

Educational needs of parents of hemophiliac children: An approach to comprehensive care

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Abstract

In Chile, hemophilia was incorporated into the System of Explicit Health Guarantees (GES), which ensures access to treatment and financial protection for these patients. To support patients and their families, educational programs have been proposed that focus on managing possible complications of the pathology, first aid, and prophylaxis, however, there are no educational instances focused on the needs of the patients.

Objective: To know the educational needs of parents with hemophilic children and adolescents regarding contents, people, place, methodology, and stage of the illness.

Subjects and Method: Descriptive qualitative study of 15 parents with hemophilic children in outpatient care. For the data collection, we used a semi-structured interview with five open questions, aimed at the search for educational needs such as what (contents), how (methodology), when (moment), who (person), and where (place) is education needed. For data analysis, we used the Berelson's content analysis technique. To guarantee the scientific validity of the qualitative results, the methodological rigor criteria of Guba and Lincoln were used. **Results:** The most frequent educational needs reported by parents include content such as venipuncture training, injury prevention, pathophysiological aspects of the disease, among others; with methodology developed in group workshops and guided by a peer; in a comfortable and familiar place; in three stages of the disease's development (diagnosis, bleeding events, and development of autonomous activities), and provided by professionals and peers. **Conclusion.** Knowledge of educational needs is the basis for the creation of an educational program that guides the comprehensive care of hemophilic children and their parents. © 2021, Sociedad Chilena de Pediatría. All rights reserved.

Author keywords

Health Education; Hemophilia A; Hemophilia B; Self-Management