Self-Management of Chronic Disease in Children

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Contributor: Marta Catarino

Self-management of chronic illness leads to improved health outcomes. The acquisition of self-management skills in pediatrics is a process supported by the family, health professionals and the community, in which the nurse, in partnership, can promote communication and health education through cognitive strategies, behavioral programs included in physical or online programs, adjusted to the patients' needs.

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1. Introduction

Since the beginning of the 20th century, scientific and technological innovations in neonatal and pediatric health care have led to evident changes in the epidemiology of health conditions at these stages of the life cycle. Infectious diseases have decreased substantially and life expectancy has increased, reflected in an increased prevalence of chronic disease [1], with associated physical and psychological comorbidities [2][3]. Up to 60% of these children have at least one concomitant psychological disorder [3].

Despite the changing pattern of illness, healthcare continues to be directed towards the treatment of acute illness and healthcare expenditure associated with chronic illness is increasing [4][5]. The accountability of people in the control of their own health [6] and a transfer of health care to non-hospital domains could be important strategies in the face of this reality [7].

Self-management is recognized as a public health intervention and an important component of health care, in all age groups [8][9][10]. It is considered a multidimensional and complex phenomenon, as it requires a variety of actions, in a wide variety of patients and conditions [1][7]. It has been applied to health promotion activities, as well as activities related to acute or chronic illness; however there is more evidence of its relationship with chronic illness [11][12].

According to the theory of individual and family self-management, which explores the self-management process components, these actions should involve patients as dyads, within the family or in the family unit as a whole and at all stages of development [7]. In turn, the pediatric self-management model adds that self-management behaviors require the involvement of the patient, family, community and the healthcare system in a triadic perspective [11][13][14].

The aiming of acquiring the capacity for self-management of the disease is to improve health behavior, reduce admission to health services and, consequently, improve the patient's quality of life. It can be a challenge for them to acquire the ability to self-manage their disease, with little or no additional ongoing support, so it is essential to find support strategies to provide and promote this competence [15].

Although the world scientific literature identifies promising results, regarding the self-management of chronic illness in the pediatric population, there is little consensus on the procedural components [16]. In this population, this phenomenon is more complex, as over the life cycle roles change, family balance changes, information and support needs vary according to age and stage of development [7][17][18].

Promoting self-management in children/adolescents constitutes a real challenge to nursing practice. Nurses manifest the need to identify interventions that enable the acquisition of knowledge, skills and social facilitation for self-management of health in pediatrics [7][16], in order to achieve a positive impact on the health of this population [19].

2. Self-Management of Chronic Disease in Children

There is a consensus that effective self-management can be achieved at an early age, enabling the prevention and management of diseases throughout life, with the development of the capacity to respond to daily challenges and solve problems [20][21]. Although the studies apply to populations of school age, from the age of 6 years, revealing that at this stage it is already possible for the child to develop a process of self-management skills, most studies are aimed at adolescents, at the stage of the life cycle in which there is a more evident progression towards the construction of their identity and autonomy. As this age group progresses in growth and development into adulthood, enhanced self-management skills and knowledge are essential to promote health and prevent problems [22].

Knowledge from the disciplines of nursing, medicine, psychology, physiotherapy, occupational therapy, nutrition, social work, and education can be integrated, using cognitive and/or behavioral strategies [23][24][25] as a basis for support to self-management of chronic illness in the child/teenager.

In the nursing discipline, these interventions represent, above all, health education, being the elementary school space in this approach. School-age children face many barriers to self-management in the school environment. Achieving self-management at this stage is important for maintaining health and quality of life into adulthood [20][26].

Self-management programs attempt to provide chronically ill patients with the knowledge, skills, and self-efficacy needed to take an active role in managing their health condition [27][24].

Nursing resources are not always sufficient, identifying in a study, the potential role of nurses in partnership models or support strategies, to provide schools with much-needed health resources [28]. In the analyzed studies,

successful partnerships with nursing and medical students were identified [28]. Peer support, often in conjunction with family and teachers, was also an activity identified as positive [29][30][31].

In a study developed in the United States of America, in 19 classrooms where children with asthma were enrolled, 12 teachers (80%) participated in small group education sessions conducted by master's degree students in nursing. In a second phase, sessions with the children and parents (48 students) and daily health records were developed, and 100% of the children were able to correctly verbalize the care to have with their specific condition, at the end of the study [28].

One study using Airways, a cystic fibrosis self-management program run by the child and caregiver using pen and paper records to aid decision-making, provided strategies to overcome barriers to the treatment of asthma. There was an increase in knowledge of asthma in all defined skill areas during the intervention period. Satisfaction was high, with 88% (14/16 participants) stating that they would continue to use the system [25].

Peer support interventions also include information-based programs, as well as cognitive and/or behavioral approaches aimed at increasing knowledge, self-confidence, or self-efficacy, as well as the use of self-care behaviors [23][32]. A study conducted on a holiday camp in Portugal on a program aimed at adolescents with spina bifida, by peers, revealed unanimous results and confirmed the importance of the program for the development of self-management activities. The psychoeducational intervention strategies used in the program (problem solving, role play, action plan, and modeling) were clearly demonstrated and may be associated with significant improvement in self-management behaviors [32].

In recent years, technology-based interventions to improve self-management have been shown to be useful in promoting self-management of chronic illness [9][27][33][24][34].

Patients with poor asthma control, in a study carried out in the Netherlands, were able to acquire the ability to self-manage their asthma through the internet (65%) [35]. High ratings were given in terms of the system's ease of use and ease of learning through text messages. Compared with control patients, patients in the intervention group showed a significant improvement in adherence at 7 days, with a mean gain of 1 day of adherence and a median change of 4 to 6 days, compared to no median change in the control group [35].

One study using a Plan My C-Day mobile app specifically designed to promote cognitive self-management skills among adolescents with celiac disease had promising results. It demonstrated that content, resources and functions were operative in the process of self-management of the disease [24].

The app repositories include hundreds of apps claiming to improve self-management of illnesses, health outcomes, and health-related behaviors. However, there are few evidence-based solutions developed with the involvement of health professionals, patients and caregivers [34][36]. Most applications that collect patient-generated health data are not integrated into the care plan or clinical workflow. Without such integration, technologies can have only a minimal impact on the care and self-management of chronic diseases [34].

A Self-Management Platform for Children and Adolescents with Cystic Fibrosis (Genia) illustrated successful integration characteristics. The findings highlighted cultural characteristics of the clinical environment that are more likely to support the viable integration of new technologies as well as mHealth design components that contribute to successful self-management [34].

Although some support/support interventions promoting self-management show user acceptance and positive preliminary adoption of self-management practices, the field lacks detailed research that explores the perspective of users of these technologies [36].

3. Conclusions

Interventions that promote self-management of chronic illness in children and adolescents include activities, based on information, designed to achieve knowledge about the disease and the acquisition of skills. These presuppose a multidimensional and interprofessional support approach at a stage of the life cycle that requires a gradual adaptation, due to the development of cognitive and motor skills that takes place during this period.

Some of the activities mapped are aimed at children and adolescents themselves, but also at reference figures (family, teachers, health professionals), with the objective of conducting a process of supported self-management, according to personal needs (physical and emotional) of each patient. These activities are included in programs that use cognitive and/or behavioral strategies designed to increase self-confidence and self-efficacy.

Promoting chronic disease self-management emphasizes the role of patient education in preventive health care activities, disease self-monitoring, therapeutic management, action plan building, emotional management, treatment adherence, and patient control symptoms.

The nurse, in collaboration with other members of the multidisciplinary team, together with parents and teachers, may develop interventions conducted through direct contact, between members of this triad or through technological support means created for this purpose, provided that they are scientifically validated and constructed according to the needs of users.

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