

Ro52 autoantibody-positive women's experience of being pregnant and giving birth to a child with congenital heart block

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Introduction: Congenital heart block may develop in the fetus of women with Ro/SSA autoantibodies. The aim of this study was to investigate how women expecting a child with congenital heart block (CHB) experienced their pregnancy and postpartum period.

Methods: Women pregnant with a child with CHB in Sweden during 2000-2009 (n=21) were identified in a population-based manner and individually interviewed post pregnancy using a semi-structured interview guide. The interviews were audio taped, transcribed verbatim and analyzed by qualitative content analysis.

Results: Three categories emerged from the responses; learning, suspense and facing.

The category learning contained both learning about the child's heart block, but frequently (16/21) also of autoantibody-positivity and a potential rheumatic diagnosis in the mother. The medical procedures and information differed considerably depending on area of residence and whom was encountered in the health care system. In many cases ignorance about this rare condition caused a delay in treatment and surveillance. The category suspense described the women's struggle to cope with the feeling of guilt and that the child had a serious heart condition and might not survive the pregnancy. The category facing included the postpartum period, leaving the hospital and adjusting to everyday life. It also describes contacts with child care welfare and relatives. Most of the women had tended to put their pregnancies "on hold", and some described that they needed prolonged time to attach to their newborn child.

Conclusions: Increased awareness and knowledge of CHB are needed to provide adequate and secure care. Offering psychological support by a health care professional to the women and families to give them tools to handle the situation with a potential rheumatic diagnosis for the mother and to facilitate the early attachment to the child should be considered.