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Family care for infants with respiratory diseases: an exploratory descriptive study

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ABSTRACT

Aim: To describe the family care aimed at infants with respiratory diseases from the educational practice of nurses. **Method:** This is a descriptive study using a qualitative approach. An outpatient pediatric clinic of a university hospital in Rio de Janeiro was the study scenario. Data collection took place between the months of September 2013 and January 2014 through semi-structured interviews with the mothers of infants. A thematic content analysis was used. **Results:** The data collected produced two categories: home-based care for infants with respiratory diseases, and family facilities and difficulties in terms of the home care aimed at infants with respiratory diseases. The practice was guided by life-sustaining care, by means of the adoption of environmental control measures and repair, with the prevalence of self-medication. **Conclusion:** A dialogic educational practice helps to take care of the integral mode of infants in the context of environmental health.

Descriptors: Health Education; Family; Respiratory Tract Diseases; Child Care.

INTRODUCTION

Respiratory diseases are among the prevalent childhood maladies that deserve attention due to their high morbidity. In 2009, morbidity indicators of hospitalizations by respiratory diseases in the Unified Health System within the metropolitan region of Rio de Janeiro was 36.63% in children under one year; and 42.65%, between one and four years[1].

These diseases affect children under five years because of the "immaturity" of the respiratory tract, particularly at risk are newborns and infants which present greater vulnerability and the need for comprehensive care to promote healthy growth and development[2].

The classification of risk for this service follows the Follow-up Committee of the state Pediatrics Society of Rio de Janeiro, a pioneer in Brazil, which suggests the follow-up of premature infants with low birth weight who have genetic syndromes, as well as other diseases that affect their quality of life[3].

In an attempt to change this scenario, several programs and strategies have been restructured and created by the Ministry of Health. These require health professionals to invest in educational activities involving and encouraging family participation in the adoption of preventive measures and other necessary interventions, thus becoming protagonists in their own health care, and that of their dependents, and achieving autonomy in providing child care[4].

Children's development is dependent on the family care received. The result can promote the overall health of children, which is essential to human development, and is considered one of the elements that can break social inequity, benefiting the development of a country[4].

This perspective, of helping the family in the care of their children, includes nurses, as their educational practices in health are part of their daily lives and are very developed through the nursing consultation, characterized as one of their private activities[5].

In the pediatric clinic of a university hospital in the State of Rio de Janeiro, we realized the recurrence of respiratory diseases in infants at risk during the nursing consultation, despite discussions with families regarding the adoption of life maintenance care and repair.

This fact causes unease to the professional and requires investigation, considering that these diseases may be related to the loss of weight or low weight gain, indiscriminate use of antibiotics, corticosteroids and inhaled solutions, which hinder the growth and development of children. We highlight the risks of complications such as pneumonia, which may require hospitalization, raising the costs and greater complexity of family health services and the possibility of death.

During the consultation a strong tendency was found for the family to use medicalization resources as the prevalent form of care, rather than preventive measures, which apparently are not appreciated in their speech. This situation is worrying because some respiratory diseases can be avoided with the adoption of maintenance care of life, including environmental control.

Life-sustaining care includes nutrition, hydration, cleanliness, comfort, affection and others. In this study we also include prevention measures, that is, environmental control. Repairing care is related to the care provided by family members for respiratory diseases[6].

However, some actions of the relatives concerning the worsening of the infant health can harm their growth and development. In this regard, a significant relationship was observed between morbidity and mortality from respiratory diseases, the precariousness of family knowledge in terms of the disease, and the quality of care received by the child in its home[7-8].

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During consultation with the families of infants, nurses must invest in the educational practice of health care as a strategy to minimize complications from respiratory problems and promote family autonomy in terms of care through a progressive, liberating and dialogical educational component. This technique enables reflection and critical vision[9] with a view to the construction of new knowledge directed to infant care.

Progressive education is not indifferent to the student's living reality; therefore, it is a political action that needs to be contextualized, believing conscious changes are possible for making decisions freely, expressing the so desired autonomy.

Starting from the importance of the quality of family care for infants with respiratory diseases and investment in educational practices during the nursing consultation, the following question emerges: from the educational practice of nurses, what home care is implemented by the family for the prevention and recovery of infants with respiratory diseases?

Thus, the objective of this investigation is defined as the description of family care aimed at infants with respiratory diseases based on nurse's orientations.

METHOD

This study is part of the research "Educational practice involving the relatives of infants with respiratory diseases", presented to the Professional Masters in Nursing Care of the Aurora de Afonso Costa Nursing School, Fluminense Federal University in June 2014. This is a descriptive and exploratory research using a qualitative approach. Such an approach aims to meet the needs generated by the guiding questions of the study and seeks the understanding of a specific reality. It works with the universe of meanings, motives, aspirations, beliefs, values and attitudes[10].

The setting of the research was a pediatric clinic, a follow-up sector for newborns and infants at risk in a university hospital in the state of Rio de Janeiro, which prioritizes care for newborns and infants at risk, and in need of skilled care.

The team is composed of health professionals: a nurse, a doctor and a nutritionist per shift. The service takes place in the morning and evening, on a daily basis, except weekends and holidays. Every Monday afternoon, the families of newborns and infants also receive the services of a psychologist.

Family caregivers of infants with respiratory problems who have previously received specific guidance on nursing care for respiratory diseases were included in the survey. Obtaining such data for the selection of respondents was based on nursing records and the knowledge of users who attended monthly consultations in a follow-up, at risk clinic. Family members with physical (e.g., impaired speech and hearing) and mental (cognitive impairment, thought disorder and mood) disorders that prevented their participation in the interview were excluded. This assessment was based on records of prior consultations registered in medical records.

An informed consent form (ICF) has been prepared for all participants, with accessible language and in duplicate. The participants were informed about the objectives, securing their anonymity and voluntary participation. They formalized their participation by signing the informed consent form.

Data collection occurred through semi-structured interviews according to the script. In the first stage, sociodemographic data were completed by the researcher; in the second stage, the respondents' answers were recorded

by a digital recorder. All interviews were conducted by the researcher from September 2013 to January 2014. Seventeen mothers participated in the interviews, and the criteria for the closure of data collection took place when there was a sufficient repetition of lines that enabled a consistent discussion on the subject.

The interviews were transcribed considering the opinions, attitudes, words and representation of the subject of that moment, as well as emotional expressions, voice intonations, pauses and other relevant aspects. After transcribing the interviews, we carried out an exhaustive reading of the material to start the steps of organizing the results into categories and subcategories for analysis.

The analysis was the thematic content type, where the theme is the main element and can be represented by a word, sentence or summary. It consists of discovering the units of meaning present in the communication that may have significance for analysis, according to the frequency of appearing in the speech or text[10].

The trajectory of this analysis followed the following steps: pre-analysis, material exploration, proper analysis and processing of results, inference, and interpretation.

The pre-analysis consisted of organizing the material through exhaustive reading, to have a vision of the testimonials and consequent development of the assumptions that supported the analysis with a choice of ways for initial classification. The material exploration phase involved the distribution of passages, sentence fragments partial sentences, new reading, the identification of units of meaning by inference, core analysis in order to group it by themes, and the development by themes linking to the theoretical framework.

To process and interpret the results, the data was held in categories for further analysis, establishing a correlation between goals and theoretical frameworks.

Data were organized into two categories: home care aimed at infants with respiratory diseases, and family facilities and difficulties in terms of home care for infants with respiratory diseases.

The study was approved by the Research Ethics Committee of the university hospital in 08/12/2013, under opinion No. 357,188 provided in accordance with Resolution No. 466/12 of the National Health Council, which regulates research involving human subjects.

RESULTS

Seventeen interviews were held with family members who care for infants with respiratory diseases. All participants were mothers of infants and the age range varied between 22 and 44 years.

The risk situations presented by the infants of the mothers interviewed for monitoring at the follow-up clinic were: six by congenital malformation; three by genetic disease; three by prematurity, in which two were born with 29 weeks of gestation; two by gastroesophageal reflux disease; one by birth asphyxia; one by neurological disease; and one by congenital disease.

Home care provided to infants with respiratory diseases

It was observed that the care provided by mothers to their infants when they presented respiratory problems was related to the environmental control measures for prevention and the direct care of infants.

Regarding the care of environmental control, the mothers reported that they aired the environment; removed carpets and curtains from the home, or at least from the infant's room; they eliminated dust by mopping floors and wiping furniture; they avoided sweeping and cleaned their house on a daily basis, or more

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often than they did before; they withdrew soft toys; they did not use cleaning products with a strong odor; they did not use talc and fragrance with infants; they did not wash their clothes with laundry detergent; and had no domestic animals with fur.

> I used carpets, curtains; I removed the curtains, the carpets and the plush toys. I took everything. I put an end to everything. (E 01)

> I don't wash his clothes with laundry detergent. I wash it with coconut soap. (E 05)

> First I mop the floor, then I sweep it. I have no animals, animals with fur. This is how I take care of it. (E 07)

> I avoid leaving him near perfume ... I don't even use it ... I clean the house with a disinfectant without perfume. (E13)

> There is no teddy bear, there's nothing that can gather dust ... (E 17)

Reports on the direct care of infants with respiratory problems pointed to drug use, offers for good food and liquids in larger volumes, improving nostril hygiene with a saline solution to thin secretions, external cleaning of secretions with a handkerchief or hygienic paper tissues, and elevation of the head of the bed while sleeping to improve breathing.

> Nebulization, serum in the nose, you know? Wash the little nose and much nebulization with a saline solution... (E 03)

> I nebulize her at home and give the syrup when she begins to cough... For the nebulization, I use serum and atrovent®; I do not use berotec® because it speeds up the heart. When she gets really out of breath, her breathing increases and she gets a fever, then I take her to the hospital. (E10)

> I nebulize her with serum, berotec® and atrovent®. I put two drops on one and a drop on the other... (E 12)

> I change the medication. I give her the crisis dose. (E13)

> When he is very short of breath, I lift him up, I put him straight... Don't leave him lying directly straight; always put his little head up too. (E 01)

> I give him food and plenty of fluids. That's what I do. (E 04)

> I try to give him more fruits, more liquid, orange juice, cashew juice because he likes it so much, lemon juice, all he can drink, acerola, and acerola with orange, grated carrot... I put his pillow high, so he can lie on a higher position. (E 12)

> I don't clean his nose with a cloth... I wipe it with paper, that paper, tissue paper to protect him from some bacteria; because it is no use to clean him if you get a piece of cloth and wipe his nose and after a while clean it again. (E 05)

Family facilities and difficulties in the home care of infants with respiratory diseases

The facilities reported by interviewees were very attached to the guidelines previously received from nurses and doctors. As a result of educational practice, some emphasized a change in behavior while taking care of infants with respiratory diseases.

> When I arrived here I didn't do anything. I knew that my son had that problem, but I didn't know what to do. The nurses were the ones who helped me in the consultations. I've been talking to them... (E 04)

> Anything we have, you explain, provide guidance, talk about the care we are supposed to have. (E 07)

> The nurses say they that we have got to take it off, we can't have it, and we have to clean it. I realize that the nurses are right. (E10)

> It's easy for me because they've already explained it to me, I was trained to do it; we learn many things here that we take and do at home. (E14)

The difficulties that interviewees experienced in terms of care are attributed to emotional imbalance, unfavorable living conditions, routine changes and the rejection of drugs by infants.

> There is much mold at home... The weather is very cold where I live... When the weather is cold his bronchitis gets way worse. (E 01)

> When he's like that, I cannot do anything but spend the whole day taking care of him. I cannot leave him alone because he gets suffocated, because at night he begins to stifle and cough. I sleep with him sitting on my lap, because he can't breathe... I stop doing everything I have to do. (E 04)

> I live on the roadside, so it's hard... As for dust accumulation in the environment, the difficulty is that he gets very stuffy, so he rejects the medicine a little, rejects the serum... It's not easy. Respiratory problems are always very inconvenient. (E 06)

> My house, the house where I live, has no ventilation, it is very damp on the walls, the wardrobe smells musty and the bathroom smells very bad too. (E 09)

> I find it hard because I'm too scared, like she is moving all night long, so I start to cry with her; I'm a little out of control. (E 17)

DISCUSSION

Family concerns are directed to the maintenance actions of life and repair, or treating the disease according to their beliefs, values, practices and knowledge already experienced. These arise from the knowledge shared through social interactions with members of the nuclear family and social support, which includes relatives, friends and neighbors, especially when facing the disease[6].

There are limits to family care" perhaps during health aggravations, given the lack of technical knowledge on the part of relatives. However, the family is the primary provider of care to its members, regardless of whether these members have any disease or not. In a

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disease condition, family care, however simple it may be, deserves professional intervention in order to avoid complications from the disease or inadvertent care that can generate other health problems[6]. Healthcare professionals should encourage the family to preserve care for the maintenance of life, especially during illnesses. These are indispensable to continuing the development of the person and should be added to the repair care, or treatment, to prevent destabilization or aggravation of the disease[6].

This investigation pointed out family care, both repairing care and the maintenance of life during respiratory diseases; however, the maintenance of life was less expressive regarding hydration and nutrition. This finding was also observed in another study in the city of Rio de Janeiro[11]. Nonetheless, a study in Singapore highlights food and hydration as the most used maternal care for the treatment of diarrheal disease[12]. The supply of liquid and eating healthily are the recommendations issued by the strategy of the Integrated Management of Childhood Illness (IMCI)[2] and by another author[6] as essential home care during illness; in this case respiratory disease.

This result may reflect the worldviews of most mothers with regard to the treatment of diseases, whose change, in terms of conscious behavior against the illness, requires discovering the reasons of being and acting. Therefore, educational practice has a responsibility to disseminate information to mothers and families to improve their knowledge, attitudes and practices to reduce the morbidity of respiratory diseases, which is one of the IMCI strategies[2]. Moreover, this practice should enable the user to view the interface of social, economic, environmental and cultural factors, whose influences are essential to ensuring the health.

The literature indicates that respiratory infections are the main causes of self-medication[13-14], and mothers are the main reasons for this practice. Studies have shown that the choice of drugs occurs through the use of previous prescriptions[13-15], and can be justified by a deficiency and the quality of the health care system in certain contexts[15]. Such findings were not found in the statements of the mothers in this study, considering that their infants have access to high-complexity services and are assisted by a multidisciplinary team.

Self-medication was highlighted in this research, and the mothers have primary responsibility. Besides being the available family resource, self-medication constitutes a culturally constructed knowledge in terms of community practice, and is observed in other studies[11-13-14]. Self-medication is performed based on previous prescriptions or the previous guidance of a pulmonologist for administering medication to infants with lung diseases and in a crisis situation. This maternal behavior worries nurses; despite the fact that this practice brings security to mothers and avoids the physical and emotional exhaustion in the search for more frequent visits. However, it may postpone the evaluation of the child by undue medicalization when signs of wheezing and dyspnea can be those of bronchitis or pneumonia, requiring professional intervention. In this case, the author[6] is emphatic in expressing that any sign of abnormality should be evaluated by a health professional, establishing that the limit of family care should be restricted to life-sustaining care[6].

A positive finding of the study was not checking the administration of antibiotics. This can be explained by the implementation of the Resolution of the Board of Directors (RBD) no. 20/2011, of the National Health Surveillance Agency (ANVISA), with the sale of this drug controlled by presenting a prescription[16].

Healthcare organizations need to welcome its users, and allow them the right to express

themselves regarding the situations or objects in the pursuit for the service. The theme of self--medication has been discussed between the nurse and family members of infants during the nursing consultation, considering the risks of complications to the child's health, and the opportunity to listen to the mother or other family members in terms of the reason for this conduct. Nurses are responsible for talking to mothers and families about the risk of complications for infants' growth and development when drugs are randomly administrated without a medical evaluation. Along with this, they are supposed to propose care for the maintenance of life such as food, oral hydration, and comfort to the infant, through cleaning the nostrils, postural drainage by raising the head of the infant, and strengthen the guidance to family members to identify the disease signals from the infant's respiratory condition when professional care is required.

As to maintenance care, we also highlight the care aimed at environmental control, which is widely used by mothers during both respiratory diseases and to prevent these problems. Environmental control care[17] is often discussed with mothers and/or family members of infants during the nursing consultation, and was apparently little cited by them during consultations as one of its home care practices. However, the results of this research show that mothers used various types of environmental control care, and associated odors and dust with the appearance of respiratory problems. They also mentioned the difficulties and facilities they perceived when carrying out such care.

Some obstacles have been experienced by mothers for the achievement and effectiveness of care and were related to feelings of apprehension, despair and insecurity in the face of complications. This emotional instability was observed in other studies related to maternal care in children with respiratory diseases, and in family life while coping with chronic diseases, especially in abnormal situations[11,18]. However, the mothers who reported emotional imbalance, attributed to a lack of knowledge in terms of home care when dealing with respiratory diseases, are those who reported caring for their children with medication and comfort care to improve respiratory distress. They recognize the gravity of the situation, which can lead to infant death.

Unfavorable living conditions, with little or no ventilation, infiltration, and mold on walls and cabinets, were cited by mothers as difficulties for care. Environmental conditions are among risk factors for the emergence of respiratory diseases of allergic etiology[17]. One of the mothers cited the difficulty in keeping the house clean due to the fact that she lives on a street with heavy traffic. This situation is evidenced in the literature relating to environmental pollution caused by fumes from cars, as another trigger for allergic respiratory diseases[17].

Other difficulties described by mothers when their babies had respiratory diseases related to the mother's change of routine, lack of collaboration for care, and the rejection of medication by the infants.

The facilities found by mothers were associated with the guidelines previously received from health professionals such as nurses and doctors, viewing behavioral changes in terms of the care aimed at infants with respiratory diseases. Some mothers attributed their facilities in care because of previous experiences with respiratory problems.

A survey showed the perceptions of nurses in terms of their humane approach, with an appreciation for, and respect of, the health needs of family members of infants during nursing consultation in child care. They realized that this form of care helped to strengthen ties between mother/child/nurse, favoring the accession of

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the family regarding the guidance received. The dialogue established between nurses and families positively impacted on the health problems detected and gave visibility to the nursing consultation as a space for dialogue and bonding opportunities, so essential in improving the quality of care received by the infant at home, thus favoring child growth and development[19].

Educational practices have long been used by various professionals and in various care settings; however, some professionals still do not realize that the essence of this practice is related to a dialogue and the sharing of knowledge to promote health, and not only for disease prevention.

A study conducted at the Family Health Strategy in Paraíba, on the perceptions of doctors, dentists and nurses who guided their educational practices with children and adolescents suffering from chronic diseases, showed vertically integrated practices aimed at the prevention of disease, without an appreciation of the knowledge of their clients and without the recognition of the potentiality of individualized care as a health promotion space[20].

When the approach of professionals with users occurs through dialogue, contextualizing their living conditions and enhancing their knowledge and experiences, the link between professional and user is established, constituting a foundation for the production of health. Moreover, there is an opportunity to stimulate the transformation of a naïve consciousness into a critical one, not only in terms of care, but also in terms of the exercise of citizenship.

CONCLUSION

The survey results infer that educational practices contributed so that mothers could adopt environmental measures to prevent and control respiratory diseases among their infants, thus contradicting the initial assumption of little appreciation from mothers in terms of these measures. However, some mothers realized that the effectiveness of this care finds barriers in their own living conditions, demonstrating the reflection on their care practice and the environment, and it can generate mobilizations to solve their problems.

We realized the need to expand discussions on self-medication and reinforce the search for care at health services when infants present alarm signals, for this moment requires evaluation and professional intervention.

The educational practice of nurses brought contributions to the family care of infants with respiratory disease, and confirmed the importance of the nursing consultation, a welcoming environment, dialogue, reflection and the construction of new knowledge. It is necessary for nurses and other health professionals to recognize users in their entirety, since their life stories cannot be dissociated from the health-disease process. Thus, educational practice demands knowledge from professionals in terms of the social, economic and cultural conditions that influence all relationships established between human beings, particularly in care.

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