Erfarenheter av stöd bland föräldrar till barn med medfödda hjärtfel

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Akademisk avhandling

som med vederbörligt tillstånd av Rektor vid Umeå universitet för avläggande av medicine doktorsexamen framläggs till offentligt förvar i Hörsal B, 9 tr, Norrlands universitetssjukhus, fredagen den 12 december, kl. 13:00.
Avhandlingen kommer att förvaras på svenska.

Fakultetsopponent: Professor Emerita, Elisabeth Hall,
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Abstract

**Background.** Parents of children with congenital heart defect (CHD) have higher demands for psychosocial health compared to parents of children with other illnesses and healthy children, pointing to a need for increased support for these parents.

**Aim.** The overall aim of this thesis is to illuminate parents’ experiences of support when they have a child with CHD and also to translate and test the psychometric properties of the instrument “Iceland – Family Perceived Support Questionnaire” and to report estimations of perceived support to families from nurses.

**Methods.** The thesis consists of four studies. In three of the studies (I, II, III), narrative interviews with parents were interpreted using a phenomenological-hermeneutic method. In the fourth study (IV), a translation and psychometric testing of the instrument “Iceland - Family perceived support questionnaire” (ICE-FPSQ) in the Swedish context was performed. Furthermore, the intention was to describe how a sample of parents of children with CHD estimated perceived family support from nurses.

**Results.** The phenomenon of support as disclosed by the parents in this thesis was “support as creating in a spirit of community”. The findings from study I showed that meanings of the lived experience of support for the parents of adolescents with CHD was a need to be supported so that they, in turn, could be supportive to each other within the family and also to persons in their adolescent’s surroundings. Study II showed that the meanings of the lived experience of support for the mothers of young children with CHD was to be supported in order to be able to handle their own concerns and family life. Study III revealed the meanings of the lived experience of support among fathers of young children with CHD, was to be supported by sharing relationships within the family and being invited to be involved in the care of their child. The fourth study reported that the Swedish version of the instrument ICE-FPSQ was valid and reliable in the Swedish context. The results from the parents’ estimations of support from nurses showed that parents scored a low level of perceived cognitive and emotional support to the family from nurses.

**Conclusion.** The results of the thesis (I, II, III) shows that meanings of the lived experience of support for parents pointing towards family-centered care in which the whole family is included in the care as a unit. The instrument ICE-FPSQ, which is based on the theory of family-centered care (IV) shown acceptable psychometric properties. The findings illustrate that parents estimated low levels of support to families from nurses. This indicates that parents in this sample might have perceived limitations in family-centered care.

**Keywords**
congenital heart defects, family-centered care, ICE-FPSQ, narrative interviews, parents, phenomenological-hermeneutic method, pediatric nursing, psychometric properties, support