Should I go on or terminate my pregnancy? How do women engage in the decision-making process in case of severe fetal anomaly?

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Objective

To identify the factors involved in women's decision-making process for pregnancies complicated by life-threatened fetal anomaly. To provide a better understanding of women's maternal profile and intention regarding pregnancy, with the development of categories leading to a better comprehension of their experience. These categories will also provide a framework for future research.

Methods

Qualitative study based on in-depth interviews of women facing a diagnosis of life-threatening fetal anomaly. Women were recruited at CHU Ste-Justine, Université de Montréal, until data saturation. Interviews were taped and verbatim. An inductive thematic analysis was done with the assistance of NVivo software to explore emerging themes related to decision-making process, based on rooted theory approach.

Results

Ten interviews were analyzed. Three women planned for active care after birth, two for comfort care and five terminated pregnancy. Two type of maternal profiles were described: actualized maternity and maternity project. No association between the maternal profile and the intention regarding pregnancy could be demonstrated. Thematic analysis shows that the medical explanations theme is major. Certain themes are more specific for a profile or an intention; emotional themes are more frequent in women with actualized maternity and rational themes for maternity project.

Conclusion

Decision-making process in women confronted with life-threatening fetal anomaly during pregnancy is influenced by multiple personal and socio-cultural factors, besides their child's diagnosis. Themes identified in this study interact in a dynamic way for these women. Comprehension of this dynamic could help clinicians to explore different themes with patients in order to offer personalized care and decisional guidance that correspond to their needs.