



Needs of psychopedagogical training for the care of children with chronic disease: perceptions of hospital nursing

Necessidades de formação psicopedagógica para a atenção de crianças com doença crônica: percepções da enfermagem na atenção hospitalar

Necesidades de formación psicopedagógica para la atención de niños con enfermedad crónica: percepciones de enfermería hospitalaria

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ABSTRACT

Objective: To identify the psychopedagogical training needs of the pediatric nurses in the largest public hospital of the Balearic Islands, Spain. **Method:** This study was developed with a quantitative and qualitative design, where 78 nurses (97.5% of the service) answered a questionnaire, and 15 participated in interviews that were analyzed via content analysis. **Results:** The quantitative results show gaps in the knowledge and psychopedagogical skills of the staff. These aspects could facilitate the development of tasks tailored to the personality and the psychoevolutional time of children with chronic diseases, as well as to the emotional state of families. The qualitative data was organized into four categories: family support; hospital and education; psychopedagogical training and difficulties in practice. The little communication between nurses and teachers is evident. **Conclusion:** The data reinforces the need to implement training strategies and interdisciplinary work among health professionals, educators and families.

DESCRIPTORS

Child; Pediatric Nursing, Education, Nursing; Chronic Disease; Quality of life.

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INTRODUCTION

Hospital Pedagogy has traditionally focused on the psychoeducational aspects of children with chronic diseases, providing support both at emotional and academic level, and developing its scope in the hospital itself, in classes at the hospital or in the rooms and even in patients' homes when this is necessary⁽¹⁻⁵⁾. However, there are few studies that consider Hospital Pedagogy from a broader perspective, taking into account not only the educational work with children with chronic diseases, but also by extending the field of study to the identification of training needs of health professionals, and the development of proposals for educational intervention in hospital environments. Our study is focused on this last aspect, taking the three following groups of investigation as reference:

Firstly, the studies assessing the impact of the illness of a child on the family and how the disease influences the quality of life of all family members. Hence, we highlight the contributions of a worldwide comparative study that describes the impact on the quality of life of caregivers⁽⁶⁾, and another one that shows the family repercussions at psychological, social and functional levels caused by living with the chronic illness in children and the need of professionals' intervention⁽⁷⁾. Furthermore, the literature has described the needs families face when a child has kidney disease⁽⁸⁾, the state of distress in families with children with cancer⁽⁹⁾, the model of family management when dealing with the chronic illness of a child⁽¹⁰⁾, the impact on the quality of family life produced by the health of children⁽¹¹⁾ and the impact of asthma and diabetes on the stress and vulnerability of families perceived by children⁽¹²⁾.

Secondly, the studies focused on the relationship of pediatric patients with a chronic illness and its impact on their schooling process. This approach focused on how the disease can affect care and socializing⁽¹³⁾, self-image and school absenteeism⁽¹⁴⁾ or adaptation to school⁽¹⁵⁾. Similarly, previous studies have designed questionnaires aimed at families and teachers, with the objective of detecting the emotional and behavioral problems of children with chronic illnesses⁽¹⁶⁾. Also in agreement with this approach, the literature shows that the non-provision of the educational process in hospitals is a source of distress to families and has consequences in terms of developing self-esteem and the quality of life of patients and their context⁽¹⁷⁾.

Finally, although scarce, there are recent studies that specifically investigate psychological and pedagogical training needs, i.e. psychoeducational skills of the health personnel. Such studies explore the psychosocial effects of a disease and how pediatricians should act accordingly⁽¹⁸⁾, and also the importance of communication between health professionals and asthma patients, illustrating the relevance of psychopedagogical guidance in child intervention⁽¹⁹⁻²⁰⁾. More specifically, in a study carried out in the same hospital where our research was undertaken, deficient communication skills of pediatricians and nurses were detected when they addressed sick children, such as the lack of adapted vocabulary, insufficient gestural communication or the lack

of tailored educational resources⁽²⁰⁾. In line with this previous study, and based on previous research that determines how childhood diseases have an impact on the family and may also influence the schooling process, the present study is based on the premise that the role of pediatric nurses is key for providing close and continuous attention to children, in coordination with other health professionals and in close communication with their families. This study aims to identify the educational and psychological needs presented by nursing professionals assigned to pediatric services, taking into account the relevance of psychoeducational skills for a better performance of their tasks.

METHOD

CONTEXT OF THE STUDY

This study was carried out in the Department of Pediatrics of the Son Espases Hospital, a public referral university hospital in the Balearic Islands, Spain. In this country, the public health system is decentralized at the regional level, organized mainly into primary health care in health centers, and then specialized care in hospitals⁽²¹⁾. Traditionally, public health has enjoyed great prestige in the country. Although the Son Espases Hospital has an assigned area with a population of 330,000 people, it is considered the referral hospital for the whole Balearic population, because it has the most technologically advanced facilities and services, and is where the most complex interventions are carried out. Family and community care develop mainly at the primary level with pediatricians and pediatric nurses. However, children are often cared for during long periods at the specialized care when they have chronic illnesses.

PARTICIPANTS AND STUDY DESIGN

This is a descriptive study developed with a quantitative and qualitative mixed methodology. The quantitative part was carried out first using the questionnaire technique in order to have an overview of the greatest psychopedagogical needs as identified by nurses. The questionnaire was developed in different phases, including an initial literature review and a review of previously developed questionnaires on this particular research topic. As no validated instruments focusing on the targeted issues were found in the literature, a specific instrument was eventually designed, with expert participation in its development and validation. In addition, a pilot test was conducted in a context similar to the one of subsequent application in a smaller hospital, as recommended for this type of method⁽²²⁻²³⁾.

The final version of the instrument consisted of a self-assessment questionnaire with 32 items that examined participants through a Likert scale. The first part of the questionnaire was structured with sociodemographic questions such as the name (optional, since the possibility of being anonymous was offered), gender, years of professional experience and the department or unit of work. Then, the questions were presented in four parts:

Part 1: Involvement of family factors in the management of a chronic disease. The participants had to answer

their level of agreement (none, little, pretty or much) on factors such as family history of the same disease, educational level of parents, socioeconomic status, health habits, housing conditions, the ability to learn and inform oneself, as well as the support and cohesion of the family.

Part 2: Level of knowledge about aspects of child development, psychoeducational aspects and support services. The questions referred to the knowledge of the physical, psychomotor, intellectual, emotional and social development of children, to the knowledge of community and hospital resources of help to sick children and their families, as well as knowledge about educational services of hospitals and schools. In this part, participants were also requested to indicate in what way this knowledge is truly necessary to their daily practice at the hospital.

Part 3: Level of training in professional skills related to teamwork, communication with other professionals, families and children. This part also included specific questions about their training to deliver bad news or contacting the school.

Part 4. Level of agreement on six statements concerning the management of chronic childhood diseases and the psychoeducational resources in the region.

The questionnaire was provided to all pediatric nursing staff during the month of May 2013. The sample that participated in the study consisted of 78 nurses (18 men and 60 women), representing 97.5% of participation, with a confidence level of 95% and a sampling error of 0.075. In terms of years of experience, 17 participants had more than 16 years of experience, 28 had between nine and 15 years of experience, 22 had between four and eight years and one had less than three years. As the department or hospital unit where they work, 18 were staff nurses, 27 worked in the intensive care unit, six in the emergency room, one in external consultations and 28 in other services such as neonatal nursing and multipurpose nursing.

The purposive sample of the qualitative part of this study consisted of 15 nurses in total. There were three men and 12 women from the following departments: general plant (9), newborns (2), oncology (3) and emergency (1). This sample of professionals had a structure similar to the general population of the study. The professionals were selected from the sociodemographic data obtained from questionnaires and through snowball sampling.

The in-depth interviews were developed after following recommendations from the literature⁽²⁴⁾. They were carried out, recorded and transcribed during the months of October and November 2013. Subsequently, a content analysis was carried out following methodological steps of ordering, classification and final data analysis⁽²⁵⁾. We searched for information saturation, which is the time of the investigation when opinions of participants are repeated, redundant and no new information is provided. The rigor of this study has been achieved by various processes, including obtaining data from multiple sources and methods, which allowed the triangulation of data⁽²⁶⁾. Furthermore, ethical considerations were also taken into account during design and implementation, particularly concerning the rights and confidentiality of participants. To ensure the anonymity of participants,

they were given pseudonyms consisting of the letter N (indicating they are nurses) and a number (N1 to N15).

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RESULTS

Regarding the first part of the study, the studied nurses believe that the family factors that have *pretty* or *much* influence in the management of a chronic disease are family support (98.75%) and family cohesion (97.5%), followed by the level of knowledge of the disease (95%), family history (93.75%) and healthy hygiene habits (92.5%). Conversely, fewer respondents believe that doing sport regularly (21.25%), housing conditions (15%) or the socioeconomic status of the family (13.75%) have any influence.

Regarding the second part on the self-reported level of knowledge about childhood and adolescence development, 73.75% of the sampled nurses acknowledge they have *much* or *pretty* knowledge about the physical and psychomotor development and about intellectual and cognitive development (71.25%). The percentage stating to have this level of knowledge about socio-emotional development in children and adolescents (67.5%), or about the development of personality (53.75%) is slightly lower. On this last item, participants with more work experience also claim to have more knowledge about the development of children's personality.

With respect to knowledge on organizational aspects and the services provided to patients with chronic diseases, only 48.75% of surveyed nurses say they have *much* or *pretty* knowledge about associations and organizations related to the diseases of children they treat, and about the educational services of the hospital (51.25%). A lower percentage of nurses (43.75%) claim to know the work done in schools for children with chronic illnesses. Exactly 70% of participants feel that they have limited knowledge (*little* or *none*) of the services offered by the Balearic Islands' administration.

As to whether nurses use the aforementioned knowledge in their daily activities, it is noteworthy to mention that they responded affirmatively to all items related to psychomotor and educational development, as well as those related to organization and services. However, they stated that the most required knowledge in daily work relates to physical and psychomotor development in childhood and adolescence (85%) and intellectual development (83.75%). This result agrees with the issues on which participants claim to have more knowledge on. The knowledge considered less necessary for daily work is about the educational services of the hospital (76.25%), about the work of schools with children with chronic illness and the services offered by the administration of the Balearic Islands for patients with chronic diseases (75%). This result agrees with the issues on which participants claim to have less knowledge on.

Regarding the third part of the questionnaire, the respondents mostly recognized as having significant training

in the acquisition and use of teamwork skills (100%) and for work with other health professionals (97.5%). However, they felt they had little or no training on how to deliver bad news (67.5%) or how to communicate with the schools of children with chronic diseases (52.5%).

The fourth part of the questionnaire where respondents evaluate different statements regarding psychoeducational aspects stands out that 96.25% of nurses agree that patient education (understood as an optimal level of information and comprehension) is an important factor in the treatment and management of any chronic illness. In addition, 86.25% of respondents agree that in the Balearic Islands there are a lack of services that provide educational and psychoeducational help for health professionals.

The data from the qualitative part of the study confirms and deepens the results of the quantitative part. This section presents the results from the four categories identified in the thematic analysis: family support, psychopedagogical training of nurses, difficulties in the practice, and the role of the hospital as an educational institution. Regarding the first theme, the contributions of those interviewed who believe that family support is essential to provide good health care are noteworthy, and although one cannot always count on that, it is their function to get this support and involvement. In general, the participants believe that families bear a psycho-emotional, physical and financial burden due to the impact of the children with chronic diseases on their families. It is common that families seek the collaboration of nurses to cope with the many duties required by the sick child, sometimes in ways the nurses consider apart from the professional tasks in their field of work, as illustrated by the following quote:

It is important to have family support. We have children whose parents do not comprehend them ... and neither does the rest of the family. And they provide less support. I think the cultural level also matters. With new technologies, the parents try to monitor everything and be up to date in every way to help their children through the internet and the associations. But many times they delegate to the nurses and want us to take the initiative of certain things... (N6).

With regard to training, in general, the group of respondents felt they have gaps in terms of psychology training. From their perspective, this knowledge is important for the development of their professional practice. However, it is perceived as more relevant in primary health care than in specialized care due to the role of continuity of care for families throughout the life cycle in the primary level.

I don't think I have much knowledge about the psychological development of children. I had some notion of psychology, but very superficial (N1).

What I know I've learned by myself because in college I had no such training. For me, the practice and my children were what really taught me (N5).

I think they need this knowledge in primary health care more than we do. They are the first to notice if they have language disorders or other alterations. I believe that this training should be mandatory for primary health care, because they are the first screening. For us I don't see it as mandatory, but as basic training (N3).

Despite considering that psychopedagogical knowledge is important in, for example, health guidance, their answers reveal the complexity of its implementation. It also shows that nurses do not have the status of a teacher to make suggestions for parents, as illustrated by the following statement:

However, in these aspects we have our hands a bit tied. Perhaps the teachers spend more time with the kids, but we are rarely alone with the children, the parents are always present. And in front of a parent ... it doesn't even occur to make any comments on the child's behavior because they often believe that it's justified by the disease. We try to make parents see that this is not the solution, but of course, it is not easy (N4).

Finally, from the interviews it stands out that coordination between school and hospital is virtually nonexistent. The staff's knowledge about community public resources to support families is also scarce, despite the awareness of the role of patient associations and families. In general, they consider that in hospitals, preferably, there should be educational activities for professionals related to the grieving process of the disease or its acceptance in order to provide well-based support for children and their families. In this regard, they report that learning is based on what they consider their own errors in practice. Participants believe that in this way, they could be in a better position to provide long-term support and not just punctual. As example they have mentioned the interdisciplinary group sessions for accompanying the families carried out by the oncology service of the hospital. However, other services do not do this.

The family needs the support afterwards, not on occasion. When you give the bad news, it is important to do it in a good way, knowing how to do it, but then they have to process what you've told them and this is not taught anywhere. You do it wrong the first time, the second not so much (N2).

In connection with the above, the participants agree that the support for families is favored when there is a significant level of trust and continuity of care. Thus, they consider that nursing professionals are located in a privileged position to provide psychological and emotional support. As these professionals exercise care continuously, they get to know the families more deeply than other professionals who provide punctual care:

We're the ones who stay 24 hours with the children and their families. The amount of confidence that they have in us, they won't have in the doctor. We get to know them more, both the family as the children, we're the ones 24 hours there (N3).

DISCUSSION

The present study results show that family support is a key factor for the good management of chronic diseases in agreement with findings from previous research^(19,27). This makes it important that professionals properly explain to families and children about the disease process and how to deal with it adequately. However, data from this study refers to how nurses perceive their knowledge as limited when it comes to personality development in childhood and adolescence, key elements to launch psychoeducational strategies. Thus, it is revealed in this study that learning these strategies is based primarily on professional or personal experiences with one's own children and less so on a previous college education or specific training during professional practice.

The consideration that training in social, family, emotional and cognitive aspects and their influence on children belong more to the field of primary health care than to hospital care puts such knowledge in a place of relevance for monitoring healthy children or those with less serious pathologies, and to a lesser extent children with chronic illness requiring hospital care. Although the importance of these issues in primary health care is undeniable, in light of the results of this study, the nurses themselves recognize that care for children with chronic illness becomes so continuous, complex and intense that it undoubtedly lies in a privileged place that has to overcome the attention to the disease process experienced by the child to be placed as an essential pillar to meet the multiple needs of families⁽²⁸⁾.

All this shows that, somehow, although the knowledge of psychological and pedagogical nature are necessary for the practice, these aspects were insufficiently or inadequately treated during the previous education of participants in the universities where they graduated, pointing to the fact that it would be desirable to have training updated and specifically designed for pediatric services in hospital settings. According to other authors⁽²⁹⁾, a broader concept of health that goes beyond just biological basis demands a new professional profile, and needs to incorporate new ways of thinking about education into the training process, particularly when it comes to educating health professionals involved with children⁽²⁹⁾.

The consulted group testified that they have little knowledge of the work carried out by schools and a low mastery of the professional skills needed to communicate with teachers, although the literature suggests that schools represent a system close to children, in which the separation due to continuous hospital visits or stays can have a disruptive effect on them⁽¹⁷⁾. The need for training on communication skills, including the delivery of bad news to families is in accordance with other studies^(18,29).

In turn, the nursing staff of this hospital demonstrates limited knowledge of the services offered to the community, and of the educational services for the chronically ill and their families available at the hospital. This is similar to the findings in other studies with other professionals in the field of pediatrics⁽³⁰⁾.

Given this data, it appears that the clear identification of other areas where children participate, such as education, could serve as the backbone to improve the initial and continuing training of health professionals in pediatric services. Incorporating an enlarged view of children's everyday lives can also help to expand the view of professionals, by relocating the center of therapeutic intervention not only on physical wellbeing, but also on social and emotional wellbeing, with a positive impact on children and their families.

At the same time, the study suggests the convenience of implementing educational programs for children and their families, aiming at improving quality of life when living with a chronic disease, including not only the aspects related to healthy habits and the specific care required by the disease, but also emotional aspects, mourning processes and conflict resolution. Taking into account the considerations shown by the study participants and the results of other studies⁽¹⁷⁾, a better communication between health staff and hospital classrooms is recommended, as well as designing multidisciplinary programs that consider the experiences developed in other hospital services, allowing an accompaniment more sustained over time and of greater reach. In this sense, it seems appropriate that the implementation of these programs takes into account the technologies of information and communication, which can allow families not only to learn about pathology, but also to maintain more direct contact with professionals and others living with the same situation⁽⁵⁾.

These results also support the commitment to interdisciplinary work among nurses, pediatricians, educators and/or teachers and other staff involved in the care of children and their families, serving as a basis for closer communication channels and collaborative work aimed at improving the physical, mental and social wellbeing of children and their families. Knowing what children do at school can also be useful to identify how the school center can favor a better quality of life for the child or prevent hospital admissions is an important pillar for the development of preventive actions. Furthermore, the school is where it is possible to exercise a hospital pedagogy focused on explaining to children about issues related to hospital care.

Finally, it is worth mentioning the study's limitation of referring only to a group that works in the same hospital and has graduated from different universities. Although the results allow us to provide contextual and useful information for making proposals for intervention, in this study the organizational aspects that might be influencing the role of professionals were not taken into account. Faced with the possibility of developing a guide to good practice and transferable to other contexts, it would be appropriate to continue this project through expanding its participation to other hospitals, counting on the group of nurses working in primary health care and other professionals involved in pediatric services.

CONCLUSION

The results of this study show that the nursing staff within hospital pediatric services is performing continuous care for children with chronic illness. This leads to a relationship with these children and their families that should

be addressed to inform them about the pathology and its evolution, the delivery of bad news, to support them in accepting such news or to inform about care strategies. However, it seems that there are gaps in the staff's psychopedagogical knowledge, and such knowledge could facilitate the development of tasks tailored to the personality and psycho-evolutive time of children, as well as to the emotional state of families.

gological knowledge, and such knowledge could facilitate the development of tasks tailored to the personality and psycho-evolutive time of children, as well as to the emotional state of families.

RESUMEN

Objetivo: Identificar las necesidades formativas psicopedagógicas en enfermeras de pediatría del mayor hospital público en las Islas Baleares, España. **Método:** Se trata de un diseño cuanti-cualitativo, donde 78 enfermeras (97,5% del servicio) contestaron un cuestionario y 15 participaron en entrevistas analizadas con análisis de contenido. **Resultados:** Los resultados cuantitativos muestran lagunas en conocimientos y competencias psicopedagógicas del personal, aunque estos aspectos podrían facilitar el desarrollo de tareas adaptadas a la personalidad y momento psicoevolutivo del niño con enfermedad crónica y el estado emocional de las familias. Los resultados cualitativos fueron organizados en cuatro categorías: apoyo familiar; hospital y la educación; formación psicopedagógica y dificultades en la práctica. Destaca la poca comunicación entre enfermeras y profesores. **Conclusión:** Estos datos refuerzan la necesidad de implementar estrategias de formación y un trabajo interdisciplinario entre profesionales de la salud, educadores y familias.

DESCRIPTORES

Niño; Enfermería Pediátrica; Educación en Enfermería; Enfermedad Crónica; Calidad de Vida.

RESUMO

Objetivo: Identificar as necessidades formativas psicopedagógicas entre enfermeiros de pediatria do maior hospital público das Ilhas Baleares, Espanha. **Método:** Trata-se de uma pesquisa quali-quantitativa, na qual 78 enfermeiros (97,5% do serviço) responderam a um questionário e 15 participaram de entrevistas examinadas por meio da análise de conteúdo. **Resultados:** Os resultados quantitativos mostram lacunas no conhecimento e nas competências psicopedagógicas do pessoal, embora estes aspectos possam facilitar o desenvolvimento de tarefas adaptadas à personalidade e ao momento psicoevolutivo da criança com doença crônica, além do estado emocional das famílias. Os resultados qualitativos foram organizados em quatro categorias: apoio familiar, hospital e educação, formação psicopedagógica e dificuldades na prática. Destaca-se a pouca comunicação entre enfermeiros e professores. **Conclusão:** Os dados reforçam a necessidade de implementar estratégias de formação, assim como um trabalho interdisciplinar entre profissionais de saúde, educadores e famílias.

DESCRITORES

Criança; Enfermagem Pediátrica; Educação em Enfermagem; Doença Crônica; Qualidade de vida.

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