

Interdisciplinary care for children with rare diseases

Abstract

Children with chronic diseases, and in particular with rare diseases, require health, social and educational strategies to improve their quality of life. This article illustrates some the research developed in the Spanish context, as well as the aims of a current research project developed in the Balearic Islands. Paediatric health care has become very complex and requires interdisciplinary and transdisciplinary approaches that take into consideration the different environments in which the children spend their lives. The school means an educational but also the main social context for children. The strategies addressed to facilitate inclusion of children with rare diseases as well as the training of the teaching staff and the coordination with the health services make necessary contextualised and applied research with impact for families and the efficiency of public services.

Keywords: rare diseases, paediatrics, quality of life

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Mini Review

Children with chronic diseases require in many cases not only a continued care in health centers and hospitals, but also a particular attention in their schools. Then, in the different stages of education, teachers could have in their classrooms, at some point of their professional career, students with chronic diseases, which may be a rare diseases (RD). In general, illnesses tend to cause in children, among other consequences, school absenteeism, academic delays and the need to seek educational compensation mechanisms.¹⁻³

Although the education system in many countries has taken steps for the attention to the diversity of the students, a lack of coordination between the educational center and the health services has been detected in some contexts.⁴ Another study describes the relationships between family, school and health services and highlight the need for coordination among all of them.⁵ Different investigations show also the complexity of the pediatric health care and the different needs that families present in this area, beyond the therapeutic attention to the children.⁶⁻⁸

From another point of view, in a previous study, developed under the R & D funding program of the Spanish Ministry of Science and Innovation (EDU-2010/18777), deficiencies were detected in the communicative skills of pediatricians when they visited sick children, such as the absence of adapted vocabulary, insufficient communication or lack of adapted teaching resources.⁹

Results of these studies show the need for further research regarding the pedagogical and psychological training needs of health personnel. It is known that diseases may affect children psychosocially and, consequently, pediatricians should act taking that into account.¹⁰ Other studies analyze the communication between health professionals and patients with chronic diseases, illustrating the importance of psycho-pedagogical guidance in intervention with children.¹¹

This previous research was continued with other studies^{12,13} which specifically revealed the educational and psychopedagogical needs of pediatricians and nurses, providing proposals for improvement adapted to the Balearic context and transferable to similar contexts at national and international level. These include the needs related to the communication of the diagnosis or giving bad news to families, promoting the self-management of the disease by children and

coordination among health professionals and teachers.

As said before, among the results of this project, it was highlighted the need of improving the communication and coordination with schools. There was particularly identified the need to inform and train teachers about the diagnosis, health condition and continuous care of the child taking into consideration the ethical issues involved such confidentiality. Although parents recognized in this project their role in giving this information to schools, in general it was considered that health professionals are the most appropriate professionals to do so, especially regarding the prevention of the physical symptoms of the disease, possible emergencies and side effects of the medication.

So, besides the fact that some children count with specific assistance in schools, very often the lack of communication with teachers translates into anxiety and gives rise to doubts about what is best for the child in the school context. Teachers are afraid of being involved in an emergency situation if the child becomes ill in school and this gives them a lack of confidence to deal with unexpected events. Beyond these particular situations, it seems that children with chronic disease require a coordinated intervention which involves teachers, families, health professionals, as well as their peers.

When it comes to Rare Diseases (RD), it is possible to observe a high degree of dependence, as well as social, health and economic burden for the families.¹⁴ According to the World Health Organization (WHO), there are about 7000 different RD (of which about 5,860 are in the Orphanet database), which affect those patients in their physical, mental and/or their sensory condition.

At European level, it is considered rare disease when affects less than 5 persons per 10,000 inhabitants. It is estimated that in Spain there are more than 3 million people with RD, and in the European Union (EU-27) between 27 and 36 million, equivalent to 6-8% of the population.¹⁵ The 50% of these diseases begin to manifest in early childhood, two out of three before 2 years; and attributed to 35% of the deaths during the first year of the disease, 10% between 1 and 5 years, and 12% between 5 and 15 years.¹⁶ Due to the low prevalence of RD, there are many obstacles (late or non-existent diagnosis, lack of information, lack of knowledge of doctors and teachers, among others) which may lead children and families to a sense of inattention and isolation.¹⁷

Despite the fact that some RD are compatible with a normal life if diagnosed on time and treated,¹⁸ being affected by RD usually involves to suffer from birth or very young age a chronic, severe and progressive disease that generates a variable degree of sensory, motor or intellectual disability, for which it is not usually available in the short term a curative treatment, and all too often it is difficult to obtain information based on research.^{19,20} To respond to some of the above described needs, it is currently being developed in the context of the Balearic Islands the research project “Educational solutions for improving the quality of life of children with minority illness through innovative and transdisciplinary interventions” (EDU2016-79402-R), financed by the Spanish Ministry of Economy, Industry and Competitiveness.

The project aims to analyze the educational, social and health care that children and adolescents with RD receive to design educational solutions to improve their quality of life. Among other strategies the project will include the design and implementation of coordination and communication protocols between the school and the pediatric health services, as well as development of inclusive strategies aimed at raising awareness and training in health and teaching professionals. Then, the expected outcomes will impact on the improvement of educational and health services and therefore the quality of life of children affected by RD and their families.

Among the expected outcomes are:

- i. Elaboration of a practical guide with strategies to raise awareness about child RD.
- ii. Establishment of a communication and coordination protocol between the different services involved in care and education of children with rare diseases.
- iii. Improvement of the family quality of life by simplifying procedures in the social, health and educational public services.
- iv. Development of virtual environments and technological resources to raise awareness about RD and improve the communication and coordination among the different groups.
- v. Report of recommendations for improving the inclusion of children with RD in school.

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Conflict of interest

The author declares no conflict of interest.

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