

RIASE

REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

NURSING CARE NEEDS FOR THE FAMILY OF THE CHILD WITH CHRONIC ILLNESS

Susana Evangelista Ribeiro – General Care Nurse - Pediatric Urgency Center Hospital of Setúbal, EPE - São Bernardo Hospital, student of the Master Course in Nursing Association/Specialization in Child and Pediatric Health Nursing

Gabriela Calado – Coordinating Professor/Specialist in Child Health Nursing and Pediatrics- University of Évora/Nursing School of S. João de Deus

ABSTRACT

From the birth of a child with a chronic and/or complex disease, there is a need at an all priorities level within the family and/or the primary caregivers of these children. A chronic illness is a condition that interferes with the day-to-day functioning of the child and their caregivers. As such, the **purpose** of this integrative review is to identify the needs of nursing care for parents/caregivers or family of children with chronic or complex illnesses.

Methods: The research was carried out on the EBSCO platform, and all databases were selected using the descriptors needs, parents, pediatrics and nursing. Taking into account the research delimiters and the inclusion and exclusion criteria, a final sample of eight articles was obtained, which were analyzed.

Results: The results were obtained from a free reading/analysis of the articles selected from the research in the databases, leading to the extraction of results that addressed the needs of nursing care to the parents/caregivers/family of children with chronic diseases.

Conclusions: Families and/or caregivers of children with chronic diseases and/or complex diseases circumvent many barriers and many of them difficult to overcome, but never giving up because they have many skills and power to deal with them.

Descriptors: Needs; nursing; chronic disease; pediatrics.

INTRODUCTION

Scientific and technological advances have positively influenced the decrease in infant mortality rates. That led to a consequent increase of these children's lifespan. Thus, it's important that the professional nursing practice focused in the interpersonal relationship of a nurse with a person or of a nurse with a group of people take into consideration the main needs of both the child and the caregivers. The nursing care provided by Specialist Nurses in the areas of Child and Youth Nursing are focused in the family, and they foster partnership in the care. A model of paediatric nursing care that recognizes parents as active partners and values their skills as caregivers for their children⁽¹⁾.

According to the model referred this is seen as a constant in a child's life, thus providing care for the intervening parties⁽²⁾. As such, providing care to maximize the health potential should begin in the early stages of the child's life⁽³⁾. For, it is in the family that interactions are established, and relationships are an essential element in the environment of the child's development⁽⁴⁾.

Chronic diseases are increasing world level at an exponential rate, without a differentiation of places or social groups. It is expected that until 2020 the chronic diseases account for 78% of all diseases in developing countries⁽⁵⁾. The declared not-mandatory diseases, such as cardiovascular diseases, diabetes, obesity, cancer and respiratory illnesses represents 59% of the total of 57 million deaths per year. 46% of the total of diseases represents a significant impact on health issues⁽⁶⁾.

The increased prevalence of chronic disease as well as the implicit needs for care and impact in the family emerges as a challenging opportunity for the nurses' intervention. Care is sustained or prolonged over time due to the chronic disease condition, which can be specified as a long-term disease that involves healthcare and specific treatments⁽¹⁾.

According to Fonseca and Canavarro^(a) the congenital anomaly is described as "as reações parentais iniciais são semelhantes à resposta de luto (choque, tristeza, ansiedade, culpa e raiva), que evoluem num processo gradual de adaptação, geralmente conducente à restituição do equilíbrio emocional." The same authors mention that "perante o confronto com o diagnóstico [...] o nascimento de um bebé [...] passa a ter uma tonalidade emocional predominantemente negativa". For the parents of these children the diagnosis constitutes a loss of their healthy and perfect baby, of their expectations as parents "esta vivência ultrapassa a intimidade familiar e passa a ser amplamente partilhada para com os profissionais de saúde"⁽⁷⁾.

Confrontation with the diagnosis implies the resetting of family roles, with different implications, emotional, social, personal, financial and functional⁽⁸⁾. Feelings of anxiety, stress, revolt and depression are experienced, according to personal standards that cannot be generalized⁽⁹⁾. Due to the very characteristics of the disease, such as hospitalizations or therapies of different nature, the family is faced with additional tasks, responsibilities and concerns regarding monetary issues and health care. Other problems are related with an uncertain future, emotional mourning, stigmatisation and prejudice perpetrated by society. All these factors can lead to social isolation, for instance⁽¹⁰⁾.

Nursing interventions should begin by signalling and promoting support for children with chronic disease, as well as their families. Thus, contributing to an articulation with the different intervening parties to support these children. In the sphere of specialized care in Child Health, nurses can intervene with the intent of promoting a progressive adaptation both of the child and its family in order to cope with the chronic disease⁽²⁾.

(a) Fonseca, Canavarro, 2010 apud (7).

Therefore, the mentioned intervention, can aspire to minimize the impact of stress factors related with hospitalization and with the chronic disease in itself. It is also within the specialist nurse's scope of action to refer children with chronic diseases to Healthcare Institutions or other specialized facilities⁽¹⁾.

To be able to care in a holistically manner, it is important to know the needs of the nurse care services. Literature review, as a method, will allow the identification and characterization of the needs that parents and caregivers have.

METHODOLOGIES

Literature review is an extensive revision method, which includes revising both and empirical literature. Different methodological approaches are also an important issue to address. The aim is to synthesize obtained results on a theme⁽¹²⁾.

The research was carried out on EBSCO platform, by selecting available data bases: CINAHL Complete; MEDLINE Complete; Nursing & Allied Health Collection; Comprehensive; Database of Abstracts of Reviews of Effects; Cochrane Central Register of Controlled Trials; Cochrane Database of Systematic Reviews; Cochrane Methodology Register; Library, Information Science & Technology Abstracts; MedicLatina; Health Technology Assessments; NHS Economic Evaluation Database.

The selection of articles was carried out on January 5, 2017 with the DeCS descriptors in English: *needs*, *parents*, *paediatrics* and *nursing* combined with the Boolean operator AND and delimited by integral text, without restriction of research field, date of publication, language or age group.

The following criteria inclusion were established: primary studies on the needs of family/parents/caregivers of children with chronic diseases and nursing care.

Exclusion criteria were also established: review articles and articles on project implementation (excluded because they focused on the methodology of the project and not on the needs of nursing care).

From the research carried out in the mentioned databases, with the selected descriptors and considering search limitations, an initial sample of 34 articles was obtained. 17 articles were selected after a first reading. 3 articles were eliminated based on duplication. 14 articles constituted the final selection. Exclusion criteria were applied and from those 14 only 8 were selected for full reading.

It is important to point out that ethic and deontological precepts, inherent to any academic work, were followed. The principle of academic integrity was respect⁽¹³⁾.

RESULTS

The obtained results derived from an interpretation of the selected articles researched in the databases. The results were extracted based on the care needs shown by parents/caregivers/family of children with chronic diseases. The following figure exhibits the flowchart according to PRISMA recommendations⁽¹⁴⁾.

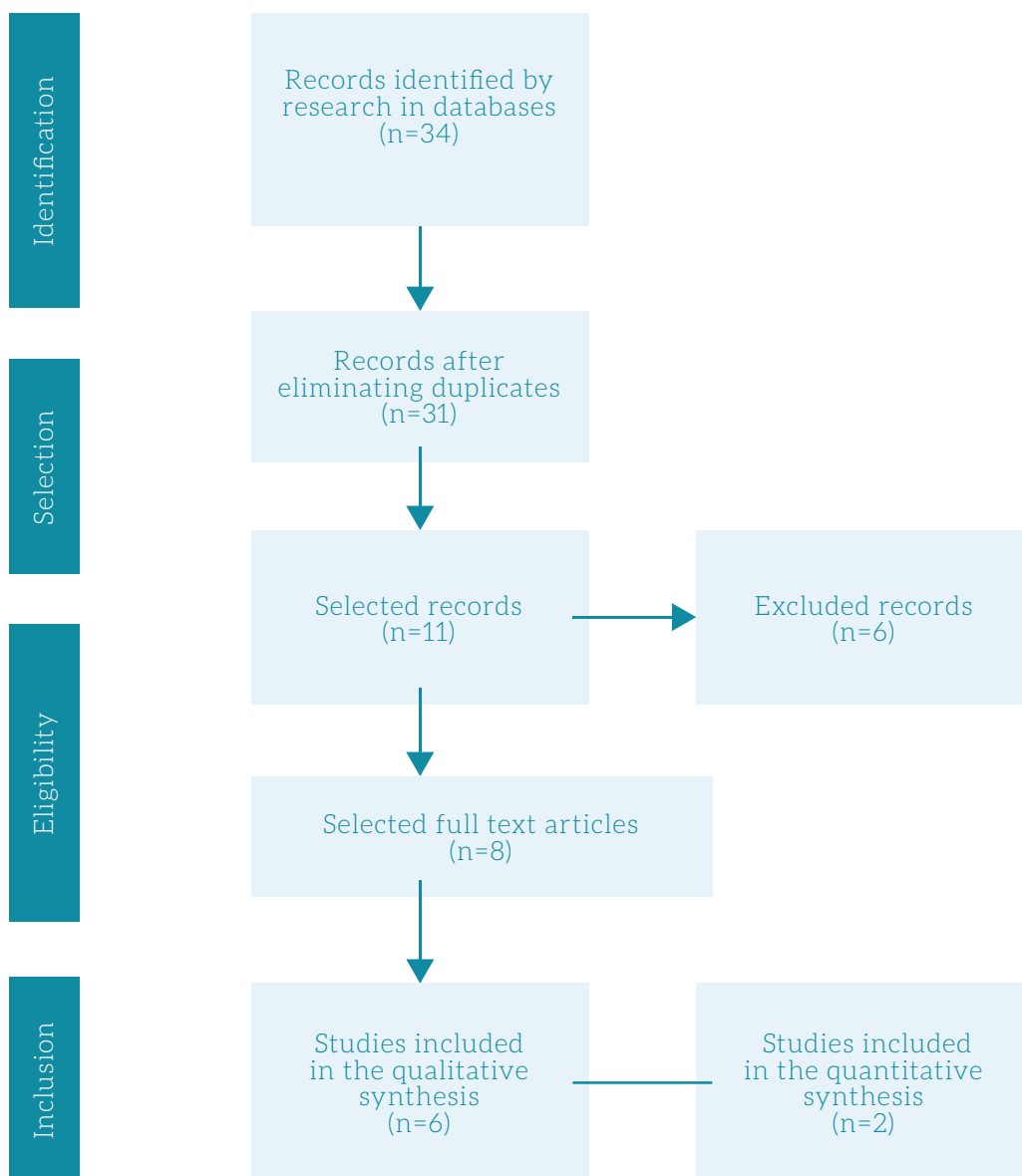


Figure 1 - Flowchart of the strategy of results.

After an exhaustive reading, the main elements of each article were systematized in table 1.

Table 1 – Data collection of selected articles.

Author and year	Methodology and Sample	Identified needs	Level of evidence
Juliet S. Tan, M.D., B.A.; Sharron L. Docherty, Ph.D., CPNP; Raymond Barfield, M.D., Ph.D., and Debra H. Brendon Ph.D., R.N., CCNS, FAAN. 2012	Descriptive and longitudinal qualitative method n=72 interviews to parents	<ul style="list-style-type: none"> • Expectations • Continuity of health care • Memory construction • Support network • Altruism 	VI
Mark Whiting. 2013	Qualitative Method - data collection from interviews to 30 children from 33 families. 26 only with mothers, 1 just with the father, 6 with both and 1 including the stepfather.	<ul style="list-style-type: none"> • Time • Dysfunctional family • Multiple rules 	VI
Ying Zhang, MinWei, Yaqing Zhang, and Nanping Shen. 2013	Quantitative method – data collection from questionnaires (analysis supported by SPSS and Cluster analysis) n = 388 intentional non-probabilistic sample 387 caregivers	<ul style="list-style-type: none"> • Material supply • Emotional support to all family members 	VI
Kimberly A. Allen. 2014	Qualitative descriptive method. Literature review n = 31 articles	<ul style="list-style-type: none"> • Information • Disease severity • No treatment options • Child interests • Religiosity and Spirituality • Support • Emotional Support 	V
N. A. Murphy; B. Christian; D. A. Caplin; P. C. Young. 2006	Qualitative method – filling in of a questionnaire. Next, there was a method collection data through a focus group (audio records of the discussion groups interactions). Data content analysis technique. n = 40 caregivers.	<ul style="list-style-type: none"> • Stress • Continuity of future care • Negative impact on caregivers' health 	VI
Mark Whiting. 2013	Qualitative method – interview technic (semi-structured interviews – individual conversations based on a schedule). 34 children from 33 families. 26 only with the mothers, 1 just with the father, 6 with both and 1 including the stepfather.	<ul style="list-style-type: none"> • Early diagnosis of the disease • Personal factors • Cultural factors • Personality factor 	VI

Table 1 - Data collection of selected articles.

Author and year	Methodology and Sample	Identified needs	Level of evidence
Gail M. Kieckhefer; Cristine M. Trahms; Shervin S. Churchill; Jessica N. Simpson. 2009	Cross-sectional descriptive study (questionnaires with descriptive, correlational and inferential statistical analysis) n = 129 parents	<ul style="list-style-type: none">• Deal with the disease/situations of exacerbation• Strategies to improve self-efficacy• Coping teaching strategies to deal with the chronic disease	VI

Of the selected articles, 6 use qualitative methodology and only 2 use quantitative methodology. Consequently, the samples are of small size, varying between 31 and 72 in the qualitative methodology and 129 and 387 in the quantitative methodology.

The level of evidence of the articles is also reduced with 7 articles with level VI of evidence, that is, evidences derived from a single descriptive or qualitative study and only 1 article has level V of evidence. This leads to the conclusion that the topic needs further study and depth.

The studies were analysed to identify elements that influence parents' needs. The needs to be found in these articles support a categorization in 3 distinct areas, technical support and emotional and continuous support (Figure 2).

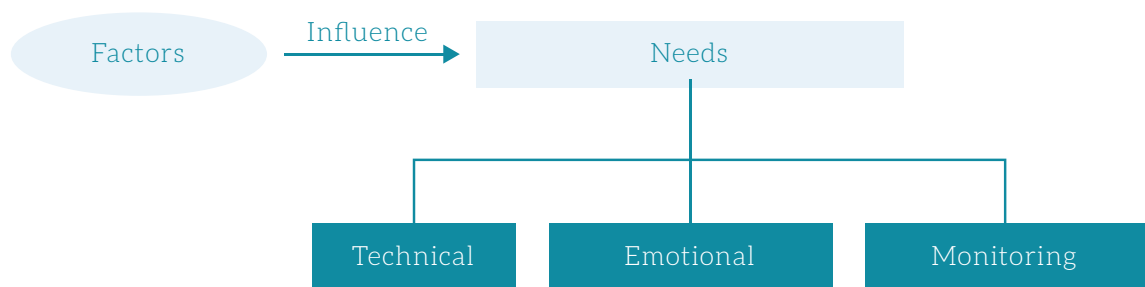


Figure 2 - Parent's main needs.

Then, the nursing care needs found in the 8 articles were listed and distributed in the 3 main categories as shown in table 2.

Table 2 - Subgroups of parental needs.

Needs		
Technical	Emotional	Monitoring
Information needs	Support Network	Deal with the child's special needs
Technical support	Stress	
Supply of material and technical means	Manage a family	Continuity of care
	Copying strategies	Memories construction
		Child's interests
		Early diagnosis
		Altruism
	Time	

DISCUSSION

When analysing the obtained results, it is possible to conclude that the healthcare needs to be mentioned by the parents are of diverse nature. They are worried about the **continuity of care** and future perspectives related to the child's health⁽¹⁵⁾.

The child support must include **technical** issues and **supply of materials**, but also strategies that diminish the impact both at the physical and emotional level. The circumstances do not only affect the child but all the family, having an impact on the family's quality of life⁽¹⁶⁾.

It is in the first years of life that the child develops family bonds, requiring constant care. This will only be possible if there is a calm, comfortable and affectionate environment attending for the best **interest of the child**. Most authors recognize that parents have a privileged role in the development of attitudes and beliefs regarding health issues⁽¹⁷⁻¹⁸⁾.

Parents/caregivers/families with a chronic disease diagnosis engage in a risky process, that is, they are more vulnerable due to the disease's circumstances. The disease takes away the parents'/carers'/families' strength. The disease involves an alteration of the family's routine and context. It can, as referred in the study, affect the mental and physical health of caregivers. It is important the existence of a **support network**, both on the psychological and emotional level, to help the carers overcoming existing barriers. One of the referred aspects is the support of third parties, in other words, the comfort of social media and their stories impact. The support of friends and institutions is significant for the families to successfully face the alterations that the disease brings to their lives. **Altruism**, that is, the solidarity or the satisfaction from similar situations is also referred as a need of caregiver parents⁽²¹⁾.

In an initial phase when the diagnosis is still in progress, it is very important to act sensibly when approaching caregivers. This is one aspect mentioned in the studies: non-existent of sensibility in the first approach to the disease. An **early diagnosis** is one factor that helps the adjustment and balance at the family level. The strategies adopted by the family, for example "**coping strategy**", are also important. Parents may face or confront problems. Parents develop skills to control stress factors that result from the different moments of the disease. This is an essential issue emphasized by parents⁽²¹⁾.

An aspect identified by all studies is that the frequent hospitalizations of the child are a **stress** factor. Parents are confronted with other situations, such as caring for their siblings, managing the family life and ensuring school activities. Parents describe the need to stand for the child in all aspects of daily life. Feelings of anguish, sadness, anxiety and fear of death explain the vulnerability that families experience. Sometimes families show deep exhaustion, lack of physical, mental, spiritual, religious and social strength to proceed. The expectations of a better life for the child and the possibility of having more **time** of coexistence also emerge as needs. The fear of not having enough time to be with the sick child leads caregivers to physical and emotional exhaustion⁽²¹⁻¹⁵⁾.

CONCLUSIONS

The present literature review intends to enable nurses, as health professionals, to acquire and update their knowledge of children needs with chronic diseases and their families' needs, based on scientific evidence.

Family has an essential role in the lives of these children because they see parents as behavioural models. After a chronic disease diagnosis, the parents/caregivers/family must readjust themselves to the disease and the care it requires. As a result, caregivers tend to suffer from physical and emotional stress, due to overprotecting the sick child, but also to the minimal attention given to the rest of the family.

In nursing practice, it is not rare to find negative emotions related to the suffering child. Yet, these feelings should be used to consciously improve the quality of the care provided. The work should be centred in the child and in the family, developing different levels of supervision⁽²⁴⁾.

BIBLIOGRAPHY

1. Ordem dos Enfermeiros (PT). Regulamento dos Padrões de Qualidade dos Cuidados Especializados em Enfermagem de Saúde da Criança e do Jovem. Lisboa (PT): OE; (2011).
2. Ordem dos Enfermeiros (PT). Regulamento das Competências Específicas do Enfermeiro Especialista em Enfermagem de Saúde da Criança e do Jovem. Lisboa (PT): OE; 2010.
3. Hockenberry MJ. Wilson D. Wong; Enfermagem da Criança e do Adolescente. 2.^a ed. Loures (PT): Lusociência; 2006.
4. Gonçalves M. Simões C. Práticas de intervenção precoce na infância: as necessidades das famílias de crianças com necessidades educativas especiais. Professores de Educação Especial. Gestão e Desenvolvimento. 2009; (17-18): 157-174.
5. Organização Mundial de Saúde [CH]. Cuidados Inovadores para condições crónicas. Relatório Mundial. Genève (CH): OMS: 2002.
6. Organização Mundial de Saúde [US]. Prevenção de doenças crónicas: Um investimento vital. Washington [US]: OMS, Organização Pan-Americana da Saúde; 2005.

7. Ramos M, Paulo V. A implicações da Doença Crónica na Família. *Revista Almada Forma*. 2015 Jun 8: p. 45-9.
8. Santos S. A família da criança com doença crónica: Abordagem de algumas características. *Análise Psicológica*. 1998; 1(XVI): 65-75.
9. Barros L. *Psicologia Pediátrica: Perspectiva desenvolvimentista*. 2.^a ed. Lisboa [PT]: Climepsi Editores: 2003.
10. Hockenberry MJ, Wilson D. Wong: *Enfermagem da Criança e do Adolescente*. 9.^a ed. Loures [PT]: Lusociência; 2014.
11. Direção-Geral da Saúde [PT]. *Programa Nacional de Saúde Infantil e Juvenil*. Lisboa [PT]: Ministério da Saúde; 2013.
12. Melnyk BM, Fineout-Overholt E. Making the case for evidence: based practice. In: Melnyk BM, Fineout - Overholt E. *Evidence - Based practice in nursing & healthcare. A guide to best practice*. Philadelphia: Lippincot Wilkins; 2005, p. 3-24.
13. Nunes L. *Considerações éticas a atender nos trabalhos de investigação académica de enfermagem*. Setúbal [PT]: Departamento de Enfermagem ESS/IPS: 2013.
14. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*. 2009; 6(7 e1000097). <http://dx.plos.org/10.1371/journal.pmed.1000097>.
15. Whiting M. Children with disability and complex health needs: the impact on family life. *Nursing Children & Young People*. 2014; 26(3): 26-30.
16. Kierckhefer GM, Trahms CM, Churchill SS, Simpson JN. Measuring Parent-Child Shared Management of Chronic Illness. *Pediatric Nursing*. 2009; 35(2), 101-127.
17. Allen KA. Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*. 2014 5(9): 1289-1304. <https://doi.org/10.1016/j.ijnurstu.2014.02.003>.
18. Whiting M. Support requirements of parents caring for a child with disability and complex health needs. *Nursing Children & Young People*. 2014; 26(4): 24-27.
19. Oliveira BR, Collet N. Criança hospitalizada: Percepção das mães sobre o vínculo afetivo criança-família. *Revista Latino-Americana de enfermagem*. 1999; 7(5): 95-102.

20. Zhang Y, Wei M, Zhang Y, Shen N. Chinese family management of chronic childhood conditions: A cluster analysis. *Journal for Specialists in Pediatric Nursing*. 2014; 19(1): 39-53. DOI: 10.1111/jspn.12046.
21. Whiting M. What it means to be a parent of a child with a disability or complex health need. *Nursing Children & Young People*. 2014; 26(5): 26-29.
22. Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health & Development*. 2007; 33(2): 180-187. DOI: 10.1111/j.1365-2214.2006.00644.x.
23. Contim D, Chaud MN, Fonseca AS. As questões familiares e a criança e o adolescente com doença crónica: um estudo de revisão bibliográfica. *Nursing (São Paulo, Brasil)*. 2005; 8(85): 267- 271.
24. Smith PE. *Emotional labour of nursing revisited: Can nurses still care?* 2.^a ed. Hampshire (UK): Palgrave Macmillan: 2012.

Correspondence: mcalado@uevora.pt