Prenatal Disability Diagnoses

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Maria Ault
You identify abortion and ableism as a special interest. What ethical concerns arise when prenatal screening identifies a fetus disability, and how can clinicians provide accurate, compassionate counseling without directing parents toward a predetermined decision?

Michelle Buenrostro
Yeah, I have a special interest in the discourse around children with disabilities because I had a child with terminal illness. And I feel like there are a lot of misconceptions about what life looks like with living with a disability. Selectively aborting fetuses because of a disability reinforces this cultural norm that people with disabilities have less valuable lives.

Michelle Buenrostro
I see it in the discourse all the time when people talk about how cruel it is that the fetus might grow up and need hospitalizations and surgeries. And hearing those things is really hurtful because my daughter did need hospitalizations and surgery, and that's not a bad thing. It extended her life. It allowed us to have more time with her.

Michelle Buenrostro
And needing interventions, needing treatments does not make your life any less valuable. So there's the ethical concerns that a predicted outcome is not always certain. For example, infants with trisomy thirteen and trisomy eighteen can live longer than expected, especially when there are medical interventions, and this is important to note.

Michelle Buenrostro
This happened to someone close to me, where they were told that their daughter had Down syndrome, and she was handed pre-filled abortion consent paperwork and said, "Just sign below, and we can get you in by the end of the week." And it turns out that they weren't even right in their diagnosis, and her daughter did not come out with Down syndrome. If death is inevitable for the fetus, palliative care can reduce suffering.

Michelle Buenrostro
I think there's a lot of misconceptions on what palliative care looks like. I saw it myself with my daughter. Symptoms, especially pain, are managed by healthcare professionals. We had a doctor come to the house and 24/7 nurse support. And unfortunately, there's a persistent idea that getting dismembered with a D&E procedure is more humane than palliative care.

Michelle Buenrostro
So some recommendations that we have is that there should be better education around disabilities and connections to resources that could be passed along to parents, especially things like support groups of other parents that have children with that same condition, and balanced counseling that presents a

range of possible outcomes.

Michelle Buenrostro

We do speak with parents who have had a prenatal diagnosis, and oftentimes there's an overemphasis on the negative outcomes. One of our moms said that medical staff told her about the chances that her husband would divorce her as she moved along with the pregnancy. So we're asking for a balanced approach and also greater access to perinatal hospice and palliative care and better insurance and financial support for families raising medically complex kids because, yeah, you do miss a lot of work. It is expensive, so we should really wrap our arms around these families.

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