Declining treatment during maternity care can foster tension between patients and providers

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When a pregnant person declines a recommended treatment such as prenatal testing or an epidural, tension and strife may ensue between the patient and provider, according to a new analysis by researchers at NYU Rory Meyers College of Nursing and the University of British Columbia.

"People should feel safe, respected, and engaged in their maternity care, but our findings suggest that when providers do not listen to patients, it can foster mistrust and avoidance," said P. Mimi Niles, Ph.D., MPH, CNM, assistant professor at NYU Rory Meyers College of Nursing and the lead author of the study, which is published in the journal *PLOS ONE*. "These situations deprioritize a person's autonomy and preferences."

In recent years, the World Health Organization and *The Lancet* have published frameworks about quality of care during pregnancy, birth, and the period after birth. Notably, they emphasize not just physical outcomes, but also a person's psychosocial experiences. These experiences are greatly influenced by interactions with healthcare providers—including physicians, midwives, and nurses—and factors such as respect, trust, agency, and autonomy have emerged as critical aspects of maternity care.

"Providing care is an act of respect and regard, and how we provide care is just as important as what care we provide," said Niles, a practicing midwife.

But many times, healthcare interactions fall short—or worse—and patients report dismissive, disrespectful behavior by providers. Participants in the study described not having choice in their treatment and experiencing a lack of respect when asserting their autonomy, which can hurt their self-efficacy, mental health, and willingness to engage with healthcare in the future.

These interactions are particularly fraught when a pregnant person declines or refuses care that is offered or recommended by healthcare providers. In maternity care, this may include foregoing certain prenatal testing (e.g. gestational diabetes or genetic testing), medications (e.g. epidural or other pain relief), or childbirth interventions (e.g. inducing

labor), as University of British Columbia researchers and Niles demonstrated in a recent study in *Reproductive Health*.

To better understand the experience of childbearing women, Niles and her colleagues conducted a qualitative content analysis of 1,540 written accounts from more than 1,000 women in the Canadian province British Columbia. The accounts were part of the Changing Childbirth in British Columbia study, conducted in 2014 using an online survey with open-ended questions, including those about the experience of declining care.

Four themes emerged:

- Contentious interactions: In interactions fraught with tension, participants described "fighting" for the kind of care they wanted and the right to refuse a procedure or intervention.
- Knowledge as control and power: Knowledge was viewed as a source of power both for providers, considered keepers of medical knowledge, and for patients, who found strength in knowing about the procedures or interventions they were declining.
- Morbid threats: Providers made extreme threats—for instance, "Do you want your baby to die?"—when pregnant people declined interventions. These were particularly powerful during labor and were often experienced as coercion or manipulation to accept the procedures being offered.
- Compliance as valued: Many recounted the sense that obedience to clinical recommendations—being a "good client"—was valued in their healthcare experience, but it could also suppress their questions or desire to decline care.

"Our findings demonstrate the complex experiences that patients have when declining care in a traditional, gendered healthcare system," said Niles. "As providers, learning how to support our patients' autonomy and

decision-making process means that we must understand how to interact and continue to provide care when what we suggest is not in alignment with what the patient wants."

The researchers write that supporting patient autonomy requires bringing their values into care planning—not as an event, but as an ongoing process reflected in the idea of person-centered care.

While the study focused on childbearing people in British Columbia, the researchers note that their findings are part of a global phenomenon and likely translate to other populations.

"In the U.S., one in six people report being mistreated during childbirth, which includes feeling threatened or coerced in their care. Among women of color, this increases to one in three," added Niles, citing the Giving Voice to Mothers study. "Healthcare exists in relationships, not just as a service. We're not auto mechanics. The same things we value in our relationships—trust, autonomy, respect—are what should be valued and supported by providers and the healthcare system."

More information: P. Mimi Niles et al, "I fought my entire way": Experiences of declining maternity care services in British Columbia, *PLOS ONE* (2021). DOI: 10.1371/journal.pone.0252645

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