

A questionnaire study of Ro/ SSA autoantibody mediated congenital heart block indicate need for increased information, support and highly specialized medical care

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Introduction

Congenital heart block (CHB) may develop in the fetus of women with Ro/SSA autoantibodies. The aim of this population based study was to generate quantitative data on findings from a previous hypothesis-generating interview study investigating how women expecting a child with CHB experienced their pregnancy and post-partum period.

Methods

Women with Ro/SSA autoantibodies giving birth to a child with CHB in Sweden were identified in a population-based manner (n=88) and offered to participate in the study. A questionnaire was constructed based on findings from previous individual interviews in a subgroup of the women. The questionnaire response frequency was 89% (n=78).

Results

More than half of the women (57%) did not think that information on CHB obtained from health care personnel was sufficient, and close to 1/3 did not understand the information given to them. Most women attended both the regular maternity health care program and visited at least one specialist for supervision of the pregnancy, but commonly more. However, half of the women did not know who had the medical responsibility for them or for the child (50% and 46%, respectively). Further, the medical care differed substantially depending on the experience of the caregiver of the situation. The majority of the women (60%) expressed that they felt afraid when thinking about the child, and 48% felt responsible for the child developing CHB. The women were supported during the pregnancy and postpartum period by several persons; both relatives and caregivers, but 1/3 did not feel that it was enough and 45% wanted additional support. Despite this and the rareness and seriousness of the condition only 18% of the mothers were offered professional psychological support.

Conclusions

Increased awareness and knowledge of autoantibody-mediated CHB are needed to provide adequate care. Information should be provided both to patients and professional care givers. Referral to specialized centers and offering psychological support could increase the quality of medical care and release the families from unnecessary stress and feeling of guilt.