

## Common Health Education Needs of Children and Adolescents with Chronic Complex Diseases and Their Families

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### Abstract

**Introduction:** Chronic complex diseases during childhood and adolescence are associated with morbidity and mortality, and present an emotional and social burden for patients and caregivers. Health education in self-care activities and patient empowerment are essential aspects in improving the quality of life of this population. Children and adolescents with chronic complex diseases, as well as their families, tend to present common health education needs related to disease management and patient's empowerment.

### Objective

To identify the common health education needs of children and adolescents with chronic complex diseases and their families.

### Materials and Methods

Qualitative design study through two focus groups with 15 family members and patient representatives.

### Setting

Sant Joan de Déu Children's Hospital, Barcelona (Spain). Period of the study: From November 2021 to March 2022.

The Study was Carried out in Three Phases

- 1) Review of bibliographic and grey literature
- 2) Field work: design implementation, data collection and analysis
- 3) Development of recommendations.

### Results

Patients and families need to receive training and education on the patient's disease and medical devices, as well as clear information at the beginning of the disease process. It is important to maintain the main caregiver's good health status and well-being. The patient-provider relationship and patient's relationship with friends and school are essential to achieve a good adaptation to the recovery process. Information on economic and social aids for families is necessary. The mixed format combining face-to-face and online sessions is the most preferable for patient and family health education.

**Conclusions:** It is important to develop basic content for all patients and family members about common health education needs, regardless of the specific pathology they present. This training must include caring for emotions, psychological support and well-being; as well as the main aids or resources available for patients and families, among other topics of interest.

**Keywords:** Pediatrics, Childhood, Adolescence, Chronic Complex Diseases, Health Education Needs, Patient Empowerment.

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## Introduction

Chronic diseases are the main cause of death and disability in the world and, despite growing evidence of their epidemiological and economic impact on society, the global response to the problem still seems inadequate<sup>1</sup>. These diseases mean a great burden both, in the personal and in the health, economic and social areas of a person. Different studies have been carried out to determine the impact of these diseases on the Population<sup>2-3</sup>. This situation is also true for children and adolescents with chronic illnesses. These patients usually present comorbidity and psychological impact, which represents a greater challenge for the management of the disease<sup>4</sup>. Within the group of pediatric chronic diseases are chronic complex diseases. A characteristic of these lies in the difficulty to respond to the overall needs of the patient<sup>5</sup>. In this sense, different international care programs have been developed considering these pediatric diseases a public health priority<sup>6</sup>. Thus, a key element in the different care strategies for children and adolescents with chronic complex pathology is the comprehensive approach to the person and their environment, taking into account that it is a population group with differential characteristics<sup>7</sup>. Even more, although disease management can be different depending on a specific illness, the needs that a group of patients with chronic complex diseases and their families can face in terms of information, emotional and educational aspects, psychological support or economic aspects, among others, can be shared and common<sup>8</sup>.

In this situation both, patients and their family members or caregivers, must feel empowered to make informed decisions in dealing with the disease. The participation and empowerment of patients are crucial aspects to improve their health outcomes and experiences<sup>9</sup>. In pediatric settings, in addition, guaranteeing the well-being of caregivers, usually parents, is essential. Health education for patients and family members plays an important role in this regard. The Sant Joan de Déu Children's Hospital, in Barcelona (Spain) has been working for more than a decade incorporating patients and families in the management of the disease itself, as well as in their participation in the development and improvement of health services<sup>10</sup>. In the case of pediatric and adolescent patients with chronic complex diseases, empowerment through health education is a key aspect<sup>11</sup>.

This study is part of a broader Hospital project aimed to care for complex chronicity and rare diseases in children and adolescents<sup>12</sup>. In this environment, the Hospital School of Health was also created. The mission of the School is to contribute to improve the health and quality of life of the population served through health promotion and education initiatives. In order to understand the common health education needs of this group of the population, it is essential to know the opinion, experience and expectations of the people affected by the disease and their families<sup>13-14</sup>. The main objective of this study was to identify the common health education needs of children and adolescents with chronic complex diseases and their families.

## Materials and Methods

The study was conducted in the Sant Joan de Déu Children's Hos-

pital from November 2021 to March 2022, through a qualitative design using focus groups. The study was carried out in three phases that are described below.

### Phase 1: Literature Review

The research team (RT) carried out a bibliographic search in different documentary sources and in the Medline database (searching for English and Spanish papers published in the last five years and with the key words: children, adolescents, chronic complex disease, and educational needs). The purpose of this search was to review the main educational needs of children and adolescents with chronic complex diseases and their families. Specific scientific journals in the area of health education, medical education and child pedagogy were also reviewed. Next, the RT conducted a benchmark of good practices on health education in different international health organizations and pediatric health centers.

### Phase 2: Field Work

#### Design implementation, data collection and analysis

The RT designed a strategy to analyze the health educational needs of patients and relatives with chronic complex disease. For this, investigators conducted two focus groups with eight and seven family members and representatives of patient associations, respectively. The team of health professionals who cared for the patients in the Hospital selected the participants. The selection criteria were parents who have children (or represent a patient or family association) with a chronic complex disease, have been treated in the Hospital and agree to participate in the study. On November 24, 2021, from 10 a.m. to 12 p.m., the RT conducted the first online focus group with eight family members (or patient's representatives) of patients with chronic complex diseases. During the session, there were an observer and a moderator, both of them members of the research team, with experience in the aspects and codes to observe, as well as in how to conduct a focus group. On February 18, 2022 from 7:00 p.m. to 8:30 p.m., the second online focus group was held with seven families and representatives of patient associations who also met the inclusion criteria. In this session there were an observer and a moderator, also members of the research team and trained for this purpose. At the beginning of both focus groups, once the participants and team members were introduced, the moderator explained to the participants how the meeting works and its objectives. Participants were asked about the content and format characteristics that they considered most important for a health education strategy for themselves and for other patients and families with similar pathologies and situations. Two open-ended questions were asked to the participants of both groups: the first about their health education needs (which could refer to specific issues of the disease itself or to general issues about addressing the difficult situation that these families were going through). In addition, the second question, being also open-ended, focused on the preferred format when receiving the training (such as a face-to-face class, a workshop, a video or any other format or combination).

In both cases, the dynamics of the meetings were recorded, as well as the comments and contributions made by the participants. For

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this, their prior consent was requested and they were informed about the subsequent treatment on the information. Likewise, confidentiality and anonymity were guaranteed in the management of the information provided. After carrying out both focus groups, the recordings were reviewed and the results were extracted from an information content analysis reviewing codes, categories and themes<sup>15</sup>. Two members of the team initially carried out the analysis, independently; and, subsequently, it was validated by two other researchers (observers) and by the participants of the meetings themselves.

### Phase 3: Development of Recommendations

After the analysis of the information from the 2 groups, and among the following 24 hours from the meetings, the most relevant conclusions that emerged from the debates were drawn and sent by email to the participants. Then, they agreed on the key points to be highlighted from the sessions. This third phase allowed the RT the elaboration of some recommendations regarding what the first health education activities to be programmed should be and with what content; as well as what modalities would be best adapted to the needs of these patients and their families.

### Results

In the opinion of the participating families, the health training and education needs may change over time, the evolution of the disease, and the specific circumstances of the family.

some expressions in this sense were the following:

*“Each stage is important by itself. When [the children] grow up, there are other needs.”*

*“When they [the health professionals] give you a diagnosis, you can't imagine everything that comes after.”*

*“For me, the easiest thing is not to think about tomorrow, but sometimes you think about what it will be like when the child is a teenager.”*

The participants highlighted the need to receive technical training on how to use the different medical devices or how to mobilize the patient at home. They also stressed the importance of offering information and training at the beginning of the process or diagnosis when, normally, one does not know what to do. This gives them security.

*“Health education is very important, when wearing a gastric button, for example. Time makes you an expert, but at first you feel very lonely, you need to be given security”.*

*“When a family has a diagnosis, it is hard and everything collapses.”*

*“Psychological support from the beginning is basic; as well as health education, physiotherapy and speech therapy”.*

It also seems clear for participants the need to have a hospital platform that concentrates the necessary information and health training and education resources for families. That contributes to optimizing the self-care potential of patients and careers at hospital discharge.

*“When leaving the hospital, families have many doubts and need to consult often.”*

*“They explained it to us very well at the hospital, but when we went home we felt helpless.”*

Another outstanding aspect was having tools to maintain the health and well-being of careers, as well as to be able to share the situation with other people. For example, being able to speak and meet with families who were going through or had gone through a similar situation is an important aspect.

*“At first it's a long time without a good sleep, but you should have time for yourself.”*

*“It's very important to share with other parents and talk among families.”*

*“When you start the path in this type of disease, training is very important and finding families to help us, professionals who support, is key.”*

*“Meeting with other families, even in the hospital, gives you a lot of support and you learn a lot.”*

Participants also showed a general feeling of need for information on how to talk to the child and siblings about what is happening.

*“We have another younger son but he is already 10 years old and we started to have problems with him.”*

*“He asks questions and we don't know how to answer him. Questions like: Why me? How do we tell him? My son psychologically needs a calendar of what is going to happen: When do they take this away from me?”*

*“We would like to know how to talk to her. How to get her to lead a normal life”.*

The relevant role of peers and the school was also highlighted.

*“Do not forget the child's social sphere, school, and friends. We have to talk in schools about how to deal with these situations”.*

*“It would be necessary to help teachers and students understand what the child has. It could be done from the hospital.”*

*“It is important that the school provides continuity in the lives of the children.”*

*“You see that the teachers and other classmates are afraid.”*

Participants also highlighted the figure of social workers and other professionals, to find out what different options apply in each case and moment.

*“You could make a guide of all the aids there are for cases like ours. Alternatively, send us a message with the links of everything, to look at our own pace. When they tell us everything all at once, we cannot understand it well”.*

*“They give you everything suddenly and there are moments when you don't have a clear head. It would be good to give you the tools and that each one can incorporate the information at their own pace. Each one making our way, knowing that what is important now is this. Later on you can look at the other”.*

*“Sometimes we parents don't know what there are entitled to.”*

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*“Administration resources, know what they are. Families are very lost.”*

Finally, other comments emerged from the overall conversation, such as a general concern about continuity of care, about coordination among health centers and professionals or about how to help other families with the same problems.

The second question referred to the format in which the health training and education activities should be conducted. The participants considered a mixed format between face-to-face and distance/online training as ideal.

Some expressions in this sense were the following:

*“Everything can be combined, streaming, informative brochures and the web.”*

*“It can be in person and posted somewhere that anyone can access.”*

*“Combine face-to-face and virtual, so more people can access.”*

*“Emotional issues will be better with face-to-face groups.”*

Among the recommendations made during the third stage of the study, the preparation of a basic content package for any patient/family in a situation of chronic complex disease arose. These contents should include: 1) attention and care for emotions; 2) psychological support; 3) how to take care of yourself to be well and be able to care for the patient; or 4) main aids and resources available; among other general topics. These general contents should be useful for patients with chronic complex diseases and their families. The table presents a summary of the results about the most important contents of the training.

Apart from this first training program and depending on the specific characteristics of each patient or group of patients, another program, this time more specific, should be developed to cover the singularities of each case. In this second program, the contents would be related to care needed at the patient’s home, the specific treatments or devices to be used in each case, etc. As previously mentioned, the format of each program will depend on the type of content, but a combination of face-to-face and online sessions seems to be the best option for participants.

## Discussion

Among the most relevant conclusions drawn from the two focus groups, the participating families commented that health education needs change over time and circumstances. They agreed on the need to receive technical training on how to use medical devices, or how to care for the patient at home. A main theme was the need for psychological and emotional care for family members, both at the beginning of the diagnosis and in the process of caring for the child. Participants highlighted the importance of being in contact with other families in the same or similar situation.

How to talk to the patient about what is happening was another topic highlighted by the participants, as well as knowing how to manage social aspects of the child’s life, such as relationships with friends or school life. The participants stressed the importance of having a specific health education agenda with all these topics,

collected in a digital platform where families can find information and training resources when needed. Regarding the most appropriate formats to receive the training, the opinions were diverse, since the preferences will depend on each moment; but different formats or a combination of them (face-to-face and online), seems to be the best option.

The RT conducted the two focus groups with 15 participants. A limitation of the study was the difficulty in the recruitment due to the special situation these families were going through having two focus groups to obtain the information may be another limitation of the study, since it only represents the opinions of the participants. However, the objective of this strategy for collecting information from this exploratory group was not the external validity or general representativeness of the information. Instead, the RT focused in gathering qualitative information, which compiled the opinions of key, specific people, and who were experiencing the situation under study (chronic complex disease in children and adolescents at the Hospital and their families).

The question that arises in this type of qualitative design is whether similar results would have been obtained by selecting other people, carrying out more sessions or using other methodologies. In order to verify this, the information was triangulated through the bibliographic review, the experience of the research team and the professionals who cared for the patients under study, as well as the results of the focus groups presented here<sup>16</sup>.

Information saturation was also checked. In other words, when carrying out the second focus group, no new ideas or information different from what was collected in the first group emerged. In this case, adding more groups or sessions probably does not guarantee obtaining new information compared to what has already been collected. This is, in part, logical since the study is focused on a very specific patient population, who also have specific and common health education needs among those affected and their families. The results of this study have a double implication: on the one hand, carrying out the needs assessment on health education has helped RT to understand what the main issues to be addressed are so that families feel more secure and empowered. These topics should be part of a health education program for these patients and their families and of a digital platform that encompasses and collects the different training resources created for this purpose. On the other hand, the direct incorporation of the patient and the family in the process favors their participation in the decision-making process and the improvement of overall health results.

Sharing these spaces for reflection between professionals and families adds value to the obtained results<sup>17</sup>. These results arise from the combination of qualitative research methods and can serve as support for other researchers with a similar objective. Involving patients and their families in these cases, regarding the type of information and education they need, allows them to feel empowered and safe to participate in improving their health and well-being. Meeting the health education and empowerment needs of these patients is key to achieving effective self-care. In this sense,

there is a set of common health education needs, identifiable and consistent with what other studies suggest<sup>8</sup>. These needs can be considered as a specific educational package, with an ad hoc platform that can act as a reference for people and minimize Internet searches with the risk that this action entails.

Collaborative work with patient associations to build this common educational package can be useful as it incorporates different visions and experiences of these associations as well. In turn, the combination of traditional educational methods with the new digital-based pedagogical models can offer a set of possibilities that responds to the needs of these patients and their families. Finally, the empowering dimension of the patients is necessary in the approach to chronic complex diseases in children and adolescents. For this reason, the existence of the Hospital's School of Health in the knowledge area of chronic complex diseases could be a good

initiative to model health education in vulnerable pediatric groups and apply it more effectively. The results of this study can contribute to the broader umbrella project about health education at the Hospital School of Health.

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**Table. Health education contents for children and adolescents with chronic complex diseases and their families.**

Area	Topics
Basic concepts of health literacy	Management of the information (access and utilization)
	Digital literacy
	Hospital and Health System characteristics
	How to prepare the medical visit
	Patients' rights and responsibilities
Clinical and tecnic health information	Characteristics of the disease
	Technical or Medical devices
	Common evolution of the disease over time
How to take care of yourself	Psychologic and emotional support
	Managing uncertainty, fatigue, and sadness
	Tools to achieve greater well-being
	Information resources
	Sharing with others
	Information resources
How to talk with your child	Doubts and questions of the child
	Most frequent concerns
	Stages in the child growth and development
The social life of the child	Relationship with siblings and friends
	Fellow students and classmates
	The school, the institute and the teachers
	The transition from child to adolescent and from adolescent to adult
Resources and aids	The role of the social worker
	Different types of family, social and economic support
Other common needs	Coordination of care, mentoring for new families, support groups, etc.

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