

The Reproductive Justice Story Project is an independent grassroots organization founded in 2017, directly motivated by patient experiences at St. Joseph's Health Centre in Toronto, Canada and grounded in the knowledge that **informed decision-making, patient autonomy, and consensual, trauma-informed care in childbirth are reproductive justice issues**. The organization exists to bring attention specifically to mistreatment and abuse within our healthcare system as a result of a culture that is not always patient-centred and does not consistently prioritize informed decision-making and consent. We're using our platform to speak up about disrespectful and abusive care during pregnancy, childbirth and postpartum, and while accessing other forms of reproductive healthcare, in an attempt to hold harmful systems accountable and influence change across the province.

As our first initiative, we conducted an independent survey of people who had received care at St. Joseph's Health Centre Family Birthing Centre (St. Joe's) in Toronto in recent years. At the time the survey was created, St. Joe's was still not actively soliciting feedback from all patients of their Family Birthing Centre. The purpose of our survey was to gather feedback that would likely not have otherwise reached the hospital to ensure that patient voices are truly heard.

The survey was open from September 2017 - January 2018. Responses to the survey varied widely, from people who had very positive care experiences, to those who had very negative ones. We acknowledge that these findings may not be fully representative of all people who have given birth or received reproductive healthcare at the Family Birthing Centre, as parts of the survey were intentionally focused on experiences of obstetric violence and traumatic childbirth at St. Joe's, as well as other areas for improvement. With this in mind, our report does not aim to discount the many positive, empowering experiences that patients report, but to highlight the very real distress and trauma that a significant number of people have endured as a result of accessing reproductive healthcare at St. Joe's. **This report focuses on areas for improvement.**

We hope that St. Joseph's Health Centre will examine the policies and culture within the institution that allow these distressing experiences to occur. We believe it's an opportunity for St. Joe's to demonstrate their commitment to their own values by taking action against obstetric violence and patient mistreatment within their facilities to become a leader in patient-centred, trauma-informed care in our community.

Important Terms

Obstetric Violence is defined as “the act of disregarding the authority and autonomy that [pregnant and birthing individuals] have over their own sexuality, their bodies, their babies, and in their birth experiences.”(1) Though it exists at the intersection of structural/institutional violence and gender-based violence (2), obstetric violence can be perpetrated by care providers regardless of title or gender and can have a disproportionate effect on marginalized populations.(3) Much like other forms of gender-based violence, obstetric violence can be subtle and underhanded, rooted in the stark imbalance of power between patient and care provider throughout the childbearing process. **Healthcare providers may be committing acts of obstetric violence, regardless of intent, when they reinforce this power imbalance, by prioritizing their own needs or plans, communicating disrespectfully, or removing opportunities for patients to exercise informed, autonomous decision-making and have agency over their own bodies.** In reviewing survey responses dealing with bodily autonomy and consent, it is important to note that “labour and birth can be framed as sexual events, with obstetric violence being frequently experienced and interpreted as rape.”(4)

Birth Trauma refers to symptoms of post-traumatic stress disorder (PTSD) experienced by some individuals after giving birth. Although birth trauma can be caused in many ways (i.e. a frightening emergency situation during labour, unexpected complications, etc.) for some patients it can be a direct result of obstetric violence, for **“it is not always the sensational or dramatic events that trigger childbirth trauma but other factors such as loss of control, loss of dignity, the hostile or difficult attitudes of the people around them, feelings of not being heard or the absence of informed consent to medical procedures.”**(5) It is estimated that 33-45% of individuals who have given birth perceive their experiences to be traumatic, while as many as 9% experience postpartum post-traumatic stress disorder following the birth.(6)

Trauma-Informed Care is care that recognizes the far-reaching, pervasive impacts of trauma on people from all backgrounds and walks of life. Trauma-informed healthcare providers, institutions, and organizations respond to the widespread nature of trauma “by fully integrating knowledge about trauma into policies, procedures, practices and settings.”(7) The idea is that hospitals and medical staff incorporating trauma-informed practice treat all patients in a compassionate manner recognizing that the childbearing process, for example, can be harrowing even for individuals without previous trauma, and for those with trauma histories there are many opportunities to be retriggered by interventions and situations that may arise. Trauma-Informed Care means that “an individual should not need to disclose previous trauma in order to access care that is sensitive to their needs.”(8)

1. Dr Amali Lokugamage’s address at the RCOG World Congress 2014 <https://www.youtube.com/watch?v=Ziy5kSFm7U8>

2. “Obstetric Violence” <http://www.may28.org/obstetric-violence/>

3. “About Gender-Based Violence” <http://www.swc-cfc.gc.ca/violence/strategy-strategie/gbv-vfs-en.html>

4. “Moving beyond disrespect and abuse: addressing the structural dimensions of obstetric violence” <https://doi.org/10.1016/j.rhm.2016.04.002>

5. “What is Birth Trauma?” <http://www.birthtraumaassociation.org.uk/help-support/what-is-birth-trauma>

6. “Lessening the Risk of Birth Trauma” <https://awhonnconnections.org/2017/03/16/lessening-the-risk-of-birth-trauma/>

7. “Trauma-Informed Toolkit” http://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed_Toolkit.pdf

8. “#Metoo shows we need trauma-informed maternity care” <http://www.birthrights.org.uk/2017/10/metoo-shows-we-need-trauma-informed-maternity-care/>

Survey Results

In this section we present overall survey response percentages as well as direct quotes to contextualize responses. **Some comments deal with obstetric violence and patient distress and may be upsetting.**

Who Took the Survey?

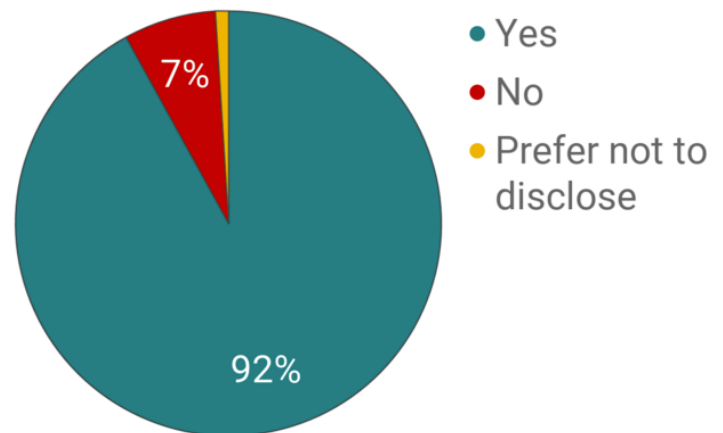
In total, we received 410 survey responses. The question of race and ethnicity was asked as an open-ended question. Seventy-seven percent of respondents explicitly identified as being white/caucasian or of Western European heritage (77%). Other most common responses were “Canadian” (5%), East Asian (5%), mixed race (3%), South Asian (2%), Latin/Hispanic (2%), Eastern European (2%), and Black (1%).

According to Census Data from 2016, the number of neighbourhood residents in ridings surrounding the catchment area for St. Joe’s with a mother tongue other than English is greater than one third of the area’s population, whereas the majority of our survey respondents spoke English as their first language. The numbers, by riding, are as follows: Parkdale-High Park 32%, Davenport 44%, Etobicoke-Lakeshore 38% and York South - Weston 47%.⁽⁹⁾

Question: Is English Your First Language?

Response Breakdown

Most individuals who took our survey spoke English as a first language (92%). Most were over 30 years old (85%) at the time of the survey, with 88% reporting that their pregnancies were planned and 98% having a partner and/or a support person with them at the hospital.



Considering the preponderance of survey respondents with less vulnerable life circumstances, we’d like to note that rates of patient abuse, and of patients viewing their hospital experiences as negative or traumatic are likely higher than reflected in this report, as we know that these issues (and others related to health care equity) can have a disproportionate impact on marginalized individuals and communities including Indigenous, Black, and people of colour, young pregnant people, those living on low incomes, whose first language is not that of their care provider, people with disabilities, diverse gender expression or presentation, less conventional family structures, mental health or trauma histories, and many others.

9. “Census Profile, 2016 - by electoral district” <http://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E&TABID=2>

Comments

A number of participants were able to look back fondly on their birth experiences when completing the survey. Some reflected on how their own privilege had a role to play in their experiences:

“Having a solid education in biology helped to make me better informed and understand what was going on”

“Because my husband and I are English-speaking and could insist on being informed about procedures, I feel our care was better than it might otherwise have been”

“I was fully aware that I was a white Canadian without health, immigration or addiction issues. The women in my New Toronto community are terrified of St. Joe’s if they have ever had issues with CAS or the law”

“I am a white, gender-conforming, heterosexual, middle-class, able-bodied woman. I cannot imagine the horrors that more marginalized people must experience giving birth at St. Joe's”

Characteristics of Hospital Visit

The majority of participants (87%) provided feedback on their experiences of healthcare while in labour/giving birth. Others visited St. Joe’s because of a pregnancy complication (6%), because they were referred to the hospital by another healthcare provider (4%), or for another pregnancy-related visit (2%). Most respondents gave feedback on a visit within the last year (32%) or the last five years (57%). For 65% of participants, this was their first pregnancy. Most participants began their visit in the care of an obstetrician (45%) or midwife (37%), while others were in the care of a family doctor (8%) or another care provider (11%). However, the care provider changed at some point in the visit for 48% of respondents.

Dignity, Compassion, & Respect

St. Joseph’s Health Centre lists respect, dignity, and compassion as core organizational values.⁽¹⁰⁾ Questions in this section relate to whether respondents felt that these values were reflected in their experiences at the hospital.

10. “Our Mission and Values” <https://stjoestoronto.ca/your-health-centre/about-us/our-mission-and-values/>

Question: How often did medical staff treat you with courtesy and respect?

Response breakdown

Most survey respondents (62%, 50%) felt that medical staff always treated them with courtesy and respect. About one quarter of participants said they usually did so (23%, 25%).

Some (15%) felt that their doctors/medical students and midwives only sometimes or never treated them with courtesy and respect while 19% said the same of their nurses.

Comments

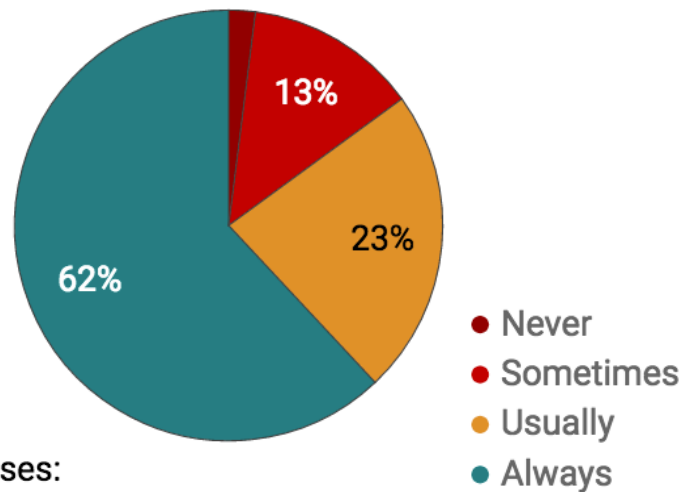
Many respondents had positive memories to share of being treated with courtesy and respect by staff during their hospital stay:

"Lots of praise and gratitude for the wonderful service and care they provide me and my sons"

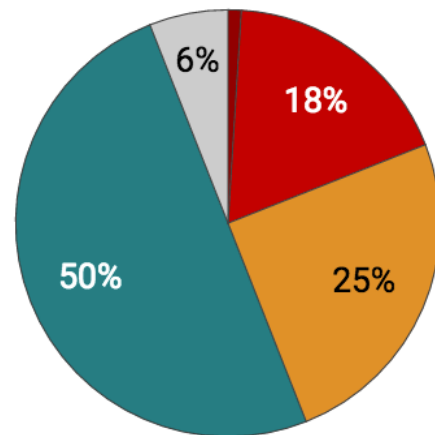
"I have given birth at St. Joe's twice and have had a wonderful experience each time"

"I really liked the doctor I had on call, she really respected my wishes even though they could not be carried out"

Doctors/medical students or midwives:



Nurses:



"Hospital staff were very accommodating and always treated me with respect"

"Everybody was wonderful. They showed so much compassion and care for me"

"All staff we encountered - physicians, nurses - all professional and courteous"

Some had experiences that were mixed depending upon staff members that were on duty at the time:

"My nurses were really great - they were the ones attempting to advocate for me. The doctors seemed almost put off every time I asked a question"

"Not enough space here to describe the condescending behaviour of some nurses"

"My experience with nurses varied. I had some amazing nurses that took a lot of time and care but then others that were just in and out, with no interpersonal skills"

"The staff changed frequently, so some were kind and some were rude, and some just seemed very busy"

Others had less positive experiences to share:

"The residents and doctors treated me as a case, not a person. It was troubling"

"Nurse was extremely rude and said "Keep quiet!" I had back labour and was vomiting from the pain for hours"

*"The nurse who was supposed to help discharge me rolled her eyes a million times at me. This same nurse refused to give me a pad for the postpartum blood. She said "why the F*CK did you not bring your own pad. Do you think this is a charity hospital?" I cried a lot after hearing that. I was tired, disrespected and now felt guilty for forgetting my pads in the delivery room. I bled a lot after birth and leaked on the bed. That same nurse kept huffing and puffing and felt so inconvenienced about changing the sheet. Again I felt guilty. When I got feeling back into my legs I was supposed to be helped in taking a shower. I was told that I was a 'big girl' and can 'do it myself'. I was so angry and so hurt from the treatment that I honestly think about it still"*

The National Institute for Health and Care Excellence (NICE) out of the UK recently updated their guidelines on care throughout labour. They include recommendations for respectful communication and highlight “the importance of tone and demeanour, and of the actual words used”(11) by healthcare providers when addressing their patients. Some survey respondents recalled times during their hospital visit when communication with their healthcare providers did not feel as courteous and respectful as it could have been:

“The nurses who ‘cleaned me up’ after my caesarean talked about me in front of me as if I were dead. One of them said to the other, as they were cleaning my vagina and my surgical wound, ‘Her vagina is ENORMOUS!’”

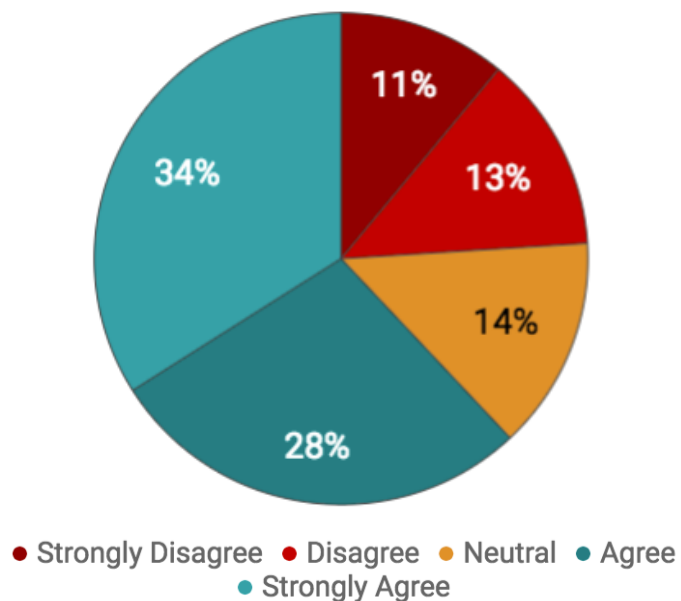
“[The doctor] was quite arrogant and rarely took my concerns seriously. He actually started sentences with ‘Since you are a woman this must upset you’”

“The OB called me ‘this patient’ and ‘that woman’”

Question: I felt that my bodily autonomy was honoured and respected.

Response breakdown

Thirty-four percent (34%) of respondents strongly agreed and 28% agreed that their bodily autonomy was honoured and respected at St. Joe’s. Fourteen percent (14%) felt neutral and nearly one quarter of participants (23%) either disagreed or strongly disagreed that their bodily autonomy was honoured and respected while receiving care at the hospital.



11. “Intrapartum care for healthy women and babies - 1.2 Care Throughout Labour”
<https://www.nice.org.uk/guidance/cg190/chapter/Recommendations#care-throughout-labour>

Comments

It was important for many survey participants to be kept informed about what staff were doing to their bodies and for their ownership of their bodies to be honoured and respected. For some respondents, this did not always happen during their time at St. Joe's:

"I had been digitally penetrated against my will in my past. This did not seem to matter to the staff"

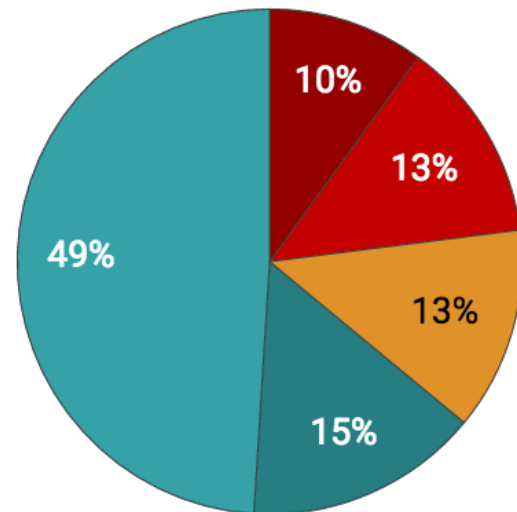
"Once having the epidural I felt like staff were less respectful of my body"

"Most often, the experience over three days of labour and no sleep, felt like no one was listening to my partner or I. In fact, during the birth, I was screaming 'what's going on?' and everyone was ignoring me"

Question: I felt as if my plans, preferences, and decisions were respected.

Response breakdown

Forty-nine percent (49%) of survey respondents strongly agreed that their plans, preferences, and decisions were respected. Fifteen percent (15%) agreed, Some (13%) felt neutral, and nearly one quarter of participants (23%) either disagreed or strongly disagreed that their plans, preferences, and decisions were respected.



● Strongly Disagree ● Disagree ● Neutral ● Agree
● Strongly Agree

Comments

When care providers took the time to explain decisions and obtain informed consent, participants generally reported very positive birth experiences:

"Both of my children were born there and I felt heard, respected and cared for at all points"

"I had a great and empowering experience - I smile when I see the hospital from the highway"

When patients reported that they were not involved in discussions about their care and when their plans and preferences were not respected, they suffered consequences ranging from mild discomfort to significant trauma:

"The staff treated me as if I was yet another nuisance. The first doctor to take over my OB's shift never listened to me"

"I had a birth plan, they told me to make it on the hospital tour but then no one even looked at it"

"[The doctor] works with an old boys attitude and clearly trained on unconscious and non-consenting women. He often treated me like I was an unconscious object"

"It was extremely clear my doctor didn't agree with having a plan. He talked over me and my doula, to my husband directly, often. He very rarely spoke with me"

"There was a disagreement about the course of care between the nurse and doctor and they had a verbal altercation at my bedside at three in the morning without acknowledging my presence or right to weigh in"

"I was told extremely little, and no preferences or birth plan was discussed at any time. The nurse seemed to run the show and she just ignored me, scolded me, yelled at me, or just talked over me"

"I felt that decisions re: my care were made behind the scenes and I was given the info after"

"I was involved in some of the discussions but given my vulnerability and the fact that I didn't know these people, compounded by the fact that I didn't have midwives advocating for me, I felt pressured and assaulted"

Some survey participants recalled feelings of vulnerability and powerlessness during their time at St. Joe's. There is extensive writing on the importance of feeling involved and in control of decisions about one's own care as "a crucial piece of preventing birth-related trauma is making sure [pregnant and birthing individuals] don't feel they've been stripped of their voices during childbirth, even though (or perhaps because) so much of what happens during birth is simply beyond their control."¹²

"The doctors had their own agenda and mine was seen as secondary and inconvenient"

"I asked questions despite getting the clear impression that my job was to shut up and submit"

"[The doctor] was cold, rude and treated me like I wasn't in the room"

"I felt anger and resentment towards the doctor - experienced an abusive situation based on my vulnerability and his power"

"My first baby's birth still brings me to tears. I had no control and no voice"

"I showed up the morning of my birth, and I had originally be scheduled for an external cephalic version (ECV) to try to turn my breech baby. I was desperate for a vaginal birth. When I checked in at the nurses station they said, "You're here for the C-section?", and when I said no, I was there for an ECV, they rolled their eyes. From that point forward I felt like they'd already decided I was having the section and didn't try to turn the baby"

Continuity of Care

The St. Joseph's Health Centre Family Birthing Centre has a unique culture of limiting the scope of practice for the midwives with admitting privileges. Unlike other hospitals in Toronto, patients who have made the choice to access midwifery care during their pregnancies must have their care transferred to the obstetrics team at St. Joe's in the event that they require the use of exogenous oxytocin for augmentation or induction of labour, or epidural pain relief during labour. As a result of the hospital's policy limiting the ability of midwives to practice to their full scope, continuity of care is disrupted and, consequently, the patient experience suffers.

12. "Inside The Painful, Lonely Experience Of Birth Trauma"

https://www.huffingtonpost.ca/entry/inside-the-painful-lonely-experience-of-birth-trauma_us_5751a7cae4b0ed593f142c91

Research bears out the fact that an approach to healthcare that includes well integrated care teams, thorough and prompt handover, and efficient and accurate communication, lead directly to better outcomes.⁽¹³⁾ Regardless of the hospital's policy on epidural and oxytocin management, transfers of care will inevitably need to happen as a result of emergencies, client choice, or due to any number of other circumstances. However, these transfers should happen seamlessly; a strong focus on interprofessional collaboration would ensure that the hospital creates an environment of support and respect for *all* patients. Throughout the survey, respondents identified this physician-centred culture of limiting interprofessional collaboration as a problem area with potential for growth and development:

"I wanted my midwife to catch the baby but she wasn't allowed because I was under OB care"

"After the transfer of care there were several decisions made I felt I did not have full input into"

"I wish it didn't feel like midwife vs doctor. The midwife has the relationship with the patient, why does the doctor have to feel like they can't support the midwife/they have to be in charge? My doctor was a female and she acted this way - so I'd say it's macho but that doesn't really make sense"

"I feel like the fact that I had a midwife created issues with the nursing staff"

"I don't even know where to begin. How do you teach empathy to a group whose baseline culture is hostility towards birthing women and, from what I can tell, midwives? There is a systemic problem at this hospital"

"A nurse said with DISDAIN, in a stage whisper, to another nurse, 'They're the HOMEBIRTH people.' and rolled her eyes right in front of me, as if I were not there. Another nurse later made a racist comment about my midwife, saying something to the effect that because she was from [another country] and received her training there, she was incompetent"

13. "Safer Births Through Better Teamworking"
<http://patientsafety.health.org.uk/sites/default/files/resources/7.teamworkinginobstetrics-v3b.pdf>

Informed Consent

Ontario's Health Care Consent Act requires that healthcare providers obtain informed consent from patients before performing any proposed treatment. They should not coerce or pressure the patient into a particular decision, and consent for one particular treatment does not necessarily imply consent for any other treatment.(14) Importantly, in order for consent to be informed, the patient must understand information relevant to making the decision, and be able to anticipate the reasonably foreseeable consequences of the decision. The requirement for consent can be waived in cases of emergency, which may occur during childbirth, but the act of giving birth itself is not grounds for waiving the requirement for informed consent. Consent may be refused as well as withdrawn at any time. The following questions relate to informed decision-making and consent.

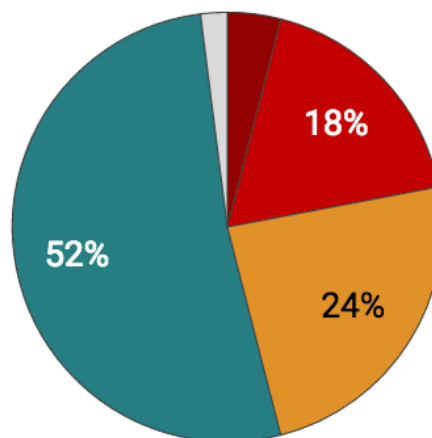
Question: How often did medical staff introduce themselves as they were entering the room and before speaking with you?

Response breakdown

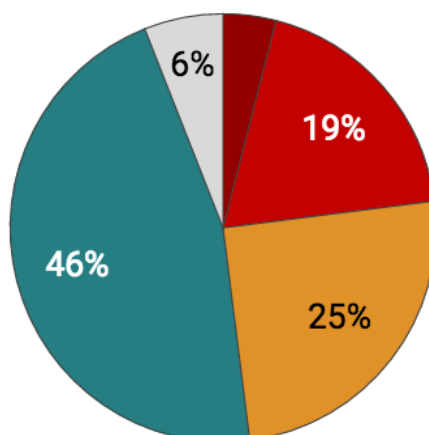
Most respondents (52%, 46%) reported that medical staff always introduced themselves as they were entering the room. About one quarter (24%, 25%) said they usually did.

Some respondents (2%, 6%) did not report interacting with staff they were not already familiar with (Not Applicable), while others said that medical staff only sometimes (18%, 19%) or never (4%, 4%) introduced themselves.

Doctors/medical students or midwives:



Nurses:



14. "Informed Consent to Treatment" https://stjoestoronto.ca/wp-content/uploads/2016/02/informed_consent.pdf

Comments

"A lot of people came and went without introduction"

"To start, all staff should be REQUIRED to introduce themselves when they enter the room. And doctors should ask before touching people, especially before checking the cervix"

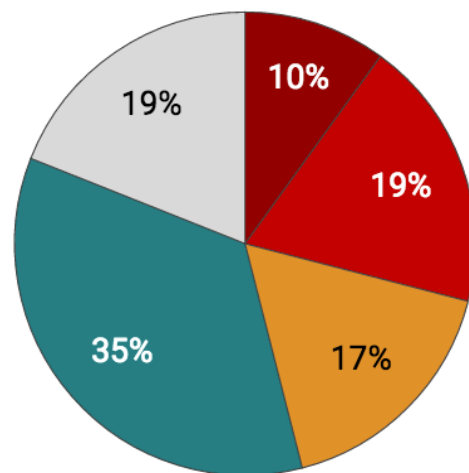
"There's a difference between entering a room talking while flipping through papers vs pausing by the bed, making eye contact and introducing yourself. I think they 'checked the boxes' on a few of the questions asked here but did they do them effectively? In a way a mother in labour or non medical person could absorb & process? No. My birth was an induced one, but not urgent or in distress, there was time to do these things - connect and explain and listen to me like an adult human being"

"I felt like anyone could walk in. It was not a safe space at all. I didn't like that nobody explained why all these people were in the room, who they were and what they found so funny. They were also very loud and made it hard for me to concentrate on birthing. There seems to have been no concern for my privacy or modesty, which was very important to me"

Question: Before giving you any new medicine, how often did medical staff describe possible side effects and next steps in a way you could understand?

Response breakdown

Some respondents (19%) were not given any medication during their hospital visit. Most respondents said that medical staff always (35%) or usually (17%) explained medications, while others said that they sometimes (19%) or never (10%) did so.



● Never ● Sometimes ● Usually ● Always
● Not Applicable

Comments

Some patients felt that they needed to ask many questions, rather than staff proactively explaining medication and next steps:

"I had to fight for answers. I was treated with disdain & resistance any time I asked questions"

"The doctor talked down to me when I insisted on no medication. 'So give me a reason' was his literal response"

"No one explained side effects and I had to keep asking if certain symptoms were normal"

"I understand now some of the choices that were made because I am now a birth doula but the choices were not explained to me at the time - and some were still not necessary"

Patients were most unclear about the effects of the epidural, induction medication, and IV:

"I understood the procedures abstractly but they were carried out with little explanation of how they would apply to my case"

"Nobody ever told me what exactly was in the epidural or how it might affect me or the baby"

"I was given medication by a nurse without explanation that it constituted a transfer of care"

"My water was broken and I was induced because labour was progressing slowly. At no point was my child in distress, yet my husband and I felt pressured to agree to these interventions. The induction was explained in a very hurried manner, and the resultant need for an epidural was not communicated"

Feeling supported by one's healthcare providers and involved in one's own healthcare decisions are proven ways to maintain a sense of agency and control to combat the risks of birth trauma and lessen the potential for other perinatal mental health challenges.

Patients whose care teams provide empathetic support, clear communication, and encouragement during labour and birth “can better transition to home, experience less anxiety, have more positive feelings about themselves and improved bonding with their babies.”(15) This information is promising in that it poses an inexpensive, effective way to improve the patient experience at St. Joe’s by reducing the number of patients reporting that real choices were not offered, procedures were not explained, or that they did not always feel included in conversations about their own care at the hospital.

“Though I was burning internally from the cervidil, a resident berated me for not allowing a [cervix] check. She only listened once my husband told her to back off”

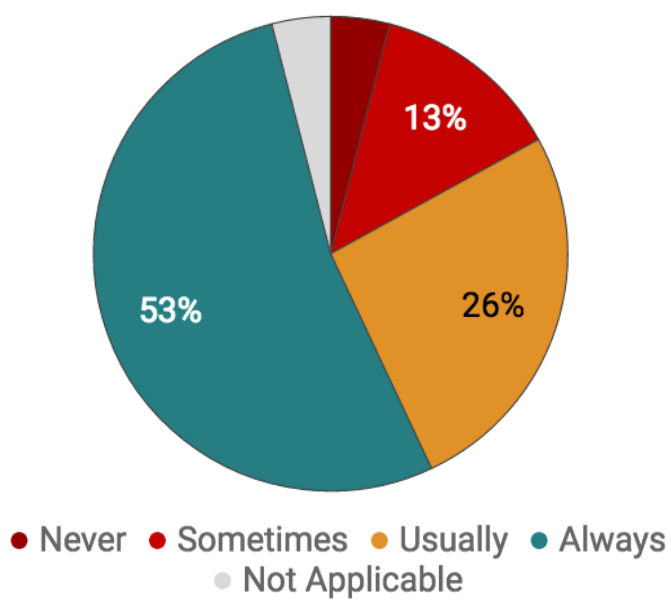
“We were made to feel as if speaking up was not acceptable as we were not the ‘experts’”

“Decisions about my care were discussed and made without my input. They were explained to me after, or were communicated as the only real option for me to ‘choose’”

“I was not included in discussions, I was just told what I ‘had’ to do”

Question: Before touching you to perform a task or procedure, how often did medical staff explain what they planned to do and why?

Response breakdown
 Most survey participants said that medical staff always (53%) or usually (26%) explained what they planned to do before touching them. However, 13% said that they only sometimes explained, and 4% said that they never did.



15. “Lessening the Risk of Birth Trauma” <https://awhonnconnections.org/2017/03/16/lessening-the-risk-of-birth-trauma/>

Comments

In cases where patients felt unclear about what was going on, this was sometimes due to a genuine emergency situation:

"I had a very, very fast delivery with some complications so there was not always time to explain everything"

"All plans went out the window because it was a life or death situation"

"Some urgent procedures weren't fully explained due to time"

However, most births are not complicated emergencies and many respondents felt that care providers did not ask for consent when they should have. This was most distressing when performing a pelvic exam or another procedure requiring penetration:

"My water was broken without my consent by the attending OB. I understood that he was simply doing an examination"

"When I first visited to see if I was in labour, [a doctor] performed a stretch and sweep without my consent claiming that she was checking if my water had broken"

"[A doctor] checked my cervix without warning very aggressively. It was quite painful"

"On more than one occasion a nurse entered the room and uncovered me or penetrated me without saying a word"

Many survey participants also expressed concerns about communication and informed decision-making surrounding episiotomies. Some even reported that episiotomies were performed on them at St. Joe's without their knowledge or consent:

"I was given an episiotomy but I wasn't told about it until the next day right before I went home. The doctor did this without my consent, and didn't tell me they did it - how is that legal?"

"I was never informed of the episiotomy and I never consented to it. I hadn't had an epidural. It was horrifying"

"I was confused about the use of forceps and episiotomy"

"I spoke with my OBGYN, and she falsely suggested that the episiotomy was probably better than ripping!"

"My wish to have no episiotomy was laughed off"

"I was given an episiotomy without warning"

"The epidural-free vacuum and episiotomy felt like horrific acts of violence against me and my baby. My daughter was injured by her birth and had a very rough babyhood. I'm still recovering from this trauma. [That doctor's] treatment of me and my baby bordered on criminal, it felt like assault"

"An OB that was not communicating with me triggered my PTSD from being a rape survivor. When I told [the doctor] that I was having a hard time pushing she said "Ok I'm going to help you." But that's all she said, she did not warn me or explain that she would use forceps or give me an episiotomy - she did it without explaining or consent!"

Other respondents felt significant pressure to consent to proposed procedures. In order for consent to be valid, it must be freely given; not forced, pressured, or coerced.(14) When the expected answer from the patient is always yes, there isn't room for a patient to decline or ask questions. Without the option to say no to any proposed intervention, there can be no informed consent.(16)

According to the Ontario Public Health Association's 2017 position paper, Informed Decision-Making for Labour & Birth, pregnant and birthing patients "often unknowingly defer decision-making for their care decisions to their healthcare providers which can result in a decision more congruent with the care provider's values or motivations. This deferral of decision-making to healthcare providers has eroded the legal and ethical right to informed consent and has resulted in consent processes not always being provided.

A power differential may lead to acceptance of a healthcare provider's preferences without question. It can be assumed that for those often marginalized, a greater health equity gap will be created."(17) Some survey respondents shared examples of this playing out at St. Joe's:

"They were often explaining or obtaining consent while already touching me/doing it. They also weren't open to me having an opinion. They would listen to me talking but not really listen and end up doing what they wanted anyway"

"we were not given any information and essentially were forced to consent without being given an option... The doctor/nurses would often wait until the midwife left the room before coming to see us"

"I understood the intentions but was not given the option to refuse"

"I actually had an obstetrician not introduce themselves... she just shoved her hand up to check on the baby, without any warning"

"I was given numerous pelvic exams with students present. It's hard not to give 'consent' when there is a crowd already standing expectantly in your room"

"I had one nurse that kept trying to 'teach me' to breastfeed but never asked before grabbing my body"

"The initial OB was very forward and would go pull the sheets back for an exam as he was explaining what he was doing - not after"

17. "Informed Decision-Making for Labour & Birth"
<http://www.opha.on.ca/Events-News-and-Media/News/Informed-Decision-Making-for-Labour-and-Birth.aspx>

“The nurse would enter the room and basically just fist me without saying much at all, except barking orders to move my leg this way or that. When I complained of the pain, she said that I wasn't feeling pain. I knew that she was trying to manually move the baby but she didn't tell me anything about what she was doing”

Impact of Hospital Experience

Current research confirms that those who have perceived their birth experience to be distressing or traumatic may feel the effects long after they've left the hospital. These kinds of experiences can have long-term consequences and directly impact mental health, self image, and relationships in the perinatal period and beyond.(18) In the current age of #MeToo and #MeTooInTheBirthRoom, there is increasing support for naming and sharing experiences of trauma as a way to dispel stigma, find healing, and catalyze change. With that in mind, the following comments are from patients who experienced unnecessary emotional/psychological distress or trauma as a direct result of the care they received at St. Joseph's Health Centre:

“My OB basically told me I should be happy my baby didn't die in labour. My partner and I were surprised by how alone we felt during the labouring process. I was beyond shocked that they would administer pitocin when the anesthesiologist was nowhere to be found. I panicked but was in so much pain I couldn't speak to say how scared I was... I couldn't talk about it for three weeks afterwards. It took me almost two years to talk about it without crying”

“I didn't want to be treated that way again... I felt violated, talked down to, and got lots of conflicting information about breastfeeding and told how I should parent. I did have PPD after that birth experience, and it took a long time to heal”

“It was traumatic. Had nightmares for months after. Still makes me sad to think about it sometimes”

18. “Exploring women's descriptions of distress and/or trauma in childbirth from a feminist perspective”
”<https://www.rcm.org.uk/learning-and-career/learning-and-research/ebm-articles/exploring-women%E2%80%99s-descriptions-of-distress>”

"For several months, I was having nightmares about my delivery. I would have trouble breathing when driving along the Gardiner and passing the hospital. I came back into the hospital only by my husband's continuous encouragement to seek medical care for my postnatal check up"

"The birth of my son was traumatizing and it didn't need to be"

"I can't bear the thought of ever having another child"

"I had no voice in my birth and I was the least powerful person in the room"

"I have often wondered how things would have been different if I'd had a supportive nurse in that vital time. Everything about how I was treated undermined my confidence in my transition to the hospital"

Other Factors

As outlined on pages 3-4, a patient's healthcare experience can be influenced by their identity and life circumstances. For example: spoken language, age, body size, family structure, occupation/income source, education, racial or ethnic background, religion, (dis)ability, chronic health conditions, and many other factors. These may, in a healthcare setting, lead care providers to make assumptions or judgements about a patient which directly impact the patient experience and outcomes. These comments offer examples of instances in which St. Joseph's staff may have failed to meet the unique needs of some patients:

"Due to the fact that my partner and I are not married and an interracial couple I felt judged. Also they had assumed I was not taking care of myself because not all prenatal info was available"

"I was listed as "single mother" on their records. I have NO idea how that happened. The staff person who admitted me may not have understood that the woman with me was my wife? My wife attempted to advocate for me and the baby but it was largely ignored"

“It was hard for me to speak clearly all the time and they were not patient with me while I tried to explain” [ESL]

“The ‘nursing’ expert had trouble understanding my discomfort with exposing my breasts as a butch-identified woman. It was so awkward”

“I was a very young first time mother who had done my research. I felt dismissed, ignored, and most of all pushed into a corner and made to be fearful. I felt threatened and unable to make my own decisions or stand up for myself for fear I would be made to feel incompetent again. I didn’t feel comfortable asking questions because when I did they were met with anger and disdain”

“The discharge was a hurried 10 min rambling by one nurse with no written information other than the public health booklet on breastfeeding... I honestly don't know how people with less understanding (health literacy or literacy/language in general) would ever understand any of this”

Recommendations for Change

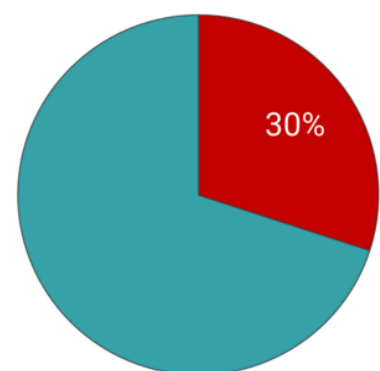
At the end of the survey, we asked respondents to state any changes that they would like to see at the Family Birthing Centre to improve the patient experience. We grouped responses into five broad categories and present them here from most common to least common suggestions. Each category is broken down into sub-categories. Many responses fit into more than one category, and thus, responses add up to more than one hundred percent.

Communication and Informed Consent: 30% of responses

The most common recommendations related to ensuring that patients had a good understanding of what was going on during their hospital visit and that their plans, preferences, and requests be respected.

Sub-categories

Communication - Recommendation that staff should keep patients involved in conversations about their own care and in the decision-making process. Staff should clearly and thoroughly explain all proposed procedures before beginning



and review next steps in the treatment plan. Staff should take the time to explain the purpose of any medications and answer questions with courtesy and respect.

Autonomy and choice - Recommendation that after understanding options and proposed procedures, patients should be free to make autonomous, informed decisions in collaboration with their care team, and their wishes should be respected without pressure or coercion.

Midwifery at St. Joe's - Many respondents who were midwifery clients recommended that the hospital staff respect their choice of care provider, and that nursing and physician staff work more collaboratively with midwives. Many felt that their midwives were openly and subtly discriminated against by nursing and physician staff which resulted in a lack of interprofessional collaboration and contributed to a culture of disrespect at the hospital, directly impacting their patient experience.

Comments:

"Education and training around power & consent - adopt an anti-oppressive framework"

"All medical staff must introduce themselves and all procedures explained and parents given the opportunity to clearly verbally consent to every procedure"

"I would like the residents to explain exactly what they are going to be involved in doing. I would like to consent more specifically"

"Less animosity towards midwives. Less confrontation in front of patients"

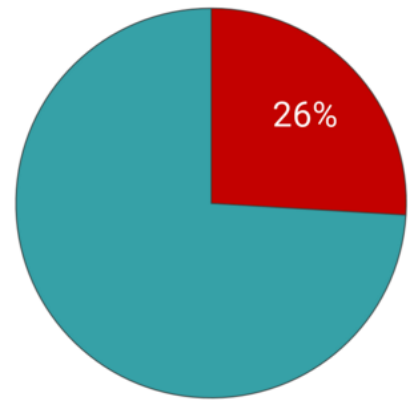
"I would like to see more respect toward midwifery teams"

"There is a huge disconnect between midwives and OBs. The staff at the hospital treats midwives disrespectfully"

"More support of midwives, better relationship between midwives and nurses/doctors"

Would Not Change Anything: 26% of responses

Just over one quarter of respondents indicated that they had a very positive experience at St. Joe's and did not have any changes to recommend.



Comments:

"Fantastic experience!"

"I really would change nothing about my experience"

"I felt well taken care of from the moment we arrived to the moment we left"

"I really like the new Family Birthing Centre"

"I owe that hospital so much, they are amazing"

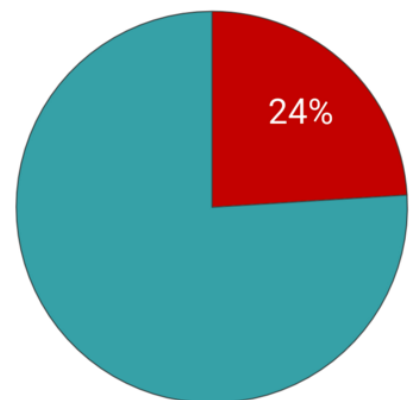
"I say keep up the good work. I like that they provide educational sessions regarding baby care, breastfeeding etc., especially as I am a first time mom"

"It was fine. They seemed a bit rushed and would have rather done things their way than answer our questions, but were generally decent in accommodating our preferences and requests"

"I have nothing but positive things to say about the entire experience. Both births were different (one long and heavily induced and one fast and natural). Especially during the induction, I felt listened to, respected and consulted about everything"

Bedside Manner and Compassionate Care: 24% of responses

Almost one quarter of responses included a recommendation related to improving the bedside manner of medical staff, and training to treat all patients with dignity, compassion, and respect.



Sub-categories

Bedside Manner - Recommendation that hospital staff should receive more rigorous training on therapeutic communication & bedside manner; recognize the vulnerable position of a person who is in labour or giving birth, and interact with empathy, kindness, and professionalism.

Patient-Centred Care - Some respondents felt that their clinical and/or emotional needs were neglected at times throughout their hospital stay in favour of their healthcare provider's goals, preferences, or convenience. Care should centre the birthing person to optimize the labour and childbirth experience for both birther and baby.(19)

Trauma-Informed Care - Recommendation that medical staff receive more rigorous training on anti-oppressive principles and trauma-informed care. Implement trauma-informed practice to lessen the occurrence of traumatic/distressing experiences for patients.

Comments:

"More education for doctors about patient-centred care, treating patients with respect as human beings and not subjects"

"More empathy, less rigidity, better bedside manner, more humanity"

"Treat birthing women as human beings deserving of respect and kindness. It seems simple, doesn't it?"

"I would change a lot. Mostly I would suggest a much larger focus on bedside manner, informing patients of their full range of options, and respect. I understand that doctors and residents are working hard and fast, but if it's at the expense of patient care then the system is broken"

"Sensitivity training in OB departments in regards to dealing with women who have PTSD and traumas"

"Birth is traumatic for some women. Please do not forget that. We need your kindness not your frustration"

"Training for all staff on why labouring/birthing people need to be treated with extra care and gentleness"

"I believe they need acceptance of birth plans and wishes. Common decency. Empathy. Far more empathy"

19. "WHO recommendations: intrapartum care for a positive childbirth experience"
<http://www.who.int/reproductivehealth/publications/intrapartum-care-guidelines/en/>

"More training on caring for women after pregnancy or infant loss"

"Having experienced the death of my first born baby. Staff did not seem to understand the trauma of pregnancy and parenting after loss"

"I would like to see a more patient-centred focus on care for the nursing staff. I understand they are very busy, but a few extra minutes could have had a great impact on my family's experience"

"I'd love to see the staff have more empathy and display kindness. I was a very young first time mom and felt completely dismissed due to my age and made to feel like I couldn't possibly make sound decisions for myself or my child. The doctors were intrusive and rough at a time where women are at their most vulnerable. I felt violated and scared but most of all angered at having being treated that way and allowing it to occur. A few extra minutes to explain a procedure or answer a patient's questions without making them feel uneducated or stupid would go a long way"

"The nursing staff should be better at handling what is an emotional time for women. They should also be trauma informed. I was a doula for another woman's birth and I was the one who was informing her about things vs the staff"

"Overall, I think the bedside care of the doctors and student doctors need a massive overhaul. They need to listen to the parents and give them the respect that they know what they need or that their concerns are valid. It was astonishing how little listening they did and how much talking to each other they did"

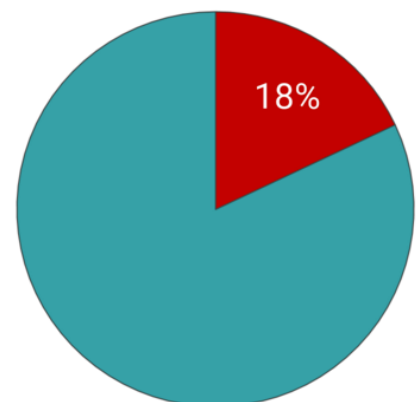
"More coaching/assistance from the nurses during labour. We felt very alone in there. My OB had very little empathy"

Post-birth Care: 18% of responses

This category has significant overlap with others, however, due to the high number of recommendations related specifically to care after birth, we feel that it warrants its own category.

Sub-categories

Minimize parent-baby separation - Respondents recommended that parents and babies be separated as little as possible after birth, and given the opportunity for immediate skin-to-skin contact regardless of mode of delivery. Initial steps of



infant resuscitation should happen on the parent as supported by NRP guidelines in addition to assessments by Paediatricians and Respiratory Therapists if baby is transitioning well.(20)

Lactation consultation - Recommendation that individualized lactation assistance be given by a trained professional in a timely manner for all breastfeeding/chestfeeding families.

NICU - Recommendations for times when the baby is in need of intensive care.

Comments:

"Once I birthed my daughter I found the care to almost stop. We were there for 48 hours and I was checked once only"

"More support for breastfeeding on weekends, when the lactation consultant is not there"

"More communication between birthing centre and NICU"

"More emotional support for parents in the NICU"

"There was a private room with a bed and bathroom that parents could stay in in the NICU. It was always empty and I kept asking to stay there to be close to my babies but was denied every time I asked"

"I was not comfortable with my experience in the NICU, the doctors never spoke to us; each nurse had a different story; they patronized us and made me feel like we had no say/choice in our child's care"

"I was told that I was being unhygienic when sitting in the NICU when I didn't have a bra on. I was discouraged from skin to skin and nurses were not encouraging of my breastfeeding"

"More info on skin to skin during C-sections, more access to breastfeeding support regardless of holidays!"

"Nursing staff was rough and unkind when trying to assist with breastfeeding"

"I couldn't find anyone who would help me learn how to pump milk and had to wander around the hospital knocking on doors looking for the lactation consultant"

"I really struggled with breastfeeding and did not feel that my postpartum nurses took the time to help me with breastfeeding, or offer any support or guidance. I left the hospital not knowing how to care for myself (after 3rd degree tearing) or how to breastfeed. I had a lot of emotions around the lack of care and support I received by the maternity ward team"

"I would like to see the NICU support new mothers - I was treated like a normal person and not someone who had just given birth. Parents need to be part of the decision making process (informed choice). I was shamed for doing too much skin to skin and wasn't allowed to breastfeed until 14 hours after my son was born because no doctor was on duty to 'prescribe' it"

"My L&D nurses and triage nurses were great- my postpartum nurses, particularly 2 older nurses on day shift (versus younger nurses at night shift) were completely different and made the entire postpartum experience much less pleasant than the labour and delivery process. If I had better postpartum care - if the nurses were respectful and treated me like I was hearing them around me, if they took more care to show me things (considering it is my first baby), my experience would be different"

"I would like some more support for postpartum depression. As a first time mom, there's no way I would have been able to anticipate the storm that follows. There is a problem if I don't want to hold or look at my baby. There is a problem if I didn't want to take the baby home. Looking back, I showed very obvious signs of depression and anxiety. I should have received counselling immediately"

"Zero support with breastfeeding - zero support at all, to be honest. I think [our nurse] was in our room twice during her 12hr shift. - during the night, we called to ask for help as baby was crying non stop, probably due to hunger. It took them 3h to go see us. I'm still upset and angry about our postpartum experience. I was contemplating filing a complaint, but didn't want to go relive that day"

"I am a healthcare provider in a different hospital myself - I feel comfortable asking questions and strongly advocating for myself, and I likely have an above average health literacy coming into this experience. That being said, that also allowed me to experience things from a patient perspective, and the postpartum care I received left much to be desired - even on a personal level with the nurses I interacted with on my day shifts. Part of this is entirely dependant on nurse personalities and not the St. Joe's atmosphere, but it needs to be addressed when the staff here are dealing with so many different patients in a very new and scary experience"

"I had so many issues with breastfeeding and received no support or help. It was only when my midwife showed up to check in with me that I finally had an advocate to help me figure out a plan. At no point did anyone talk to me about how I planned to feed my baby, they just assumed I'd breastfeed. But then no one helped me figure it out. They kept promising that a lactation consultant would come the following morning (ignoring that I was desperately struggling in the meantime). The following morning, they offhand told me that the lactation consultant called in sick"

"My experience with the hospital as I negotiated breastfeeding was calamitous. No two health care providers agreed on anything and seemed to have knowledge of breastfeeding only from personal experience either with their own children or members of their families, no clinical consensus was present whatsoever. And I cannot say enough times that the attitude that best describes all of my interactions with St. Joe's staff was rushed, condescending and often hostile"

"Better breastfeeding support. Ideally, a lactation consultant would come to help you straight away for baby's first feeding and then come back periodically for extra help. The consultant was sick during my stay. I had no real breastfeeding support or help during my stay. Therefore, we did not get off to a good breastfeeding start & it was a big challenge in the several weeks that followed. I had to seek out my own help. A good start would have made all the difference"

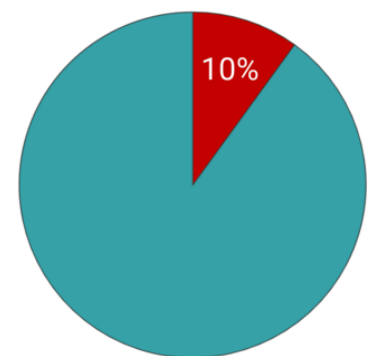
"The only thing I would have liked to be different was if the lactation consultant had come directly to my room in the morning to assist with breastfeeding instead of having a group discussion"

Miscellaneous and Operations: 10% of responses

Responses in this category are either less common recommendations, or recommendations that are operational in nature, such as recommendations related to staff scheduling and hospital amenities.

Sub-categories

Staff availability - Recommendations to ensure that the Family Birthing Centre is adequately staffed. (For example, midwife patients often wait much longer for epidurals than physician patients as they have to wait for nursing staff, often understaffed, to be available and physician patients are prioritized with the anaesthetist.)



Amenities - Recommendations related the birthing tub that remains in a state of disrepair, food, etc.

Comments:

"Working bath (and more of them)"

"Get the tub working and offer the shower to any mom in labour"

"I would have loved to have a working whirlpool and laughing gas on hand"

"I waited 7 hours for an epidural even though I requested one at the beginning of my stay"

"I couldn't help but feel that the nurses, especially, were very unhappy in their positions. Another factor that influenced my experience was the high rate of temporary nurses - some who did not have sufficient experience in the ward"

"I thought that a lot of the treatment (or lack of) came from the fact that I was there over the holidays. I was told there was no one to induce me because of the holidays. I didn't have a lactation consultant or ANY consultant post-birth because it was the holidays"

"Re: supplies - we also got attitude when my baby had a poop right after we took all our bags out to the car - and asked for a diaper and a wipe- the nursing staff sighed and gave us one diaper and no wipe, saying they had none- really?... I am lucky to afford and be able to bring many of my own supplies, but I do not believe that this should be the standard of care"

"Hospital was extremely dirty - bathrooms and showers not clean"

"Better food!! Especially after giving birth. I needed energy and they gave me sugary, bland food and never offered a vegetarian or vegan option"

"More staff. Better bedside manner. More than one lactation consultant and one that works on the weekends"

Feedback Process

Some survey participants shared their reasons for not providing feedback about their negative, distressing, or traumatic experiences at St. Joe's:

"There was literally no one I felt I could speak to. Not one medical professional on my side who made me feel at ease"

*"I was too overwhelmed"
"I was not asked for feedback"
"I was afraid and didn't think I could"*

"It was entirely too traumatic. Three years later I still tear up talking about it"

"I should, but suffering from PTSD has made me avoid talking about it. Remembering what happened can upset me for days"

"Providing critical feedback is too emotionally exhausting -- I don't have the resources"

"It was actually too traumatic to even deal with until now"

"I didn't realize a complaint letter was possible until fairly recently... I doubted the validity of my negative experience for a long time"

"We expressed [our concerns] to our nurse and she wasn't surprised at all. She suggested we write in to the hospital knowing things needed improvement. We were overwhelmed with having a newborn, we never got around to doing it so I'm happy to be filling out this survey"

"Afterwards, maybe one or two weeks later, my doula asked me to consider sharing feedback with the hospital as she had never witnessed anything as bad as my experience. I never did. I'm unsure why. I'm wishing I had now that I relive this"

"I went through the process to retrieve my records to try to make sense of what happened. But the records don't show all the ways in which I was coerced and traumatized"

"I told one nurse, who was with me the day my baby was born, that I have never in my life experienced such improper care. She didn't seem to care. In fact, she filed a complaint against me with Child Services. I think the nurse was upset that I called her out on her abysmal care and filed a complaint against me in spite. My husband and I are wonderful parents"

"I wanted to. I began to write the letter, but I was still filled with so much fear and shame that I never went through with it. I still write the letter in my head sometimes when a trigger brings back some of my experience"

For some respondents, the thought of reaching out to provide feedback about their hospital stay felt overwhelming, frightening, exhausting, or even re-traumatizing.

The creation of this independent patient feedback survey was a direct response to the absence of such a survey by and for the St. Joseph's Health Centre Family Birthing Centre at the time our survey was created.

We believe that it's in the best interest of patients for St. Joe's to make improvements to their feedback channels to ensure that patient voices are heard, as "[h]aving a better understanding of the care process from the patient's perspective enables healthcare providers to improve quality of care and support better health outcomes."(21)

21. "Patient Experience Measurement" <https://www.oha.com/quality-safety-and-patient-and-family-centred-care/patient-experience-measurement>

Conclusion

We urge the St. Joseph's Health Centre Family Birthing Centre to:

- **examine the culture and policies in place that allow the negative, distressing, and traumatic experiences outlined in this report to continue to occur**
- **improve the patient feedback process to ensure that individuals who have been directly harmed by their experiences at the hospital are better able to communicate their concerns**
- **hold accountable those who are doing harm; make an intentional commitment to end obstetric violence and patient mistreatment**
- **create more opportunities for relearning and retraining for staff to keep pace with current evidence on patient-centred care, trauma-informed practice, interprofessional teamworking, and other areas that patients have flagged for improvement**

Pregnant and birthing individuals are experts on their own experience. Consistently soliciting and listening to patient feedback (the good *and* the bad) may be challenging, but it's the most powerful way for any hospital to ensure they're making the improvements necessary to give patients and families the best possible start.

We hope that St. Joseph's Health Centre will continue to learn from patient feedback and seize this opportunity to become a leader in patient-centred, trauma-informed care in our community.

The Reproductive Justice Story Project - June 2018
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