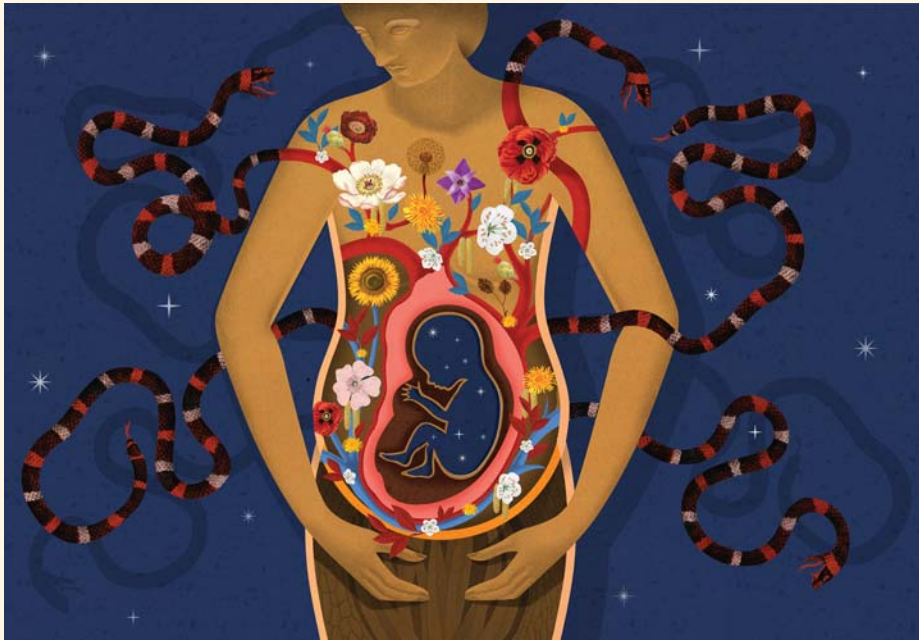


# NARRATIVE MATTERS



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## My Story Of Trauma And Reproductive Health

*Trauma-informed care is essential—and currently lacking—in reproductive health care.*

BY ANGELICA L. AL JANABI

**T**he nightmares of labor began around eight weeks. I started waking up in the night, panicked and sweaty. My thoughts raced: “There is a **THING** inside of me, and it has to get out!”

For as long as I can remember, pregnancy and childbirth both horrified and fascinated me. Even before I became pregnant, I periodically Googled birth photos and anxiously pored over labor stories. I couldn’t look away. Giving birth seemed like the worst thing that could happen to someone, and I had to know how it felt because it might happen to me someday. Many people think birth is beautiful, but I thought it

sounded like Hell: some unknown but excruciating amount of pain, potentially lasting several days, all naked and vulnerable with strangers touching your private parts and watching you lose control of your body. It sounded like rape—public, sanctioned rape that I was supposed to be grateful for.

I have a complicated story and a handful of mental health diagnoses, including posttraumatic stress disorder (PTSD) and anxiety. The earliest years of my childhood were marked by severe sexual abuse, and that was only the beginning of the significant challenges I have faced. My adverse childhood experiences score is a 6 of 10, and during my life I have experienced various forms of

abuse, violence, chronic stress, hardship, and trauma. I am also neurodivergent, with autism and attention deficit hyperactivity disorder. Autism is the lens through which I experience the world. It influences everything about my existence, including my perceptions of pain and how I communicate, which are important factors when seeking medical care. My brain is brilliant and unique.

I have always experienced body issues arising from my trauma history and anxiety. Trying to undress in front of peers or at medical appointments always makes me freeze, my heart pounding, and has often led to tearful breakdowns that baffle observers. Any exam requiring undressing can cause me major stress. Pain and feeling trapped are other triggers. Having an intravenous drip during a hospitalization once made me feel so physically bound to my bed that I sobbed for hours in a whirlwind of dizzy dissociation, and I have yelped in panic and pulled away from providers during invasive procedures such as COVID-19 tests or Pap smears. I’ve also felt violated because the providers didn’t listen to my “no,” whether it was explicitly stated or implied through body language and tears.

Unsurprisingly, pregnancy and childbirth caused complicated fears to bubble up. If a quick pelvic exam caused so much distress, what would hours of labor do? Or multiple cervical checks by strangers? What about pushing something the size of a watermelon out of my body when I couldn’t even manage the use of a speculum? The idea of the pain and other sensations of birth horrified me, but an epidural also scared me because I knew I would feel especially vulnerable if I couldn’t move. I would feel trapped at the hospital, regardless, particularly as labor progressed. Leaving midway through would be impossible. I also knew that there was a point of no return, wherever I was: If I decided during pushing that I couldn’t tolerate the pain or found the sensations upsetting, what could I do? Nothing. For me, birth seemed like the ultimate humilia-

tion, with an audience witnessing me helpless and out of control. I had also heard about altered mental states, dissociation, or reliving past trauma during birth, and I was worried about complications such as tearing, which could require even more invasive exams and procedures and contribute to long-term dysfunction.

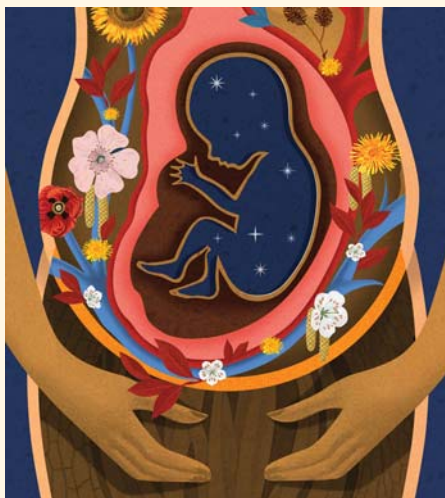
As a public health professional, I had learned about obstetric violence, a shockingly common issue that can include abuse or mistreatment in labor, such as denial of pain relief or forced procedures. Practically, I knew I would be unable to defend myself, particularly as pain increased, and I might not even know what procedures were happening. Birth trauma was another concern; it can occur as a result of pain, fear, loss of control, or other factors.

Many people are nervous about childbirth, but I was battling something debilitating: tokophobia, a profound fear of pregnancy and childbirth often associated with early trauma. It can be so severe that it leads to the abortion of much-wanted pregnancies. Whether or not tokophobia is present, people with trauma histories often have special needs in health care, particularly reproductive care.

### Inappropriate Care

Despite my fears, I became pregnant. At first, I was overjoyed. I rubbed my flat belly and whispered love to my child before I told anyone else. Shortly after, I developed hyperemesis, which also can be associated with trauma, and spent seven months shaky and pale, constantly fighting nausea. This was interspersed with vomiting, temporary relief, and then returning nausea. I spent much of my pregnancy moaning on the couch and pleading to the universe. I also faced complications such as gestational diabetes, heartbeat irregularities, and a fibroid.

When the novel excitement of my pregnancy test subsided, the emotional reality of my pregnancy also set in: There was a baby inside my body. I began obsessing about the delivery. As much wonder as tracking fetal growth weekly brought me, it also reminded me that my child was growing and time was barreling on. A friend suggested that learning



what to expect could help me feel prepared, and I spent nearly all my free time absorbing all the information I could. I was not afraid of worst-case scenarios; I largely learned about “normal” births, but even they horrified me. I felt increasingly isolated because online recordings of women screaming in pain were followed by comments such as, “What a wonderful birth!” Had we watched the same video? None of the options seemed tolerable. Unmedicated, I thought, the pain would be unbearable, but I could probably progress faster. With medication, it seemed as if I would still suffer—although probably less—but risked experiencing other complications.

Navigating the health care system during my pregnancy was extremely challenging. Most providers I saw had a pattern: carrying out exams that seemed routine to them without realizing that they were not routine to me, hurrying through the procedure or appointment, and not expecting to be questioned.

Early in my pregnancy, I made an appointment at my obstetrics-gynecology office to discuss my concerns because I was consumed by panic and had started feeling detached from my pregnancy. “You have to let go!” the nurse practitioner said, brusquely. “You can’t control everything. You’re going to have so many things. ...Genetic testing is coming up, and you can’t panic over everything!” I tried to tell her that my anxiety was only about birth and that I needed her to give me back control and choice. But her lack of ability to grasp what I was telling her, and her insistence that letting go was what I needed to do, was exactly the opposite of what I needed

from her. She didn’t understand.

The health care I received throughout my pregnancy was neither trauma informed nor appropriate for my needs. Health care providers made insensitive comments or assumptions, brushed off concerns I asked to discuss, or told me what I “had to” do. This kind of language might not seem harmful to a provider, but it is insensitive because it takes away agency and informed consent from the patient. My providers’ words and actions negatively affected my sense of safety and bodily autonomy.

One afternoon, when I was thirty-five weeks pregnant, a nurse tossed a gown to me and told me to get undressed for a group B strep swab. I had come prepared with research and questions about the risk of not doing the test, particularly as I had a cesarean delivery scheduled to take place at thirty-nine weeks, meaning that the results would likely not be relevant. The nurse was shocked. “You can’t opt out,” she said. My heart dropped, my face flushed, and I glanced anxiously around the room and at the door, feeling trapped and unsure of what to say, before I angrily told her that I didn’t want to and that she couldn’t force me. I wanted to respond: “Are you going to strap me to the table?” Visibly frustrated, she told me I could discuss it with the provider, and she left the room. As it turns out, the nurse was wrong. Regardless of clinic policies and preferences, patients have the right to decline care. Emotional and vulnerable, I was no longer able to even consider the test that day. At my next appointment, another provider asked, and I declined again, until she mentioned offhand that patients always swabbed themselves privately at the office where she used to work. When I asked her if I could do that too, she considered it and agreed. I felt pressured into doing the test, but at least I was comfortable with this accommodation.

Mental health care also failed me. I was eventually referred to two providers who were supposedly skilled with reproductive health. Neither was helpful to me. The psychiatrist brushed me off with a comment that labor couldn’t be that bad or nobody would have more than one child. She told me she would not necessarily agree with my having a C-section as a solution because surgery

## Policy Checklist

**The issue:** Trauma deeply affects health, and there is a dire need for trauma-informed care throughout medicine, particularly in reproductive and perinatal care.

### Related reading:

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- Lukasse M, Vangen S, Øian P, Schei B. Fear of childbirth, women's preference for cesarean section, and childhood abuse: a longitudinal study. *Acta Obstet Gynecol Scand.* 2011;90(1):33–40.
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her sensitive immune system. When I reached my own apartment, on the tenth floor, I turned on the air conditioning to refresh the stuffy air and then collapsed on the couch in relief, glad to be home after days of hospital discomforts and hours waiting to be discharged. Suddenly feeling grown up, I realized that this was the start of my new life. I was excited to settle in and use the baby supplies waiting for us, but I wondered what I was supposed to do now, at least for the months of leave time that I planned to stay home.

I had little support and was overwhelmed with the never-ending demands of an infant who cried incessantly and always wanted to be held. I struggled to function without adequate sleep or nutrition. Sitting in a dark room each day, blinds closed, half-naked, I alternated between trying to breast-feed a child who couldn't latch and endless pumping sessions. I felt chained to the pump and paid money that I couldn't afford to well-intentioned lactation consultants, who only made me anxious that I was already failing my child. I experienced severe depression that led me to cry for hours every week and talk about running away. This affected my ability to bond with my child and enjoy those precious months. It also strained my family tremendously and led to further isolation from my friends and community.

My child was two and a half years old before I was diagnosed with postpartum depression, despite seeing multiple providers postpartum and having tried to explain my struggles and answer screening questions honestly. One provider surmised that I was fine because I was wearing makeup and did not “look” depressed. But I was also terrified to talk about my mental health concerns in depth. I was afraid that my child would be taken away if I expressed that I was struggling to engage enough or if I wasn't “happy enough” with motherhood. Another year passed before I began to talk openly about my true experience, after reassurances from a new provider, a psychologist I met with individually each week through a local parent-training program. My opening up to her was primarily because of my own progress, as well as my frustration keeping this inside for years. She was

is also hard. When I started crying, she told me that it was a fifteen-minute appointment and that we were out of time, ushering me out the door while I struggled to gather my things and wipe my tears.

Fortunately, I met a doula who was also an experienced nurse. Before I met her, I knew that I wanted a C-section, and she seemed to be the only one who understood why and reassured me that she would advocate for this if I received pushback from my obstetrician-gynecologist. She talked me through my fears and agreed to support me; that was a turning point in my care. Although I was prepared to have to fight for a C-section, based on others' experiences I had heard, the physician who ultimately performed my surgery told me that he supported my decision if it was well informed. My doula also helped me come up with plans for terrifying possibilities, such as going into labor early, and we discussed in detail how she would advocate for me in each situation and explain my special needs to providers I might not know.

I believe I made the right decision for myself. My C-section was not “elective.” It was necessary for my overall health and well-being. Mental health is health, and the level of stress I was experiencing was not healthy for me or my baby. Suffering through an entire pregnancy of

all-consuming phobia was not in anyone's best interest. My blood pressure had been rising solely at obstetrics appointments because of the panic I was feeling.

I also knew that fear and feeling unsafe could stall labor, increasing the risk for complications, including an eventual C-section. I imagined myself bracing for every contraction and likely panicking. I trusted my intuition that surgery would be a better experience for me, and I was correct—the surgery and recovery both went very well. Furthermore, caring for a newborn while experiencing birth trauma or retraumatization seemed far more debilitating than not being able to walk well for a week after delivery. My entrance into motherhood would not be another casualty of my abuse.

## Postpartum

My daughter was born on Monday morning; I returned home from the hospital on Thursday afternoon, physically exhausted and already sleep deprived, but proud of my tiny daughter, who was dressed in a lovingly selected black and white “coming home” outfit. Returning to my apartment building was a familiar comfort, but I was still struggling to walk comfortably. I held my daughter tight against my chest on the elevator, anxious about germs that could hurt



very kind. She spent an hour with me during each session, and we had several appointments to discuss less sensitive topics first, which helped build trust. I began sharing more, little by little, and continued to open up over time, based on her reactions and reassurances.

### Trauma-Informed Perinatal Care

We are only beginning to understand how deeply trauma affects health. Beyond PTSD, relatively recent research is exploring how trauma can affect not only mental and behavioral health but also physical health, sensitivity to pain, and the development of disease. I have spent my career in public health helping populations with significant trauma, and I see myself reflected in my work.

There is a dire need for trauma-informed care throughout medicine, and particularly in reproductive and perinatal care. A key facet of this care includes patients having control and a voice in their care. Each person should have autonomy over their body and medical decisions. Professionals may be experts in their fields, but patients are the experts in their own lives and bodies. All birth involves risk, and patients have the right to decide what they accept. Perhaps because of my autism, I am honest and outspoken. I challenge social norms, and I am deeply concerned with justice and equity. Through my work, I have also learned to be an advocate. This is not the case for every pregnant patient. Some patients do not realize that they can question the provider. Some have limited English proficiency or are unfamiliar with their rights. Some patients will not or cannot speak up for many reasons, including socialization, fears of racialization, cognitive disability, and even fears of repercussions such as having their children taken away.

Perinatal screening for special needs, including trauma and mental health challenges, should be routine, beginning before pregnancy or early in pregnancy and continuing for at least one year after childbirth. Tokophobia, in particular, is not widely understood or discussed, so additional provider education on the condition is needed. I also recommend reevaluating the standard

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postpartum depression screening questionnaire to ensure validity among patients today, including neurodivergent people who may interpret questions differently. For example, my autistic brain, especially after weeks of sleep deprivation, interpreted some of the questions literally and overfocused on the wording; I struggled with questions such as, “I have looked forward with enjoyment to things” because there was nothing happening in my life to look forward to except the monotony of infant care. In addition, questions like, “I have felt scared or panicky for no good reason” can be hard to interpret because an anxious or new parent is unlikely to say this is happening “for no good reason.” For me, neurodivergence also means that I have trouble with quantitative survey questions in general: I often cannot pin down which response to select, or I see myself in different, perhaps even contradictory, responses, depending on particular situations or incidents. For these reasons, alternative screening mechanisms and formats, such as questionnaires and discussions, should be considered.

Other types of screening are also needed. Patients should be screened for perinatal conditions beyond depression, such as anxiety and obsessive-compulsive disorder. Providers should also try to identify other issues needing further attention, such as trauma history, birth trauma, or other struggles. To do this and more, providers need more time for patient visits. In addition, having a professional check in more regularly during the often-challenging postpartum time would allow further support and screening for any type of issue (physical, mental, or logistical) and would show the birthing parent that their needs should also be prioritized, as society often shifts focus to the newborn

after birth.

For me, appropriate screening would begin with providers opening the conversation through education. I would like to see health care providers routinely provide all patients with brief reading material regarding how past trauma can affect reproductive health care, health, and perinatal experiences, with patients told that the provider will discuss this topic at their next visit. This could help provide important patient education, allow time for patient reflection, and open the conversation. Patients should also receive reassurances that they can expect trauma-informed care at this facility and that their providers are trained adequately to understand and discuss these topics (only if this is true and backed by practice, of course). Examples of what trauma-informed care might look like, and what additional accommodations patients can request, would also be helpful. I recommend offering screening questions regarding trauma and giving patients the option to submit their responses in advance, bring them to the appointment, or simply have a discussion. (Of course, the patient can also decline.) Patients should always be told how the information disclosed will be used and given as much choice as possible over how their responses will be shared or documented.

Showing such sensitivity accommodates individual preferences and invites disclosure; for example, I feel uncomfortable watching a provider read my responses. Too often, when these topics are asked about at all, I have seen questions on intake paperwork such as, “Have you experienced abuse?” with “yes” and “no” responses. I remember worriedly wondering what types of follow-up questions I might receive, what I would feel pushed to disclose, and whether it would catch me off guard or upset me. Alternatively, when patients are orally asked sensitive questions, we may feel pressured to either lie or disclose something we prefer not to. If a patient declines to answer or says that they have not experienced trauma, trauma-informed care should still be implemented for everyone. For many reasons, not all patients will disclose or even recognize their own trauma histories, but basic trauma-informed care practices help everyone.

Perhaps most important, adequate follow-up should always occur. Years before my pregnancy, I remember working up the courage to answer questions about past abuse on an intake form, only to never have a follow-up discussion about it. I had taken a risk, and I was disappointed to imagine this paperwork filed away somewhere, perhaps unread. When I have received responses to my disclosures, I have also encountered inappropriate responses (including shock, discomfort, lack of understanding, or inappropriate comments), as well as empathetic responses but no follow-up.

Follow-up may include a referral to appropriate, vetted, or specialized mental health treatment, educational programs focused on birthing people with trauma, peer support, doula care, or other external resources. But that is not enough. Providers also need to discuss potential impacts of trauma with the patient and work together to accommodate them throughout the duration of care (and beyond). For example, a patient with a history of sexual assault may have difficulty breast-feeding. Better education could inform patients about possible concerns and provide the resources and support needed to prepare or quickly adapt if this occurs. Depending on the situation, follow-up could include making special effort to build trust with a

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patient, making simple changes to ensure that they feel safer during childbirth and other care, anticipating possible triggers, or discussing the patient's preferences and expectations around what they would like to happen if something unexpected or time-sensitive occurs during labor and there is not a lot of time for discussion.

A year after my child's birth, I trained as a full-spectrum doula, hoping to use the training to increase my knowledge, explore my interests, make connections, and integrate aspects of birth work into my public health career to help others like me. Doulas can support, educate, and advocate for patients. We need additional funding for doula programs, policies supporting universal doula care as a standard part of childbirth, and increased accessibility to doula care (such as via insurance coverage or state-funded programs).

Finally, we need increased funding and support designated for research, prevention, early detection, and treatment related to trauma's effects on reproductive physical and mental health. These are critical and common issues that require greater attention at all levels of the public health and health care systems.

When I look at the bright, beautiful, and affectionate child I am raising, I see even more reason that we need to work for something better. Although I hope my daughter never faces the adversities I have, I believe that we have the obligation to shift policies and systems and provide education and training that will create better care, healthier people, and stronger families and communities—for our generation, for the next generation, and for those to follow. ■

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**Angelica L. Al Janabi** is a project specialist at the University of Southern California, in Los Angeles, California. This is her personal story and is not submitted as part of her work at the University of Southern California. The opinions expressed here are hers alone and do not represent any employer or other entity. This is an open access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC-ND 4.0) license, which permits others to distribute this work provided the original work is properly cited, not altered, and not used for commercial purposes. See <https://creativecommons.org/licenses/by-nc-nd/4.0/>. To access the author's disclosures, click on the Details tab of the article online.