

HOME CARE FOR CHILDREN WITH ASTHMA

CUIDADO DOMICILIAR NA CRIANÇA COM ASMA

CUIDADO DOMICILIARIO EN EL NIÑO CON ASMA

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Objective: to identify how family members/caregivers develop care for children with asthma at the home context. **Method:** qualitative research carried out in the first semester of 2014. The study was conducted with 15 family/caregivers of children with asthma through semi-structured interviews submitted to French discourse analysis. **Results:** after data analysis, the following categories were obtained: Children with asthma and social deprivation; Care mediated by knowledge acquired through experience. It was observed that caregivers develop the care process with overprotection of children. In addition, due to the fact that care is developed aiming to avoid exposure to factors that trigger the disease, social deprivation of the children takes place. Family care strategies come from everyday experience. **Conclusion:** the family/caregivers carry out the care process aiming at overprotection, causing social deprivation to the children and, often, to themselves.

Descriptors: Child. Chronic disease. Family Nursing.

Objetivo: identificar como os familiares/cuidadores desenvolvem os cuidados na criança com asma no domicílio. *Método:* pesquisa qualitativa desenvolvida no primeiro semestre de 2014. O estudo foi realizado com 15 familiares/cuidadores de crianças com asma por meio de entrevistas semiestruturadas submetidas à análise de discurso francesa. *Resultados:* após a análise dos dados, obtiveram-se as seguintes categorias: A criança com asma e a privação social; Cuidados mediados pelo saber da experiência. Identificou-se que os cuidadores realizam o processo de cuidado atrelado à superproteção da criança. Ademais, devido ao fato de o cuidado ser desenvolvido para evitar a exposição a fatores desencadeantes da doença, ocorre a privação social das crianças. As estratégias de cuidado dos familiares advêm da experiência do cotidiano. *Conclusão:* os familiares/cuidadores realizam o processo de cuidado voltado à superproteção da criança, ocasionando a privação social dos filhos e, muitas vezes, de si mesmos.

Descritores: Criança. Doença Crônica. Enfermagem Familiar.

Objetivo: identificar cómo los familiares/cuidadores desarrollan los cuidados en el niño con asma en su domicilio. *Método:* investigación cualitativa desarrollada en el primer semestre de 2014. El estudio fue realizado con 15 familiares/cuidadores de niños con asma por medio de entrevistas semi-estructuradas sometidas al análisis de discurso francés. *Resultados:* después del análisis de los datos, se obtuvieron las siguientes categorías: El niño con asma y la privación social; Cuidados mediados por el saber de la experiencia. Se identificó que los cuidadores realizan el proceso de cuidado junto a la superprotección del niño. Además, debido al hecho de que el cuidado sea desarrollado para evitar la exposición a factores desencadenantes de la enfermedad, se da la privación social de los niños. Las estrategias de

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cuidado de los familiares surgen de la experiencia del cotidiano. Conclusión: los familiares/cuidadores realizan el proceso de cuidado dirigido a la superprotección del niño, ocasionando la privación social de los hijos y muchas veces de sí mismos.

Descriptores: Niño. Enfermedad Crónica. Enfermería Familiar.

Introduction

Asthma is a chronic inflammatory disease with high incidence in children and adolescents. It is estimated that 300 million people worldwide are diagnosed with asthma. Clinically, the disease is characterized by recurrent episodes of sibilance, dyspnea, typical wheezing, chest tightness and cough⁽¹⁻²⁾.

Brazil is among the countries with the highest prevalence of asthma in the world, precisely occupying the eighth position ranking. Asthma is responsible for approximately 350 thousand hospitalizations in the Unified Health System (SUS) and it is the third cause of hospitalizations among children and young adults⁽¹⁾. Expenditures on severe asthma consume almost 25% of the income of the patients' families of less favored social classes, while the World Health Organization (WHO) recommendation is that these expenses should not exceed 5% of the family's income⁽¹⁾.

For all these reasons, chronic conditions are included in the strategic priorities of the country's public policies, mainly because they are associated with high-cost treatment and hospitalizations. Chronic diseases generate significant disorders among children, including school absenteeism, clinical fragility and drug dependence. These children need, therefore, a therapeutic plan to the follow up of their needs and also of the needs of their families⁽¹⁾.

The prevalence of asthma is high, ranging from 2.1% to 32.2% among schoolchildren and from 4.1% to 32.1% among adolescents. Despite the high prevalence in Brazil, epidemiological studies are still precarious, causing ignorance about the true dimension of the disease in different regions and states, which also depends on the level of environmental pollution⁽³⁻⁴⁾.

In children and adolescents, asthma control is directly related to the care exercised by family members or caregivers. Knowledge about the disease, adherence to treatment, proper use of medications and information are important allies in the control of asthma. However, the low percentage of asthma control, inadequate use of medications, low rates of diagnosis, inadequate treatment, popular myths, misinformation, and lack of monitoring may directly reflect on worsening of asthma and hospital readmissions⁽⁵⁻⁶⁾.

With regard to family caregivers, they are regarded as fundamental in the adherence to treatment. They are often instrumented to develop health care in the home context and the family experience a reorganization in order to cope with the chronic disease.

Family caregivers of children with chronic diseases need to reconcile work and study, share household tasks, adapt their home, and seek resources in the institutional and social support network⁽⁷⁾. In view of these aspects, it is fundamental that the nursing work act in favor of care, recognizing the knowledge that family caregivers have and helping to promote their autonomy to develop home care⁽⁸⁾.

Families that deal with chronic diseases have to face demands for care that require constant vigilance, care measures that family members need to incorporate into their daily lives in order to maintain the children's health, which represent a challenge the families⁽⁹⁾.

Therefore, it is necessary to mediate care practices based on the fundamental knowledge of Nursing. In this sense, it is necessary to know the meaning that the children and their relatives attribute to asthma, then explain the illness and its treatment to them with an appropriate

communication method to their level of understanding and, in relation to the relatives, minimize the anxiety and possible feelings of guilty. Children need to be encouraged to enjoy the typical life and activities of their age, as well as parents encourage need to be encouraged not to overprotect their children⁽³⁾.

The present study is justified by the need to unveil the uniqueness of the home care developed by family members/caregivers of children with asthma. In view of the above, the question set for the study was: how do family members/caregivers of children with asthma develop home care? This study aimed to identify how family members/caregivers develop home care for children with asthma.

Method

Exploratory and descriptive study with qualitative approach. Data collection was performed through a semi-structured interview, in order to give voice to the study participants⁽¹⁰⁾.

Open questions were used to make participants to retrieve their latent memory regarding the home care provided for children with asthma. The questions were: Do you know what asthma is? How do you recognize an asthmatic crisis? With whom did you learn to care for this child? Has anyone advised you on how to develop home care? Do you get help from anyone to develop this care? When you have doubts, whom do you go to? What is your "child's name" care routine? From the moment you started to take care of "child's name" on, what has changed in your routine? Do you find it difficult to care for "child's name"? For how long has "child's name" being under treatment?

The study scenario was a public reference center for care of children with respiratory diseases located in the western border of southern Brazil. The service develops care by the SUS and represents a reference in the care of children with respiratory diseases, assisting a total of 1,950 children and adolescents at the date of realization of this study, with an average of 400 monthly consultations.

Participants were relatives/caregivers of children with asthma, who are part of the Childhood Asthma Prevention Program (CAPP). The study included family members/caregivers who attended the health service, as well as those who provided cared for children with asthma in the home environment. Family members who were unaware of the child's diagnosis or did not practice home care were excluded. The sampling was delimited by saturation, which is operationally defined as the suspension of the inclusion of new participants when the data obtained present some redundancy in the researcher's judgment⁽¹¹⁾.

Fifteen family members/caregivers were interviewed.

Data collection was carried out in the first half of 2014. Interviews were audio recorded and later transcribed in full-length. The French Discourse Analysis (DA) based on Michel Pêcheux's references, was used to give meaning to the texts produced and the organization of meanings⁽¹²⁾.

The DA allowed greater immersion with the universe of senses, the understanding of the subject, and the effects of meaning that determine their social position in the world. The DA reveals that the spoken language is not transparent, that speech is the word in movement, made up by the conditions of production, immersed in politics, in the debate and the confrontation of meanings. The discursive formation reveals the subjects ideological position and the different voices present in their discourse. These voices may be meaningful in polysemy, as well as in discourses built over time, such as guidelines received and/or information on child-care with asthma.

For applicability of the discourse analysis, after the transcription of speeches, linguistic materiality was given to the text by means of orthographic signs, chosen by the researchers, such as: (/) Short reflexive pause; (//) Long reflexive pause; (///) Very long reflexive pause; (...) Incomplete thought; (#) Interruption of the subject's speech; (||) Explanation/Correction of incomplete word or phrase; ([...]) Cut out of an

excerpt from the speech; (“...”) quotes indicate the speech or text of another. Subsequently, the figures of speech such as paraphrase, polysemy and metaphor were highlighted.

The study was approved by the Research Ethics Committee of the Federal University of Pampa under number 498.734. The participants’ anonymity was preserved, using the FC (family member/caregiver) coding followed by an ordinal numbering. The ethical precepts of research involving human beings were respected⁽¹³⁾.

Results and discussion

Fifteen family members/caregivers who deal with the chronic condition of their children in

the daily home context and who were followed up at CAPP were interviewed. Among these, 15 were female; 8 were between 30 and 40 years old, 5 over 40 years and 2 between 20 and 29 years. As for schooling, 7 had not finished elementary school and 4 had finished high school.

Regarding socioeconomic characterization, 53% lived with incomes of up to one minimum wage, and 47% declared income of up to two minimum wages.

These results show that child care is still exclusively carried out by women, mothers or relatives, as shown in Table 1. Factors such as financial difficulty and low levels of schooling expose families to social and health vulnerability.

Table 1 – Characterization of relatives/caregivers of children with asthma followed up by specialized services. Uruguaiana, Rio Grande do Sul, Brazil, 2014

FC	Link with child	Age	Schooling	Income (Minimum Wage)	Marital status
1	Great grand mother	76	Incomplete elementary school	Up to 2	Widow
2	Mother	32	High school	Up to 1	Married
3	Mother	43	Incomplete elementary school	Up to 1	Married
4	Mother	38	High school	Up to 2	Stable union
5	Mother	29	Elementary school	Up to 1	Married
6	Mother	31	High school	Up to 2	Married
7	Mother	33	Incomplete elementary school	Up to 2	Married
8	Mother	33	Elementary school	Up to 2	Married
9	Mother	31	Incomplete elementary school	Up to 1	Single
10	Mother	22	High school	Up to 2	Single
11	Mother	34	Incomplete elementary school	Up to 1	Married
12	Mother	34	Incomplete high school	Up to 1	Stable union
13	Grandmother	57	Elementary school	Up to 1	Divorced
14	Grandmother	69	Incomplete elementary school	Up to 1	Widow
15	Grandmother	49	Elementary school	Up to 2	Married

Source: Created by the authors.

The qualitative analysis of the audio-recorded responses based on the elements of the DA

allowed the identification of two categories in relation to the care developed by family

members/caregivers, presented and discussed below: “Children with asthma and social deprivation” and “Care mediated by knowledge acquired through experience”.

Children with asthma and social deprivation

Due to the chronicity of the disease, the family routine has to be modified, because the children need care that changes the habits of the family nucleus. These changes are related to everything that should be avoided to protect the child. However, this deprivation, which includes physical, emotional and social aspects, occurs with varying degrees of intensity in the daily life.

I'm more careful with him [...] I do not let him do what he used to do before, he does not do it anymore, if he rides the bike for too long, he gets tired! So, I already took the bike from him. Playing ball also ... [...] I do not let him run [...] I will not let him leave to play! I no longer let him do certain things, which I know will harm him [...] (FC3).

[...] he has a puppy that I sometimes don't like so much [the family member smiles], but he has a dog, which in this case would not be very advisable, but if I turn my back [metaphorically speaking] he wants to play with the dog, but I do not allow it. (FC4).

You cannot have a rug, you cannot have curtains, a teddy bear [...] a cat inside the house, thus we do not have anything! (FC7).

My house has no carpet, my house has no curtain. All because of him, right? We do not have a cat, I do not have things like that... [...] run lotto much, he cannot. When he is [is] having an attack [in crisis] then ... he cannot do the things that others [other children] do ... he keeps practically resting all the time! (FC 15).

We can observe that family members/caregivers develop a care of deprivation and overprotection of the child with asthma. In order to avoid the asthmatic crisis, children are constantly subjected to restrictions in daily life.

It is critical that all children/adolescents and their families be aware of the asthma phenomenon. Professionals must also meet their biological, psychological and social needs, respecting the belief and culture of each family. The onset or worsening of the symptoms of asthma is common during school tests, stressful situations and/or family problems. Therefore, it is important that nurses promote dramatic therapeutic play sessions with these children⁽¹⁾.

Even so, families become fearful before the situation imposed by the disease, because they often do not know how to act in the role of caregiver or do not feel prepared to develop care and live with the child's chronic condition⁽¹⁴⁾. This situation may lead to an exacerbated home care. This excessive care is linked to insufficient guidance from health professionals, who do not prepare the family for developing home care. They only guide on what the children can or cannot do. Thus, relatives end up restricting the children in their social relations, in an attempt to prevent them or protect them from possible asthmatic crises.

The social relations of children in their socio-cultural environment can be hampered by the overprotection to which they are subjected and this, in turn, may be detrimental to their own intellectual and emotional development. These children are often unable to exercise their autonomy because of the norms and routines imposed by relatives⁽¹⁵⁾.

We also verified that the children are prevented from experiencing pleasant situations due to this excessive care, which may lead to feelings of sadness, since they are not allowed to play, run, eat ice cream, get wet by rain, be exposed to the sun as much as other kids, all activities that are considered normal in childhood.

Because of the complexity of the disease, children have trouble in personal and emotional relationships due to the exacerbated care displayed by their parents, family members and even teachers. This overprotection can make the children insecure and anxious, and may facilitate their crises. In this sense, adjusted measures of education and health promotion may reduce the incidence of crises, as well as the overcoming of asthma as a limiting and incapacitating disease⁽¹⁶⁾.

For the treatment of this condition, the children's active participation must be incentivized as much as possible, otherwise the disease will lead to physical, emotional and social limitations. In addition to drug treatment, it is necessary that family members have full knowledge about what the disease is, what are the triggering factors and the preventive measures for the acquisition

of skills that contribute to a better prognosis and quality of life of the children and of their families⁽¹⁷⁾.

The guidelines provided by health professionals about the management of children with asthma should help family members/caregivers to reduce overprotection and restrictions on children. Thus, it is critical that family members learn about illness, treatment, and care. In this context, we believe that the child's clinical condition is related to the way in which the family reorganize itself⁽¹⁸⁾ in face of the impact of this new health condition.

Thus, nurses must act as mediators between these families and the health services, in order to promote health education. Nursing consultation is recognized as one of the opportunities for developing bonding with these families with the objective of providing quality health care for the humanization and effectiveness of family care for children with asthma⁽¹⁷⁻¹⁸⁾.

In the nursing consultation, the nurse must provide integral care for the children's needs and also for the needs of their family, modifying the approach centered in the disease. Through consultation, it is possible to monitor, evaluate and intervene in the disease/health process, revealing a strong interactional and educational component centered on the family⁽¹⁹⁾.

Care mediated by knowledge acquired through experience

Family members/caregivers develop continuous care at home to control the disease and keep the child free from asthma attacks. In this way, some have learned to take care of the developed practice, perfected within their conditions and limitations and by the experience of seeing the disease in other relatives. Polissemically, this knowledge from experience was acquired through questioning family members about learning for care, as the following fragments show:

It was by seeing the other people I know who had the problem [asthma] that I've began to take care of him [the child with asthma]. [...] (FC1).

With my sister, who is a retired nurse. (FC2).

Alone! Alone, because I take myself as basis, so I learned... (FC3).

Look, most of if I learnt by researching, trying to get more informed. On the internet, books, things like that... (FC7).

My grandma! [...] she even does home remedies, she used to do them at the time of her children. My father also had asthma, so it's an old thing, right?! My great grandmother taught her and she taught me. (FC10).

I take care of them; I have always taken care of them. My father also had this problem [...] This is a family thing [the illness] it is by having to care for so long that we end up learning. (FC15).

The results show that the care process developed is based on the knowledge of experience, so that family members/caregivers rely on daily practice and experiences already lived and shared with other family members.

In this way, care is carried out according to the family's conception, through previous knowledge acquired through practice, search for other means, such as books and the internet, and also through the experience gained or performed by other family members.

In this perspective, another study also pointed out grandparents, just as the participant FC10 reports, as the main responsible for transmitting knowledge and practices about child care, through their life experiences acting as facilitators in child care⁽²⁰⁾.

Thus, the family faces the children needs, becomes aware of them and, faced with the scarcity of financial and social resources, feels anxious to offer the best possible quality of life, as the cure is not possible⁽²¹⁾.

Given this context, nurses should solve the doubts and inform on consequences that the lack of information and inadequate care may cause to the children and their families. With a comprehensive strategy to deal with the problem, nurses are expected to provide a more humanized assistance, integrating the families with the care provided to the children⁽¹⁷⁻¹⁹⁾.

It is important to emphasize that health professionals, especially nurses, need to be attentive to the expressions of the family members, since there is no innocent and neutral discourse. All reproduce a form of ideology that

gains value when contextualized in the daily life of the participants. Nurses should be able to identify the discourse as an event with the relative, and in this case, this happens when speaking about their existential situation and the daily care of the children who live with asthma⁽²²⁾.

Furthermore, it is essential to recognize the importance of the family as a participant in care. Health professionals must respect their limitations and difficulties, beliefs and values. This perspective advances in the model of health care in the sense of including the family as a participant agent of care, with a view to the prevention and promotion of children's health⁽²³⁾.

Families must not be blamed for frustration in the therapeutic process, because it is the responsibility of health professionals to review the forms of discursiveness with the family, proposing their more dynamic and active action in children care. The professionals must act as facilitators in the educational process, mediating the care shared with the family⁽²²⁾.

Nurses should carry out health education by realizing that this is an area of theories and practices that uses the links between knowledge and the health/disease processes of each individual and of the community. This knowledge is made possible by an interlocution between knowledge elaborated and constantly revised by science and common-sense knowledge⁽²⁴⁾.

In view of this, it is imperative that health education be included in Nursing care, based on the principle of respect for cultural diversity and the knowledge and practices of the family of these children. Assistance at the home environment and the Nursing Consultation in Child Care may be appropriate occasions to carry out health education activities and thus provide care focused on the promotion, prevention and treatment of respiratory diseases in childhood⁽²⁵⁾.

Conclusion

We conclude that family members/caregivers perform the care process aimed at overprotection of children, causing social deprivation of the children and, often, of themselves.

Restricted activities that are common in the daily life of children are normal in the perception of caregivers, who believe that deprivation is a care strategy, restricting the social network of the asthmatic children.

The knowledge gained and strategies used by family members/caregivers to develop home care come from shared information with other family members, friends, and people who have experienced similar situations, and from the experience gained in daily care.

Such care is mediated by the knowledge acquired through experience, developed through many efforts and routine care for the maintenance of the children's lives. This predominantly familiar care is shared with close people such as parents, grandparents and uncles, and sometimes solved in solidarity.

Although these children are in continuous follow-up at the health service through a specialized program for the treatment of asthma, we observed that the information provided to these families may not be enough, or even that the non-dialogical educational approaches used do not satisfy their needs to develop home care.

The study allowed to collect answers, but also led to new questions about the intervention developed with families in need of providing home care for children with chronic conditions. From this perspective, we suggest that nursing professionals, and especially nurses, promote health education with family members and be effective in guiding and monitoring home care.

Collaborations

1. conception, design, analysis and interpretation of data: Camila Fernandes Wild and Andressa da Silveira;

2. writing of the article, relevant critical review of intellectual content: Camila Fernandes Wild, Andressa da Silveira, Neila Santini de Souza, Fernanda Luisa Buboltz and Eliane Tatsch Neves;

3. final approval of the version to be published: Camila Fernandes Wild, Andressa da Silveira, Neila Santini de Souza, Fernanda Luisa Buboltz and Eliane Tatsch Neves.

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