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Women's experiences and reactions when a fetal malformation is detected by ultrasound examination

AKADEMISK AVHANDLING

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ABSTRACT

Background: Second trimester ultrasound examination among pregnant women in Sweden is almost universal. The detection of a fetal malformation on ultrasound puts health care providers and pregnant women in a difficult and precarious situation. What information and how it is communicated is crucial to women's decision-making about continuing or terminating at pregnancy. The main aim of this thesis was to describe and analyze women's experiences and reactions following the detection of a fetal malformation on an ultrasound scan. **Methods:** Two semi-structured in-depth interviews were performed, with women informed of a fetal malformation following an ultrasound scan. A total of 27 women took part in the first round of interviews: women continuing their pregnancy were interviewed, either in gestational week 30 or three weeks after the diagnosis; those terminating their pregnancy were interviewed two to four weeks after termination (Paper I). A second interview with 11 women who terminated their pregnancy was conducted six months after termination (Paper III). Two questionnaires were also administered. The first, answered by 99 women (Paper II) and comprising 22 study-specific questions along with emotional well-being and socio-demographics variables and medical and obstetric history, was conducted at the same time as the first stage of interviews. The other questionnaire, answered by 56 women incorporated common self-report instruments and was performed three times: first in gestational week 30, and then two respectively six months postpartum (Paper IV). Qualitative data were analyzed through content analysis, and quantitative data were analyzed through descriptive statistics. **Results:** The timing, duration, and manner of women's initial counseling and ongoing support were shown to be important in the interaction between women and caregivers. Positive interactions improved the women's ability to understand the information and fostered feelings of trust and safety, which in turn reduced their anxiety. Most of the women who expected a baby with an abnormality expressed their need for information on several occasions to help them make this difficult decision. They also wished for information from different specialists and continuity of care. These needs were even stronger in women who chose to terminate their pregnancy. We found women continuing their pregnancy to be at high risk of depressive symptoms, major worries, and high anxiety levels, both in mid-pregnancy, and at two months and one year postpartum. Despite these findings, the results of the maternal-fetal attachment scale for women who continued their pregnancy with a fetus diagnosed with a malformation indicated a high level of attachment. **Conclusions and Clinical Implications:** Effective communication, empathy and compassion, and consistent follow-up routines are important to ensure good treatment and care of this group of women. Taking these results into account may improve caregivers' ability to counsel these vulnerable patients and to ensure that their needs are properly met.

Keywords: Prenatal diagnosis; ultrasound examination; information; decision-making; prenatal depression; postnatal depression; anxiety; attachment; care