

Researchers provide insights on families' experiences with fetal anomalies

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Learning during pregnancy that something might be wrong with the fetus is a life-changing event for expectant parents. Researchers at UMass Chan Medical School recently published an [integrative review](#) on fetal anomaly and family experiences in the *Journal of Perinatal & Neonatal Nursing* to help nurses and other health care providers understand the

evidence about what emotions parents feel, their coping strategies, and what information and support are needed after they receive this unexpected diagnosis.

People receive [bad news](#) in a number of ways, said co-author Rosemary Theroux, Ph.D.'00, recently retired associate professor of nursing. "But somehow, the impact of learning that your baby that you hoped and dreamed would be normal—your expectations have basically been shattered."

Co-author Cathy Violette, DNP'18, assistant professor of obstetrics & gynecology and nursing, said the paper, which grew out of her scholarly project when she was pursuing her Doctor of Nursing practice from the Tan Chingfen Graduate School of Nursing, mentored by Dr. Theroux, was also about how best to educate and support multiple disciplines of health professionals who work with expectant parents in crisis.

The authors synthesized qualitative research from 16 peer-reviewed articles that met their study's inclusion criteria. They focused only on people who decided to continue their pregnancies after learning of an anomaly because the decision to terminate brought in a wider set of issues.

A sense of profound isolation, uncertainty, grief and lack of information were common experiences, according to the researchers. Health care systems did not always offer a supportive response.

"Providers make their own decisions about how a woman should respond to this pregnancy or future pregnancies," said Dr. Violette. "And so, our work tries to focus on how to help those professionals from a multidisciplinary point of view, to be able to impact that care."

Theroux, noting the importance of working as a team, said, "You might

have a [social worker](#), you might have a surgeon, you might have the NICU doctor. The family is having all these specialists coming and going and the nurse is the one who can pull everything together."

The authors said they were shocked at how some patients in the articles they reviewed reported being treated.

"One of the articles still rings in my head about the mom's body becoming public property," said Violette. "When your time with your baby is limited, you really don't have to share all that. So, helping mom to figure out how to safeguard her emotions was a really important intervention that we talked about, to figure out how to deflect a question that makes you feel sad."

Theroux and Violette created a table summarizing clinical interventions around sharing fetal anomaly diagnosis and information with parents and family; promoting parental attachment and family participation; planning adequate time at visits; care coordination needs; interprofessional communication; discussion of setting for delivery; and enhancing [coping strategies](#).

Theroux said the article, part of an ongoing focus of research, integrates the role of developing evidence with the role of turning evidence into interventions. "The big focus in nursing today is evidence-based care," she said. "We feel there is a crossover between the roles, and we hope that we can prevent some of these unhelpful care experiences."

More information: Rosemary Theroux et al, Fetal Anomaly: Family Experiences and Preferences for Care, *Journal of Perinatal & Neonatal Nursing* (2023). [DOI: 10.1097/JPN.0000000000000752](https://doi.org/10.1097/JPN.0000000000000752)

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