

Towards a Respectful Childbirth

Designing for support & preparedness

Antonia Yunge Soruco · May 2020

We come to the world crying, covered in blood and bodily fluids. Although it is usually romanticized, childbirth is a noisy, messy, violent—but natural—event. This kind of violence is unavoidable, it is part of the circle of life. But childbirth is often also accompanied by a common, invisible, and avoidable type of unnatural violence: obstetric violence. A normalized set of practices that relegate birthing people to a secondary plane, focusing solely on the well-being of the baby while infringing on people's fundamental rights of dignity and respect, making the experience of childbirth traumatic for many of those who go through it.

The causes of obstetric violence involve a complex system of factors, primarily related to gender discrimination, unequal power dynamics between patients and providers, a legal system set up to protect providers and medical systems instead of the patients they serve, lack of provider accountability, and misinformation or lack of education about birthing rights—both in patients and healthcare students & providers.

1/3 of pregnant people in the US report having been victims of obstetric violence. Addressing this issue is especially important when considering that the country's maternal mortality rate is the highest among developed countries. There are two birth violence-related factors that increase the risk for the birthing person and, ultimately, contribute to increasing mortality rates: unnecessary medical procedures (such as unneeded C-Sections), and discrimination—primarily gender and race—that leads to ignoring the patient and missing important signs of emergency.

This thesis project explores the role of the designer in this complex system and how we might improve the experience of birthing people from a perspective of rights and respect.

Pregnant people need to be prepared to face this not-uncommon threat, but they can't fight this battle alone. People need support from organizations, the city government and their communities to be able to move towards meaningful change in the system. With this in mind, the project proposes the creation of a program called Respectful Birth Care, that aims to stop the normalization of obstetric violence, disseminate information about birth rights, create a support community, and provide the resources and support needed to decrease violence during birth.

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OBSTETRIC VIOLENCE

DISRESPECT AND ABUSE DURING CHILDBIRTH

Childbirth used to happen at home, where the birthing person would be surrounded by their family or midwives. Home births greatly decreased in the 1930s, with the popularization of facility-based labor and delivery. In a society where medical practice is often shaped by efficiency rather than by personal care, giving birth, a normal physiological process, became highly medicalized. Over the years, the rates of cesarean section, use of oxytocin, episiotomy, epidural, enema, electronic fetal monitoring, intravenous infusions, among other medical practices, have increased and have even become routine.

Today, as high as 30% of childbirths in the US are C-Sections (double the World Health Organization recommendation), half of which are not medically necessary, putting patients in danger.¹ Furthermore, despite medical advances, the US has the highest rate of maternal deaths among developed countries². Black women are three to four times more likely to die in childbirth than white women³ regardless of education, income, or any other socio-economic factors.⁴

Unnecessary medical procedures and medicalization of childbirth are not the only threats birthing people face. There is a normalized and ignored culture of childbirth mistreatment called obstetric violence: a disrespectful, abusive or neglectful treatment of the patient during pregnancy, childbirth, and the postpartum period.

Venezuela was the first country to define and prohibit this type of violence in 2007. As defined in their Organic Law on Women's Right to a Violence-free Life, obstetric violence is:

"[...]the appropriation of a woman's body and reproductive processes by health personnel, in the form of dehumanizing treatment, abusive medicalization and pathologization of natural processes, involving a woman's loss of autonomy and the capacity to freely make her own decisions about her body and her sexuality, which has negative consequences for a woman's quality of life."

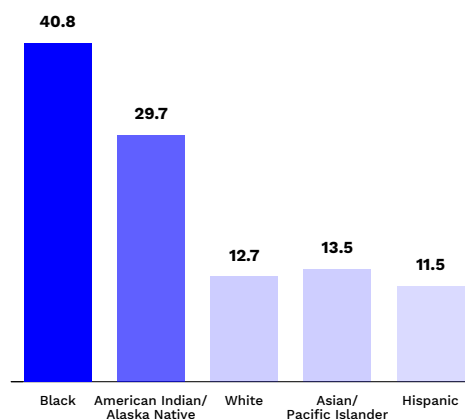


Figure 1: Pregnancy related deaths per 100,000 live births in the US. Source: CDC, Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths.

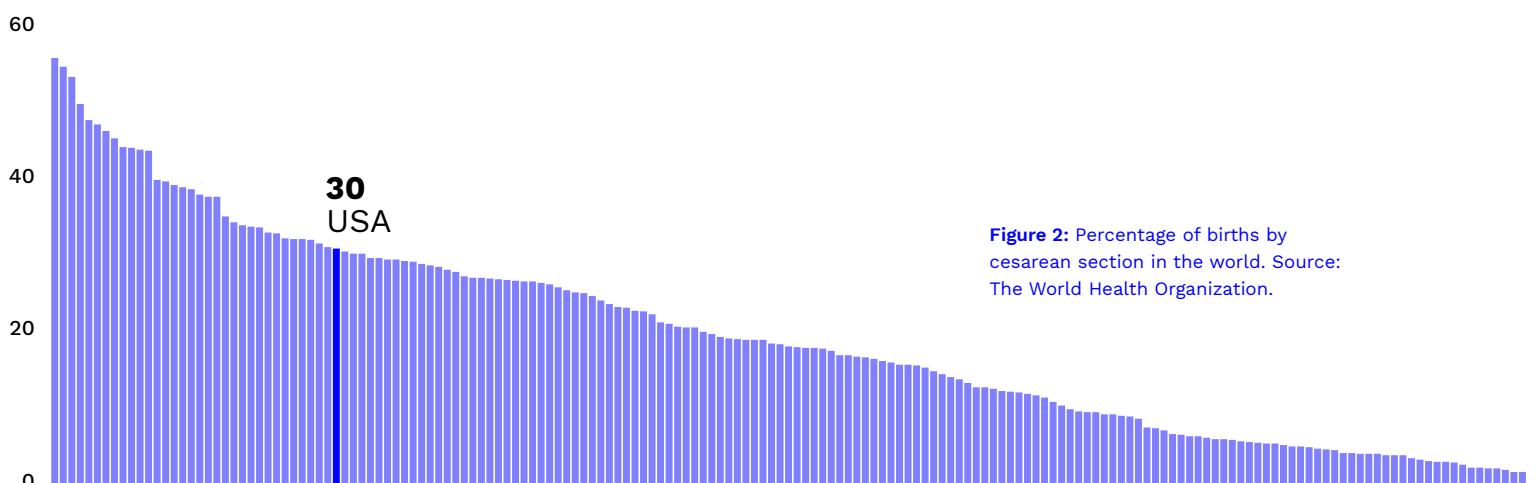


Figure 2: Percentage of births by cesarean section in the world. Source: The World Health Organization.

In the US, around 1/3 of birthing people report having been victims of obstetric violence, and describe their childbirth experience as traumatic⁵⁻⁶. Practices considered obstetric violence include: physical and psychological violence, rough treatment, coerced or forced procedures (episiotomies, use of anesthesia, C-Sections, chemically induced labor, among others), lack of informed consent, disregarding of pain, intimidation, mocking, bullying, ignoring birth plans, questions, and concerns, restricting movement, threatening about the baby's safety, denying food or drinks, among other practices. As a matter of gender, obstetric violence differs from medical violence against patients as *“the laboring body most often constitutes a healthy, powerful body that has much more in common with the dancing, running, or erotic body than it does with the pathological body in need of cure and healing”*⁷

Some women experience obstetric violence as a diminishment of their embodied selves: a reduction, repression, and objectification of their otherwise capable and powerful bodies⁸.

The causes of obstetric violence involve a complex system of factors, primarily related to: gender discrimination and unequal power dynamics between patients and providers, a legal system set up to protect providers and medical systems instead of the patients they serve, lack of provider accountability, and misinformation or lack of education about birthing rights—both in patients and healthcare students & providers.

Obstetric violence has particular features demanding a distinct analysis: it is a feminist issue, a case of gender violence; labouring women are generally healthy and not pathological; and labour and birth can be framed as sexual events, with obstetric violence being frequently experienced and interpreted as rape⁹

EXPLORING & UNDERSTANDING EXPERIENCES

Gathering pregnancy and childbirth experiences—not only from patients, but also from their support network and service workers—provided a valuable framework to develop the project. Collaboration with Public Health Solutions (PHS), the National Advocates for Pregnant Women (NAPW), and a partnership with the Birth Justice Defenders (BJD) played very important roles throughout the project.

Birth Justice Defenders is a community group formed mainly by Latin American women. They meet once a month to discuss challenges and ways of moving forward towards respectful childbirth. The group constantly participates and organizes events where they educate different communities about birthing rights, increasing awareness about obstetric violence. Attending

What is respectful childbirth?

A FIGO/WHO/WRA/ICM/IPA Mother/Baby-Friendly Birthing Facility¹⁷:

Offers all birthing women the opportunity to eat, drink, walk, stand, move and assume the position of her choice/comfort, unless medically contraindicated.

Has clear, nondiscriminatory policies and guidelines for the treatment and care of HIV-positive mothers and their newborns, as well as policies for counseling and provision of postpartum family planning, and youth-friendly services.

Provides all mothers with privacy during labor and birth.

Allows all birthing women the comfort of at least one person of her choice to be with her throughout labor and birth.

Provides culturally competent care that respects the individual's customs, nonharmful practices, and values around birth, including those women who experience perinatal loss.

Does not allow physical, verbal, emotional, or financial abuse of laboring, birthing, and postpartum women and their families.

Provides care at affordable costs in line with national guidelines and assures financial accountability and transparency. Health facilities should have a process for payment that does not include detention of the woman or baby. Refusal of care for the mother or the baby because of inability to pay should not be permitted.

Does not routinely employ practices or procedures that are not evidence-based, such as routine episiotomy, induction of labor, or separating mother and baby, etc.

Educates, counsels, and encourages staff to provide both nonpharmacological and pharmacological pain relief as necessary.

Promotes immediate skin-to-skin contact and actively supports all mothers to hold and exclusively breastfeed their babies as often as possible and provides combined care for mother and baby as appropriate.



Figure 3: Birth Justice Defenders Meeting.
Photo credit: Birth Justice Defenders.



Figure 4: Workshop session with members of The Birth Justice Defenders.

their monthly meetings and listening to their experiences, hopes, and fears provided the project with insightful and inspiring perspectives on the topic, especially from a community point of view. A small subgroup of the BDJ was also able to participate in a research workshop for this project, where we got the chance to deeply explore their stories of pregnancy, labor, and birth (Fig.4).

Pregnancy and childbirth involve a wide network of stakeholders. In the clinical setting, pregnant people interact with obstetricians, midwives, doctors, nurses, technicians, and administrative staff. Outside of that area, stakeholders appear at the family and community levels. Within a pregnant person's community, support groups, organizations, doulas, social workers, case workers, and nurses from different programs provide essential assistance to them and their families. Stakeholders at the family level greatly vary, but the support network can include partners, parents, siblings, other family members, neighbors and/or friends (Fig.5).

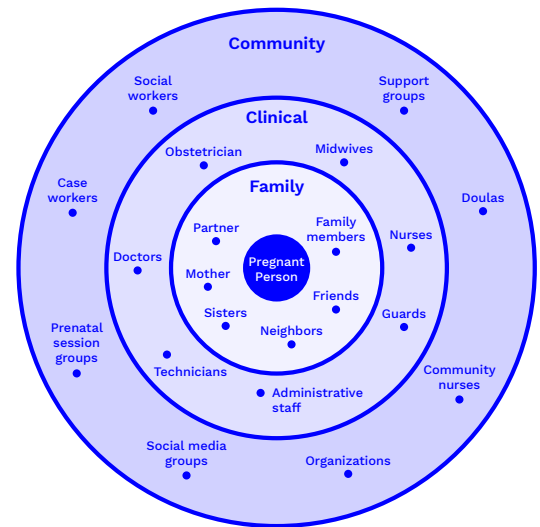


Figure 5: Stakeholders Map

Partners/Collaborators

Birth Justice Defenders (BJD):

a community based group passionate about ensuring that everyone has a dignified and respectful birthing experience, regardless of their race, ethnicity, religion, age, gender identity, immigration status, income, or type of health insurance. They educate, empower and support pregnant people (Fig.3).

Public Health Solutions (PHS):

a nonprofit working to improve health outcomes in New York City by providing services directly to the most vulnerable neighborhoods and supporting community-based health organizations who share in our mission to improve public health. They have multiple programs focused on Family, Sexual & Reproductive Health.

National Advocates for Pregnant Women (NAPW):

National Advocates for Pregnant Women (NAPW) is a non-profit organization that works to secure the human and civil rights, health and welfare of all people, focusing particularly on pregnant and parenting women, and those who are most likely to be targeted for state control and punishment—low income women, women of color, and drug-using women¹⁸.

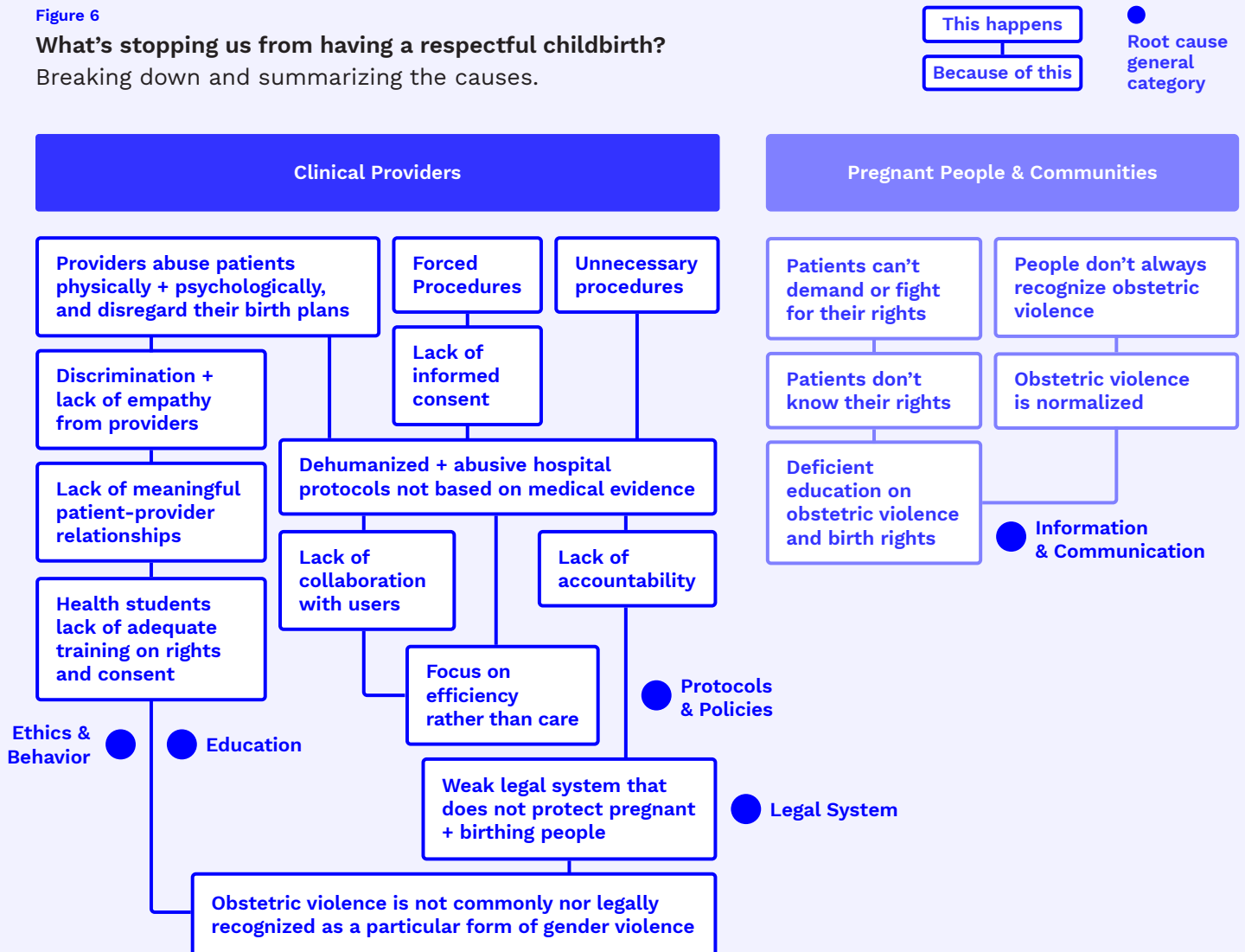
A COMPLEX SYSTEMIC PROBLEM

As mentioned before, obstetric violence involves a complex system of factors that enable and influence its occurrence. They can be categorized into: ethics & behaviors, health education, protocols & policies, legal system, and information & communication (Fig.6).

Figure 6

What's stopping us from having a respectful childbirth?

Breaking down and summarizing the causes.



Ethics & Behavior + Education

Starting by the question of who is being directly violent towards pregnant people, hospital providers are put in the spot. Doctors, nurses, and other health providers have established a culture of mistreatment and dehumanization towards pregnant people and women. There's a widespread lack of empathy coupled with

many forms of discrimination that silences patient's voices, succumbing to unequal power dynamics. It's very common—at least for western cultures—to see the pregnant person as somebody who now has a single focus in life: the well-being of their future baby. Pregnant people are regularly expected to accept pain and be more resilient, more tolerant, more submissive, generally stronger. Be more of the baby and less of themselves. They are expected to be secondary.

Changing culture is a complex and long-lasting task. It can't happen suddenly. Thus, obstetric violence needs to be addressed through intervening the factors that enable such violent behaviors, which, in many cases, are not considered as violent by the perpetrators.

The origins of the violent behaviors many providers exhibit can be traced to as early as their education. Although some medical schools are starting to incorporate a training about patients rights and consent to their curriculums, there's frequently no special focus on birth rights and shared decision-making.

“When you are pregnant, you immediately lose a lot of rights, rights that even dead people have. Doctors can't just go and remove organs from dead people, they need consent. They can't go and do procedures on a patient in a coma, they need consent. But what happens with pregnant people? They can force them to go under medical procedures to save the life of the baby—who has more rights than the birthing person. Everything counts when saving the baby.”

—Interview extract

National Advocates for Pregnant Women (NAPW)

“It's not that providers *want* to be violent. They just don't recognize what they are doing as violent or out of the ordinary. They think they are doing the right thing for them and the patients. They believe that because they have the medical knowledge, they are the ones who should be making the decisions, why waste time debating if they know what's best?”

—Interview extract (paraphrasing)

National Advocates for Pregnant Women (NAPW)

Policies & Procedures + Legal System

Hospital policies and procedures also have a great influence in the perpetuation of obstetric violence. They almost always prioritize efficiency and utilities above all, leading to a poor quality of care for the patients. It's common for hospitals to have protocols that are not based on the most recent medical evidence, making the patient go through unnecessary—and sometimes forced—procedures. For instance, hospitals

“When I was a student I was frequently told to go and *get* the consent from the patient, or just to go and *do* a vaginal exam. If I was not able to do it, I was a failure. I couldn't accept a no for an answer.”

—Expert Panel, Demanding a Respectful Birth on Staten Island. 2019

Midwife

“I did not have an episiotomy; the baby ripped me and the doctor just brought in all these students to observe me, and he did not ask...”

—Voice Your Vision, Share Your Birth Story: A Conversation on Maternal Health in New York State

Participant

commonly deny patients the possibility of giving birth vaginally after having a cesarean, even though there's medical evidence that having a Vaginal Birth After Cesarean (VBAC) is possible in many cases. The same approach can be seen with the use of epidural, C-Sections, continuous electronic fetal monitoring, membrane rupture, episiotomies, among others¹⁰.

Providers and hospital attitudes and practices are even more surprising when considering that there's evidence pointing to humanized and respectful births leading to better health outcomes and decreasing preventable maternal mortality¹¹.

As early as the 1970s, midwives, nurses, and doctors in low-resource countries began relating improved outcomes, including fewer cesareans, enhanced bonding, improved breastfeeding, decreased reports of stress after birth, and reduced need for operative deliveries, when women had companions during labor and birth, were treated as equals in the birth process, and were allowed to hold and breastfeed their babies immediately after birth.¹²

The legal system also plays a role in this issue. Obstetric violence is not recognized in US laws or in the constitution, making it very hard to make hospitals and providers accountable for it—not to mention how hard it is for patients to sue them on this matter and win. This lack of accountability enables a system of mistreatment and poor care, leaving obstetric violence in the darkness.

Information & Communication

Information has the ability to empower people. It's a tool for action and advocacy. But this is not the case for obstetric violence. Even if the lack of information available has a certain influence in the problem, it is not as great as the factors mentioned before.

On the one hand, lack of information about birthing rights contributes to worsening the experience during pregnancy and birth. But on the other hand, an informed person will not have the power to reduce or stop obstetric violence from happening, as patients have little or no power over providers and a system of accountability built to protect hospitals.

“... they told me, according to hospital policy I had to have another C-section.”

—Voice Your Vision, Share Your Birth Story: A Conversation on Maternal Health in New York State

Participant

“Doctors have a lot to learn from midwives and doulas. Doctors see a procedure; doulas see a mother.”

—Voice Your Vision, Share Your Birth Story: A Conversation on Maternal Health in New York State

Participant

ADDRESSING OBSTETRIC VIOLENCE FROM A DESIGN PERSPECTIVE

The complexity of this system is a fertile ground for design interventions that can improve the experience of people along their pregnancy and birth journeys. The process of making the systemic and cultural changes needed to effectively combat obstetric violence is long and complex, and requires a lot of resources and structural changes. A problem of this magnitude cannot be approached directly nor can it be changed by a single, simple intervention. There's no magic solution to it.

Three design skills emerge as key in addressing this problem. First, a system thinking perspective allows for a better approach to obstetric violence by not focusing solely on the pregnant person, but also considering systems and stakeholders around them. Through system thinking, design has a unique form of creatively approaching complex problems and breaking them down into small, achievable milestones. These interventions initiate change and movement inside systems—like a growing snowball rolling down a hill—and impact the future development of it.

Second, design's ability to facilitate learning. This project is tightly related to information. The role of design is not only to make it visually attractive, but also to facilitate its understanding by designing the learning process and how the information is going to be accessed and consumed.

Third, collaboration*. Addressing obstetric violence is not something that a designer alone can achieve from their desk. Incorporating multiple stakeholders and their perspectives into the process is key, not only during research, but also during the development of the project.

The purpose of this thesis project is to understand the challenges and leverage points for tackling obstetric violence, and to empower pregnant people about their birthing process. The project focuses on design's agency or capacity of affordances on the following:

- + How might we empower pregnant people and improve their experience before, during, and after childbirth?
- + How might we make obstetric violence visible?
- + How might we reduce information gaps and power imbalance between providers and patients during pregnancy and childbirth?
- + How might we better support pregnant and birthing people?

* The process of collaboration was interrupted and affected by the COVID-19 pandemic. Efforts were made to be in touch with participants, but given the circumstances, it wasn't possible to achieve a co-creative process.

LEVERAGE POINTS: INTERVENING THE SYSTEM

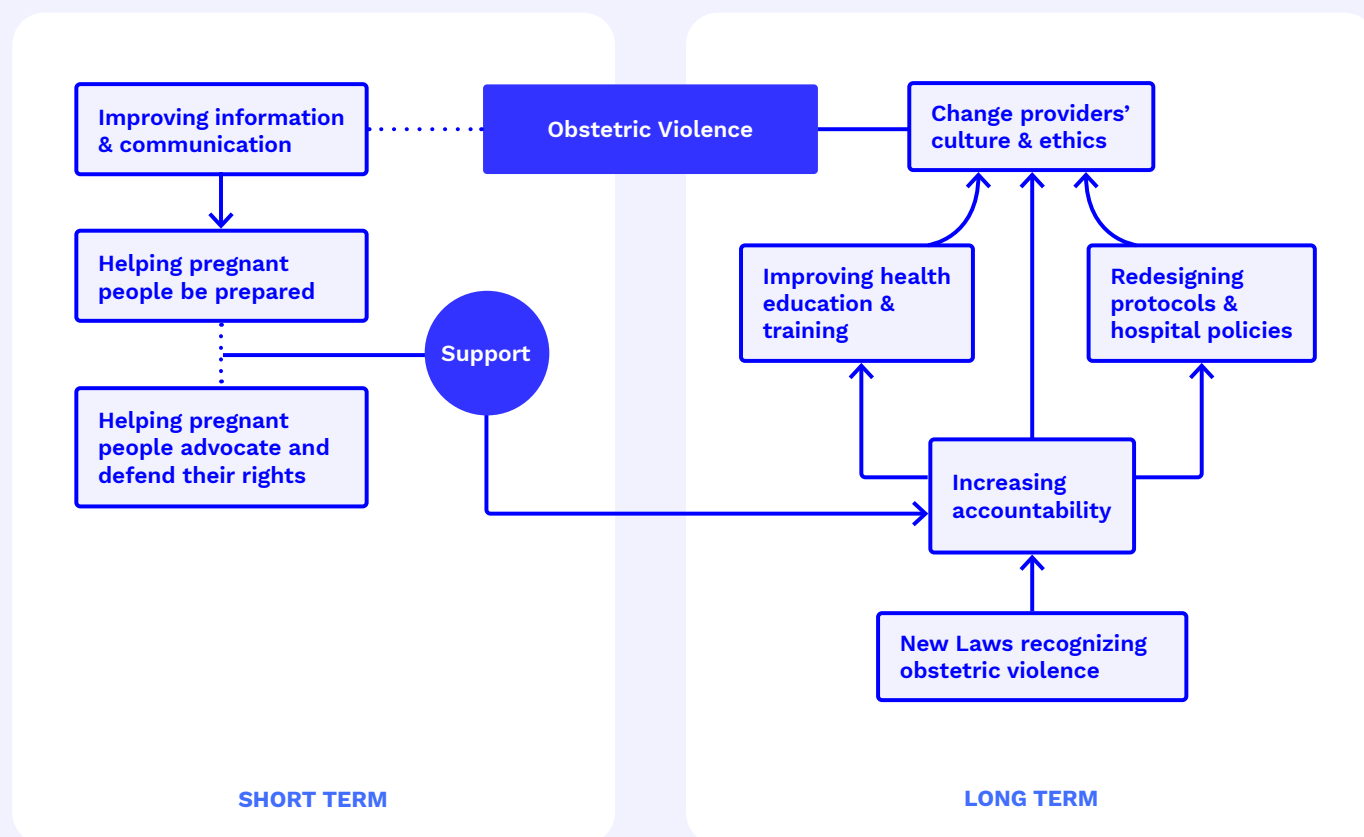
Obstetric violence can be tackled from different points of view, as many factors and stakeholders contribute to its existence. This complexity allows for design to intervene at different levels of the system, to start tearing down the structures in which violence supports and feeds itself.

When considering timespans as a first parameter to determine leverage points, there's a clear distinction between what can be achieved in the short term and in the long term. Provider culture, ethics and behaviors need to change, but that transition needs to be supported by other systemic interventions. The creation of new laws that recognize obstetric violence could probably lead to increasing accountability and influence the redesign of health curriculums, training programs and hospital protocols, that could eventually lead to a better ethic of practice. Even if these are necessary milestones, they are situated in the long-term realm (Fig. 7).

Figure 7

What can we do to address obstetric violence?

A summarized diagram of action



Providing information is a short-term intervention. However, as mentioned before, it has little influence in obstetric violence rates, as patients don't have any power over providers and hospitals.

In this context, the importance of accessing information does not radiate in being an enabler for action, but in its capacity to help people be prepared to face events of disrespect and abuse. Preparation provides new tools for the pregnant person to combat these situations and reduce the negative effects that they might have. For instance, in the case of a faulty informed consent, knowing that you have the legal right to receive information about the benefits, risks, and alternatives of every procedure, might help patients guide the conversation, ask the right questions, and demand to receive all the information they are entitled to.

Advocating against and reacting to obstetric violence are not easy things to accomplish. Pregnant people need support, but not of any kind: it needs to be one that leads to increased accountability in order to break the circle of abuse.

DESIGNING FOR SUPPORT: HOW MIGHT WE DESIGN A BETTER SYSTEM THAT SUPPORTS BIRTHING PEOPLE?

The research uncovered a diverse range of leverage points that would be key to achieving the right kind of support. The main three that guided the design process are: informed consent, the support person, and education & preparedness. These areas served also as a basis to define the design principles that helped develop the project.

Informed Consent

Informed consent is a legal right¹³. Patients have the right to receive information and make non-coerced decisions about what happens to their body. Informed consent should take the form of a conversation between the patient and their provider, where the patient receives all the information—risks, benefits, procedures, alternatives—necessary to ensure that they fully understand what they are agreeing to. In reality, informed consent is not usually a shared decision-making process. Instead, it becomes a short exchange where the provider limits themselves to letting the patient know they are performing a certain procedure—the patient's agreement is assumed as a given.

Regularly infringing the right to informed consent is one of the main issues of obstetric violence. During childbirth (and other medical practices), "informed consent" is often not really informed, nor truly consensual. The right to consent does not only apply to medical procedures, but also to every interaction providers have with the patient and their body. Touching, observing, teaching, and practicing with people's bodies requires true informed consent.

I will touch you now to see the baby's position, ok?

vs

I need to check the baby's position because_____. In order to do that I'd have to gently touch your belly. It should not hurt and it's not risky for either of you. Are you okay with that?

“There was some issue with my cervix, I don’t remember exactly what it was, but the midwife came in and said she had to do this procedure to speed things up because the baby was in distress. She didn’t explain what she was going to do, she didn’t tell me that it was going to be painful as hell. She just put her hands inside me and told me to breathe.”

—Interview extract

Translated from Spanish

“I repeatedly told the doctor I didn’t want an epidural, he kept insisting that it would make things easier. He asked me more than 10 times. I ended up having one, even though I didn’t want it.”

—Interview extract

Translated from Spanish

Proper informed consent is a key element to address obstetric violence, as it’s what would keep providers from forcing procedures onto birthing people.

Support Person

Most pregnant people decide to have a support person with them during labor and birth, such as their partner, family, friends and/or a doula. Holding the birthing person’s hand is no longer enough support—the patient’s support person also has an important role in advocating for their right to a respectful childbirth. In such a moment of vulnerability, birthing people need to be able to rely on their companions to advocate for the fulfillment of their birth preferences and the guarding of their rights. The role of the support person needs to shift in this direction so that birthing people can attempt to regain some control over their own childbirth.

“My partner was aware that I didn’t want an epidural, he was there to respond to the doctors every time they would insist on giving me one.”

—Interview extract

Translated from Spanish

“They were going to induce the birth, I was ok with it, but my partner started asking questions—what are the risks? What happens if you don’t do it? Is the baby suffering? Long story short, there wasn’t really a medical reason to do the procedure. They just wanted to speed up the process. It didn’t occur to me to ask all those questions, I was trying to focus on getting my baby out of me!”

—Interview extract

Translated from Spanish

DESIGN PRINCIPLE 1

Not only provide information, but also ways of recognizing and acting upon it. Show it, don’t just tell it. It is not only necessary for pregnant people to know that they have the right to informed consent, but also to know what real informed consent it looks like. This same principle applies to obstetric violence. In order to fight against it, people need to recognize it as such, and also have the tools and knowledge to respond to it.

DESIGN PRINCIPLE 2

Leverage the role of existing support networks. Pregnant people are already receiving support from their inner circle, community and organizations. Providing them with the tools and resources to improve how they help birthing people is an important step towards respectful childbirth.

“The midwife was being very rude to us, she kept saying how I was being a bad mother for not wanting my birth to be induced, even though the baby wasn’t at risk. My mom stepped in and confronted her. I was able to relax after that, but I didn’t have the energy to confront her myself”

—Interview extract

Translated from Spanish

Education & Preparedness

Not all pregnant people are well informed about their pregnancy and birthing rights. Obstetric violence is so ingrained in western culture that people have a hard time recognizing when their rights are being infringed. Pregnant people are often expected to sacrifice everything and go above and beyond for the benefit of their baby, without taking into consideration the consequences this could have for them.

“I would frequently hear them saying ‘you can do this, the only thing that matters is a healthy baby,’ and I couldn’t stop thinking, when did I stop being important?”

—Interview extract

Translated from Spanish

“Thinking back to when I gave birth almost 30 years ago, a lot of the things that happened then are now considered obstetric violence, but at that time it was just how things were. You would just lay, give birth and do everything the doctors said without questioning. Did I want an epidural? Did I want my labor to be induced? I don’t know, none of that was my choice.”

—Interview extract

Translated from Spanish

The tricky thing is, no matter how well educated pregnant and birthing people are in these matters, they will not be able to stop the abuse from happening, because Obstetric violence is not the patient’s fault or responsibility. They are not to be held accountable.

If educating patients and their families about obstetric violence won’t really affect its recurrence, what is the role of education and awareness in this system? Mainly, it can help people be prepared to face a potentially hostile situation, and to manage their expectations.

“We don’t know our rights, we don’t know what is not okay during childbirth, we don’t know what we are entitled to. We are used to being mistreated and we just accept it as ‘something that happens.’ We are always looking at the doctor as a kind of god that always knows what’s best for you, but that’s not true. We have rights and women should know them to be able to fight for them.”

—Birth Justice Defenders Meeting

Translated from Spanish

DESIGN PRINCIPLE 3

Help people be prepared without being alarmist.

Pregnant people need to know the reality of obstetric violence, but the last thing they need is something else to be scared of. Information must be provided in a way that makes people feel supported while delivering empowerment.

DESIGN PRINCIPLE 4

Make information easy to digest and approachable.

There is a lot to learn about birth rights and advocacy. Information needs to be designed in a way that it is perceived as approachable and friendly for it to be internalized.

THE RESPECTFUL BIRTH CARE PROGRAM

Pregnant and birthing people need a network of support to achieve a respectful childbirth. Different organizations across New York City do an amazing job connecting people with resources, spreading information, and supporting families before and after childbirth. But during labor and birth, the role of support is relegated to the patient's companions and family, and organizations have little influence to directly push for the kind of legislative and policy change that could lead to increasing provider accountability and decreasing obstetric violence.

The Respectful Birth Care program is conceived from the need to support pregnant and birthing people and of pushing for policy change. It provides free support and education on birth rights to pregnant people in New York City to decrease episodes of violence and ensure the best chances at having respectful care at birth. As most of the research was conducted among Latin American communities (the cultural segment I'm closest to in NYC), the first pilot of the program is targeted at that segment.

The program could be implemented within different contexts: as part of the city government, as an NGO, or within an existing organization. But connection with local government is key for its success, as they bring the authority and power required to push for meaningful change. The best case scenario would be for the program to be run by the city government, but indirectly providing its services through partner organizations and programs that already have an established community network.

The program is inspired by the *Standards for Respectful Care at Birth* (Fig.9), published in December 2018 by the Health Department's Sexual and Reproductive Justice Community Engagement Group (SRJ CEG) in collaboration with NYC Health + Hospitals/Harlem. "*The NYC Standards for Respectful Care at Birth creates the foundation to support and engage patients, community members, and health care providers in advocating for respectful care at birth.*"¹⁴ The Standards focus on six key areas of respectful birth care: education; informed consent; decision making; quality of care; support; and dignity and non-discrimination, and seeks to incorporate them into clinical and maternity care. Posters and brochures were distributed to hospitals and other clinical settings, community-based organizations, and neighborhood health action centers citywide¹⁵.

Initiatives like this show a growing interest in addressing obstetric violence and providing better maternal care to pregnant people. In this context, the Respectful Birth Care program aims to expand what NYC already started by not only providing information, but also helping people recognize and react to abuse and violence.

INTERVENTIONS

For the participants:

- My respectful birth care guide
- Translation aid tool
- Stickers and wristbands
- Support person pin
- Deck of cards
- Website
- Chat and phone number
- Emergency number

For the organization/ government:

- Poster
- Social media material
- Facilitator guide
- Slideshow presentation
- Case reporting system
- Reports database

- designed ● proposed
- planned

<div> <div>EDUCATION</div> <div>  </div> </div> <div> <p>You deserve to ask for and receive simple information that you can easily understand about your health care, health care provider and birthing experience options. This includes information about the following:</p> <ol style="list-style-type: none"> 1. Obstetricians, gynecologists, midwives, doulas or family medicine doctors, and their qualifications and professional experience 2. Options for where to give birth, such as a hospital, a birthing center or your home 3. The policies and practices of the place where you choose to give birth 4. Resources to prepare for childbirth and feeding your baby, such as childbirth education classes and nursing counselors 5. A description of all possible outcomes of birth for you and your baby 6. Information and referrals for benefits and services you may need, such as housing, food, legal support and health insurance* </div>	<div> <div>QUALITY OF CARE</div> <div>  </div> </div> <div> <p>You deserve the highest-quality health care. This includes:</p> <ol style="list-style-type: none"> 1. Timely attention to your needs, including taking your pain level seriously, for your entire stay at a hospital or birthing center, or during the birthing experience at your home 2. A safe and clean environment during your labor and delivery, and a quiet and safe room after you give birth 3. Providers who are trained and skilled in current best practices for care during pregnancy and childbirth 4. Courteous staff who introduce themselves when they enter the room, if you have a negative experience or do not feel comfortable with a staff member for any reason (e.g., behavior, skill or experience level, etc.), you can ask for and receive a different staff member </div>	<div> <div>DECISION-MAKING</div> <div>  </div> </div> <div> <p>You deserve to decide what happens with your body and to make decisions for your baby. This includes:</p> <ol style="list-style-type: none"> 1. Making health care choices, such as which medical procedures you will and will not allow to be performed on you, based on your values, religion and beliefs 2. Deciding where to give birth, whether at a hospital, birthing center or your home 3. Choosing how to feed your baby - whether with breastfeeding/chest feeding, formula or a combination of both - and receiving the help you need to feed your baby 4. Holding your baby immediately after birth (also known as skin-to-skin), even if you have had a C-section 5. Making choices about the care of your baby, such as whether or not to be with your baby for their medical tests and procedures (unless there is a medical reason not to) and where your baby stays (in the same room with you or in the nursery) 6. Having your decisions documented and that you understand their associated possible risks </div>
<div> <div>INFORMED CONSENT</div> <div>  </div> </div> <div> <p>You deserve to know and make your own decisions about all of your medical procedures. This is called "informed consent" and is a legal right.* Providers should share accurate, judgment-free explanations and discuss all possible risks and benefits of each procedure with you. After you have made your decision, you have the right to change your mind and have your new decisions respected - even if your health care provider disagrees with you. Informed consent includes:</p> <ol style="list-style-type: none"> 1. Your health care provider's recommendations about procedures, tests, treatments or drugs 2. Any risks, benefits and alternative procedures </div>	<div> <div>DIGNITY AND NONDISCRIMINATION</div> <div>  </div> </div> <div> <p>You deserve to be treated with dignity and respect during pregnancy, labor and childbirth, as well as after childbirth - no matter what.** This means health care providers are expected to:</p> <ol style="list-style-type: none"> 1. Treat you and your family fairly, regardless of race, gender, religion, sexual orientation, age, disability, HIV status, immigration status, housing status, income level or form of insurance 2. Provide an interpreter so that you can understand your health care provider and they can understand you 3. Protect your privacy and keep your medical information confidential 4. Let you decide who you do and do not want in the room, including staff members, during exams and procedures, and respect this decision 5. Ask for and use the name and gender pronouns you prefer 6. Use the name and gender pronouns you use to refer to your baby 7. Respect the decisions you have made about your family, such as whether you have a spouse or partner, what your spouse's or partner's gender is, how many children you have, or if you have chosen to place a baby for adoption 8. Acknowledge concerns or complaints you may have about your health care, and give you information about how to file a complaint about any aspect of your care </div>	<div> <div>SUPPORT</div> <div>  </div> </div> <div> <p>You deserve to receive support during pregnancy, labor and childbirth, as well as after childbirth. This includes:</p> <ol style="list-style-type: none"> 1. Having the people you choose present during delivery and other procedures, such as your partner, family members, friends or doula (a trained professional who provides information and support before, during and shortly after childbirth) 2. Receiving information, counseling and support services if you experience depression after giving birth (also known as postpartum depression) 3. Receiving information, counseling and support services for you and your family if you experience a miscarriage, stillbirth or loss of an infant </div>

*If you would like to sign up for public benefit programs, call 311 for more information. **If you believe your right to informed consent has been violated, you should contact an attorney who specializes in personal injury. The New York City Bar Association has a legal referral service that may be able to help you find an attorney by calling 212-626-7733. ***If you believe you have been mistreated or denied care or services because of your gender, your pregnancy or any other protected category under the New York City Human Rights Law, call 311 or 718-722-3131 to file a complaint with the New York City Commission on Human Rights.

Figure 9: Standards for Respectful Care at Birth, brochure

The Respectful Birth Care program tries to fill this gap by providing support at different stages of pregnancy and birth. To that end, it is divided in 4 phases: prenatal session, preparing at home, childbirth support, and postnatal follow up.

PHASE 1 Prenatal session		
Length	When	Objective
2 hours	2-3 trimester of pregnancy	Introduce the program, provide information and tools, connect with resources

The prenatal session is aimed at pregnant people and their support person, ideally during their second or early third trimester. The session introduces the program, its services, tools and resources. Participants go through different activities and role playing as they learn about their birth rights and how to manage the different situations that might arise during childbirth. They also receive the respectful birth care package that contains the *My Respectful Birth Care* guide, a translation aid tool, stickers and wristbands to share information with providers, a pin that identifies the support person, and a deck of cards with prompts to role play at home.

The person facilitating the session will also act as the participants' caseworker during the next phases.

**ALL PREGNANT PEOPLE
HAVE THE SAME RIGHTS!**

Join us in the next prenatal session to learn about how to advocate for your rights during birth.

Check when is the next session in our website respectfulbirthcare.nyc

All pregnant people and their support person welcome!



Figure 10: Prenatal Session Poster

PHASE 2

Preparing at home

Length	When	Objective
2-6 months	Before going into labor	Prepare for a respectful childbirth, agree and discuss the role of the support person

After the prenatal session, the pregnant person and the support person continue to work together to complete the activities on the guide and prepare for childbirth. They should spend time discussing and deciding about the type of assistance the pregnant person is expecting, and defining the role of the support person.

People from the program are available to answer questions regarding birth rights, hospital protocols, how to manage situations, getting a translator, among other needs, by phone or online chat. The case manager, who they met during the prenatal session or was assigned to them later, will also be in touch with them to provide personalized information and connection to resources.

The program's website, complementary to the guide, provides information, resources, videos and tools that participants can use to further expand their knowledge of respectful childbirth.

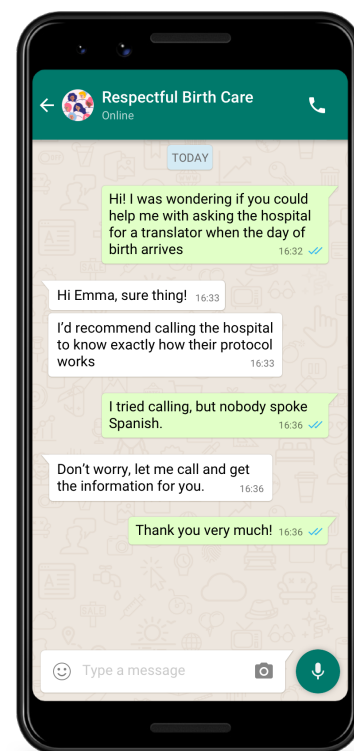


Figure 11: Whatsapp chat between the pregnant person and their program case manager

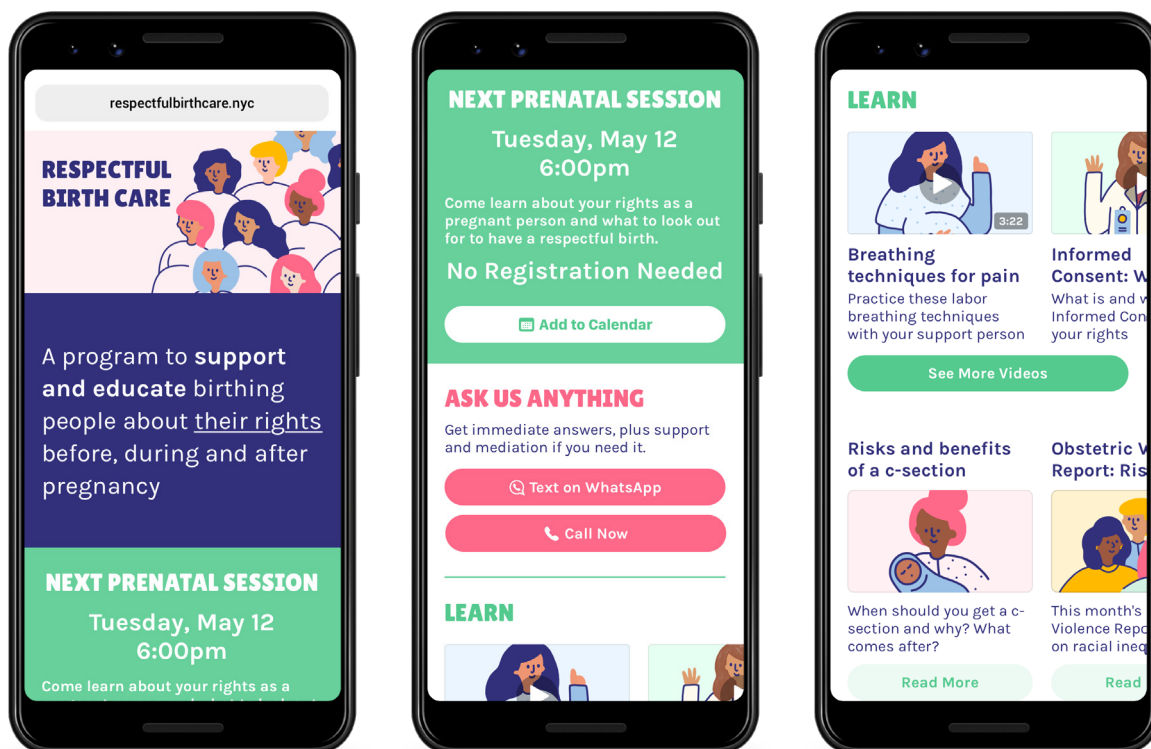


Figure 11: Respectful Care at Birth website

PHASE 3

Childbirth Support

Length	When	Objective
1-48 hours depending on labor and delivery times	At the hospital during labor & delivery	Provide immediate support in case of abuse, violence or infringement of rights during labor and delivery.

Once the pregnant person goes into labor and delivery, the program makes itself available to provide support mediating conflict situations, providing translation assistance, and contacting the hospital or birthing center directly, if an issue with providers cannot be resolved otherwise. To access this service, the pregnant person or their support person can call the program's emergency phone number, available on the website. If they assisted to the prenatal session, the number should already be in their contacts.

The translation aid tool can also play an important role during this phase. If the pregnant person does not speak English, they can use the translation tool to communicate when arriving at the hospital or while waiting for a translator. The pregnant person can also use the stickers and bracelets provided to communicate their preferences to the staff and providers through their body.

PHASE 4

Postnatal follow-up

Length	When	Objective
Minutes to hours	After childbirth	Checking in with the participant, report case if needed, and connect them with resources and support groups

After childbirth, the case manager will follow up with the participant to check in with them and provide connection to resources and support groups as needed. They will also discuss their experience during childbirth. If there was any disrespectful or abusive situation, the case manager will ask the participant if they'd like to file a report. This information is collected in a database and later used to provide reports of the quality of care provided in different hospitals to help women choose the best place to give birth, and pressure hospitals into improving their policies and communication strategies.

If a hospital has recurring reports, they will receive a notification and be asked by the city government to report back with the measures they are going to take to prevent future situations.

STORYTIME - EXAMPLE CASE

Emma goes into labor alone at home and rushes to the hospital while she calls her support person. She doesn't speak English, so she uses the translation aid tool when arriving at the hospital to communicate with the staff.

After some time, Emma's support person arrives, and can act as translator. They are in the delivery room when the doctor rushes in, and tells Emma she's going to need a C-Section. They try to ask multiple times why she needs the procedure, but the doctor is not being helpful and leaves the room telling them that he'll be back once Emma is ready to agree.

Frustrated, they decide to call the program's emergency number. They help Emma and their support person mediate the conversation with the doctor and obtain the information she needs to make an informed decision.

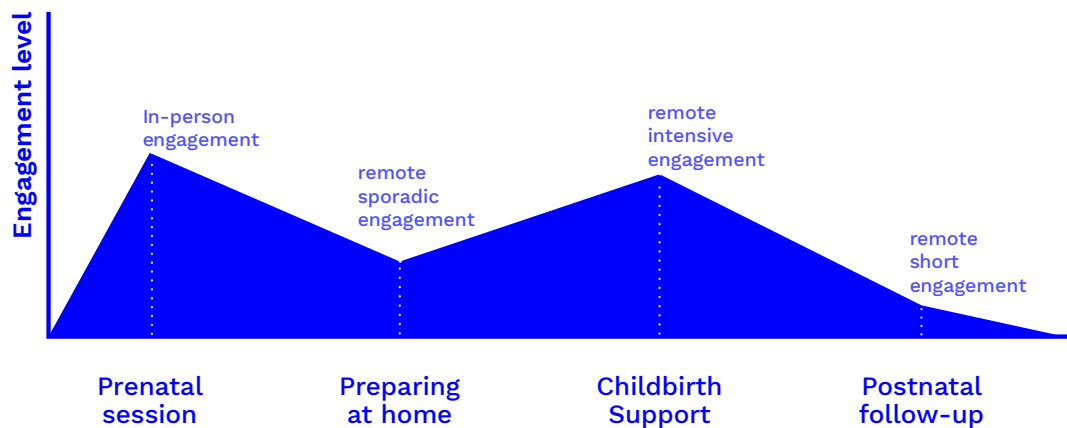


Figure 12: type and level of engagement in the different phases.



Figure 13: My Respectful Birth Care Guide

MY RESPECTFUL BIRTH CARE GUIDE

The *My Respectful Birth Care* guide (Fig.13) educates about birthing rights and obstetric violence through different activities, tips, storyboards and illustrations that portray different situations and dialogues. The guide exemplifies some of the situations that the pregnant person and their support person might face, and how they could respond to them. The goal of the guide is to help people:

- + Know their rights
- + Recognize how their rights should look like in different contexts
- + Define the role of the support person
- + Identify obstetric violence and provide guidance on how to act against it
- + Encourage discussion about birth preferences and hospital policies with providers

Browse through the chapters in Spanish and English in antonaiyunge.cl



GUIDE CONTENTS

Respectful Birth Care Program

Purpose of the guide

When to use this guide

Why is it important to be prepared?

1. Right to receive support

Main activity: building a support network

2. Right to quality of care

Main activity: what can we do when we encounter violence, disrespect, or mistreatment?

3. Right to receive clear information

4. Right to informed consent

Main activity: making decisions

5. Right to make decisions

Main activity: discussing birth preferences and hospital protocols

6. Right to dignity and non-discrimination

Worksheets

1

RIGHT TO RECEIVE SUPPORT

YOU HAVE THE RIGHT TO:

- * choose who is present during delivery
- * have at least one support person
- * receive information, counseling and support services for you and your family if you experience a miscarriage, stillbirth or loss of an infant

All pregnant people deserve to receive support from their inner circle and medical staff at all times: during pregnancy, labor, delivery and after giving birth.

The support person, who will accompany the pregnant person through the entire process, will perform key duties of emotional and communicational support.

Chapter 1: Right to receive support

THE RIGHT TO RECEIVE SUPPORT INCLUDES:

You deserve to have the people you choose present during delivery and other procedures, such as your partner, family members, friends or doula (a trained professional who provides information and support before, during and shortly after childbirth)

I'd like my partner to be my support person

I'd like my mom and my partner to be present during childbirth, could I have two support persons?



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ACTIVITY

BUILDING A SUPPORT NETWORK

It's important that the pregnant person has a support network during childbirth.

- 1 Ask the place where you're planning to give birth how many people are allowed in the delivery room. Usually, hospitals allow one support person to be present.

How many people are allowed in the delivery room?

- 2 Will you have, or would you like to have, support from a doula?

☐ Yes ☐ No

Does the hospital allow both a doula and a support person to be present in the delivery room?

☐ Yes ☐ No

I'd like to receive support from my sister and a doula. What's the hospital's protocol regarding doulas?

TIP

Would you like to receive support from a doula? There are many organizations in NYC that provide doula services free of charge. See the Resources section of respectfulbirthcare.nyc



- 3 Who would you like to receive support from while giving birth? Talk to your closest people to build your support network:



SUPPORT PERSON

They will accompany you while you give birth. Usually, hospitals only allow one support person to be present during birth.

Who will have this role?



SUPPORT NETWORK

Who else will support you during birth? Be it by helping at home, running errands, being in the waiting room, or anything else.

- 4 How would you like to be supported while giving birth? While these decisions can change in the moment, it's recommended that you and your support person talk about these topics in advance:

PHYSICAL CONTACT

Would you like your support person to hold your hand, caress you or talk to you during birth?

COMMUNICATION AND BIRTH PREFERENCES

Would you like your support person to be responsible for communicating with medical staff?

Would you like your support person to advocate for the respect of your rights and birth preferences?

UMBILICAL CORD

Would you like your support person to cut the umbilical cord? Do they want to?

Would you like to cut the baby's umbilical cord?

Yes, I'd love to!



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YOU ALSO HAVE THE RIGHT TO RECEIVE SUPPORT AFTER GIVING BIRTH:



You deserve to receive information, counseling and support services if you experience depression after giving birth (also known as postpartum depression)



You and your family deserve to receive information, counseling and support services if you experience a miscarriage, stillbirth or loss of an infant

How have you been? How are you feeling?

Honestly, these past few weeks have been hard. I haven't felt like getting out of bed, feeding my baby, or spending time with him.

We're here for you. Many people experience postpartum depression. It's nothing to be ashamed of.

Thank you



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TRANSLATION AID TOOL

17% of Latin Americans in NYC don't speak English¹⁶. The translation aid tool (Fig. 14) is aimed at helping pregnant people communicate basic information when arriving at the hospital and while waiting for a translator to arrive. As Spanish and English face different sides, it can be used by the pregnant person and the provider at the same time (Fig. 15).



Figure 14: Translation aid tool Spanish to English



Figure 15: Translation aid tool prototype

STICKERS, WRISTBANDS AND PIN

The Respectful Birth Care package also includes a set of wearable materials designed to provide fast information to the staff and remind them the importance of consent. They include a pin to identify the support person, bracelets for pregnant people to wear on their wrists or ankles, and stickers to place in their hospital gown. Phrases in the wereable materials include:

- + No epidural
- + I only speak Spanish
- + Ask for consent before touching
- + Do not induce birth without consent
- + No episiotomy without consent
- + No artificial rupture of membranes without consent



Figure 16: Bracelet and sticker prototype

NEXT STEPS & REFLECTIONS

During the development of this project, the world began suffering through the COVID-19 pandemic. New York City was hardly hit, and rapidly all work and meetings were cancelled, postponed or transitioned online. Due to this unforeseen situation, collaboration with stakeholders and participatory efforts within the project were severely impacted. The most important next step of this project involves testing and further iteration through a restored cadence of collaboration, especially with its intended users. Additionally, the program and all its materials need to be adapted to different languages and contexts.

The following important milestone would involve designing a pilot version of the program to test its services and analyze the level of impact that each element brings to determine priorities for implementation. The pilot program would start with the physical elements, and slowly transition into more complex services, such as the emergency phone number.

Developing this thesis project was inspiring and amazingly educational. Design has an important role in addressing complex problems and fighting to give each human being the dignity they deserve in every context of their lives, especially in an extremely vulnerable moment such as childbirth. But design cannot act alone. It needs buy-in from all different actors within a system to truly achieve its maximum impact. It needs to simultaneously be in complete alignment with the final beneficiary's cultural predispositions in order to be well received, and gain the attention of the institutions with the power and resources to elevate the problem space in order to generate long-term change that scales. This can only be achieved through close partnerships and active collaboration on both fronts.

I'm deeply grateful to all the partners and collaborators that contributed to this project with their experience and knowledge. Their contributions have made this project much richer and meaningful, and hopefully valuable to the people it will touch.

The *My Respectful Birth Care* guide will be completed in Spanish and English, and will be distributed to the organizations that supported the process in hopes that it can help guide future pregnant people through the complexities of giving birth in today's world.

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