I felt so much conflict instead of joy. An analysis of narratives from pregnant people in British Columbia who declined care recommendations

Kathrin Stoll (✉ kathrin.stoll@ubc.ca)

The University of British Columbia Faculty of Medicine <https://orcid.org/0000-0002-5944-7945>

Jessie J. Wang

The University of British Columbia Faculty of Medicine

Paulomi Niles

The University of British Columbia Department of Family Practice

Lindsay Wells

The University of British Columbia Department of Family Practice

Saraswathi Vedam

The University of British Columbia Department of Family Practice

Research

Keywords: Respectful maternity care, declining care, refusal of care, shared decision-making, lived experiences, care narratives, informed consent, childbirth, person-centered care

Posted Date: June 16th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-35291/v1>

License: This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Version of Record: A version of this preprint was published at Reproductive Health on April 15th, 2021.
See the published version at <https://doi.org/10.1186/s12978-021-01134-7>.

Abstract

Background

No Canadian studies to date have examined the experiences of people who decline care during pregnancy and birth. The current analysis bridges this gap by describing narratives from 892 people in British Columbia (BC) who refused a test or procedure that their care provider recommended.

Methods

In the *Changing Childbirth in BC* study, childbearing people designed a mixed-methods study that captured experiences of receiving maternity care, including novel items describing provider-patient interactions. We conducted a descriptive quantitative content analysis of 1540 open ended comments about declining care recommendations.

Results

Close to half of people who participated in the survey (n = 892; 46%) declined a test or procedure. Participants most commonly declined genetic or gestational diabetes testing, ultrasounds, induction of labour, pharmaceutical pain management during labour, and eye prophylaxis for the newborn. Some people reported that care providers accepted or supported their decision, and others described pressure and coercion from providers. These negative interactions resulted in childbearing people feeling invisible, disempowered and in some cases traumatized. Loss of trust in healthcare providers were also described by childbearing people whose preferences were not respected whereas those who felt informed about their options and supported to make decisions about their care reported positive birth experiences.

Conclusions

Declining care is common during pregnancy and birth and care provider reactions and behaviours greatly influence how childbearing people experience these events. Our findings confirm that clinicians need further training in person-centred decision-making, including respectful communication even when choices fall outside of standard care.

Plain English Summary

Conflict between pregnant people and providers can ensue when there is a difference in opinion about the right care for the mother or newborn. In these situations, pregnant people retain the right to decline care they do not want. While much of the literature focuses on the experiences of healthcare providers when care is declined, very little is known about how childbearing people experience these interactions. The current paper addresses this gap by presenting findings from 892 childbearing people in Canada who

declined a test or procedure that their maternity care provider recommended. Results showed that declining care is common. Gestational diabetes testing, ultrasounds, induction of labour, pharmaceutical pain management during labour, and eye prophylaxis for the newborn were most commonly declined. Respondents gave many reasons for declining care, with the most common being the belief that the test, medication, or procedure was not necessary, or did not align with their values. Childbearing people described three types of interactions with health providers when they declined care: being informed, feeling pressured, and losing trust. Feeling respected and heard and having all of the information to make decisions enhanced their comfort, but pressure to comply led to feelings of disempowerment and distrust. One way to avoid conflict and differences in opinion is for care providers to ask about and understand the expectations, needs, fears, and preferences of pregnant people early on and to provide enough time for discussions about care options.

Background

In 2020, the British Columbia (BC) Patient Safety & Quality Council, in close collaboration with patient partners, clinicians and other stakeholders, co-developed a set of seven health quality dimensions. The first two dimensions are respect – i.e. respecting a person's choices, needs and values; and safety – i.e. avoiding harm and fostering security. Safety as defined by the council includes physical and psychological safety, cultural humility, and avoidance of harm. Harm is defined as inflicting physical harm but also as limiting a person's autonomy (1).

In a high-quality care system, providers respect the right of pregnant people to make informed choices and facilitate this process by providing complete, relevant, and objective information in a non-authoritarian, supportive manner. Pregnant people and their caregivers generally work together to make decisions (2). Occasionally, however, a pregnant person declines recommended treatment, or requests treatment that a care provider believes is unsafe. When this occurs, childbearing people retain the right to respectful care. However, these situations can cause conflict between a childbearing person and their caregiver that can impede communication, compromise care, and contribute to poor outcomes (2).

How pregnant people experience care when they make choices outside of community standards or against their provider's recommendations is not well understood. By analyzing open-ended responses from an online survey from the *Changing Childbirth in BC* Study (3, 4), we describe experiences of people who declined their care provider's recommendations during pregnancy, birth, and/or the postpartum period. Increased knowledge in this area may assist care providers in supporting autonomous decision-making and providing respectful care to all pregnant people, regardless of their choices.

Gaps in knowledge

The published literature on refusal in maternity care mostly focuses on care providers' experiences (5–8). Frameworks for practitioners to guide informed decision-making have been developed out of this

research. Very few studies identify reasons why pregnant people decline care recommended by their midwife, obstetrician, family physician, or nurse, or the impact that this has on them.

Cahill identified recurring issues of paternalistic and defensive practice with regard to providing patients with informed choices (9). Clinical decision-making was based on physiological indicators, rigid adherence to protocols, poor communication and documentation, and failure to acknowledge people's views and feelings. Lyster et al. stated that the perception and communication of risk is an ongoing challenge in maternity care and can lead to care that is neither evidence-based nor patient-centered (10). Ultimately, the goal of informed choice is that pregnant persons understand all of their options and are able to decide what is in their or their newborns' best interest. Not only do paternalism and perceptions of risk influence many informed choice discussions, but care providers' opinions and experiences have been prioritized over patient preferences and experiences within the literature. Two papers described midwives' experiences when their clients declined standard care with no reference to the impact that this had on their clients (5, 8).

Research exploring the experiences of those who decline care is scarce. Jenkinson and colleagues explored the experiences of people, midwives, and obstetricians when people declined recommended care (6, 11). Specifically, researchers interviewed healthcare providers (n = 12) and childbearing people (n = 9) who received care at a tertiary hospital in Australia that instituted a process to document refusal of care. While care providers felt "protected and reassured by the structured documentation and communication process", childbearing people and some midwives felt that risk discourse and pressure to accept unwanted care were still prevalent (11). In another study, Chigbu and Iloabachie interviewed 62 Nigerian childbearing people postpartum to explore reasons for declining cesarean Sect. (12). Reasons included fear of death, economic factors, desire to experience vaginal delivery, and inadequate counselling. These studies provide important information about the phenomenon but are based on very small samples, and some are restricted to declining a specific procedure. They do not provide insight into the response of the healthcare system, nor the ultimate impact on patient well-being. The current paper provides the most comprehensive analysis to date, based on a large dataset, on the types of tests and procedures that childbearing people decline, why they declined, perceptions of their care providers' reactions, and how they describe the impact on their quality of care, safety, and mental health.

Methods

A Steering Council of 18 people with previous childbirth experiences and a few planning to become pregnant met with the research team to design *Changing Childbirth in BC*, a provincial community-led mixed methods study of people's experiences while accessing pregnancy and birth care. Steering Council members represented various groups, including immigrants and refugees and those with a history of incarceration and housing instability. Prior to convening the Steering Council, through our community partner (Midwives Association of BC) we surveyed 1333 people across the province, who provided feedback about key areas for study. Two topics prioritized by those surveyed were: 1) *My birth experience* and 2) *My experience around how decisions were made during my pregnancy*. Data collection via online

survey and focus groups were common choices among respondents when they were surveyed about preferred modes of data collection.

Following a broad literature review to collect relevant validated items for a cross-sectional survey, the Steering Council members participated in a content validation process to assess relevance, importance, and clarity of items to their constituents, adapting or creating new items when necessary. The final instrument collected information on demographics, preferences for and access to model of care, maternal and newborn outcomes, and 31 items describing preferences for and experiences of decision-making over the childbearing cycle, including experiences of declining care.

Recruitment

Following approval by the University of British Columbia Behavioural Research Ethics Board (# H12-02418), the survey was made available through a public website, and all non-governmental organization (NGO) and community partners disseminated the link and information to people of childbearing age across BC. The survey was advertised through posters and social media outlets, and reminder notices were sent by email, postcards, community listservs, and NGO websites. All institutional partner organizations, including a large provincial referral hospital and maternity clinics, recruited study participants. Clinician team members encouraged their colleagues to disseminate to their patients/clients. In the current paper, we report survey responses for people who declined care at some point during their pregnancy, birth, or the postpartum period.

Analysis

We conducted descriptive analysis of open-ended responses to the question: *At any time did you refuse to accept any care that a nurse, doctor or midwife offered to you or your baby? "Care" includes anything that might be done or given to either of you or that you were asked to do (take a test, treatment, medicine, etc.).* People who answered "yes" were prompted to answer an open-ended follow-up question: *Please tell us what you refused, why you refused it, how the staff reacted, and how you felt about it. We would appreciate as much detail as you would care to provide.* People could answer this question for up to three pregnancies/births. Of the 1958 people who answered the question about whether they refused any care, 892 responded in the affirmative (45.6%) and provided a total of 1540 comments. Some responded with a few words, and others wrote one or more paragraphs.

The analysis team included two midwife clinician researchers (SV, PN), medical (JW) and midwifery (LW) trainees, and a reproductive health researcher with a background in psychology and sociology (KS). We used quantitative content analysis (13, 14), a data analysis approach that is well suited to descriptive analysis of short response segments. This approach involved line-by-line counting of 1) tests and procedures that people declined, 2) reasons for declining, 3) care provider reactions, and 4) childbearing people's feelings about the situation. Prior to analysis, three team members (SV, KS, JW) reviewed the first 200 comments and agreed on a preliminary list of data categories for each of the four elements of the question. JW used this list to code the data, added new categories as needed, and conducted the line-by-

line counting of all responses under the supervision of SV and KS. For the last component of the question (*how you felt about it*), midwifery trainee LW reviewed the categories and relevant comments to provide a more detailed description of this section. KS and PN collaborated to develop meaningful interpretation of the findings, and SV and PN contributed insight on clinical relevance of the findings. Data was analyzed using NVivo software. Three of the analysis team members are also parents with lived experience of declining aspects of maternity care or opting for care that did not align with community standards.

Results

Sample characteristics

The majority of people who reported refusing care (90.2%) experienced their last birth between 2010–2014 (i.e. within 5 years of data collection), and all people had experienced pregnancy in BC at least once. A small number (7.3%) self-identified as persons of colour and the rest as white (92.7%). The majority (n = 668; 90.8%) were college educated, and the average age of people was 32.6 at the time of data collection. Most cited receiving care from midwives (n = 740; 83.0%), followed by family physicians (n = 88; 9.9%) and obstetricians (n = 64; 7.2%). Intervention rates in this subsample were low: of the 892 people who refused care, 131 (16.2%) had their labours induced, and 137 (16.9%) had a cesarean section. One in seven (n = 122; 13.7%) reported medical or social risk factors during pregnancy.

What types of tests and procedures did people refuse?

A total of 2478 different references to tests, medications, and procedures that people refused were identified (see Fig. 1). During pregnancy, the most commonly declined assessments were genetic testing (e.g. amniocentesis, chorionic villi sampling), gestational diabetes testing, and ultrasound(s). During labour and birth, participants most often declined induction of labour (e.g. membrane sweeping, oxytocin, etc.), pain relief (e.g. nitrous oxide, epidural etc.), fetal or maternal monitoring, and medications (e.g. antibiotics, rhogam, magnesium sulfate, anticoagulation, castor oil, etc.). The pain management method most often refused was epidural (40 references), and the medication most often declined was antibiotics (48 references). In the postpartum period, the most commonly declined procedure was application of eye ointment to the newborn (erythromycin antibiotic prophylaxis), followed by vitamin K for the newborn, and selected procedures, such as cord clamping (immediate or delayed), suctioning, in-hospital bathing, baby foot printing, newborn metabolic screening via heel blood draw, circumcision, mother-baby separation, hearing screen, etc.

Why did people refuse tests and procedures?

There were 1366 comments that described why tests or procedures were declined. Responses could be categorized into 9 categories, the most common of which were that the test, procedure, or medication was deemed **unnecessary** (572 comments) or did not align with the **person's values** (303 comments); they **preferred an alternative** (135 comments) or considered the test/procedure **bad for baby or unsafe** (104 comments); or they had **access to information** or had reviewed research that did not support use of the

test, medication, or intervention (86 comments). Less commonly reported were refusals because they **felt uncomfortable**, because of **health reasons**, because **healthcare providers were being rude or incompetent**, or because they felt that it was too **inconvenient**. Some comments fell into the **Other, Unspecified** category. Categories and illustrative quotes are listed in Table 1.

Table 1: Reasons people declined tests or procedures, with illustrative quotes

Why did people refuse tests and procedures?	Illustrative quotes
Unnecessary (n=572)	<i>"I did not see the need to"</i> <i>"I did not have risk factors"</i> <i>"I later accepted the intervention when it became necessary"</i>
Did not align with the patient's values (n=303)	<i>"I did not want one"</i> <i>"I would not terminate pregnancy anyways"</i> <i>"I wanted to labour naturally"</i>
Preference for an alternative (n=135)	<i>"We opted for oral vitamin K"</i> <i>"I decided on forceps instead"</i> <i>"I kept a healthy diet instead of taking insulin"</i>
Considered bad for baby (n=104)	<i>"I did not want goop in my baby's eyes"</i> <i>"The risks of amnio are too high"</i>
They had access to information or had reviewed research that did not support the medication/intervention (n=86)	<i>"The research says the intervention does not improve outcomes"</i> <i>"I heard that the test is inaccurate"</i> <i>"The false positive rate is too high"</i>
They felt uncomfortable (n=38)	<i>"I have a strong fear of needles"</i> <i>"Putting in an epidural is too painful"</i>
Health reasons (n=31)	<i>"I have a suspected allergy to analgesics"</i> <i>"Laughing gas made me feel sick"</i>
They felt that healthcare providers were being rude or incompetent (n=28)	<i>"The doctor was very pushy"</i> <i>"The nurse was incompetent"</i> <i>"I refused to see that OB again"</i>
They felt it was too inconvenient (n=14)	<i>"I have a toddler at home"</i> <i>"I was busy with work"</i>
Other, Unspecified (n=55)	<i>"I didn't like it the last time"</i> <i>"I was abused in the past"</i>

How did care providers react?

Care provider reactions were described in 1414 comments. The majority (603 comments) were about care providers **accepting the decision**, and 373 comments were about healthcare professionals **supporting the decision**. However, 180 comments referred to care providers **reacting with disrespect** in response to the refusal, or providers **trying to convince them** to accept care they did not want (158 comments). Some comments (72) were about care providers not accepting or honouring the decision and **proceeding without consent**. Finally, 28 comments could not be categorized and fell into the **Other category**. Themes and illustrative quotes are listed in Table 2.

Table 2: Care provider reactions, with illustrative quotes

How did care providers react?	Illustrative quotes
Provider accepted the decision (n=603)	<i>"The nurse respected my decision"</i> <i>"They were fine with it"</i>
Provider supported to decision (n=373)	<i>"I felt supported"</i> <i>"My midwife was very supportive"</i> <i>"The doctor presented the pros and cons and left the decision up to us"</i>
Provider did not react respectfully (n=180)	<i>"The nurses seemed offended"</i> <i>"They clearly thought I was making the wrong decision"</i> <i>"He belittled me"</i>
Provider tried to convince them to accept care (n=158)	<i>"I felt very pressured"</i> <i>"He tried to scare me into taking insulin"</i> <i>"She pulled up all these scary stats"</i>
Provider did not honour decision and proceeded anyways (n=72)	<i>"She did it without my consent"</i> <i>"I asked for delayed cord clamping but they cut it right away"</i> <i>"I screamed for her to stop and she just kept going"</i> <i>"She fed the baby behind my back"</i>
Other (n=28)	<i>"I don't recall their reaction"</i>

How did childbearing people feel about the situation/encounter?

There were 341 comments in this section that could be grouped into three categories: 1) being informed, 2) losing trust and 3) feeling pressured.

Being Informed

Participants reported that informed choice discussions and feeling respected enhanced their care experience. In situations where care was declined, participants stated that feeling validated and respected led to the experience of *“feeling informed”*. Participants also appreciated having both knowledge and choice in deciding what was right for them and their family. One participant wrote: *“I didn't really feel like I was refusing treatment so much as making a choice.”* The link between information and choice was vital, and it framed choices around care as an *“offer”* rather than being prescribed or ordered. This approach led to clients feeling in control of their care. One participant wrote:

...We discussed these topics, I asked questions and expressed my concerns, she addressed my concerns directly and then left the decision up to me. I felt she provided me with enough information to make my own decisions and that she trusted me to do so. I really appreciated that my midwife never seemed nervous or afraid of my decisions, and never tried to intimidate or influence me by emphasizing or exaggerating risk factors...

When care providers support person-led decision-making, by offering information and options, “refusing” care is viewed as a choice rather than a refusal. One person observed:

[...] since everything was presented as options to be considered and decided upon, it didn't feel like I was 'refusing to accept care' when I said no to things. I did say no to a number of things...like prenatal testing, eye gel for the newborn, some of the gestational diabetes guidelines I was given.... but none of that felt like refusing care, it was just part of the care I received while pregnant [...]

Being Pressured

While the above participants described situations of being in control of their care decision, others felt dissatisfied and disappointed in their care experiences. Pressure to conform, combined with a state of vulnerability, led to these feelings of disempowerment. A predominant theme of *“feeling pressured to give in”* arose. Participants used language such as *“persuaded”, “ganged up on”, “coerced”, “badgered”, “forced”, “pushy”, “convinced”, “submitted”, and “insisting”* to convey how their decisions were received by providers. Participants described that they *“felt disappointed about feeling that pressure”*.

Childbearing people recounted these as forms of coercion or pressure that were imposed upon them by healthcare providers. Some participants found themselves in a vulnerable position and ultimately

relented, giving in to doing things they did not want. When reflecting on this vulnerable state and the situations that occurred, some described being disappointed in themselves:

[I] refused formula in the hospital when having challenges learning how to breast feed. I didn't want my baby to receive formula. Staff respected [me] in that moment but came back multiple times with pressure to accept formula every time after we would try breast feeding. Eventually my husband agreed to give formula in a moment where I was feeling too emotionally drained to keep refusing. I felt like a failure. Like I couldn't give birth properly and couldn't feed my baby properly either.

Some participants described treatment by healthcare providers that made them feel humiliated and powerless, akin to torture:

I did not want to lie on my back or go in an ambulance but was forced to do both via physical force. I was also tied down in the ambulance which I did not want and which felt like torture. Also my midwife kept exposing my buttocks and privates in the ambulance and I felt humiliated as there was a male ambulance attendant right there. I do not understand why this was done and it made me feel completely powerless and humiliated.

A small number of participants described the trauma caused by feeling coerced:

I had been told about episiotomies prior to labour, and was clear that I didn't want one. I thought that my doctor understood, as she didn't pursue it. However, during the delivery she said she was going to give me the episiotomy. I refused. She said it was a routine procedure to prevent tearing. She did it without my consent. During the episiotomy I screamed out for her to stop, that I could feel her cutting. She told me that was impossible and kept going. The pain was extreme...I felt traumatized by the whole birth. I subsequently avoided gynaecological exams for years...

In an extreme case, another participant described how the experience of coercion in a prior birth led to their decision to give birth unassisted:

"The midwife and the nurse kept applying fetal monitors even though I was throwing them off and yelling "NO, NO, NO". By this time I had been on pitocin for 10 + hours, it had been 2 days since I last ate, and all the pain meds had worn off. They kept trying to get me to agree to a c-section and told me I would be allowed pain meds if I agreed, and that I could eat afterwards too. It was a horribly disgusting abuse of power. It is totally unacceptable that people are treated this way. I am currently pregnant and am planning an unassisted birth because I refuse to go back to the hospital and be battered and abused again - with NO recourse available and no accountability whatsoever. I will not pretend that it's okay to treat people like that."

Losing trust

Interactions of a paternalistic nature often lacked information and consent, which contributed to an overall mistrust of care providers. Some chose to decline recommendations if they felt under-informed

about the decisions they were making, leading to a perception of negative care experiences. One participant wrote: “...[the doctor] came in telling me *WHAT* was going to go on with my labour, rather than asking what my partner and I wanted to do, and explaining the options.” Participants did not appreciate feeling like they lacked information and decision-making power during their care. This is evident in another participant’s story:

I refused to be induced at 38 weeks because they never had any solid reasons for wanting to induce me, and kept talking about this very early on (prior to 30 weeks). First they said baby would be too big, and so they wanted to induce. Then they said baby would be too small, and so they wanted to induce. They never stated what made them think this, or why, and I refused to consent to that. I said that we would wait until 40 weeks and THEN we could start discussing it, if it was needed.

Disrespect or disregard for the wishes of people also generated mistrust. When they felt that their decisions were not respected and supported by their care provider(s), one participant recounted making the decision to discontinue care:

I was diagnosed with gestational diabetes at about 34 weeks gestation with my twins. I tried using insulin to control my blood sugars but felt terrible when on the insulin and chose to stop treatment. The endocrinologists and diabetes clinic nurses at [name of hospital redacted] were very aggressive in pushing for treatment with insulin and actually played down some of the risks/dangers associated with insulin usage. They could not provide me with any other options other than I HAD TO USE THE INSULIN, to the point where I was told my twins would be premature, have immature lung development, and low blood sugars at birth. I stopped going to the clinic and using the insulin treatment and tried controlling my dietary sugar intake. My twins were delivered on their scheduled date (at term) and had no health problems at birth and currently.

In another account, the participant reported that their needs and wishes were disregarded, which led to loss of trust in the midwife and stress for the client:

Although my second pregnancy was over a decade later, emotionally I needed to have as few people as possible involved. The midwife tried to persuade me to allow the practicum student. I remained clear that this was my pregnancy and that I had to have my need for privacy respected. When I next showed up for an appointment, there was a practicum student waiting in the room. I respectfully reminded the midwife that I had chosen not to have a practicum student involved. The midwife said that she was here now, so couldn't she just stay. I said sorry, but no. She said that the practicum student came all this way for nothing. Again, I said sorry, but no. The practicum student left, but the midwife was visibly displeased. I felt stressed by this incident, and it negatively impacted my trust and respect for the midwife.

Discussion

This is the first study in Canada to explore the experiences of childbearing people declining care offered or recommended by midwives, physicians or nurses. In our sample, close to half of participants declined

care at some point during pregnancy, birth, or the postpartum period (46%), making this a common phenomenon. The most commonly declined test or procedure was prenatal testing, such as genetic or gestational diabetes testing, and newborn treatments (eye ointment for the newborn, vitamin K); declining tests or procedures during labour or birth was less common. Participants described many reasons for declining care, but the most commonly cited were beliefs that the test, procedure or medication was unnecessary or did not align with their values.

A study with maternity care providers in the Netherlands, about maternal requests that go against medical advice, revealed that women most frequently declined gestational diabetes screening (66.3%), hospital birth (65.3%), and fetal monitoring (both continuous and intermittent) during labour (39.6%) (15). These results align with the findings of the current study and warrant further exploration of how care providers can best communicate the rationale for these tests and procedures to clients and remain respectful when clients decline care.

Our finding that childbearing people most often decline care during pregnancy

is supported by research with more than 2000 pregnant and postpartum people in the United Kingdom, who were surveyed about their ability to exercise informed consent. Perceptions of informed choice were very different for tests/procedures in the prenatal period compared to birth. For instance, 73% reported making an informed choice about genetic screening during pregnancy, but only 31% felt they made an informed choice about electronic fetal monitoring (EFM) during labour (16). The best available evidence shows that continuous EFM versus intermittent monitoring is associated with an increase in Cesarean sections and instrumental vaginal deliveries but no decrease in neonatal mortality. (17) The authors of the Cochrane review acknowledge the challenges of communicating evidence about EFM to pregnant people, so they can make an informed decision 'without compromising the normality of labour'. Hersh et al have published a case report that describes how care providers can support decision-making around intermittent auscultation by using a woman-centered decision- making pathway for fetal monitoring. (18)

These results, together with findings from the current study, emphasize the need for care providers to begin discussions during pregnancy about the pros and cons of common labour and birth interventions and procedures, including the evidence basis for recommendation, so that people have time to understand different procedures, and an opportunity to consider their options. This is especially important for childbearing people who might not know their birth provider, or if they have a known provider with whom they have not developed a positive and trusting care alliance.

In the current study, feeling pressure from maternity care providers led to feeling vulnerable and invisible and resulted in loss of autonomy. Pregnancy, childbirth, and the postpartum period are a critical emotional and transitional period in a person's life. Evidence confirms that a lack of involvement in decision-making about care results in negative patient experiences (19, 20). These findings suggest that both what is offered and the way it is being communicated are equally valuable to childbearing people. Being pressured into complying with unwanted care can have long-lasting psychological consequences and can lead to termination of care, as our results indicate. In one study with more than 1500 people in

the United States (US) who recently gave birth at a hospital, predictors of birth-related post-traumatic stress disorder (PTSD) were assessed. Pressure from care providers to have an induction or cesarean section was one of the factors significantly linked to PTSD symptoms (21). In an analysis of the full *Changing Childbirth in BC* dataset with 2051 childbearing people from British Columbia Vedam et al. (22) identified that pressure to have an induction or cesarean section, along with perceived differences in opinion between childbearing people and their providers (about care options), were significantly linked to loss of autonomy among childbearing people. These findings, together with results from the current analysis, establish a firm connection between pressure and coercion from care providers, loss of autonomy, and post-traumatic stress (15).

Our findings show that failure to gain clear, unambiguous consent for procedures or treatments contributes to mistrust of care providers among people who decline care. Feeling betrayed and powerless and losing trust in care providers were also themes that emerged in the stories of 40 women who described their births as traumatic (23). In another study with 2192 women from the Netherlands who described their birth as traumatic, loss of control and fear for the baby's life were the two most commonly reported reasons that people felt traumatized. When asked what care providers could have done to prevent the traumatic experience, the most common answers were: 1) communicating more and explaining things better, 2) listening more, and 3) providing emotional support (24). Our findings support the results from the Netherlands, as many participants noted that care providers did not listen and/or did not take the time to explain if and why a test or procedure was necessary.

Our findings also echo results from other studies about care provider behaviours and interactions. Reed et al. surveyed 748 women in Australia who described a traumatic birth experience (25). Common themes included "prioritising the care provider's agenda", "disregarding embodied knowledge", "lies and threats", and "violation". These themes resonate through our data as well, with many accounts of care providers ignoring people's knowledge of their own bodies and/or rigidly promoting care plans that people did not agree with.

Negative birth experiences and birth trauma impact the transition to parenthood negatively (26) and are linked to decisions to avoid contact with the healthcare system in future pregnancies (27).

Care providers are also affected. Midwives and physicians who witnessed abusive care felt moral distress and were at increased risk for post-traumatic stress symptoms. (28, 29) These negative experiences in turn contribute to burnout, which is linked to attrition of care providers and provision of lower quality care (30). These studies highlight the negative impact of witnessing disrespect and abuse among care providers and the indirect impact on patients, making a strong case for the need to eradicate disrespectful and abusive care provider behaviours through education, professional codes of conducts, hospital policies, collection of accountability metrics, remediation and sanctions. Framing disrespect and abuse in childbirth as human rights violations and gender-based violence (31) raises awareness about the severity of these issues and the importance of zero tolerance when it comes to mistreatment of childbearing people.

Midwives, family physicians, obstetricians, and nurses can provide respectful maternity care by ensuring client autonomy is supported through engaging in a person-centered decision-making process (20). However, research with maternity care providers shows that they support people's right to make decisions about their own care "within reason" and that the wishes of pregnant people can be overridden in some (emergency) situations (32). The higher risk of mistreatment during emergency situation has been demonstrated from the perspectives of childbearing people. In the *Giving Voice to Mothers* study, 2700 childbearing people were surveyed about pregnancy experiences in the US between 2010 and 2016. People with emergency cesarean sections reported higher rates of mistreatment by care providers, including pressure to accept treatment they did not want, compared to those with a vaginal birth or planned cesarean Sect. (33).

In our study, participants described such interactions as "abuses of power" and were distressed by these care provider behaviours. Morton et al. surveyed close to 300 maternity care providers in the US and Canada and found that they often witnessed verbal abuse, specifically threats to the baby's health and well-being if the pregnant person did not comply with recommendation (34). Our results support Morton's findings, as several participants described being told that their newborn was in danger, with the implication that they were unfit mothers for not complying with recommendations. Bioethicist Raymond de Vries describes this phenomenon as the invisible mother, because "concerns and needs of women in labour fade in the face of hospital policies and the perceived needs of their soon-to-be-born babies" (35). Other authors have grounded their analyses of situations where childbearing people decline care in critical feminist theory and highlighted how risk discourse and the dominance of medical knowledge are used to restrict or remove women's bodily autonomy and right for self-determination (6).

One of the main findings from our analysis was the importance of being informed about test and procedures and feeling supported by care providers when making decisions. The data also suggests that childbearing people in our sample declined tests or procedures because they found them to be unnecessary, preferred an alternative or had access to information that did not support use of the test, medication, or intervention. In some situations where people declined tests or procedures, care providers presented information with the sole purpose of gaining compliance, rather than discussing options. It is well known that knowledge is power and that there are inherent power imbalances in the provider-patient relationship. (36) In one study with 22 self-identified women of colour who were interviewed about their pregnancy and birth experiences, themes of power and control emerged. Specifically, respondents felt that care providers were controlling the information that women received, and how information was provided affected the level of autonomy and self-determination of childbearing women. Information provided by healthcare providers that was perceived as truthful, comprehensive and unbiased supported autonomous decision-making whereas information that was withheld, misleading, or biased reduced autonomy. Participants also noted that the way care providers communicated information was depended on women's ethnicity, educational level, insurance status and other factors and that a trusting relationship with care providers enhanced women's experiences with care. (36)

Implications for practice and health professional education

Childbearing people who trust their care providers are more likely to accept tests and procedures and feel more comfortable discussing reasons why they prefer to decline care (37). Michelle DeBaets notes that the use of birth plans are encountered with hostility by some care providers who regard them as “uninformed and unrealistic” (37). Childbearing people make written birth plans to ensure their wishes and preferences are respected, but as confirmed by our data, this is often not the case. This appears contradictory as health systems often require written consents for procedures from the patient. As an alternative to birth plans, the author recommends ongoing discussions before and during birth, to establish a birth partnership that is focused on trust, two-way communication, mutual education, and person-centred decision-making. During early prenatal appointments, care providers are encouraged to share their own birth philosophies and practices with clients, while developing an understanding of the preferences and expectations of clients (37). An extended prenatal visit is then recommended between 34–36 weeks to discuss the client’s values, preferences, and expectations for the birth. This enables the provider to understand what matters most to the childbearing person, find out what their fears and expectations are, and discuss options in the context of the client’s medical history. This is most valuable if the prenatal care provider will also be the provider attending the birth. A central feature of the birth partnership is mutual education about choices and the “values that inform those choices” (37). The author provides a helpful set of questions that can guide these discussions (e.g. What are the person's core values and goals of birth? What are their fears? Are there specific forms of treatment that the person does or does not want? Why? If labour does not go as expected, how will the person address their options for interventions?) Childbearing people retain the right to refuse care recommendations and care providers can avoid conflict by building trust through respectful interactions, steering people towards high-quality evidence and away from lower quality sources of information, as well as discussing options ahead of time. The author also offers important guidance for obstetric teams, especially for teams with differences in birth philosophy and practices, so that they can provide consistent and respectful care to clients (37).

Findings from the current study also highlight the need for clear guidelines for providers around situations where pregnant people decline care. Some clinicians recommend having a second healthcare provider counsel the client, and documenting the informed refusal, while reassuring the client that they will continue to receive courteous, professional care regardless of their choice (2). While these recommendations provide a good framework, it should be noted that our data suggest that involving a second care provider can be perceived by childbearing people as being “ganged up on” or being pressured to comply with recommendations, which might disrupt the care alliance between the childbearing person and their primary care provider. More importantly, Reed et al. note that women who felt bullied and coerced by care providers are more likely to report birth trauma. (25) These risks should be taken into consideration when care providers decide to involve other health professionals or family members in situations where care is declined.

Our findings confirm that clinicians need further training in supporting informed choice, and greater knowledge about health human rights (31) when clients make choices outside of standard care. Efforts to identify and reach consensus about quality criteria and professional competencies for applying

person-centered decision-making in maternity care have been published (38). Several training programs in shared decision-making and person-centered decision-making for healthcare providers exist. Effective person-centered care requires developing partnerships with patients, and skillful communication among healthcare providers of all disciplines. For example, *Dialogue and Decisions* (39) is an online interprofessional course explores the value and complexity of human interactions around healthcare decisions curricula and teaches health professional learners a systematic approach to person-centred care (see Fig. 2). Case-based activities, exploring patient preferences and controversies around birth care, develop professional skills that enhance patient-centred care and improve interprofessional team functioning in the workplace. Trainees become familiar with the roles and scopes of practice of various types of health providers, as well as the skills, equipment, and personnel needed to care for childbearing families across homes, rural health centres, and hospitals. They learn best practices and evidence-based strategies to promote communication, teamwork, conflict resolution, and collaborative leadership across settings and across disciplines. Legare et al. identified 54 similar programs, including case-based discussion, small group educational sessions, roleplay, printed educational material, and audit and feedback (40). The authors conclude that there is a need to determine which programs are most effective.

Additionally, Jenkinson et al. propose a comprehensive, woman-centered, systems-level framework for documentation and communication with the goal of supporting people, clinicians, and health services in situations of maternal refusal (41). Such frameworks centre the promotion of respectful maternity care, as described by Downe et al. (42). While proactive strategies as described by DeBaets are best (37), opportunities for self-reflection and debriefing after negative encounters are important. This may provide an opportunity for people to process their labour and birth experiences, as well as for care providers to understand how disrespectful care affects childbearing people and families. Integrating respectful maternity care policies and practices into hospital settings takes time, and long-term success depends on both frequent engagement with key stakeholders and systems- and structural-level investments (42).

Limitations

The findings of this study are based on a convenience sample of childbearing people who declined maternity care recommendations in British Columbia, Canada. While the sample was geographically and socio-economically diverse, it included few people of colour and a higher proportion of midwifery clients than would be found in the population of childbearing people in BC. In addition, the experiences of pregnant people may be different in other provinces or countries where maternity care systems and care options are different.

Future research on this topic ought to include a more diverse sample of childbearing people and add questions about what tests and procedures people wanted to decline rather than did decline. Some people might not have felt comfortable declining care, especially during labour and birth. Research with more than 2000 women with a traumatic childbirth experience shows that 16.5% reported that the birth trauma might have been prevented if they had refused an intervention (24).

Conclusions

Refusal of medication, procedures, and interventions is a common during pregnancy, childbirth, and the period after birth, and care provider reactions and behaviours greatly influence how childbearing people experience these events. Those who report a positive birth experience felt supported and respected in their right to choose, whereas loss of autonomy, mistreatment, disrespect, pressure, and coercion from care providers were reported to have negative and long-lasting impacts on childbearing people. Health systems have increasingly turned their attention to expanding access to person-centred care, and British Columbia has articulated a health quality framework that centers the importance of honouring people's choices and optimizing maternal health and wellness (1). Translating these dimensions of quality into improvements at the point of care is challenging, but frameworks on how to respectfully support informed choice and refusal of standard care have been developed, (2, 10, 11) and health professional curricula are emerging.

Abbreviations

BC

British Columbia

NGO

non-governmental organization

PTSD

post-traumatic stress disorder

US

United States

Declarations

Ethics approval and consent to participate

The study received approval by the Behavioural Research Ethics Board of the University of British Columbia (# H12-02418).

Consent for publication

Not applicable.

Availability of data and materials

Study participants did not consent to have their data shared with others outside the study team. In addition, the comments include information that might potentially identify respondents or their care providers.

Competing interests

The authors declare that they have no competing interests.

Funding

The survey was supported by Vancouver Foundation operating grant #UNR12-0701 for the provincial community-based participatory study *Changing Childbirth in BC*.

The lead author was supported by postdoctoral trainee grants from the Michael Smith Foundation for Health Research and the Canadian Institutes of Health Research between 2013 and 2017. The lead of the Birth Place Lab, Saraswathi Vedam, is supported by a Michael Smith Foundation for Health Research (MSFHR) Health Professional Investigator Award (grant #17020), which also supports the qualitative analysis activities of the *Changing Childbirth in BC* project. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Authors' contributions

All authors approved the final version of the manuscript. KS contextualized the findings and wrote the first and final draft. JW performed line-by-line data analysis and edited the final version of the manuscript. LW reviewed analysed data to provide more detailed descriptions. PN collaborated with KS to interpret the findings and reviewed the final version of the manuscript. SV supervised the project, reviewed all versions, and contributed insight into interpretation, clinical relevance of findings and recommendations.

Acknowledgments

The authors gratefully acknowledge our community partners for their long-term commitment to the diverse group of people they serve. We thank academic and clinician colleagues from several UBC departments, including Education, Family Practice, Public Health, Obstetrics, Midwifery, and the Women's Health Research Institute, for their assistance with recruitment, research training, and support for the community. In particular, work group leaders Lorna McRae, Mo Korchinski, Anna Tashlykova, Raquel Velasquez, Cathryn Ellis, and Nora Timmerman liaised with community members. We are grateful to Birth Place Lab research coordinators, Barbara Karlen and Karen Gelb, for their skillful coordination of our multi-stakeholder teams. Student research assistants Kelsey Martin, Sabrina Afroz, Kerri Blackburn Esther Lindokken supported the project. **Most of all, we thank the women and families of British Columbia who shared their stories with us.**

Authors' information

KS is a reproductive health researcher with degrees in psychology, family studies and interdisciplinary studies. She completed a five-year postdoctoral fellowship in Population and Public Health at the University of British Columbia (UBC) and a one-year fellowship in primary healthcare research. In addition to her position at the Birth Place Lab (University of British Columbia), KS holds an appointment as lecturer at Hannover Medical School in Germany.

JW holds a degree in Medical Laboratory Science and is a candidate in the MD class of 2021 at UBC. She has worked with the Birth Place Lab as a research assistant since 2016.

PN is a PhD-trained midwife and midwifery care researcher who joined the Birth Place Lab as a postdoctoral fellow. She is one of the few midwives serving on the Maternal Morbidity and Mortality Review Committee of the New York City Department of Health.

SV is Lead Investigator at the Birth Place Lab and professor of midwifery at University of British Columbia. Her community-based participatory research projects have led to the development of pragmatic tools that improve person-centered care, including patient-designed quality measures that are being applied in 23 countries. She is currently PI for the RESPCCT Study examining childbearing experiences across Canada.

References

1. BC Patient Safety & Quality Council
BC health quality matrix [Internet]
[cited 2020 May 19].
BC Patient Safety & Quality Council. BC health quality matrix [Internet]. Vancouver; 2020 Jan [cited 2020 May 19].
2. Kotaska A. Informed consent and refusal in obstetrics: a practical ethical guide. *Birth*. 2017;44(3):195–9. doi:10.1111/birt.12281.
3. Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. The Mother's Autonomy in Decision Making (MADM) scale: patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care. *PLoS One*. 2017;12(2):e0171804. doi:10.1371/journal.pone.0171804.
4. Vedam S, Stoll K, Rubashkin N, Martin K, Miller-Vedam Z, Hayes-Klein H, et al. The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth. *SSM - Popul Heal*. 2017;3:201–10. doi:10.1016/j.ssmph.2017.01.005.
5. Thompson A. Midwives' experiences of caring for women whose requests are not within clinical policies and guidelines. *Br J Midwifery*. 2013;21(8). doi:10.12968/bjom.2013.21.8.564.
6. Jenkinson B, Kruske S, Kildea S. The experiences of women, midwives and obstetricians when women decline recommended maternity care: a feminist thematic analysis. *Midwifery*. 2017;52:1–10. doi:10.1016/j.midw.2017.05.006.

7. Kruske S, Young K, Jenkinson B, Catchlove A. Maternity care providers' perceptions of women's autonomy and the law. *BMC Pregnancy Childbirth*. 2013;13:84. doi:10.1186/1471-2393-13-84.
8. Danerek M, Maršál K, Cuttini M, Lingman G, Nilstun T, Dykes AK. Attitudes of midwives in Sweden toward a woman's refusal of an emergency cesarean section or a cesarean section on request. *Birth*. 2011;38(1):71–9. doi:10.1111/j.1523-536X.2010.00440.x.
9. Cahill H. An Orwellian scenario: court ordered caesarean section and women's autonomy. *Nurs Ethics*. 1999;6(6):494–505. doi:10.1177/096973309900600605.
10. Lyerly AD, Mitchell LM, Armstrong EM, Harris LH, Kukla R, Kuppermann M, et al. Risks, values, and decision making surrounding pregnancy. *Obstet Gynecol*. 2007;109(4):979–84. doi:10.1097/01.AOG.0000258285.43499.4b.
11. Jenkinson B, Kruske S, Stapleton H, Beckmann M, Reynolds M, Kildea S. Women's, midwives' and obstetricians' experiences of a structured process to document refusal of recommended maternity care. *Women Birth*. 2016;29(6):531–41. doi:10.1016/j.wombi.2016.05.005.
12. Chigbu CO, Iloabachie GC. The burden of caesarean section refusal in a developing country setting. *BJOG An Int J Obstet Gynaecol*. 2007;115(4):541–2. doi:10.1111/j.1471-0528.2007.01440.x.
13. Rourke L, Anderson T. Validity in quantitative content analysis. *Educ Technol Res Dev*. 2004;52(1):5–18. doi:10.1007/BF02504769.
14. Barrett BJ, Almanssori S, Kwan DL, Waddick E. Feminism within domestic violence coalitions: a quantitative content analysis. *Affil - J Women Soc Work*. 2016;31(3):359–71. doi:10.1177/0886109915578729.
15. Hollander M, Holten L, Leusink A, van Dillen J, de Miranda E. Less or more? Maternal requests that go against medical advice. *Women Birth*. 2018;31(6):505–12. doi:10.1016/j.wombi.2018.01.010.
16. O'Cathain A, Thomas K, Walters SJ, Nicholl J, Kirkham M. Women's perceptions of informed choice in maternity care. *Midwifery*. 2002;18(2):136–44. doi:10.1054/midw.2002.0301.
17. Alfrevic Z, Devane D, Gyte GM. Continuous cardiotocography (CTG) as a form of electronic fetal monitoring (EFM) for fetal assessment during labour. *Cochrane Database Syst Rev*. 2006; (3):CD006066. doi:10.1002/14651858.cd006066.
18. Hersh S, Megregian M, Emeis C. Intermittent auscultation of the fetal heart rate during labor: an opportunity for shared decision making. *J Midwifery Women's Heal*. 2014;59(3):344–9. doi:10.1111/jmwh.12178.
19. Bohren MA, Vogel JP, Hunter EC, Lutsiv O, Makh SK, Souza JP, et al. The mistreatment of women during childbirth in health facilities globally: a mixed-methods systematic review. *PLoS Med*. 2015;12(6):e1001847. doi:10.1371/journal.pmed.1001847.
20. Vedam S, Stoll K, Martin K, Rubashkin N, Partridge S, Thordarson D, et al. The Mother's autonomy in decision making (MADM) scale: Patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care. *PLoS One*. 2017;12(2). doi:10.1371/journal.pone.0171804.

21. Beck CT, Gable RK, Sakala C, Declercq ER. Posttraumatic stress disorder in new mothers: results from a two-stage U.S. national survey. *Birth*. 2011;38(3):216–27. doi:10.1111/j.1523-536X.2011.00475.x.
22. Vedam S, Stoll K, McRae DN, Korchinski M, Velasquez R, Wang J, et al. Patient-led decision making: measuring autonomy and respect in Canadian maternity care. *Patient Educ Couns*. 2019;102(3):586–94. doi:10.1016/j.pec.2018.10.023.
23. Beck CT. Birth trauma and its sequelae. *J Trauma Dissociation*. 2009;10(2):189–203. doi:10.1080/15299730802624528.
24. Hollander MH, van Hastenberg E, van Dillen J, van Pampus MG, de Miranda E, Stramrood CAI. Preventing traumatic childbirth experiences: 2192 women's perceptions and views. *Arch Womens Ment Health*. 2017;20(4):515–23. doi:10.1007/s00737-017-0729-6.
25. Reed R, Sharman R, Inglis C. Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy Childbirth*. 2017;17:21. doi:10.1186/s12884-016-1197-0.
26. Priddis HS, Keedle H, Dahlen H. The perfect storm of trauma: the experiences of women who have experienced birth trauma and subsequently accessed residential parenting services in Australia. *Women Birth*. 2018;31(1):17–24. doi:10.1016/j.wombi.2017.06.007.
27. Holten L, Hollander M, de Miranda E. When the hospital is no longer an option: a multiple case study of defining moments for women choosing home birth in high-risk pregnancies in the Netherlands. *Qual Health Res*. 2018;28(12):1883–96. doi:10.1177/1049732318791535.
28. Leinweber J, Creedy DK, Rowe H, Gamble J. Responses to birth trauma and prevalence of posttraumatic stress among Australian midwives. *Women Birth*. 2017;30(1):40–5. doi:10.1016/j.wombi.2016.06.006.
29. Rubashkin N, Minckas N. How should trainees respond in situations of obstetric violence? *AMA J Ethics*. 2018;20(1):238–46. doi:10.1001/journalofethics.2018.20.3.ecas2-1803.
30. Sidhu R, Su B, Shapiro K, Stoll K. Prevalence of and factors associated with burnout in midwifery: a scoping review. *Eur J Midwifery*. 2020;4(4). doi:10.18332/ejm/115983.
31. World Health Organization. Leading the realization of human rights to health and through health: report of the high-level working group on the health and human rights of women, children and adolescents [Internet]. 2017.
32. Matthias MS. The impact of uncertainty on decision making in prenatal consultations: obstetricians' and midwives' perspectives. *Health Commun*. 2010;25(3):199–211. doi:10.1080/10410230903544977.
33. 10.1186/s12978-019-0729-2
Vedam S, Stoll K, Taiwo TK, Rubashkin N, Cheyney M, Strauss N, et al. The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States. *Reprod Health* [Internet]. 2019 Dec 11;16(1):77. doi: 10.1186/s12978-019-0729-2.
34. Morton CH, Henley MM, Seacrist M, Roth LM. Bearing witness: United States and Canadian maternity support workers' observations of disrespectful care in childbirth. *Birth*. 2018;45(3):263–74. doi:10.1111/birt.12373.

35. De Vries R. Obstetric ethics and the invisible mother. *Narrat Inq Bioeth.* 2017;7(3):215–20. doi:10.1353/nib.2017.0068.
36. Altman MR, Oseguera T, McLemore MR, Kantrowitz-Gordon I, Franck LS, Lyndon A. Information and power: women of color's experiences interacting with health care providers in pregnancy and birth. *Soc Sci Med.* 2019 Jun;238:112491. doi:10.1016/j.socscimed.2019.112491.
37. 10.1016/j.ajog.2016.09.087
DeBaets AM. From birth plan to birth partnership: enhancing communication in childbirth. *Am J Obstet Gynecol.* 2017;216(1):31.e1-4. doi: 10.1016/j.ajog.2016.09.087.
38. Nieuwenhuijze MJ, Korstjens I, de Jonge A, de Vries R, Lagro-Janssen A. On speaking terms: a Delphi study on shared decision-making in maternity care. *BMC Pregnancy Childbirth.* 2014;14:223. doi:10.1186/1471-2393-14-223.
39. Vedam S. Moving from interprofessional disarticulation to transformative dialogue and action: examining a transdisciplinary process to address equitable access to high quality maternity care in North America. Doctoral Thesis, School of Public Health, Sydney Medical School, University of Sydney; 2019.
40. Légaré F, Ratté S, Stacey D, Kryworuchko J, Gravel K, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev.* 2010;(5). doi:10.1002/14651858.cd006732.pub2.
41. Jenkinson B, Kruske S, Kildea S. Refusal of recommended maternity care: time to make a pact with women? *Women Birth.* 2018;31(6):433–41. doi:10.1016/j.wombi.2018.03.006.
42. Downe S, Lawrie TA, Finlayson K, Oladapo OT. Effectiveness of respectful care policies for women using routine intrapartum services: A systematic review. *Reprod Health.* 2018;15(1):23. doi:10.1186/s12978-018-0466-y.

Figures

Figure 1

Types, timing, and frequencies of tests and procedures that were declined

Person-Centred Decision Making

Figure 2

Graphic summary of Dialogue and Decision, an online interprofessional course that teaches health professional learners a systematic approach to person-centred care