HERO – an international initiative exploring unmet psychosocial needs in haemophilia: results from a qualitative survey of 150 subjects in 7 countries

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Introduction

The HERO (Haemophilia Experiences, Results and Opportunities) initiative is an international project investigating psychosocial issues in haemophilia from the perspective of patients, caregivers and healthcare professionals (HCPs). The objective of HERO is to build a richer picture of life with haemophilia, seen from the perspective of people with haemophilia, their families/caregivers and their healthcare providers. It is our goal that their voices are heard to inform this area.

• An initial HERO International Advisory Board meeting was held in Montreal, Canada, in September 2009.
• The Advisory Board discussed and confirmed the value of a programme to investigate psychosocial needs in haemophilia.

The survey population

• Of the 31 caregivers, 30 were parents of children with haemophilia (24 mothers and 6 fathers). One of the caregivers was a nurse.
• Interviews were conducted with patients, caregivers and HCPs, generally taking place in their homes or offices. In some instances, they were conducted at the clinic or hospital.
• Mood boards were also used, and interviewees were asked to select images they associated with patients/caregivers of haemophilia.
• Interviews were conducted in the local language and subsequently translated into English.
• Patients and caregivers were also requested to complete an auto-ethnography journal.

Methods

Survey

• The survey included semi-structured, face-to-face, 60-minute interviews performed by a specialist healthcare research agency – Kantar Health.
• A range of issues relating to living and coping with haemophilia during different phases of patient’s lives was discussed.
• Mood boards were also used, and interviewees were asked to select images they associated with patients/caregivers of haemophilia.
• Interviews were conducted with patients, caregivers and HCPs, generally taking place in the homes of patients/caregivers and the hospital/clinics in which the HCPs were based.
• Interviews, in different countries (see below) were conducted in the local language and subsequently translated into English.
• Patients and caregivers were also requested to complete an auto-ethnography journal.

Survey population

• The survey involved 150 subjects in seven countries – Algeria, Brazil, France, Germany, Italy, the United Kingdom and the United States (Figure 1).

Results

• Patients and caregivers were recruited through local patient networks with the help of nurses or physicians, who informed subjects about the survey and asked them if they would like to take part.
• As quotes were set for patients with haemophilia B and/or inhibitor, these individuals were excluded in the sample.
• HCQ – physicians, nurses, psychologists, physiotherapists and social workers – were recruited from Haemophilia Treatment Centres located by the World Federation of Haemophilia.

Analysis

• Based on the information obtained, a thematic analysis was used to identify key issues raised by the interviewees, together with that opinions relating to serious matters.
• Preliminary results are given here.
• More in-depth analysis, relating the themes, is currently ongoing.

Conclusions

• The survey has highlighted areas suitable for further investigation.
• The survey identified a need to provide information in other languages.
• Further study is needed to develop methods for coping with haemophilia.

• A subsequent questionnaire-based study in a larger population will quantify psychosocial issues from the perspective of patients and caregivers, and investigate any relevant clustering.

Figure 1. The scope of the qualitative survey

a) Children with haemophilia

• The first 3 years of a child’s life can be particularly difficult for parents, who may still be learning about haemophilia and can feel overwhelmed by treatment demands.
• As a child learns to walk, there is a high risk of bleeding events and frequent visits to HCPs may be required.
• The needs of a child with haemophilia can cause a strain on the whole family. If parents feel inadequate at times and feel overwhelmed, it may give rise to a sense of helplessness in the future.
• Children with haemophilia may experience difficulties in isolation at school.
• They may be bullied by other children because of arthropathy/bleeding episodes, or be selected by 33% of parents.
• Some children may feel self-conscious at school.
• Children with haemophilia may be disabled to partake in the same activities as other children, which may contribute to a feeling of isolation.
• Early contact with other families in support networks may be appropriate.
• Other related areas requiring attention include feeling isolated, finding a job, becoming economically independent and creating a social life for the future
• Adolescents in the first 3 years of their life

b) Childhood and adolescence

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• A subsequent questionnaire-based study in a larger population will quantify psychosocial issues from the perspective of patients and caregivers, and investigate any relevant clustering.

Reference


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