why there was no screening or discussion of birth with women during pregnancy. She thought someone should inform her about the increased risks in the forthcoming delivery and the risks and benefits of the available delivery options, given her previous CS. Lack of outreach and information from the health care system made her even more concerned about the upcoming birth:

> "I don't think it's ever discussed (delivery mode) really, unless you bring it up yourself… So I think if I had been informed a bit at an earlier stage. Say, now you are in this or that situations, you have these risk factors, these are the benefits and disadvantages. Then I would have felt in safe hands." G17 Woman, gestational week 37

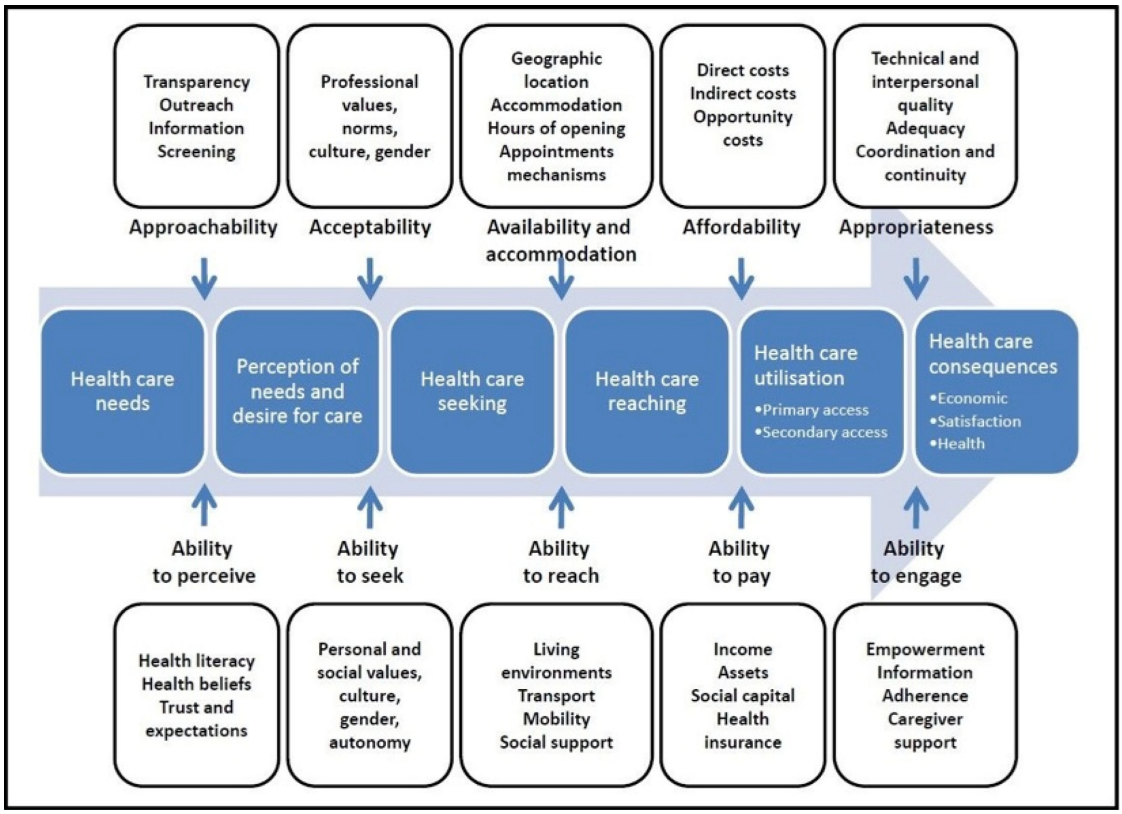

Fig. 1. Levesque et al.'s conceptual framework of access to care, licensed from (Levesque et al., 2013) http://creativecommons.org/licenses/by/2.0.

Acceptability & the ability to seek care

There was a prominent preference for VD as the outcome of counseling among all caregivers. Although planned CS could be advisable for women with a severe fear of childbirth, it was not regarded as a treatment for anxiety.

> "This group I usually start by saying that surgery is not a treatment for anxiety. That's a bad strategy, because surgery itself provokes anxiety." L10 Consultant

Obstetricians balanced the responsibility towards the individual patient and the responsibility towards society during decision-making. Caregivers found themselves pulled between the expectations of their profession and the intention to do good for the individual patient:

> "It's a bit odd, because occasionally I feel that if I get a woman who wants a C-section to change her mind to a vaginal delivery it feels just as if I've done a better job for my profession… And that dilemma I sometimes find difficult. Because if the goal itself is always a vaginal delivery, then I believe we have a preconception that isn't good for the woman's mental health" J3 Midwife

Several women had the impression that caregivers in primary and specialized care usually advocated strongly for VD. For some it appeared less trustworthy and lacking of neutral ground:

> "When they talk about C-section and birth, then vaginal delivery is great. It's natural, good for the baby, complications can occur, but they don't talk much about that… But when they come to C-section…They put a red flag on it from day 1." G1 Woman, gestational week 36

There was a common understanding among women that the clinic was very restrictive in its policy towards CS. Women were aware that a VD was preferable for the child, and a planned CS was not regarded as an easy way out. Many women indicated that they would prefer a VD had it not been for the circumstances underlying their request. Several felt a bad conscience towards the child for not being able to manage a VD. A few women had felt ashamed and vulnerable when having to engage with the health system for a mental health reason, like this woman, who admitted she did not regard CSMR as acceptable until she suddenly experienced the need for it herself:

> "And it's probably because of my own understanding of planned cesarean before, because I thought it was just nonsense. Oh my goodness, right. So I have probably met myself coming the other way." G8 Woman, gestational week 35

Availability & the ability to reach health services

A common complaint among women was that the birth counseling process was too long and that the decision was made too late in pregnancy, escalating psychological stress and uncertainty

during pregnancy. Prior to counseling, many feared they would not be understood or taken seriously and many were relieved to find the opposite. Several women were not able to enjoy their pregnancy until the decision on delivery mode was taken.

> "And even when the decision came, when she telephoned me, it was only when I got it by mail, and even then a week passed before I was able to relax." G8 Woman, gestational week 35

Caregivers emphasized the importance of getting into dialogue with women early on in pregnancy and giving the process time to mature and follow its course. Midwives spent time exploring women's fear and reestablishing safety and trust in order to help the woman find the best solution for herself.

> "Yes, and then we really want to see them again, and maybe another time, and perhaps even one more time. Just to try to accompany them towards the goal and see how do your thoughts develop?" J2 Midwife

Affordability & the ability to pay

The Norwegian health system provides delivery care free of charge. There is no private alternative for women approaching birth. The health budget for delivery clinics is performance based and paradoxically pays more for a CS than a VD. This was not regarded as an incentive among obstetricians for increasing CSMR. The clinics' capacity for surgery was otherwise fixed. Obstetricians were concerned that a rise in CS rates would mean a reduction in surgery capacity for other gynecologic conditions.

> "The capacity for surgery is fixed. So if you increase the C-section rate 1%… Then someone else won't get (surgery)." L3 Consultant

Appropriateness & the ability to engage (in decisions)

Midwives working with counseling described how they invested time and effort in establishing a good dialogue with women. Showing respect and taking women seriously often helped them reestablish trust, which had commonly been lost in an earlier birth experience. Through conversations, they guided the woman to find the right solution for her. They spent time making a birth plan, which was a document providing safety for the woman. Their goal was to follow the women, guide them through a thought process and deliver them as confident as possible to the delivery situation, irrespective of mode.

> "I believe it is very important that the woman feels she has been taken seriously. That she's been heard. That's more important than the delivery mode itself." J2 Midwife

Achieving a good dialogue was important. Both midwives and obstetricians highlighted the advantage of midwives, without mandate to make the final decision, to promote a constructive dialogue. There was a challenge of identifying which women were capable of coping with a new vaginal birth experience. Evaluating the woman's mental health was regarded as highly subjective and difficult:

> "It's you as a person sitting here, and none of us are psychiatrists. There are no kind of scoring systems where you can sit and pick out these patients. It's very much about how the patient is presenting it." L2 Consultant

Several doctors had developed strategies to avoid making the situation more tense, by avoiding a negotiation table, facilitating a shared decision-making process and acknowledging mental health problems. This would enable a better dialogue, provision of information and evoke a thought process among women.

> "These consultations I usually start by disarming the situation. We aren't going to make a decision today. Today we are just going to map out your point of view… So that it doesn't become a fight from the first time." L6 Obstetrician

Women were generally very pleased with the birth counseling provided by midwives. They usually felt seen, heard, respected and trusted on their stories. They appreciated going through previous birth records and clearing up misunderstandings and questions.

> "I am very grateful for being heard and believed by the hospital. That's what I am left with, I feel trusted on my experience, my personal subjective birth experience the first time." G4 Woman, two months postpartum

While some women felt well-informed before and during the counseling process, others expressed an unmet need for information. Some women wanted more facts presented in numbers and percentages and adapted to their specific obstetric history. No written information was given in the decision-making process. After the decision was made women scheduled for planned CS were sent a standard information sheet about the procedure and its risks.

> "But they did not have any proof in their hand. They just, like how these religious people how they convince you. How Christianity is the best. They just blindly convince you to go for normal delivery." G9 Woman, one month postpartum

Most caregivers believed the medical responsibility of the final decision should be held by the obstetrician. Patient autonomy with regards to delivery mode was usually interpreted as a right to say no to treatment, but not the right to demand an intervention without a medical indication. Professional autonomy and the right to refuse to operate on a healthy woman was mentioned.

> "You cannot come and claim a surgical intervention if we know there's a safer alternative. And it's undeniably safer." L6 Resident

Some obstetricians saw it as their main responsibility to inform the patient and help the patient make an informed choice about mode of delivery. If she were able to make an informed choice, her choice should be respected:

> "We cannot force them to give birth. It's their choice, really." L7 Resident

No clear difference of opinions was found between residents and consultants. There were variations in opinions in both groups. However, obstetricians expressed varying practices when it came to declining requests. Some obstetricians saw it as the right thing to do, or their duty, to decline a request if a woman came with a non-medical indication. Especially in low-risk pregnancies were the evidence suggest a VD was undeniably the safest option for mother and child, if the woman was very young and if she did not understand implications of surgery, making an informed process difficult.

> "Really, if I believe that there is absolutely no advantage with a C-section, and of course if they have real anxiety it's something completely different. But those who are, "No, I don't really want to give birth," right, at that level, and it's a low risk pregnancy, no contraindications to vaginal delivery. Then I make that decision." L6 Resident

Other obstetricians did not feel comfortable denying a woman a CS if she was completely reluctant towards giving birth, even in cases where fear was not prominent. They regarded it as wrong to force a woman into a VD against her will and did not see it worth their time and resources when it came to a patient dispute which was regarded time-consuming and mentally exhausting.

Some caregivers usually let the women decide. This could provide trust and allow for a better dialogue. These caregivers believed that most women still chose a vaginal birth plan.

> "I usually (say)… that if she insists on a C-section she can have it. There won't be any argument about that. But then there will be a time period where we can work on these issues." L10 Consultant

Midwives highlighted that a forced delivery was a very bad starting point for a birth experience, which again could influence the attachment between mother and child. In some situations, caregivers regarded planned CS to be an appropriate option for the individual woman. A previous traumatic birth experience and severe fear of childbirth were acknowledged as legitimate indications by several obstetricians:

If they haven't made contact with the ground all the way through the pregnancy, just walking around thinking about the birth, are so afraid that they can't be happy about the child. They aren't able to enjoy the pregnancy…For those women, it must be completely OK to have a C-section?" L11 Consultant

Women's views on autonomy were divided. A minority of the women thought the final choice should be taken by the woman herself. Arguments presented were; it was her body and should be her decision, she knows her own body and psyche the best, she was the one bearing the consequences and the outcome of an attempt for VD was uncertain.

> "At the end of the day I believe it should be the woman, I do… But I do not mean that it should be like if you are pregnant you call in and order a planned C-section, I don't mean it should be like that. But I believe there should be a process in advance." G4 Woman, two months postpartum

Most women would prefer a shared process between the woman and caregiver or a conditional autonomous choice depending on reason for the request, where ungrounded requests could be denied. Many emphasized that a good process with information and dialogue was of greater importance than who was to decide. The fact that it was a surgical procedure, with elevated risks for the mother and child, a medical choice, a possibility that women would have CS for reasons of convenience or because it was misunderstood as an "easy way out", were arguments presented for why complete autonomy would be problematic.

> "I don't believe the woman should decide for herself, not exclusively… Either way you need someone to talk to about it. Not necessarily to be allowed to decide completely. " G13 Woman, gestational week 31

Many had felt included in the decision-making, either by being able to make the final choice for themselves or having the opportunity to say no to a vaginal birth plan. Others felt as if they were presented to a judge or committee of doctors evaluating their case, without being present to defend themselves or being able to influence the decision.

> "…that I felt in a way that when I had presented my case then it was totally out of my hands. Then it was like a judge up there who was to decide." G2 Woman, gestational week 34

Discussion

The findings of this study illustrate considerable tensions as well as fruitful interplay, across the five dimensions of access proposed by Levesques' framework of access to patient-centered care, when it comes to birth counseling for cesarean requests among women in Norway. This new insight can facilitate shared reflection on what health care should entail for women requesting CS.

Appropriateness & ability to engage

There were diverging attitudes and practices involved in declining a persistent cesarean request when regarded as inappropriate. Some caregivers emphasized their responsibility for allocating societal goods and providing evidence-based care as an argument for declining requests, whereas others advocated for respecting patient choice after an informed process and avoiding harm by a forced delivery. Patients' potential complaints and litigation were emphasized as an emotional burden and some caregivers did not consider it worth their effort to decline persistent requests. Accordingly, anticipated complaints can influence decisions even in a context that protects against financial and medicolegal consequences for physicians, in line with a Norwegian survey showing a considerable variation in judgment about CS determined by risk of complaints and litigation (Fuglenes et al., 2009).

Tensions in perspectives on CSMR can also be explained by equivocal evidence. CS in the absence of obstetric indications is not expected to provide benefit for the mother or child in terms of physical health and may even cause harm (Sandall et al., 2018). Evidence is scarce concerning whether planned CS improves the mental health of the mother during and after pregnancy (Olieman et al., 2017). Studies have shown that giving birth by planned CS did not significantly improve postpartum mental health of mothers (Adams et al., 2012), but may provide a more positive birth experiences (Wiklund et al., 2007). A mismatch of preference for planned CS and not receiving it was associated with increased risk of posttraumatic stress disorder and depression (Garthus-Niegel et al., 2014). While there is uncertainty in anticipated gain of a planned CS on mental indication, there may be a mental gain of birth counseling and psychosocial therapy during pregnancy for these women (Rouhe et al., 2015, 2013; Saisto et al., 2001, 2006). After all, increasing evidence suggests that mental stress during pregnancy has unfortunate consequences for the behavioral, social and emotional development of children (Korja et al., 2017; Kvalevaag et al., 2015).

Variation in attitudes towards the appropriateness of CSMR has been illustrated among obstetricians across several European countries (Habiba et al., 2006). Our study illustrates diverging opinions and practices even within one hospital in Norway. This intraprofessional tension regarding the appropriateness of CSMR calls for a discussion and development of a more homogenous approach among caregivers. Swedish guidelines have suggested to comply with cesarean requests that are grounded sufficiently serious, when it persists after participation in a counseling program (Wiklund et al., 2012).

Acceptability & ability to seek care

Caregivers revealed a prominent culture for VD, in line with other studies from Scandinavia (Karlstrom et al., 2009; Panda et al., 2018). A prominent culture for VD was also reflected among women. Studies have shown that the vast majority of Norwegian women prefer VD (Fuglenes et al., 2011; 2012), and most women with fear of birth do deliver vaginally (Storksen et al., 2015). The majority of women, as well as caregivers in our study, did not favor maternal choice for CSMR. Hence, the interplay of shared cultural attitudes towards VD among women and caregivers in Norway may partly explain the low prevalence of CSMR.

In line with the central and highly valued role of midwives in pregnancy and delivery care in Norway, midwife-led continuity models of care for pregnancy and childbirth have been shown to increase the likelihood of experiencing a spontaneous VD (Sandall et al., 2016). After crisis-oriented counseling provided by midwife the majority of women (86%) in one study in Norway changed preference to vaginal delivery and remained satisfied

with their choice (Nerum et al., 2006). Our study thus supports the hypothesis that midwife-led pregnancy and delivery care combined with a strong professional culture for VD may help keep national CS rates at reasonable levels (Panda et al., 2018). Counseling provided by midwives was highly appreciated by women as well as obstetricians in this study. Organization of counseling as a maturation process with postponed decision-making to promote women's reflection and changed motivation for VD, increased fear and stress during pregnancy for some women. Early screening and decision-making in pregnancy have been proposed to improve care (Kenyon et al., 2016).

Strengths and limitations

To the best of our knowledge, this is the first study that in order to facilitate improvements in care explores maternally requested CS within a broad framework of access to care. The information power of the study is regarded as high based on the narrow aim and specific recruitment, narrow analysis with application of theory, and high and heterogeneous number of informants representing both parties of the counseling situation; pregnant women and caregivers (Malterud et al., 2015). Four women were interviewed after birth, which could have influenced their perception of the counseling and decision process in light of how the birth was finally experienced. However, we experienced the descriptions to be varied and heterogeneous independent on interview timepoint and mode of delivery.

Some restrictions upon transferability should thus be evaluated before interpreting the results. Women were recruited from specialized care; they had already perceived a need for care and identified that a service existed. Additional challenges in the approachability of service and ability to perceive is expected outside the context of specialized care. Also, the Norwegian health system, which avoids payment and medicolegal barriers, creates a unique context for our findings. Within this legally protected context our study setting is a university hospital that holds a low and recommendable CS rate (12.6%) according to the WHO recommendations. It is especially interesting to investigate women's access to counseling for requested planned CS in such a context where caregivers have the resources to provide CS but aim to limit the use of it. This may have influenced the findings towards a lower or more restrictive access towards *CSMR*, but not necessarily towards patient-centered *counseling* for CSMR. However, even within one hospital with a restrictive provision of CS, we are able to show variation in attitudes and values when it comes to providing and involving women in decisions for CSMR.

This study illustrates how a framework of access to health care can be useful to explore need and provision of care for women when entitlements are unclear. Whether barriers of access to care in certain situations are acceptable or even preferable, is a normative question beyond the scope of this paper. Our approach can be implemented in other contexts to facilitate understanding of local tensions and interplays to improve care for this complex issue.

Conclusion

This is the first study to investigate women's access to patient-centered counseling for maternal cesarean request through a framework of access to patient-centered care. Variations in attitudes towards appropriateness of CSMR and willingness to decline persistent cesarean requests calls for shared reflection on how to provide appropriate patient-centered care for these women. More research is needed on how to organize the counseling process. Midwife-led counseling was highly appreciated by women and caregivers. Few women or caregivers favored complete maternal choice, illustrating the relevance of dialogue-based decision-making to improve satisfaction and avoid future conflicts.

Ethical approval

This study was approved by the regional committee for medical and health research ethics in Norway December 7th 2015 (Ref. 2015/2029REK vest) and the Norwegian Social Science Data Services November 20th 2015 (ref 45158/3/MSS).

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Declaration of Competing Interest

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III

How to reach trustworthy decisions for cesarean sections on maternal request: a call for beneficial power

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Kristiane Tislevoll Eide*, Kristine Bærøe

Department of Global Public Health and Primary Care, University of Bergen, Kalfarveien 31,

5018 Bergen, Norway

*Corresponding author:

E-mail: kristiane.eide@uib.no

Phone: +4741509634

Address: Kalfarveien 31, 5018 Bergen, Norway

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Abstract

Cesarean delivery is a common and life-saving intervention. However, it involves an increased risk for short- and long-term complications for both mother and child compared to vaginal delivery. From a medical point of view, healthcare professionals should therefore not recommend cesarean sections without any anticipated medical benefit. Consequently, cesarean sections requested by women for maternal reasons can cause conflict between professional recommendations and maternal autonomy. How can we assure ethically justified decisions in the case of cesarean sections on maternal request in healthcare systems that also respect patients' autonomy and aspire for shared decisions? In the maternal-professional relationship, which can be characterized in terms of reciprocal obligations and rights, women may not be entitled to demand a C-section. Nevertheless, women have a right to respect for their deliberative capacity in the decision-making process. How should we deal with a situation of nonagreement between a woman and healthcare professional when the woman requests a cesarean section in the absence of obvious medical indications? In this paper, we illustrate how the maternal-professional relationship is embedded in a nexus of power, trust, and risk that reinforces a structural inferiority for women. To accommodate for beneficial use of power, these decision processes must be trustworthy. We propose a framework, inspired by Steven Lukes' three-dimensional notion of power, that serves to facilitate trust and allows for beneficial power in shared processes of decision-making about the delivery mode for women wanting planned C-sections.

Key words: cesarean section, maternal request, trust, power, shared decision-making

Background

A cesarean section (CS) can be a lifesaving intervention for both mother and child. While, in some parts of the world, lack of access to and underuse of CS may have devastating consequences, there is an emerging concern for the increasing use of CS conducted in the absence of obstetric indications.[1] Worldwide, the CS rates increased from 12% in 2000 to 21% in 2015.[1] The highest CS rates today are found in the Latin America and the Caribbean (44%). Disparities are wide between and within countries. In China the rates range from 2-62% between provinces.[1] Delivering by CS is associated with higher socioeconomic status in low- and middle-income countries,[1] while the opposite has been shown in a high-income country like Norway [2]. In European studies, preference for CS, is associated with psychosocial vulnerability.[3-5]

The WHO originally promoted a CS rate to be between 10 and 15% [6] Later, a worldwide study identified the lowest maternal and neonatal mortality to be associated with CS rates up to 19% [7]. There are no available evidence from randomized control trials comparing outcomes of vaginal versus cesarean delivery for low-risk women lacking obstetric indication.[8] Still, cesarean section is in general associated with increased risk for short- and long-term health complications for both mother and child, and are increasing with repeated cesareans.[9] While the risk for short term complications (including wound infections) are relatively low following planned cesarean delivery [10-12], complications can occur in subsequent pregnancies such as abnormal placentation, uterine rupture, unexplained fetal death and postpartum hemorrhage [13-15]. Consequently, decision-making, especially for first-time pregnancies, should involve consideration of future pregnancies and implications across the reproductive lifespan. For the newborns, planned CS may increase the risk for breastfeeding problems, respiratory distress [16] and transfer to neonatal intensive care unit

[17]. In the long run, increasing evidence suggest that a planned cesarean delivery, with its sterile birth environment, affects the development of the child's immune system by providing a vulnerability for immune-mediated diseases such as asthma, allergies, diabetes mellitus (type 1) and celiac disease [18-20].

Along with the general rise in medically necessary cesarean deliveries, many countries have experienced a rise in women requesting planned CS in absence of obstetric indications.[1, 21, 22] Approximately 2.5% of births in the US are suggested to be delivered as Cesarean Sections on Maternal Requests (CSMR).[23] Scandinavian estimates suggest a prevalence of CSMR between 1-3% of births.[21, 24-26] The reported willingness to comply with maternal requests and attitudes toward maternal autonomy vary among obstetricians across European countries. The lowest willingness is found in Spain and France, and highest willingness is within the UK and Germany.[27] Maternal autonomy to choose a planned CS has been debated among professionals and ethicists,[28-33] and guidelines vary between countries regarding how to handle these requests.[34, 35]

Opposing autonomous claims and the call for shared decisions

Respect for autonomy is one of the leading ethical principles of medical practice today. It is one out of the four equally important principles proposed by Beauchamp and Childress; respect for autonomy, beneficence, non-maleficence and justice.[36] According to Pellegrino, benefitting patients implicitly includes respecting their capacity and wish for self-determination.[37]

Numerous interpretations and understandings of autonomy goes beyond the general notion of self-determination.[38] In the much cited version proposed by Beauchamp and Childress, an

autonomous decision must be *intentional*. The actor needs to have deliberated on the decision with a proper *understanding* of the relevant information and needs to be *free from* internal and external *control* (e.g., mental health states, coercion, and deception).[36, p. 105, 39] In medical practice, the usual interpretation of patient autonomy is that patients have a right to refuse offered treatment, but the patient may not have a right to choose treatment outside of the 'health-care menu'[38, p. 37] as defined by the healthcare professionals and/or policy makers. According to this view on patient autonomy, a woman cannot demand a planned CS unless a physician finds it medically indicated. According to Norwegian guidelines, for example, indications for CS are met when the anticipated benefit for the mother and child is higher with a CS compared to a vaginal delivery.[35] Even if the woman does not hold a specific right to demand a treatment that is not medically indicated, she should still be respected for her ability to deliberate and take part in decisions in healthcare. But how should this capacity be respected when deliberation does not necessarily lead to consensus between the woman and the healthcare provider on the final decision?

The maternal-professional relationship constitutes a moral relationship of mutual (autonomous) rights as well as an obligation to respect each other.[37] Even if she does not have the right to autonomously demand whatever she likes, the woman's ability to deliberate and reach conclusions should be respected. The necessity of her willing cooperation with professionals during a vaginal delivery—which can be mentally and physiologically challenging—adds to the importance of involving the woman in decision-making. Professionals hold a right to act in accordance with their professional integrity and make adequate medical decisions in line with their specialist knowledge and clinical judgement.[37] An obstetrician, who is formally responsible for the consequences of the medical intervention, may thus object to operating on a woman who requests a CS against medical

recommendations. Theoretically, this can be described as a situation of opposing autonomous claims. Practically, one party must give up its claim to make the decision. This means one party must be subjected to the will of the other, which involves lack of power to control the situation. On the individual level, this can create a damaging experience of powerlessness. On the societal level, this can create structures of power that support relative domination and subordination of either professionals or patients.

Aim

In the following, we discuss the nexus of power, trust, and risk that surrounds the maternal-professional relationship. We argue that the decision-making process should be structured to facilitate trust and allow for *beneficial power* to exist rather than to focus on ideals about autonomous choices and shared decision-making. Leaning on Steven Lukes' notion of power and an account for how it can be turned to serve beneficial purposes in health, we justify a realistic rather than idealized conceptualization of a shared decision-making process and propose a framework for ethically justified decision-making in the case of CSMR.

Power, trust, and risk

In order to find conditions for an acceptable decision-making process and to promote healthcare personnel's power to do good, there is a need to broaden the context of analysis beyond the construction of autonomy. A useful perspective is proposed by Harald Grimen.[40] According to Grimen, the nature of the patient-professional relationship lies in general within what he calls 'the nexus of *power*, *trust*, and *risk*.' When someone reaches out for healthcare, that person's health is left in the custody of someone else (a professional) who is capable of taking care of it. This then transfers discretionary *power* over that person's health to a professional who possesses the special knowledge, judgment, and discretionary

space to provide care. By *trusting* the professional to provide beneficial help, that person also takes the *risk* of being provided with insufficient and/or harmful care. However, patients' options for help in a society where tasks are organized by division of labor are quite limited. According to Grimen, trust can occur voluntarily, or it can be forced due to the lack of alternative options.[40] His conceptualization of trust is thereby broader than definitions that exclude perceptions of trust as phenomena emerging from dependency.[41, 42] Overall, a patient's trust, or at least lack of mistrust, facilitates the professional's power base.[40] Trust is risky and makes patients vulnerable to adverse consequences. When one trusts, according to Mark Warren, one gets benefits of cooperation in exchange for some risk for harm[43, p. 1] Thus, trust allows power to do good to exist in healthcare and is crucial for healthcare to be provided.[40]

Power is used to provide benefits along with the ethical principle of doing good for patients in healthcare, but it can also be misused and cause harm.[36] Overall, there is no reason to believe that professionals would want to misuse power in their daily work. Still, power has this potential, and doctors' professional autonomy, which represents quite some space for discretion and clinical judgement, creates a substantial space for any kind of power. According to Grimen, the power imbalance within the patient-professional relationship manifests itself in different ways: the gap in medical knowledge and skills between the parties, the lack of options for seeking adequate help elsewhere, and the issue of professionals' gatekeeping roles for protection of social goods.[40] This leaves patients reaching out for help with a structural dependency on professionals, but this is also a dependency we might have to accept. We agree with Grimen's claim that radical changes to the nature of this relationship may not be sufficiently beneficial to patients.[40] The

alternative of leaving adequate medical education and care to everyone instead of a small group does not allow for specialization and is not a sustainable approach.

Power, trust, and risk in the maternal-professional relationship

Power can also foster *trust* through lack of options (forced trust), through delegated discretion by authorities, and through forecasted efficacy.[44] Likewise, trust can be lost due to emergence of other options, such as alternative medicine and private healthcare. Due to dismissed legitimacy, for example by representations of mixed motives such as providing care and saving public resources. Or due to perceived lack of efficacy caused by i.e. negative healthcare experiences and negative media publicity.[44] The legitimate authority of professionals has been challenged in the last few decades due to increased access to medical knowledge among patients (e.g., via internet) as well as the establishment of patient rights and structural regulations of healthcare.

Public trust has been heavily challenged by the emergence of what Onora O'Neill describes as a culture of suspicion.[45] She questions whether the evermore complex systems of accountability, in terms of requirements on reporting measurements, actually foster public trust. Proposals for how to reestablish or foster trust and power to do good in today's healthcare institutions include promotion of ethical quality and communication during the medical encounter. The ethics of meeting a patient as a whole person may replace paternalistic authority as a basis for trust.[44, 46] Introducing shared decision-making is an example of attempts to restore trust and thereby enable power to do good to exist in healthcare. Accepting division of labor in society and patients' structural dependency on medically educated others does not force us to completely reject such an idea. Rather, this prompts us to accept a conceptualization of shared decisions that is in tune with real world

presences of the very same power and dependency. It is not our aim to discuss such a complete conceptualization here, but we will argue below in favor of including dialogue in a practice-relevant concept as it relates to the case of CSMR.

Toward a beneficial 'shared process of decision-making'

Given the structural dependency of patients on professionals, it is futile to hold on to the ideal of shared decision-making while assuming that both parties influence the conclusion of what to do with equal power. Moreover, 'shared *process* of decision-making' seems more realistic to aim for than shared decision-making. This would especially be so when differences in the desired outcome are what bring the parties to negotiation in the first place. We will return to the implications of this below. Nevertheless, at this stage of analysis, there are several reasons for arguing that CSMR calls for equality in influencing the *dialogue* of the decision-making process. First, there are nuanced reasons and obstetric histories behind maternal cesarean requests. Such as previous birth and postnatal experiences, and perception of own risk and fear.[47, 48] Quality healthcare therefore calls for individual assessments and personalized, as opposed to standardized, recommendations. Morally, if clinical encounters between the woman and the professional regarding CSMR are to serve the best interests of the woman and child, both parties have the mutual obligation of facilitating an open and honest dialogue. The woman must reveal her reasons for the presumed benefit of the intervention. The professional should provide accurate information and a well-justified medical recommendation. If a woman does not provide any beneficial reason for her CS request, an obstetrician has strong reasons to object to operating in complete lack of expected benefit.[37] If the level of evidence is weak regarding the safest delivery mode, the recommendation should reflect this.

Second, the subjective perspective of the woman is clinically relevant. CS represent a surgical interference upon a physiological process the female body is made to handle and leads to an elevated risk. Therefore, vaginal delivery is recommended in a low-risk pregnancy.[9] However, an unwilling vaginal delivery increases the risk of post-traumatic stress and depression among women.[49, 50] Experience of coercion may provide more future harm than benefit for the woman and her child. Individual evaluation of the risks and benefits of planned CS should also include prospective physical and mental health for the mother and child. It is not necessarily true that professionals hold a better capacity to judge future mental health prospects than the woman herself does. This calls for dialogue.

Fostering dialogue is necessary, but it is not enough to make the notion of a shared process of decision-making both realistic and ethically acceptable in case of CSMR. To see what more is called for (again inspired by Grimen [40]), we will apply Steven Lukes' account [51] of power to explore and identify requirements for promoting beneficial power. We hereafter conceptualize 'beneficial power' as a form of power that is applied by healthcare professionals to promote patient treatment without suppressing patients' experiences or points of view.

Three dimensions of power and shared process of decision-making

According to Steven Lukes' original framework of *power*, power can be realized through three dimensions.[51] The first dimension refers to coercion (including physical force) where A coerces B to do something. The second dimension of power occurs when A is controlling the agenda for the interaction with B. In medical encounters, professionals present information and options as well as define the needs for follow-ups. Hence, they hold considerable power over the terms for the encounters, i.e., what is to be revealed to and

considered by patients. The third dimension of power entails that A controls B's view on the world and how her situation is defined (e.g., as illness/not-illness or as normal/abnormal).

For women who are requesting CS in absence of obstetric reasons, their perspective on what would be best for them often originates outside of or prior to the clinical encounter. However, when trust exists, professionals enjoy the beneficial power (and possess an obligation) to deliver honest information through counseling to avoid misconceptions about safety among women.[52] Denying a woman the option of a planned CS when she insists on a self-perceived need after an informed process illustrates the power obstetricians hold over defining her need. This is based on a conceptualization of medical indication and control over treatment options. Moreover, professionals set the agenda of interaction, controlling the process of decision-making by determining the time, schedule, and aims of the meetings. Finally, they can indirectly coerce women into vaginal delivery. In Norway obstetricians have the final say about delivery mode[35]. In the UK, physicians are expected to comply with persistent requests after counseling or refer the woman to another provider in the case of objection.[34] Hence, patient choices and informed consent in maternal care can be influenced by agenda setting, worldview control, and even coercion. Obstetricians hold *both* the power to control the content and scope of the dialog and the right to refuse to provide CSMR. This increases vulnerability in her situation and may increase her perception of risk involved in trusting professionals and their decision about delivery mode. In the following section, we suggest structural initiatives to facilitate trust and enable beneficial power in the counseling process for cesarean requests.

How to facilitate trust and beneficial power in decisions about CSMR: A framework

Based on our discussion, we here suggest a decision-making framework that promotes trustworthy beneficial power, that is, power without suppressing features. The framework consists of seven requirements, which all have to be present in order for decision-making power of healthcare personnel to be truly trustworthy.

First criterion

Deciding on delivery mode when the woman requests a CS requires a shared decision-making process to avoid harm. Equal respect between both parties requires reciprocity regarding the exchange of information. This means that the healthcare worker must knowledgably inform the woman about the intervention, and the woman must expose her reasons for requesting a CS.

Second criterion

The mere possibility of being forced into a feared vaginal delivery should be off the table when the aim is to foster a trustworthy and beneficial decision-making process without suppressing coercion. The dialog must be carried out without any agenda of pressuring the woman to opt for vaginal delivery. It must also avoid convincing her that, at the end of the day, she will not have or is unlikely to have a planned CS. Allowing for appeal for a second opinion if the dialog does not bring about consensus is a way to promote this.

Third criterion

The third criterion relates to Lukes' second dimension of the concept of power, i.e., the ability A has to control the agenda for interaction with B. For the dialog to be beneficial, it should take place on the premises agreed upon by both parties. This means that the woman should be

involved in the planning of future meetings with respect to time issues, whom to meet, and what to discuss. Some women may prefer to meet with an obstetrician while others may prefer counseling led by a midwife. Psychologically trained teams would be beneficial. Standardized protocols for these meetings and conversations could undermine the beneficial power healthcare workers might exercise toward these women.

Fourth criterion

Lukes' third dimension of power concerns A's ability to control B's view of the world as well as how the situation is described. Any authoritative use of technical medical terms, such as claims on 'normal' delivery modes or 'right' and 'wrong' procedures, by the healthcare worker does not support the use of beneficial power and should be avoided. To avoid controlling the perspective of the situation at hand, the healthcare worker should also be open about risk factors concerning the individual. Furthermore, the probability of complications should be communicated along with the certainty of evidence.

Fifth criterion

In order to ensure that all women receive the same neutrally conveyed information without any undue influence of the world view of the professional, an information sheet should be made available for them and for the public. This requirement allows for critical assessment and debate about presented interpretations of research regarding risks and benefits of *planned* delivery modes.

Sixth criterion

To support and foster beneficial power of care providers, a professional endorsement of use of beneficial power should be reflected in healthcare education programs and codes of ethics.

Seventh criterion

To institutionalize the trustworthiness of professionals' aim to use their power to do good, involves holding them accountable for their use of power. Regulatory mechanisms ensuring that requirements 1-6 are in place as well as a possibility for appeals by women who have experienced suppressing power abuse are both needed.

Lack of trust inhibits communication and cooperation. Both are vital for counseling and delivery care.[41] If this framework is implemented to accommodate ethically justified use of power in decision-making about delivery mode, then women have reasons to trust professionals' motives, information, and recommendations throughout the counseling process. If trust is ensured, benefits can emerge from the asymmetric power relations and serve the interest of women and their children.

Conclusion

In this paper we have shown how women are placed in a situation of structural inferiority in the maternal-professional relationship when requesting a planned CS for maternal reasons. Although she may not be entitled to demand a planned CS, she should be included in decision-making processes about delivery mode. We have used Lukes' account of power to illustrate a need for structural initiatives that women can find trustworthy. This may allow beneficial power to exist in these consultations and we have proposed a framework to implement these initiatives. The normative premises for this particular framework, i.e. the call for promotion of power that is beneficial for patients, might be relevant for framing other ethically challenging decision-making processes as well.

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IV

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Anne Berit Kolmannskog	55978497	07.12.2015	2015/2029/REK vest
			Deres dato:	**Deres referanse:**
			27.10.2015	

Vår referanse må oppgis ved alle henvendelser

Kristine Bærøe
Universitetet i Bergen

2015/2029 Gravide som ønsker keisersnitt til tross for anbefaling om vaginal forløsning

Forskningsansvarlig: Universitetet i Bergen
Prosjektleder: Kristine Bærøe

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 19.11.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Formålet med denne studien er å kartlegge jordmødre og legers erfaringer med gravide som ønsker keisersnitt tross faglig anbefaling om vaginal forløsning. Gravides holdninger og utfordringer vil bli undersøket ved hjelp av fokusgruppeintervju med rundt 30-40 jordmødre og leger, samt dybdeintervju med inntil 30 gravide. Intervjuene vil vare i ca. 1-2 timer og tas opp på lydbånd. Materialet vil bi analysert ved kvalitativ metode.

Vurdering
Studien er godt gjennomarbeidet og viktig å gjennomføre. Komiteen har ingen innvendinger til den forelagte protokollen. Deltakelse er samtykkebasert og informasjonsmateriellet er tilfredsstillende utformet.

Prosjektslutt
Tillatelsen til å oppbevare og behandle indirekte personidentifiserbare opplysninger i prosjektet gjelder til prosjektslutt 01.12.2018. Etter dette må data slettes eller anonymiseres.

Vedtak
REK vest godkjenner prosjektet i samsvar med forelagt søknad.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 01.06.2019, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Besøksadresse:
Armauer Hansens Hus (AHH), Tverrfløy Nord, 2 etasje. Rom 281. Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: http://helseforskning.etikkom.no/

Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komitéleder

Anne Berit Kolmannskog
Rådgiver

Kopi til:postmottak@uib.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	15.04.2016	2015/2029/REK vest
			Deres dato:	
			07.04.2016	

Vår referanse må oppgis ved alle henvendelser

Kristine Bærøe
Institutt for global helse og samfunnsmedisin

2015/2029 Gravide som ønsker keisersnitt til tross for anbefaling om vaginal forløsning

Forskningsansvarlig: Universitetet i Bergen
Prosjektleder: Kristine Bærøe

Vi viser til søknad om prosjektendring datert 07.04.2016 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet ved REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Omsøkt prosjektendring
Det søkes om å gjøre en endring i rekrutteringsprosedyren. I den opprinnelig søknaden ble det lagt opp til at jordmødrene skulle gi kontaktinformasjon om aktuelle deltakere til forsker og at forsker skulle kontakte disse direkte. For å overholde taushetsplikten legges det nå isteden opp til at jordmødre ved Rådgivningssenteret identifiserer aktuelle kandidater for studien, informerer dem om studien og oppgir kontaktinformasjon til forskerne. Vedkommende må deretter selv ta kontakt med forskerne for å delta i studien.

Vurdering
REK vest har ingen innvendinger mot endringen.

Vedtak
REK vest godkjenner prosjektendringen i samsvar med forelagt søknad.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Camilla Gjerstad
rådgiver

Kopi til: *postmottak@uib.no*

Besøksadresse:
Armauer Hansens Hus (AHH), Tverrfløy Nord, 2 etasje. Rom 281. Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: http://helseforskning.etikkom.no/

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	19.10.2018	2015/2029/REK vest
			Deres dato: 18.10.2018	

Vår referanse må oppgis ved alle henvendelser

Kristine Bærøe
Institutt for global helse og samfunnsmedisin

2015/2029 Gravide som ønsker keisersnitt til tross for anbefaling om vaginal forløsning

Forskningsansvarlig: Universitetet i Bergen, Helse Bergen HF - Haukeland universitetssykehus
Prosjektleder: Kristine Bærøe

Vi viser til søknad om prosjektendring datert 18.10.2018 for ovennevnte forskningsprosjekt. Søknaden er behandlet av REK vest ved sekretariatet på fullmakt, med hjemmel i helseforskningsloven § 11.

Prosjektendring
Det søkes om endring av prosjektslutt der ny prosjektslutt vil være 01.03.2020. Arbeidet er blitt forsinket, og man ønsker å beholde data inntil artiklene er publisert.

Vurdering
REK vest har vurdert endringssøknaden og har ingen merknader.

Vedtak
REK vest godkjenner prosjektendringen i samsvar med forelagt søknad.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Camilla Gjerstad
rådgiver

Kopi til: *postmottak@uib.no; postmottak@helse-bergen.no*

Besøksadresse:
Armauer Hansens Hus (AHH), Tverrfløy Nord, 2 etasje. Rom 281. Haukelandsveien 28

Telefon: 55975000
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Kristiane Tislevoll Eide
Institutt for global helse og samfunnsmedisin Universitetet i Bergen
Postboks 6165
5892 BERGEN

Vår dato: 20.11.2015 Vår ref: 45158 / 3 / MSS Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 14.10.2015. Meldingen gjelder prosjektet:

45158	*Når den gravide ønsker keisersnitt til tross for anbefaling om vaginal forløsning*
Behandlingsansvarlig	*Universitetet i Bergen, ved institusjonens øverste leder*
Daglig ansvarlig	*Kristiane Tislevoll Eide*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 01.04.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Marie Strand Schildmann

Kontaktperson: Marie Strand Schildmann tlf: 55 58 31 52
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 45158

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Bergen sine interne rutiner for datasikkerhet.

Forventet prosjektslutt er 01.04.2018. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)

Emne: Prosjektnr: 45158. Når den gravide ønsker keisersnitt til tross for anbefaling om vaginal forløsning
Dato: torsdag 8. mars 2018 13:57:21 sentraleuropeisk normaltid
Fra: Lasse Andre Raa
Til: Kristiane Tislevoll Eide

BEKREFTELSE PÅ ENDRING

Hei.

Viser til endringsmelding registrert hos personvernombudet 28.02.2018.

Vi har nå registrert at ny prosjektslutt er 28.02.2019 (opprinnelig 01.04.2018). Det gis ikke ny informasjon til utvalget.

Det bemerkes at ved ytterligere forlengelser må det påregnes å gi ny informasjon.

Personvernombudet forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og personvernombudets tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

Med vennlig hilsen

Lasse André Raa
Rådgiver | Adviser
Seksjon for personverntjenester | Data Protection Official
T: (+47) 55 58 20 59

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data
Harald Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
postmottak@nsd.no www.nsd.no

V

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

GRAVIDE SOM ØNSKER KEISERSNITT

Dette er et spørsmål til deg om å delta i et forskningsprosjekt om gravide som selv ønsker keisersnitt som forløsningsmetode ved fødsel. Din deltakelse i studien kan bidra til økt forståelse av problemstillingen og et bedre tilrettelagt helsetilbud i fremtiden. Studien utføres av Institutt for Global Helse og Samfunnsmedisin ved Universitetet i Bergen.

HVA INNEBÆRER PROSJEKTET?

Deltakelse i prosjektet innebærer ett intervju av omtrent 1-2 timers varighet med PhD stipendiat Kristiane Tislevoll Eide ved Universitetet i Bergen. Her vil vi først og fremst spørre om dine holdninger til problemstillinger, din bakgrunn for ønsket om keisersnitt, forventninger til og opplevelsen av ditt møte med helsevesenet. Deltakelsen er helt uavhengig av og vil ikke påvirke din behandling ved Kvinneklinikken.

I prosjektet vil vi spørre om følgende opplysninger om deg på intervjuet: din alder, om du er første- eller flergangsfødende (hvis flergangsfødende, hvordan du ble forløst ved tidligere fødsler), svangerskapsuke ved intervjuet, sivil status, yrke, utdannelse og nasjonalitet. Vi vil også spørre om tillatelse til å ringe deg 4 uker etter termin for å høre hvilken forløsningsmetode du endte opp med og hvorvidt du er fornøyd med dette etter fødselen.

Dersom du ønsker å delta eller har spørsmål kontakter du Kristiane Tislevoll Eide på på telefon 41509634 eller på e-post: kristiane.eide@uib.no.

MULIGE FORDELER OG ULEMPER

Dersom denne studien bidrar til økt forståelse om problemstillingen og pasientgruppen, vil en kunne legge bedre til rette og forbedre helsetjenesten i møtet med pasientene i fremtiden. Dette kan bli en mulig fordel for deg ved samme problemstilling i fremtidige svangerskap. Utover dette er det ingen kjente fordeler eller ulemper ved deltagelse i studien. Studien er helt uavhengig av behandlingen og fødselshjelpen du får ved Kvinneklinikken.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, eller bare ønsker en uforpliktende samtale for mer informasjon om studien, kan du kontakte forskningsansvarlig Kristiane Tislevoll Eide på telefon 41509634 eller på e-post: kristiane.eide@uib.no. Deretter avtales et tidspunkt og sted for intervjuet, hvor samtykkeerklæringen på siste side må undertegnes ved oppmøtet. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlet lydopptak og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter ditt navn til intervjuet og bakgrunnsopplysningene om deg.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

FORSIKRING

Alle deltakere vil være forsikret gjennom Norsk Pasientskadeforsikring.

ØKONOMI

Deltakerens eventuelle reiseutgifter for deltakelse på intervjuet vil bli dekket av prosjektets driftsmidler.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnr. REK vest (2015/2029).

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

JEG BEKREFTER Å HA GITT INFORMASJON OM STUDIEN

Sted og dato

Intervjuers signatur

Intervjuers navn med trykte bokstaver

Forespørsel om deltakelse i forskningsprosjektet

"Når den gravide ønsker keisersnitt til tross for anbefaling om vaginal forløsning"

Bakgrunn og formål
Formålet med denne studien er å kartlegge jordmødres og legers erfaringer med og holdninger til pasientgruppen gravide som ønsker forløsning ved keisersnitt til tross for faglig anbefaling om vaginal forløsning. Studien utgår fra Institutt for global helse og Samfunnsmedisin ved Universitetet i Bergen som del av et PhD prosjekt.

Jordmødre og leger fra obstetrisk seksjon ved Kvinneklinikken, Haukeland Sykehus eller Voss Sjukehus inviteres til deltagelse. Det er et krav at du har erfaring med pasientgruppen gjennom ditt arbeid.

Hva innebærer deltakelse i studien?
Deltagelse i studien består at et gruppeintervju av 4-8 jordmødre og/eller leger som sitter sammen i 1-2 timer og diskuterer problemstillingen under ledelse av forskningsansvarlig. Det er ønskelig med totalt 3-4 slike grupper. Diskusjonen vil tas opp på lydbånd som vil transkriberes og analyseres på tvers av diskusjonsgruppene. Kun fornavn vil bli utrykket på lydopptaket, og ved videre transkribering og bearbeiding av materialet vil deltagerne nummereres og det vil ikke være mulig å identifisere deltagerne videre. Vi ønsker å samle inn følgende bakgrunnsinformasjon om deltagerne: alder, års erfaring på feltet, kjønn, egne forløsninger, profesjon (jordmor/LIS/overlege).

Hva skjer med informasjonen om deg?
Alle personopplysninger vil bli behandlet konfidensielt. Kun forskningsansvarlig vil ha tilgang på navneliste og lydfil, og kun forskningsgruppen vil ha tilgang på det transkriberte datamaterialet for analyse. Oppbevaring skjer på en kodebeskyttet datamaskin tilknyttet universitetet.

Resultatene vil bli forsøkt publisert i et internasjonalt faglig tidsskrift. Deltakerne vil ikke kunne identifiseres i publikasjonen.

Prosjektet skal etter planen avsluttes senest 1. April 2018. Ved prosjektslutt oppbevares/lagres det anonymiserte datamateriale på en universitetsmaskin under kodebeskyttelse kun tilgjengelig for forskningsansvarlig, i tilfelle reanalysering skulle bli aktuelt. Navnelisten over deltagerne blir slettet ved prosjektets slutt.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert. Aktiv og frivillig deltagelse i studien betraktes som samtykke. Det vil ikke bli nedtegnet skriftlig samtykke.

Dersom du ønsker å delta eller har spørsmål om studien, ta kontakt med Kristiane Tislevoll Eide, tlf: 41509634, e-mail: kristiane.eide@uib.no

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

VI

Intervjuguide dybdeintervju

Kort info (den gravide skal ha fått og lest infoskriv og signert samtykke):
Målet med denne studien er å få en bedre forståelse av hvorfor gravide ønsker keisersnitt, og hvordan de opplever møtet med helsetjenesten for så å kunne legge bedre til rette for dette i fremtiden. Derfor vil jeg veldig gjerne høre din historie, og du må gjerne fortelle alt du tenker er relevant for meg å vite. Ditt bidrag i denne studien vil være viktig for andre gravide i din situasjon, og kan hjelpe oss å forbedre helsetilbudet for dem i fremtiden. Jeg har noen spørsmål, men du styrer samtalen og kan fokusere på det du synes er viktig. Den vil ta kanskje 1-2 timer. Og samtalen vår tas opp på lydbånd. Alt du sier til meg er selvsagt anonymt, det er kun jeg som skal vite at det er du som snakker på lydopptaket og jeg vil bare benytte ditt fornavn under lydopptaket hvis det i det hele tatt blir nødvendig. Jeg jobber ikke på KK, og du trenger ikke være bekymret for at dette skal få konsekvenser for din videre behandling på KK, studien vår er helt uavhengig av tilbudet du får der. Du har selvsagt lov til å trekke deg underveis i samtalen eller etterpå og få slettet lydopptaket, så sant den ikke er brukt i analyse enda.

Spørsmål:

1. **Da må du bare begynne å fortelle din historie…**
    a. **Jeg ønsker å vite litt om hvorfor du ønsker keisersnitt og hvordan det har vært for deg å søke hjelp for dette.**
2. **Årsak til ønsket (kommer ofte frem spontant)**
    a. Hvis angst – hva er det ved fødselen du er redd for?
        i. Smerte
        ii. Kontroll
        iii. Skade på deg selv
        iv. Skade av barnet
        v. Assistert fødsel (tang, sugekopp, akutt keisersnitt)
    b. Hvis tidligere erfaring/skrekkhistorie
        i. Vil du fortelle litt mer om hva som skjedde her?
        ii. Fått samtale/informasjon etterpå?
        iii. Var du forberedt på fødselen. Hvilke forventninger til hva en fødsel innebar og hva som kunne skje underveis tror du?
        iv. Fikk du tilbud om foreldrekurs (fødselsforberendende) før fødselen og benyttet du deg av dette?
    c. Er det andre grunner? Ting som har spilt inn på valget?
    d. Er det noe spesielt du kommer på som kan ha påvirket ditt valg og dine holdninger til dette?
        i. Tidligere opplevlser/erfaringer
        ii. Media
        iii. Skrekkhistorier
        iv. Slektninger
3. **Hvordan har det vært å forholde seg til andre om dette ønsket?**
    a. Har du kunnet betro deg til noen?
    b. Har du hatt noen å prate med?
    c. Ønsker du å snakke med andre om dette?
    d. Er det vanskelig å snakke om dette med andre?
    e. For eksempel partner, familie, venner
4. **Hva har du fått/funnet selv av informasjon?**
    a. Tilfredsstillende informasjon?
    b. Hentet inn på egenhånd?
    c. Hvor? Nettet? Kjente?
    d. Kritisk til kilder?

5. **Hvordan har du gått frem for å få hjelp?**
    a. Samtaler med fastlege/jordmor?
        i. Primær
        ii. Sekundærhelsetjenesten
        iii. Stoler du mer på en jordmor eller en lege i denne avgjørelsen?
    b. Har du diskutert dette med en nær person?
        i. Partner
        ii. Mor/far
        iii. Venninne
6. **Fortell litt om behandlingen du har fått hos Rådgivningssenteret på KK**
    a. Forventninger til hva som skulle skje
        i. Redd? Bekymret? Gledet seg?
    b. Opplevelsen av samtalene
        i. Tatt på alvor
        ii. Respektert
        iii. Hørt
        iv. Evt misfornøyd
    c. Hva slags **informasjon** har de gitt deg?
        i. Klarer du å stole på denne, eller vil du lese selv?
    d. Er dere kommet til en avgjørelse ifht fødselen?
        i. Fornøyd
        ii. Misfornøyd
        iii. Overkjørt
    e. Har du endret holdning etter samtalene?
7. **Er det noe du tenker kunne vært bedre i behandlingen av deg eller andre som ønsker keisersnitt?**
    a. Hvordan synes du pasienter som deg burde vært håndtert av helsevesenet?
    b. Noe som mangler?
    c. Spesielle behov?
    d. Andre måter å håndtere problemstillingen på?
    e. Sluppet tidligere til hos …?
    f. Informasjon på et tidligere tidspunkt
    g. Holdninger/imøtekommenhet/åpenhet fra helsepersonell?
    h. Psykologstøtte? Annen relevant kompetanse?
    i. Kunne dette ført til at du i større grad hadde vurdert å føde vanlig?
8. **Hvem synes du bør bestemme hva som er beste fødselsmetode for den enkelte kvinne?**
    a. Hvorfor synes du nettopp dette?
    b. Bør det være fullstendig selvbestemt?
    c. Eller et samarbeid mellom jordmor/gravid gynekolog/gravid eller fastlege/gravid.
    d. Eller er helsearbeidere best skolert til å avgjøre dette?
9. **Er det noe mer du synes jeg bør vite**? Noe jeg ikke har spurt om som bør komme frem om deg eller andre i din situasjon?
10. **Kan jeg få høre hvordan det har gått og hva du synes om keisersnittet en stund etter fødselen?**
    a. Hvilken kontakt foretrekker du? At jeg ringer, du skriver melding eller mail?
    b. 4 uker etter ok?

Bakgrunns karakteristika:

1. Paritet
    a. Nullipara
    b. Mulitipara
2. Svangerskapsuke/termindato
3. Sivil status
    a. Gift
    b. Samboer
    c. Kjæreste
    d. Singel
4. Alder
5. Yrke
6. Utdannelse
7. Nasjonalitet
    a. Norsk
    b. Innvandrer
        i. 1. Generasjon
        ii. 2. Generasjon

- Dersom en får tillatelse til å ringe den gravide (evt. sende mail) 4 uker etter estimert termin vil det spørres om forløsningsmetode og tilfredshet med forløsningsmetode.

Intervjuguide fokusgrupper

1 t til rådighet
Anbefaling:
Astrid: 4 hovedspm
Malterud: 5-8 hovedspm (2 t)

Intro:
I dag skal vi snakke om kvinner som henvises til KK med et ønske om å få innvilget et planlagt keisersnitt.

1. **Hva er deres inntrykk av pasienter som ønsker keisersnitt?**
    a. Hvem er disse pasientene?
    b. Hvorfor ønsker de keisersnitt?
2. **Hvordan er det å jobbe med disse pasientene?**
    a. Hvilke følelser vekker disse pasientene i dere?
    b. Opplever dere noen etiske utfordringer i møte med dem?
3. **Vil dere fortelle litt om hvordan dere pleier å håndtere eller behandle disse pasientene?**
    a. Har dere en egen strategi for hvordan dere møter disse?
    b. Er det noe dere kunne tenke at kunne vært organisert annerledes?
4. **Hvordan synes dere avgjørelsen om fødsel eller keisersnitt bør tas? Hvem synes dere bør ta den endelige avgjørelsen?**
    a. Delt
    b. Legen bestemmer
    c. Jordmor bestemmer
    d. Pasienten bestemmer

Bakgrunns karakteristika av deltagerne: (lag skjema som hver enkelt fyller ut)

1. Navn
2. Yrke
    a. Jordmor
    b. Lege
        i. Overlege
        ii. LIS
3. Kjønn
    a. Kvinne
    b. Mann
4. Alder
5. Hvor mange års erfaring i faget
6. Erfaring fra egne/partners fødsler:
    a. Vaginal forløsning
    b. Keisersnitt

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