

Review Article

The Role of Nurses in Patient's Empowerment the Case of A Children's Hospital

Navarro Rubio MD¹, Gutiérrez M², Bosque A¹, Tarbal A³, Cañal P³ and Gómez E²

¹ Patient Empowerment Area, Sant Joan de Déu Children's Hospital, Barcelona, Spain

² Nursing Department, Sant Joan de Déu Children's Hospital, Barcelona, Spain

³ Research and Innovation Department, Sant Joan de Déu Children's Hospital, Barcelona, Spain

*Address for Correspondence: Maria D. Navarro-Rubio, Director, Patient Empowerment area, Sant Joan de Déu Children's Hospital, Pas-seig Sant Joan de Déu, 2, 08950 Esplugues de Llobregat, Barcelona, Spain, E-mail: mnavarror@sjdhospitalbarcelona.org

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Abstract

Health institutions have been focusing on patient-centered care, placing the patient at the center of the health system. Many definitions have been developed regarding the role of the patient: from a passive subject, to a more informed one, capable of establishing a deliberative relationship with professionals.

The role of the family or the main caregiver acquires great relevance in the care of the chronic patient. In the context of chronic diseases, the pediatric patient constitutes a specific case. When children have a chronic disease, they require special care provided by professionals able to respond to their needs, as well as to those of their families.

Among the different roles of nurses, it can be highlighted educating and training patients and family members, as well as motivating a change of the patient's behavior when needed. Nurses are fundamental actors in the development of self-care skills, abilities, and competencies in patients.

With proper education and training, patients acquire those skills and competencies to know what is happening to them, understand what they should do and feel confident. This is crucial in order to make well-informed decisions.

The strategic model of the Sant Joan de Déu Children's Hospital in Barcelona (Spain) includes the empowerment of patients and families in the management of care, as well as their co-responsibility in the improvement of hospital facilities and health services. Nurses play a pivotal role in this hospital's model of patient empowerment.

This report presents an example of how nurses develop a patient's empowerment program in the hospital.

Key words: Patient-centered care, Patient empowerment, Patient's education, Nurses.

Background: Patient's empowerment and patient-centered care

In recent years both, health administrations and institutions in most of the industrialized countries, have been focusing on patient-centered care or placing the patient at the center of the health system [1,2]. Such care should be contextualized in an environment that encompasses respect and dignity towards the person, his/her needs and expectations, as well as provides patients with quality information and the possibility of collaboration and participation in the health decision-making process.

The fact that patients are at the center of health care, means that they must be and feel heard, noting that their values, preferences and opinions are taken into account in the planning of health services. In addition, a patient who is well informed by health professionals and has the possibility to share his/her doubts and concerns will be more predisposed to participate in shared decision-making process with the professional [3].

Many definitions were developed over the years regarding the figure of the patient: from the patient as a passive subject in the relationship with the health professional, to a more informed one, capable of establishing a deliberative relationship with professionals [4]. At the same time, health professionals have undergone an important transformation process. A few decades ago, decision-making was based on the knowledge and experience of the expert and the patient-provider relationship was dependent and paternalistic. The pending challenge is to train health professionals and students in skills to be able to interact with a patient, often chronic, more active than a few decades ago and who may want to know, comment on and even question the opinion of the professional [5].

Health administrations and institutions must align themselves with this new reality. The concept of patient-centered care also implies a willingness on the part of professionals (clinicians and managers) and the institutions they represent to favor this model of relationship between professionals and people who become ill.

Patient education and chronic conditions

Chronic diseases are currently the leading cause of disability and mortality worldwide [6]. Chronic patients face the physical and emotional burden that the disease implies in their lives and the changes they need to make to adapt themselves to the new situation. In terms of patients' participation in the health decision-making process, good and clear information is a key element. Informing people, making them aware of the situation they are in and the steps to follow, gives them knowledge and control that is crucial in order to make well informed decisions.

Different initiatives related to patients' education have been developed internationally. Some of these early examples have been the Self-Management Program at Stanford University in the USA [7], and the NHS expert patient program in the UK [8]. Based on these pioneer cases, additional programs have been developed in different countries to train patients in chronic disease management [9].

In these patient education programs, the first step is access to quality, valid, and rigorous information that follows the principles of health literacy. Health literacy has been studied extensively and refers to the knowledge, skills and experiences about health that make a person capable to access, process and understand information about their own health and the utilization of health services [10,11]. Different studies have shown the relationship between people's knowledge of health issues, as well as their capabilities to take care of themselves, and their level of health and quality of life [12,13].

The role of the family or the main caregiver acquires great relevance in the care of the chronic patient. This is even more evident in children. In the context of chronic diseases, the pediatric patient constitutes a specific case. When children have a chronic disease, they require special care or attention provided by professionals able to respond to their needs, as well as those of their families. In addition, this is true not only from the physical aspects, but from the psychosocial, cultural and spiritual point of view. In the pediatric population, family members (usually the mother and the

father) are the persons who accompany the child in the process. In all these cases, parents' education and training is fundamental to understand the importance of their role in the approach to the disease and their involvement in order to improve the child quality of life [14].

Nurses and patients' empowerment

Nurses develop their role at different levels of health systems, such as primary care, hospitals or nursing homes. They are also involved in school health, public health centers, administrations and other health and social entities. Its role is basic in the care of the chronic patient [15]. As discussed in the Institute of Medicine report "The future of nursing", by developing these functions, nurses have a great impact on patient-centered care [16].

The change produced in the patient-provider relationship is important, because of the interaction that occurs between the two, at crucial moments for the patient. This interaction places nurses as fundamental actors in the development of self-care skills, abilities, and competencies in patients.

Among the different roles of nurses, it can be highlighted attending to the care needs of the patient, educating and training the patient and family members to empower them and participate in their self-care activities, as well as motivating a change of the patient's behavior when needed.

The nurse's role, as a professional with competence to offer health education, comes from the promotion of the patient's autonomy and the theory of care [17]. This role as educators and trainers is a continuous and interactive process. Its objective is to obtain better outcomes regarding the health status and well-being of the patient. Patients' health education also favors the acquisition of a self-care behavior, comply with treatment and follow-up the recommendations. It also increases patients' level of general satisfaction, quality of life and psychological well-being, among other positive health effects [18].

With proper training, patients acquire skills and competencies that allow them to be in control of their life, know what is hap-

pening to them, understand what they should do and, in addition, feel confident. Patients' empowerment, therefore, means gaining knowledge, skills, and abilities and, thus, acquiring greater control over decisions and actions affecting their health [19].

Nurses incorporate the patient into self-care activities through strategies to prevent, recognize and act on their health problem. They are also in charge of assessing the personal situation of each patient, his/her beliefs, expectations and abilities. Nurses educate patients about the disease and its treatments, teach them to carry out follow-up activities and cures at home, monitor the obtained results, resolve doubts, support and empower. They help patients to incorporate the treatment into their daily life, which will be necessary to achieve the therapeutic objectives. In addition, they have an important role in the relationship with the family or the main caregiver of the patient, encouraging them to act and reinforce the patient's progress.

Nurses implement patient-centered care, favoring patient participation in decision-making with the professional. However, in order to encourage patient participation, it is necessary for nurses to have skills that favor such participation, like relational-building skills, personalized attention, or taking into account the patient's psychosocial environment, among other aspects [20]. Moreover, there may be barriers that make it difficult to implement this role, such as, for example, the constant updating on their specialty body of knowledge, the scarcity of resources or the lack of time necessary to carry out their work well [21].

Other limitations or gaps in current knowledge refer to the measurement of results. Patient's empowerment outcomes are difficult to measure. Patient Reported Outcomes Measurements (PROM) and Patient Reported Experience Measurements (PREM) can be appropriate indicators to include because of the patient-centered care strategy [22].

The case of a children's hospital

The Sant Joan de Deu 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 care. Actually,

the hospital has 306 beds and its activity is approximately 25,000 discharges per year; 240,000 outreach visits, 14,000 surgical procedures and around 120,000 emergency visits.

Patient orientation and hospitality are part of the foundational values of the center. The combination of science and humanism characterizes the hospital. 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 facilities and health services [23].

In the hospital, nurses care for patients and families and teach them different aspects about their health condition, disease prevention strategies and health promotion activities. In this context of care, nurses develop different training programs focusing in complex diseases that require specific care at home. Through personalized health education techniques, and from theory to practice, nurses empower patients and families in order to face and respond to the health care needs, safety and quality of life of children when they are at home.

Among the different education programs that nurses conduct at the hospital are the outpatient visits, the hospital discharge or specific programs for numerous conditions. As an example, training for Home Enteral Nutrition for patients and families during the hospitalization period is one of the most relevant training activities. It is essential to identify patients with nutritional risk in the context of their disease and its evolution, as well as to establish appropriate nutritional support.

In this specific case, nurses also use a registry of a Pediatric Unit with 30 beds and they followed up to 200 cases since 2012. In this registry, there is information about the nutrition program through a nasogastric tube at home, as well as other training activities, depending on the complexity of the patient, such as mechanical ventilation and/or tracheotomy.

This training program takes place in the patient's room and in other hospital facilities. All sessions are included in the patient medical record. The nurse discharge report indicates the learning process of the family members in order to offer the care needed [24]. It also favors the continuity and monitoring of care by the primary care

team when the patient leaves the hospital.

The training program begins after an assessment of the patient's status. The nurse, as an educator, offers health education sessions to the patient and family members. There are several requirements to start a training program concerning the patient, the family and the health center. In relation to the patient, it is required to have a stable clinical situation within the disease process, demonstrate tolerance to the treatment and benefit from continued therapy.

In addition, the family should be able to care for their child with the maximum guarantee of quality of care and safety. Concerning the center, nurses should be trained with a specific program, use a nursing record for the program, and include a report for the family at discharge. Nurses standardize the information of each session, increasing the quality of care perceived by the parents, as well as the safety conditions during the entire care process. At the end of the training program, parents are empowered to take care of their child once at home.

The different programs generated from the nursing care to empower patients and families are actually a transfer of knowledge that requires time during hospitalization and space (the patient's own room) to offer the maximum quality and safety in the transmission of care. The nurses, who are part of the care team during the hospitalization, assume the training process in their daily practice. The need to offer security and quality of care becomes a key element due to the complex situations that have to be resolved so that families can leave the hospital with the maximum safety guarantee. Therefore, it is the team's responsibility to share clinical and organizational decisions in a multidisciplinary environment.

Although nurses, due to their training and competence, have been performing this function of assistance and teaching for health-care up to now, at present the Case Manager is recognized as the nurse who can proactively identify people with complexity and chronicity in pediatric patients. This emerging role completes a comprehensive assessment of the patient and family, responding to situations of care planning, coordination and optimization of health resources, working together with the rest of the health professionals [25].

The quality of the training process is an important aspect of patients' education. Family members evaluate the program in which they participate. Between January and June 2017, nurses studied the experience of eight families during the first days at home. Some of the results were the importance of the information and the knowledge of the family about what they should do at home; cultural factors that can influence also the family reaction to the program; and the need to obtain indicators about quality of life at home after the program [26]. To know the experience of patients and families about their training offers the professionals different indicators to evaluate the program.

The nurse, who responds from her knowledge and experience from the professional Code of Ethics, in addition to the incorporation of the evidence in clinical practice, must also consider the introduction of the patient and family in the development of the empowerment program [27]. Because of that, the hospital directives incorporate both, nurses (and other health professionals) and patients (and family members) in the development of educational programs to empower patients and families to be part of the health decision-making process.

These programs respond to patient-centered care and require the identification and analysis of the indicators that intervene in the care process where the patient's and family's own vision is also considered [28].

In order to encourage patients and families to participate in self-care practices, health education and literacy tools are also needed. The assertive role of nurses, jointly with patients' empowerment, create a therapeutic liaison between patients, families and nursing professionals. Recent studies help us to reposition this relationship between patient and nurse, when new perspectives of respect are offered towards a focus centered on the patient, despite the barriers of some professionals [29].

Currently, patients, families and professionals can have a technological support, and our professionals use a network to monitor and evaluate the patients' health status, as well as the capacities to be developed by patients and families in their self-management.

In this situation, there is a need to study the role of patients and families in all the research initiatives carried out to improve their health and wellbeing [30].

It is also necessary to incorporate the international recommendations that provide follow-up guides and the appropriate criteria for the preparation of educational materials for patients and families in any training program [31].

Conclusions

In recent years both, health administrations and institutions in most of the industrialized countries, have been focusing on patient-centered care or placing the patient at the center of the health system.

Informing people, making them aware of the situation they are in and the steps to follow, gives them knowledge and control that is crucial in order to make well informed decisions.

In patient education programs, the first step is access to quality, valid, and rigorous information that follows the principles of health literacy. Patient education and training is fundamental for patients and families to understand the importance of their role in the approach to the disease and their involvement in order to improve their quality of life.

Nurses implement patient-centered care, favoring patient participation in decision-making shared with the professional. The role of nurses in patients' education is basic in the care of the chronic patient. Nurses incorporate the patient into self-care activities through strategies to prevent, recognize and act on their health problem. They are also in charge of assessing the personal situation of each patient, his/her beliefs, expectations and abilities.

In the Sant Joan de Déu Children's Hospital, nurses care for patients and families and teach them different aspects about their health condition, disease prevention and health promotion. In this context of care, nurses develop different training programs focusing in complex diseases that require specific care at home and empower patients and families to participate in the decision-making process about their health.

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