

The Lived Experience of Pregnant Saudi Women Carrying a Fetus with Structural Abnormalities

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Abstract : Fetal abnormalities are categorized as a structural abnormality, non-structural abnormality, or a combination of both. Fetal structural abnormalities (FSA) include, but are not limited to, Down syndrome, congenital diaphragmatic hernia, and cleft lip and palate. These abnormalities can be detected in the first weeks of pregnancy, which is almost around 9 - 20 weeks gestational. Etiological factors for FSA are unknown; however, transmitted genetic risk can be one of these factors. Consanguineous marriage often referred to as inbreeding, represents a significant risk factor for FSA due to the increased likelihood of deleterious genetic traits shared by both biological parents. In a country such as the Kingdom of Saudi Arabia (KSA), consanguineous marriage is high, which creates a significant risk of children being born with congenital abnormalities. Historically, the practice of consanguinity occurred commonly among European royalty. For example, Great Britain's Queen Victoria married her German first cousin, Prince Albert of Coburg. Although a distant blood relationship, the United Kingdom's Queen Elizabeth II married her cousin, Prince Philip of Greece and Denmark—both of them direct descendants of Queen Victoria. In Middle Eastern countries, a high incidence of consanguineous unions still exists, including in the KSA. Previous studies indicated that a significant gap exists in understanding the lived experiences of Saudi women dealing with an FSA-complicated pregnancy. Eleven participants were interviewed using a semi-structured interview format for this qualitative phenomenological study investigating the lived experiences of pregnant Saudi women carrying a child with FSA. This study explored the gaps in current literature regarding the lived experiences of pregnant Saudi women whose pregnancies were complicated by FSA. In addition, the researcher acquired knowledge about the available support and resources as well as the Saudi cultural perspective on FSA. This research explored the lived experiences of pregnant Saudi women utilizing Giorgi's (2009) approach to data collection and data management. Findings for this study cover five major themes: (1) initial maternal reaction to the FSA diagnosis per ultrasound screening; (2) strengthening of the maternal relationship with God; (3) maternal concern for their child's future; (4) feeling supported by their loved ones; and (5) lack of healthcare provider support and guidance. Future research in the KSA is needed to explore the network support for these mothers. This study recommended further clinical nursing research, nursing education, clinical practice, and healthcare policy/procedures to provide opportunities for improvement in nursing care and increase awareness in KSA society.

Keywords : fetal structural abnormalities, psychological distress, health provider, health care

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