



Patient's Advocacy in a Children's Hospital

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Abstract

The empowerment and participation of patients and families in the health decision-making process are essential elements of patient-centered care. Patients and their families, as well as the associations that represent them, have gradually organized themselves to participate in this process. The advisory councils are one method of engagement for patients. These are seen as well stable bodies of participation in hospitals and health centers.

This report presents the case of patients' advocacy in a children's hospital through stable bodies of participation.

Received: Mar 17, 2021

Accepted: Apr 09, 2021

Published Online: Apr 13, 2021

Journal: Annals of Pediatrics

Publisher: MedDocs Publishers LLC

Online edition: <http://meddocsonline.org/>

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Introduction

Empowerment is a process in which patients understand their active role, as well as acquire the knowledge, skills and confidence to participate, decide and perform different tasks [1,2]. The empowerment and participation of patients and families are essential elements of patient-centered care. Patients' participation in the decision-making process can be conducted addressing disease management issues, helping to improve health services, or representing and advocating for other patients [3]. In this context, the relationship between the health-care professional and the patient is more participatory than it was some decade's ago [4].

Parallel to these circumstances, there has been an increase in citizen participation in different fields in society. In the health area in particular, patients and their families, as well as the associations that represent them, have gradually organized themselves to participate in the decision-making process [5]. There are different levels of participation that range from information; that is, to provide patients with rigorous, truthful information and in understandable language; and consultation (through surveys or interviews), to the implication (a specific work in improvement groups), collaboration and empowerment. These different levels constitute the "ladder of participation" [6].



Cite this article: Navarro Rubio MD, Bosque A, Nadal D, Jabalera M, Serrat J. Patients' Advocacy in a Children's Hospital. *Ann Pediatr.* 2021; 4(1): 1066.

The last two steps of the ladder of participation, collaboration and empowerment, involve the existence of stable groups or bodies of participation in the health institution to represent other patients. In turn, the representation of other patients can occur in the health organizations (in order to improve the process of care, protocols or environment), or in the health administrations, concerning the establishment of health policies, program planning and evaluation

One of the established formulas of this kind of participation in health organizations is the advisory council of patients and family members. Patients and family advisory councils are one method of engagement in the health decision-making process [7,8].

These councils mean an opportunity for patients and families to approach the healthcare system and provide guidance on how to improve their experience. In turn, they allow healthcare organizations to learn from the point of view of the patients' experience and integrate their ideas into the provision of better services and quality improvement efforts. Thus, this unique perspective of patients and families have a positive impact on the development of a patient-centered approach [7].

Another participation formula refers to the alliance established with patient associations. These associations usually focus on a pathology, a group of pathologies or a specific clinical situation, as well as crossover health issues such as chronicity or patients' rights. Examples of the latter are the European Patients Forum (<https://www.eu-patient.eu>) or the International Alliance of Patients Associations (<https://www.iapo.org>) at the international level, among others.

They are an important support for patients and family members, since their purposes include contributing to informing the patient, supporting co-responsibility and empowerment, make visible the disease and its detection, promote research, ensure patients' rights, offer psychological support or increase their confidence and autonomy, among other aspects [9].

Patients and families, as well as patients' associations, have been organized to advocate on behalf of the patient and participate in the overall decision-making process of health centers and administrations. Patient's advocacy refers to both promoting and protecting the interests of patients and families [10].

Promoting and protecting the rights of the patient in a pediatric environment mean to incorporate the family or the child main caregiver into the process of care. Thus, patient and family-centered care constitutes an important strategy in a children's hospital. In this model of care, there is a collaborative relationship among health professionals, patients and caregivers [8].

The Sant Joan de Déu Children's Hospital in Barcelona (Spain) is part of the "Order of San Juan de Dios", with 150 years of history, being a reference for pediatric and OBGYN healthcare. Patient orientation and hospitality are part of the foundational values of the center. The strategic model of the hospital includes the empowerment and participation of patients and their families in the management of care, as well as their co-responsibility in the development of the health services [11].

This report focuses on the design, development and implementation of a plan for the advocacy of patients and families through the creation of stable participation bodies in a children's hospital.

Methodology

Scope of the situation

We carried out a review of the scientific and gray literature to determine the current knowledge and scope of the situation under study (patients' advocacy in health centers). The search included the last 5 years, from 2015 to 2020, in the Medline database. The keywords used were patient participation, patient involvement, patient activation, patient engagement, patient empowerment and patient advocacy.

We also carried out semi-structured interviews with health professionals (6 interviews with doctors, nurses and social workers) and representatives of patient associations (5 interviews) to assess the relevance and characteristics of a patients' advocacy plan.

Patients' associations

The hospital has been working with more than 50 patients' associations from all the country for more than a decade. In order to strengthen the alliance with these associations, on December 2017 we conducted a workshop to analyze the situation of patients' associations and the aspects of improvement perceived in patient care. We used design-thinking techniques to conduct the workshop [12]. From this meeting, a group of 20 patients' associations has met once a month with professionals and staff of the hospital following the road map created from the initial meeting.

Patient and family councils

With the aim of creating stable participation bodies, and following the recommendations from the literature review, as well as from the interviews and the work with patients' associations, in 2018 we created a Family Council. At the same time, we renewed a previous Youth Council.

The members of the Family Council are patients' relatives, mostly mothers. The number of members is 25 to 30 people who renew their position every two years up to a maximum of four. In the selection procedure, applicants must fill out an application form and conduct an interview with a member of the hospital staff. Members can also be recruited at the proposal of health professionals.

The Youth Council is made up of teenagers between 13 and 18 years old. The process of selecting its members follows the same criteria as that of the Family Council. In this case, it is a renewal since the first edition of the Youth Council was created in 2012 but stopped, as its members grew older.

Both councils met four times a year each. The meetings lasted a mean of two hours and were conducted thorough qualitative methodologies. The topics we covered in the meetings of both councils are transversal, specifically processes that the majority of patients and families of the hospital go through (hospitalization process, blood draws, telematic care or improvement of hospital architecture and spaces, among other topics).

The councils' members help us to identify critical points in these processes, recommend actions and/or propose new initiatives to improve the quality of care as well as their experience. We usually invite to attend to these meetings the chief and other professionals from the area we are working on. Thus, health professionals have the possibility to listen to the participants contributions, transmit it to their teams and assess the

possibility to implement quick quality changes.

Closing the age range of hospital patients who can participate on their own, and with the positive experience of the creation of the family and youth councils, in 2019 we created the Children's Council, consisting of children between 6 and 12 years old.

In this case, the work done by the other two councils has been complemented with the participation of the little ones. We use methodologies adapted to age such as gamification or Lego Serious Play [13,14]. In the case of children, the sessions are conducted ad-hoc and with the presence of parents. Children may participate in one or more meetings depending on the selection criteria of the professionals who attend them (agree to participate with the consent of their parents, know the process or situation of improvement to be valued, are in a situation to participate, etc.).

All the meetings have been documented and the members of the councils have reviewed summaries or minutes. At the end of each year, we present the conclusions and actions developed from the work sessions jointly to the general manager of the hospital and the councils' members. At the same time, we develop new objectives for the year ahead.

In addition, all council members (families, youth and children's parents) went through an information session about the characteristics of their participation, their rights and responsibilities and any other information they needed to know at that time about their participation. We explained them the treatment of the data and the information extracted from the work sessions. All members signed an informed consent.

Results

In a project of these characteristics centered on the design and implementation of a patients' advocacy plan, the primary indicators focused on establishing the number of activities carried out (meetings, conferences, workshops, etc.), the number of people involved in these activities and the number of improvement actions or recommendations made. Then, we review the results accomplished through all these meetings and activities.

Between January 2018 and September 2020, we conducted more than 30 work sessions with patients' associations. From them, we developed a road map and needs assessment. These needs focused on having advice in the moment of the diagnosis, giving more visibility to the patients' associations or receiving some training in specific topics related to their activity, among other needs. These needs served to perform different improvement actions like the inclusion of information about the associations in the screens of different parts of the hospital, in the training of students and health professionals, or in the development of a welcome guide for parents, among other examples.

In addition, we conducted more than 20 scientific conferences with patients and family members, and around 100 different meetings and workshops. More than 200 volunteers participated in these activities and around 4,000 people attended in total.

Between the same periods, we also conducted six meetings with the Family Council and four more with the Youth Council. From these sessions, improvement actions also emerged like the development of educational materials or the coordination between admissions and hospitalization; as well as the improvement of comfort in hospital stays, specific spaces for chil-

dren and adolescents or the information at discharge, among other actions.

Conclusion

The councils and patients' associations have been meeting with health professionals and staff in a regular basis over a 2-year period and have contributed in the improvement of the hospital health services (such as the hospitalization process, the communication of the diagnosis or the patient education materials development, among other topics of interest); as well as in the architectural design of the physical spaces of the center.

The hospital has an experience of more than a decade in the incorporation of patients and families in the health decision-making process and in the assessment of the patient's experience. Since then, we have been incorporating bodies for collaboration and participation of patients and their families into the strategic management of the institution.

In the last two years, we have been using a common methodology, based on the combination of qualitative techniques. This methodology offers a systematization in the study of the patient's participation and advocacy, which makes it applicable internally, in different hospital areas. This experience can also be applied to other health organizations. It is based on the principles of quality improvement, promotes patient-centered care, as well as system sustainability, effectiveness, and satisfaction, both for patients and professionals [15].

One of the established formulas for patients' empowerment and participation in health organizations is the advisory council of patients and family members. These councils provide an opportunity for patients and families to approach the healthcare system and provide guidance on how to improve their experience. In turn, they allow healthcare organizations to learn from the patient's viewpoint experience and integrate their ideas into the provision of services and quality improvement efforts. This unique perspective of patients and families have a positive impact on the development of a more patient-centered approach, empowering patients and families to participate in the decision-making process as well as advocating for them.

This model facilitates an integral change and improvement process in the hospital management. It takes into account the needs of patients and families, incorporates the standardization of clinical practice in a context of quality and safety and improves operations with a collaborative orientation that allows us better results.

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