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PERCEIVED BURDEN, LIVED EXPERIENCES AND EXPERIENCES OF LEARNING PROCESSES AND ILLNESS MANAGEMENT in parents of children with severe or moderate haemophilia

Akademisk avhandling
Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademin, Göteborgs universitet kommer att offentligen försvaras i Hjärtats aula, Vita Stråket 12, Sahlgrenska universitetssjukhus, Göteborg, den 15 februari 2019, klockan 13:00.

Linda Myrin Westesson

Fakultetsopponent: Docent Agneta Anderzén-Carlsson, institutionen för hälsovetenskaper, Örebro universitet, Örebro, Sverige

Avhandlingen baseras på följande delarbeten

I. Myrin Westesson L., Baghaei F. and Friberg F. (2013). The experience of being a female carrier of haemophilia and the mother of a haemophilic child. *Haemophilia*, 19(2): 219–224.

II. Myrin Westesson, L., Sparud-Lundin, C., Wallengren, C. and Baghaei, F. (2015). A tortuous route to a capable fatherhood: the experience of being a father to a child with severe haemophilia. *Haemophilia*, 21(6): 799–805.

III. Myrin Westesson, L., Wallengren, C., Baghaei, F. and Sparud-Lundin, C. (2018). Reaching Independence Through Forced Learning - Learning Processes and Illness Management in Parents of Children Affected by Hemophilia. *Qualitative Health Research*, 28(14): 2142 –2154.

IV. Myrin Westesson, L., Sparud-Lundin, C., Baghaei, F., Khair, K., von Mackensen, S., Acuña Mora, M. and Wallengren, C. Burden on parents of children with severe or moderate hemophilia - the impact of sociodemographic aspects and the child's medical condition on perceived parental burden. *Submitted.*

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Abstract

Haemophilia is a complex condition to manage, especially for parents of newly diagnosed children, and the illness affects the whole family. The parents are deeply involved in the child’s treatment, as they frequently have to administer intravenous injections at home.

The overall aim was to investigate perceived burden, lived experiences and to explore experiences of learning processes and illness management in parents of children with severe or moderate haemophilia.

In studies I-III, a qualitative approach was motivated to describe experiences of parenting a child with haemophilia. Study III employed a longitudinal design to explore the learning process, while study IV employed a quantitative method with a cross-sectional survey.

The results reveal that the mothers often needed to become reconciled both with the fact of the child’s illness and their own carriership. However, having a child with severe or moderate haemophilia was life changing for both fathers and mothers. The parents were forced into a situation where they had to learn about and manage their child’s illness in daily life. Thus, a desire to become independent of health care professionals in this respect emerged as a key incentive for learning. How this learning process developed and how long it took depended on different factors. For example, parents of children with past or present inhibitors reported higher perceived burden than parents of children without a history of inhibitors. Nevertheless, independently managing home treatment was essential for the parents to feel in control of their life-world again.

One conclusion is that female carriers need more knowledge about their carriership and would benefit from counselling before starting a family. One suggestion is that acceptance of the child’s illness and reconciliation with the new complex family situation could be promoted with person-centred care. Furthermore, the findings underline that health care professionals need to be aware of an increased burden on parents of young children and particularly the burden on parents of young children with inhibitors.

Keywords: Haemophilia, child, parent, family, learning, experiences, disease/illness burden

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