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## Mothers' experiences on children with Haemophilia

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**Introduction:** Haemophilia is an inherited bleeding disorder. It can lead to spontaneous bleeding as well as bleeding longer after an injury or a surgery. Haemophilia causes adverse physical and social effects to children who have the disease condition, as well as their mothers. Understanding the experiences of mothers who have haemophilic children can be useful to solve their problems and minimize their negative experiences. Therefore, the purpose of this study was to identify mothers' experiences on children with haemophilia.

**Methodology:** The phenomenological study was conducted from January to April 2017, at Haemophilia Unit, in Lady Ridgway Hospital for children, Sri Lanka. Fifteen mothers who had children with haemophilia were purposively recruited and in depth interviews were conducted to collect the data. Interview theme list was focused on exploring psychological, social and physical experiences of the mothers with haemophilic children. Ethical approval was obtained from the Ethics Review Committee, Lady Ridgway Hospital for Children, Sri Lanka. Data was analysed by thematic analysis.

**Results:** Emotional sufferings, interruptions of life events and interaction with body responses were emerged from the data. Worry, shock, fear, and family problems were highlighted as emotional sufferings. Mothers generally faced number of interruptions with their life events such as financial problems, daily activities, schooling and job adjustments. Cancellations and postponement of family and social plans were mostly highlighted. Fight with fatigue, insomnia and overall poor health conditions were also identified as interactions with body responses.

**Discussion:** Worry, fear, shock and family problems were reported as the emotional experiences same as the findings of Westesson, Baghaei and Friberg (2013), which may lead to psychological distresses. These were due to the thinking of the future of child and having a guilty feeling towards the genetic transmission. Further, mothers faced negative social experiences that were influenced in their daily activities, schooling and job adjustment as they need more time to spend with their children's disease management. The pressure on family life also has added strain on the mother's relationship

with father. The study findings further revealed that fatigue, insomnia, poor health conditions were common physical experiences of mothers with haemophilic children. The comparable findings were highlighted by Williams and Chapman (2011).

**Conclusion:** Mothers of haemophilic children have been frequently facing with different type of life experiences. Among these emotional experiences such as worries, fear, shock, family problems; social experiences such as interruption to daily activities, job associated work and physical experiences such as fatigue, insomnia were common. Further studies should be extended to larger population including other districts, to clearly identify the experiences of mothers with haemophilic children in Sri Lanka.

The study recommends guidance and counselling services to parents with haemophilia children.

**Key words:** children, haemophilia, mothers' experiences, phenomenology

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