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ORIGINAL ARTICLE

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

Necesidades educativas de padres de niños hemofílicos: Una aproximación hacia el cuidado integral

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What do we know about the subject matter of this study?

Scientific evidence reinforces that countries that have implemented educational interventions for parents of hemophiliac children and adolescents, present a significant improvement in the quality of life and care of parents for their children.

What does this study contribute to what is already known?

This study provides information on the educational needs of parents of hemophiliac children and adolescents, regarding content, people, place, methodology, and time of the disease.

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, were 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, blee-

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ding 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.

Introduction

In Chile, hemophilia has been recognized as a public health problem due to the high cost of its treatment and the impact of its complications on the quality of life of those affected. Thus, hemophilia was incorporated into the first series of pathologies of the Explicit Health Guarantees (GES) system, providing patients with the guarantees to access both timely diagnosis and treatment and the necessary financial protection to cope with the disease[1].

Like any chronic disease, hemophilia requires education on the topic of patients and their family group in order to encourage adequate management of the disease, adapt to changes in lifestyle, and finally promote self-confidence in the family group to ensure the comprehensive care of children with hemophilia[2]. Scientific evidence reinforces the need to educate parents of children with this health condition. Countries that have implemented educational interventions have shown a significant improvement in the management of bleeding episodes by parents[3,4].

In Chile, educational programs have been designed that aim at the management of possible complications of the pathology, first aid for minor trauma, and the importance of prophylaxis[5], but there are no educational instances that address the educational needs of the parents of hemophiliac children. The objective of this study was to know the educational needs of parents of hemophiliac children and adolescents, regarding contents, people, place, methodology, and time of the disease.

Subjects and Method

Qualitative descriptive study[6]. We carried out a sampling of 15 parents (father and/or mother) of hemophiliac children under 18 years of age who were under follow-up in a specialty polyclinic in Santiago, Chile, achieving saturation of the results.

All fathers and/or mothers of children under 18 years of age with severe, moderate, or mild hemophilia who were under follow-up at the hemostasis polyclinic of the *Centro de Especialidades de Santiago* were invited to participate. Those patients with acute complications such as hemarthrosis, intracerebral hemorrhage, and muscle hematomas at the time of data collection were excluded, since the exacerbation of the health condition may cause biases in the information obtained, as the perceived needs tend to focus on the current situation.

Data collection was carried out between December 2017 and May 2018. The project researcher contacted by telephone potential participants to invite them to participate in the study. For data collection, a semi-structured interview was used with five open-ended questions that served as a guide to delve deeper into the educational needs of parents of children with hemophilia. The questions are aimed at identifying the educational needs where research is carried out by answering the following five questions: what (Content), how (Methodology), when (Time), who (Person) and where (Place) is it necessary to educate (table 1).

The interview guideline was reviewed by a hematologist, a clinical nurse, a nurse-midwife specialist in qualitative methodology, and a mother of a child with hemophilia to ensure both the understanding of the question guide and that all the aspects mentioned in table 1 were present. Each of the interviews with the participants in this study lasted 30 minutes on average and were recorded and later transcribed verbatim.

For data analysis, Berelson's content analysis technique was used, with the initial objective of interpreting the phenomenon under study[7]. Therefore, the interview transcript was selected as the analysis unit, interpreting the accounts of the parents of hemophiliac children based on predefined categories related to the educational needs (content, people, place, methodology, and at what time of the disease) that allowed us to answer the general dimensions established in the research objectives.

Two researchers independently analyzed each of the interviews. First, the interviews were read without interpreting them; then in a second reading, they identified the predefined dimensions; and finally, each of the interviews was read a third time to verify the identified dimensions. The process ended when achieving data saturation, defined as the point at which additional interviews did not provide new elements to respond to the stated objectives[7]. After this, each researcher proposed her/his analysis, and then, in a team meeting, they reached a consensus on the results found. The results were given back to the participants to confirm the accuracy of the data analysis, achieving concordance in the dimensions identified by the research team and the participants.

To ensure the scientific validity of the qualitative results, the methodological rigor criteria of Guba and Lincoln[8] were used. We achieved Credibility after returning the categories and dimensions to the participants, who felt reflected with the findings; Reliability after the consensus meetings and the use of descriptive narratives of the participants' accounts; Confirmability through a detailed description of the research in a report, and Transferability through the validation of the findings by experts.

To ensure compliance with the ethical aspects of this investigation, we followed the seven ethical requirements of Emmanuel et al[9]. This study was approved by the Scientific-Ethical Evaluation Committee of the Universidad Andrés Bello and the Faculty of Medicine of the Pontifical Catholic University of Chile. Each participant signed the informed consent form before starting the study.

Table 1. Semi-structured interview guide

What?	What aspects of hemophilia do you consider necessary to know in order to provide comprehensive care for your child at home?
How?	If the health system provides specific education to parents about the care of a hemophiliac child, what methodology is the most appropriate for you to carry out such education?
When?	In your experience, at what times have you felt it necessary to receive accurate education about your child's health condition?
Person	Who is the best person for you to educate parents on the comprehensive care of a hemophiliac child?
Place	Where would you feel comfortable to get education related to the care required for your child's health condition?

Results

Regarding the study sample, 9 mothers and 6 fathers of children with hemophilia under 18 years of age were interviewed; all of them had university and/or technical studies. Concerning the characteristics of their children's disease, most of them had hemophilia type A/severe (n = 11), followed by B/severe (n = 2), and B/moderate (n = 2). Most report having low bleeding (n = 9), followed by moderate (n = 5), and the rest low; 9 of them are on prophylactic treatment, while the rest are not or if necessary.

Table 2 summarizes the educational needs expressed by parents of children with hemophilia. The following is a detail of the contents, methodology, time, people, and place that the parents mentioned as fundamental for providing comprehensive care to their children at home.

Educational needs in relation to the content

Preparation and administration of the deficient factor

For parents of hemophiliac children, it is essential to be educated about the intravenous administration of the clotting factor according to the deficiency, Factor VIII for hemophilia A and Factor IX for hemophilia B. Some of the accounts evidencing this content are presented below.

"...all mothers should know how to puncture their children, intravenous injections are complex and frightening, but this also creates an autonomy of the mothers with the children, autonomy from the hospital, from the clinic... I think it's essential that mothers know how to venipuncture their children". (MOM01: L150 - 166)

Measures to prevent injuries or bleeding

Parents identify them as the activities or precautions that they should learn to take, or that some of them have taken, to reduce the risk of producing injuries that can cause acute or spontaneous bleeding, especially joint and muscle bleeding in their hemophiliac children, which include protecting the joints, protecting furniture, use of helmets, among others.

"... I'd like someone to explain to me the precautions so that the child at home doesn't have any bleeding event, because for example something can happen to him in the bedroom and you don't realize it until he starts to... he starts to have problems..." (DAD04: L64 -72)

Actions required in case of blows or falls

Immediate or stepped actions that parents should perform in the event of a blow or fall that may cause an internal or external bleeding event in their hemophiliac child, such as applying ice or administering the factor as soon as possible.

"...What are the first reactions that one should have [after a fall], first ice to stop the bleeding, then heat, one could say, to dilate the coagulation..." (DAD06: L63 - 65)

Understanding of pathophysiological aspects of the disease

Information that parents of children with hemophilia need to know and understand about what he-

Table 2. Topics identified on the educational needs of parents of children with hemophilia

Education needs	
Contents (what)	• Preparation and administration of the deficient factor. • Actions to prevent injuries or bleeding. • Actions to be taken in the event of blows or falls. • Pathophysiological aspects of the disease
Methodology (how)	• Didactic development • Group workshops
Moments (when)	• Diagnosis • Beginning of autonomous activities
Person (who)	• Person with experience of living with hemophilia • Health professional
Place (where)	• Comfortable and familiar place

mophilia and clotting are, how it is treated, what the consequences are, and the serious injuries that can occur to a child with this health condition.

"...we needed to know what we're on... what was hemophilia... we needed to know what the disease was about, what it meant, how hemophilia could affect in the future... what it meant that children bleed, what was a prophylaxis, what was it that they had an event, like these big things were what we needed to know..." (MOM07: L176 - 181, L183 - 185)

Educational needs in relation to methodology

This refers to how parents of hemophiliac children consider that it would be the best way to develop educational content, the method that would be most useful for them to receive the content they mention as necessary to provide comprehensive care at home.

Didactic development

It refers to receiving the contents through examples, the transfer of similar experiences, sessions where parents perform injury prevention activities, prepare the medication, practice venous puncture, and administration of lyophilized factor.

"...then teach more in practice, more with examples so that they can make them learn... teach them to puncture, that they learn to puncture the children... that they learn to do the whole thing, their healings so that they themselves can be more independent from the hospital". (MOM01: L369 - 373)

Group talks or workshops

Group sessions that allow sharing the experience of living with a hemophiliac child, where mothers, fathers, or people who have experience with hemophilia can teach and pass on significant knowledge at each stage of the child's life.

"I'd like there to be a group, that we're a group of parents of children with hemophilia, that we could educate together... maybe, more than someone educating you, we'd have to educate each other" (MOM03: L82 - 85).

Educational needs about the time of the disease

Diagnosis

It is the moment when parents were informed of their child's hemophilia diagnosis, or in the case of mothers who are aware of their carrier status, it is the moment of their child's birth.

"When I first found out... I'd have loved it if at that moment someone would have picked us up... instead of us looking for this video, picked us up, sat us down, and talked to us..." (MOM07: L296 - 300)

Bleeding events

Instances in the life of hemophiliac children when they have presented acute episodes of spontaneous bleeding such as hemarthrosis or muscle hematomas, which is frequent in severe conditions, or produced by a blow or fall in severe, moderate, or mild conditions.

"When he has had blows, when events (of bleeding) have happened to him, one doesn't know how to react, one becomes overwhelmed, it is in these moments when my son has had events that it is like I have needed..." (DAD05: L64 - 69)

Start of autonomous activities

When children start to carry out activities on their own and to interact with other people and in places other than their home, which makes them more exposed to traumas of varying severity.

"...one of the most difficult stages was when they learned to walk... it was the most complex, because that's when they want to jump into life... because you have to crouch down with them protecting them... despite the furniture was soft, it didn't have things that could hit them... it was the most difficult stage and when they both had bleeding problems" (MOM01: L61 - 71).

Educational needs about the person

A person who has experience living with the condition.

Parents emphasize the importance of having a peer involved in the education, as they feel that experiencing hemophilia up close allows them to better pass on the knowledge to others.

"The parents.... other parents or hemophiliacs adult and well obviously guided by professional people... because I think they have learned their limitations... well I think that experience is always the wisest of all" (MOM04: L396 - 404).

Health professional

Parents emphasize the role of both the medical and nursing professional in guiding, training, and educating on theoretical and skill aspects such as venipuncture.

"I think that the specialists in hemophilia, for example, in the puncture itself, I think that the nurse in this case, who has more experience with children and with respect to hemophilia in general, I think that it should be, for example, the same doctors who have been with us all this time, who can specialize us day by day about hemophilia..." (DAD05: L86 - 92).

Educational needs regarding the location

A comfortable and familiar place

About the characteristics of the place where the educational intervention will take place, the parents highlight as the only aspects that the place to be comfortable and familiar. Within the description of "comfortable and familiar", they indicate that this place should ideally be close to the participants' homes, easily accessible and known by the parents, and provide confidence and the possibility of creating an atmosphere of calm for the participants.

"...I mean, the idea is that it should be a comfortable place where we can be calm, talk about the subject, maybe in a house it is easier because it is easier to be more reassured, because suddenly one gets very sensitive about the disease". (MOM01: L477 - 481)

Discussion

Among the sociodemographic characteristics of the participants in this study, the high educational level of the parents stands out, with all of them having technical-professional and higher education. This result contrasts with that found in the literature where the characteristics of occupation and education are lower than those reported in this article[10].

Regarding the health condition of the children, 75% were carriers of hemophilia A and 25% of hemophilia B, whereas, in the total group, the severe condition prevailed. This is similar to what has been described in national and international prevalence studies, where hemophilia A has a considerably higher frequency than hemophilia B[1, 11-13].

The participants described the educational needs through five parameters. Regarding the *contents*, the educational topics that most stood out in their accounts were the preparation and administration of lyophilized concentrates, measures to prevent bleeding episodes, actions to be taken in the case of bleeding events, and pathophysiological aspects of the disease. These aspects agree with the elements mentioned in the literature[11-17]. It should be noted that some of the aspects mentioned above, such as medication administration, are related to the confidence that parents can develop in terms of taking the best possible care of their children at home, avoiding the need to go to health care centers for services that they can learn and perform at home. This aspect not only gives confidence to the parents but also transmits security to the children, contributing to their normal development.

Concerning the methodology, parents express the organization of group workshops with a didactic component, so that they can share experiences with other people and acquire the skills they consider necessary to care for their children at home. This finding coincides with other research, showing that the social support achieved in the relationship with peers is an important aspect for parents[13,14]. It should be noted that the possibility of exchanging experiences with other parents of children with hemophilia becomes one of the main strengths of the group methodology.

For parents, the perception of support from other parents who have the experience of living with the health condition is motivating. This identification makes this type of methodology (peer education) may have a motivating effect to consider when delivering educational content to this population. The literature points out that the motivation of peer education may be because parents feel freer to share their life experiences with other parents who have lived through the same experience and thus establish a support network[15].

Regarding the most appropriate *time* to educate, parents mention that the diagnosis and the beginning of autonomous activities are the episodes of greatest educational demand. There is not much scientific evidence in this type of disease that allows us to compare our results; however, education of patients with other chronic diseases shows that the stages of greatest educational need are at the time of diagnosis, at key stages of treatment, or with the emerging needs of the users[18].

In relation to *people*, parents identify another parent as someone suitable to provide educational content, from the perspective of the experience of the disease, for home care, and to complement the educational content provided by professionals. The parents' need to identify with other parents who have gone through the stages they are going through, gives them peace of mind to better face their children's condition[15]. One finding of this study is the recognition by parents of education by health professionals. One explanation for this is that medical and nursing professionals are widely recognized by parents of children with hemophilia as a reliable and close source of information about the care of their children at home.

About the *place*, we identified its characteristics, where comfort and a sense of privacy were two important characteristics recognized by the parents in this study. Comfort and familiarity are important aspects to consider when providing information regarding the care of their children at home. There is not much scientific evidence to compare our results; however, education of patients with other chronic diseases shows that people need a trusted environment to discuss their experience[18].

In conclusion, the results of this study emphasize the importance of incorporating the aforementioned aspects in the orientation to provide comprehensive care for their children at home.

One of the limitations of this study is that its results are not representative of the socioeconomic spectrum of mothers and fathers with children with hemophilia, so future studies should include parents in social vulnerability. However, this is the first study in Chile to describe the needs of parents of children with hemophilia in a national referral center.

The results of this study provide the basis for the development of an educational program aimed at parents or caregivers of hemophiliac children. It is necessary to conduct research studies that can develop an *ad-hoc* educational intervention to the needs detected that, after its implementation, studies could be conducted to measure the impact of this educational program, based on the needs described by parents, to improve the quality of life of parents and children with hemophilia.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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References

1. MINSAL. Guía Clínica Hemofilia. 2013. http://www.bibliotecaminsal.cl/wp/wp-content/uploads/2016/04/hemofilia.pdf.
2. Furmedge J, Lima S, Monagle P, Barnes C, Newall F. 'I don't want to hurt him.' Parents' experiences of learning to administer clotting factor to their child. Haemophilia. 2013; 19: 206-11.
3. Perrin J, MacLean W, Janco R, Gortmaker S. Stress and incidence of bleeding in children and adolescents with hemophilia. J Pediatr 1996; 128:82-8.
4. Kang H, Kim W, Jeong Y, Kim Y, Yoo K. Effect of a self-help program for mothers of hemophilic children in Korea. Haemophilia. 2012; 18: 892-7.
5. Sociedad Chilena de la Hemofilia. Hemofilia en Chile. 2017. http://hemofiliaenchile.cl/todo-sobre-la-hemofilia-y-mas/
6. Hernandez R, Fernández C, Baptista P. Metodología de la Investigación. 6ª ed 2014. Ed. Mc Graw Hill. México pp 366-94.
7. Salgado A. Investigación cualitativa: diseños, evaluación del rigor metodológico y retos. Liberabit 2007; 13:71-8.
8. Guba E, Lincoln Y. Competing paradigma in qualitative research. En: Denzin N, Lincoln Y. Hand book of qualitative research. Thousand Oask: Sage Publication; 1994;105-7.
9. Emmanuel E, Wendler D, Grady C. What makes clinical research ethical? JAMA 2000;283:2701-11.
10. Ergün S, Sülü E., Basbakkal Z. Supporting the need for home care by mothers of children with hemophilia. Hom Heal Care Nurse 2011;29:530-8.
11. Cervera A. Fisiopatología y trastornos de la coagulación hereditarios más frecuentes. Pediatr Integral 2012;16:387-98.
12. Bolton-Maggs P, Pasi K. Haemophilias A and B. Lancet. 2013; 361:1801-9.
13. Federación Mundial de la Hemofilia. Guías para el Tratamiento de la Hemofilia. 2012. http://www1.wfh.org/publications/files/pdf-1514.pdf
14. Phadnis S, Kar A. The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. Haemophilia 2016;1-7.
15. Schrijvers L, Schuurmans M, Fischer K. Promoting self-management and adherence during prophylaxis: evidence-based recommendations for haemophilia professionals. Haemophilia; 2016;1-8.
16. Miller K, Guelcher C, Taylor A. Haemophilia A: patients` knowledge level of treatment and sources of treatment-related information. Haemophilia 2009; 15:73-7.
17. Dutreil S, Rice J, Merrit D, Kuebler J. Parents empowering parents (PEP) program: understanding its impact on the bleeding disorders community. Haemophilia 2011;17:e895-900.
18. Araya AX, Carrasco P, Loayza C, Fernández AM, Pérez CM, Lasso M. Necesidades educativas de un grupo de personas viviendo con VIH: diagnóstico basado en la perspectiva de los usuarios y de los profesionales que los atienden. Rev Med Chile 2013;5:582-8.