ABSTRACT

Objective: to describe the sociodemographic profile of the family members of infants with respiratory diseases. Method: descriptive study of sociodemographic data conducted in a university hospital of Rio de Janeiro, RJ, with 17 family members of infants cared for in outpatient follow-up. A form was drawn up for the collection of demographic data, which were assessed through content analysis. The research project was approved by the Research Ethics Committee, CAAE 16348113.0.0000.5243. Results: all respondents were infants' mothers, whose age ranged from 22 to 44 years old, 11 had complete secondary education, 15 had family income between one and three minimum wages, seven lived in houses with four rooms, five houses had infiltrations or mold, with little or no ventilation, and 11 infants used antibiotics and steroids for respiratory diseases. Conclusion: the description of the profile collaborates to adopt educational activities by nurses in order to assist the families in the achievement of care autonomy. Descriptors: Health Education; Nursing; Respiratory Diseases; Family; Child Care.

RESUMO

Objetivo: descrever o perfil sociodemográfico dos familiares de lactentes com doenças respiratórias. Método: estudo descritivo dos dados sociodemográficos realizado em um hospital universitário do Rio de Janeiro, RJ, com 17 familiares de lactentes atendidos em ambulatório de seguimento. Para a coleta dos dados sociodemográficos foi elaborado um formulário e a análise dos dados foi de conteúdo. O estudo teve o projeto de pesquisa aprovado pelo Comitê de Ética em Pesquisa, CAAE 16348113.0.0000.5243. Resultados: todas as entrevistadas foram realizadas com as mães dos lactentes, a faixa etária variou entre 22 e 44 anos, 15 possuíam o ensino médio completo, 15 tinham renda familiar entre um e três salários mínimos, sete residiam em casas com quatro cômodos, cinco dos domicílios apresentavam infiltração ou mofo, com pouco ou nenhum arejamento e 11 lactentes utilizavam antibióticos e corticoides por doenças respiratórias. Conclusão: a descrição do perfil colabora para adoção de prática educativa pelo enfermeiro auxiliando os familiares na conquista da autonomia do cuidado. Descritores: Educação em Saúde; Enfermagem; Doenças Respiratórias; Família; Cuidado da Criança.

RESUMEN

Objetivo: describir el perfil sociodemográfico de los familiares de lactantes con enfermedades respiratorias. Método: estudio descriptivo de los datos sociodemográficos llevado a cabo en un hospital universitario de Río de Janeiro, RJ, con 17 familiares de los lactantes atendidos en seguimiento ambulatorio. Para la recogida de los datos sociodemográficos se elaboró un formulario y el análisis de los datos fue de contenido. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, CAAE 16348113.0.0000.5243. Resultados: todas las encuestas eran las madres de los lactantes, la edad osciló entre 22 y 44 años, 11 tenían educación secundaria completa, 15 tenían ingresos familiares entre uno y tres salarios mínimos, siete residían en casas con cuatro habitaciones, cinco de las casas tenían infiltraciones y mofo, con poca o ninguna ventilación y 11 lactantes habían usado antibióticos y esteroides para enfermedades respiratorias. Conclusión: la descripción del perfil colabora para la adopción de la práctica educativa por los enfermeros, ayudando a las familiares en el logro de la autonomía del cuidado. Descriptores: Educación en Salud; Enfermería; Enfermedades Respiratorias; Familia; Cuidado de Niños.
INTRODUCTION

This research emerged from my experience as a nurse during nursing consultations in the outpatient follow-up of newborns and infants at risk, pointing the recurrence of respiratory diseases in infants as the most frequent morbidity in the consultations. This situation causes concern to the health professionals and requires investigation, since these aggravations are responsible for loss or low weight gain, delay in development, frequent and indiscriminate use of antibiotics, steroids and inhalation solutions, burdening the family budget and harming children's growth and development. It is important to stress the risks of complications, such as pneumonia, which demands hospitalization, raising the expenses of family and hospitals. In addition, it can cause the death of newborns and infants in risk situations.

In the context of this study, the risk classification for this service complies with the Follow-up Committee of the Society of Pediatrics of the State of Rio de Janeiro (SOPERJ), pioneer in Brazil that suggests the follow-up of preterm newborns with low birth weight, who exhibit genetic syndromes, as well as other diseases that affect their quality of life. These users have increased vulnerability to diseases and require full, qualified, and resolutive care.

Respiratory diseases represent one of the most prevalent childhood diseases and deserve attention due to their high morbidity. In 2009, the morbidity indicators about the hospitalizations of children under a year and between one and four years of age with respiratory diseases in the Unified Health System (UHS) of the metropolitan region of Rio de Janeiro was 36.63 and 42.65%, respectively, constituting the second most common cause of hospitalization. Acute respiratory diseases affect children under five years of age due to the immaturity of the respiratory tract in this age group, mainly newborns and infants at risk, who exhibit greater vulnerability and greater need for comprehensive care.

Acute respiratory diseases are those in which there is an infectious inflammatory process, such as common cold, sinusitis, and pneumonia, or non-infectious such as allergic rhinitis, suffering the influence of pathogens, allergenic factors, and traumas. They are classified into high and low. The high acute respiratory diseases usually have a benign evolution and the low ones last longer periods and the children may have to be hospitalized putting their lives at risk if not properly treated.

Chronic respiratory diseases also affect the upper and lower respiratory tracts and the most common are asthma, rhinitis, and chronic obstructive pulmonary disease. Their occurrence is increasing in children and older adults causing negative impact on the quality of life, as well as on the economic and social conditions of the country. The preventable risk factors for chronic respiratory diseases are associated with smoking, environmental pollution, occupational diseases, sickle cell disease, and allergenic factors. Pneumonia, bronchitis, and tuberculosis are also risk factors because they cause lung scars. Therefore, the adoption of educational activities to promote proper care for the reduction of these diseases is essential.

It is considered that the physical, psychological, and social development of children has a strong dependency relationship with the care received from their families during childhood. The family represents an institution with possibilities of interventions for the promotion of daily care, favoring the integral health of children. This result is essential to human development and can be regarded as one of the elements that can decrease social inequality, favoring the development of the country. The health team is directly involved in the assistance provided to the families providing care to their children with the participation of the nurses, whose main activity is providing care in different scenarios, namely: health units; hospitals; home care; and companies, among others, as well as performing educational activities as care provided by the nurses in the nursing consultations.

The nursing consultation is a professional activity carried out by nurses in order to assess, intervene, and perform interactively with the users, so as to encourage them to develop skills to pay conscious care, deconstructing the view of care as a mechanical and thoughtless action. To this end, it is essential to stimulate the critical consciousness of family members about care which, despite being inherent in the human being, requires knowledge, zeal, dedication, and responsibility. It means saying that care is more than a performance; it is an attitude. Therefore, it covers more than a moment of attention, zeal, and commitment. It represents an attitude of occupation, concern, responsibility, and emotional involvement with each other.

Some actions of the family members in the face of an infants' diseases can cause other...
problems, including jeopardizing their growth and development. Regarding this fact, the literature showed evidence of a significant relationship between morbimortality due to respiratory diseases and the precariousness of family members' knowledge about the disease and the quality of care received by the child at home.8,9

One of the problems that interfere with the effectiveness of care provided to infants with respiratory diseases is the socioeconomic and environmental conditions, since they are risk factors for the emergence and recurrence of respiratory problems, mainly allergic diseases.10 Taking into consideration the indissociability of social, economic, and environmental conditions of the teaching-learning process and domiciliary care practices for infants, we defined the goal of this study, i.e., to describe the sociodemographic profile of family caregivers of infants with respiratory diseases, in order to help the nurses develop educational activities in accordance with the reality of life of family members of infants with respiratory diseases.

**METHOD**

This article was drawn from the sociodemographic data of the thesis “Educational practices with family members of infants with respiratory diseases”, submitted to the professional Master's degree in Assistance Nursing of Aurora de Afonso Costa School of Nursing, Fluminense Federal University (EAAAC-UFF/RJ) in June 2014.

It is a descriptive and exploratory study with a qualitative approach which sought to describe the sociodemographic data of the family members of infants with recurrence of respiratory diseases that attended nursing consultations in ambulatory risk follow-up. Knowing these data is extremely important for the development of educational activities based on the sociohistorical and cultural context of these families.

The scenario of the research was the pediatric outpatient clinic of the follow-up department of newborns and infants at risk at a university hospital located in a municipality of the State of Rio de Janeiro. The follow-up outpatient clinic provides care especially to newborns and infants who exhibit risk criteria and require specialized care, whose referral is based on two distinct ways in accordance with the criterion of the UHS regionalization. Newborns and infants at risk born at this university hospital are referred by the neonatology service with the first consultation already scheduled for outpatient follow-up.

Sociodemographic profile of family members of infants...

Those born in other institutions that make up the Metropolitan Region II of the State of Rio de Janeiro are scheduled for the first consultation in the Service of General Pediatrics and subsequently referred to the continuity of care in the outpatient follow-up.

This hospital is integrated to the UHS as a unit of high complexity and also assumes the commitment to teach and research, since it is an institution linked to the Ministry of Education. This institutional feature allows direct interaction of professionals with teachers and students, encouraging the sharing of knowledge and a more magnified view regarding child care.

Care provided at the outpatient follow-up is multidisciplinary and the team is composed of health professionals, namely: a nurse; a physician; and a nutritionist per work shift. The service takes place in the mornings and evenings on a daily basis, except weekends and holidays. Every Monday afternoon newborns and infants are also cared for by a psychologist. This outpatient follow-up is also a field of training for undergraduate nursing, medicine, and nutrition students who are supervised by teachers. They also provide care and collaborate in the teaching-assistance integration.

Family caregivers of infants with respiratory problems were included in the research and they received specific guidance in advance by the nurses about care for respiratory diseases. The collection of data for the selection of the participants of the research was based on nurses' records drawn in the charts and users' knowledge, who attend monthly consultations at the ambulatory for risk follow-up. Family members with physical disorders (e.g. impairment of speech and hearing) and mental disorders (e.g. cognitive disabilities; thinking and mood disorders) that prevented their participation in the interview were excluded from the research.

A form was drawn up for the collection of sociodemographic data. It included questions related to the variables of interest, namely: family income; education; religion; housing conditions (ventilation, aeroallergens exposure, moisture, lighting, sanitation, garbage collection, location, number of people per household); health services used and reasons for seeking these services; exposure to smoking; and medications used. The technique used for data collection was a semi-structured interview conducted by the researcher in two stages from September 2013 to January 2014. In the first step, the sociodemographic data were filled...
handwritten by the researcher and, in the second step, the respondents answered the questions prepared by the researcher, whose replies were recorded using a digital recorder. The analysis of the data was performed using content analysis through approaches and confrontation with the results of other scientific productions about the socioeconomic influences on care provided to infants.

The research was approved by the Research Ethics Committee of the School of Medicine, Fluminense Federal University in 12th August, 2013, under Opinion No. 357,188, CAAE: 16348113.0.0000.5243 in compliance with Resolution No. 466/12 of the National Health Council.11

RESULTS

A total of 17 interviews were carried out with family members who provided care to infants with respiratory diseases. All individuals interviewed were the mothers of the infants. The situations of risk exhibited by infants of the mothers interviewed for ambulatory follow-up were: six with congenital malformation; three with genetic disease; three due to prematurity, two births with 29 weeks of gestational age; two with gastroesophageal reflux disease; one due to asphyxia at birth; one with neurological disease; and one with congenital disease.

The ages ranged between 22 and 44 years old, with eight between 20 and 29 years old, followed by seven between 30 and 39 years old, and two between 40 and 44 years old. Of the number of mothers interviewed, ten reported being the only responsible for providing care to their infants and the other seven mothers shared care with other family members and with the day care as follows: three mothers shared care with the grandmothers; two with aunts; one with the father; and one with the day care.

The educational level of the mothers ranged from incomplete elementary education to incomplete higher education. There was a predominance of complete secondary education in ten mothers interviewed, followed by three mothers with incomplete secondary education, two mothers with complete elementary education, one mother with incomplete higher education, and one mother with incomplete elementary education.

With respect to race, 13 of the interviewees were classified as mixed race, two blacks, one white, and one Asian. Regarding religion, there was a predominance of Protestant with 13 respondents, followed by Catholic with two. Two interviewees reported having no religion; however they believed in God. The marital status of the 13 participants was single, but ten of them lived with a partner. Only four of them were married. Most of the respondents were from Rio de Janeiro, totaling 14 of them, and the rest were from the states of São Paulo, Ceará, and Paraíba, with one mother from each state.

With respect to the current occupation of the mothers, 12 were housewives, two were maids, one was a manicure, one was a sewing assistant, and one was a warehouse assistant. Of the mothers who worked, three had employment relationship. The family income of 15 of the interviewees was between one and three national minimum wages, one was between four and five minimum wages, and one had an income smaller than a minimum wage, with a value of R$ 678.00.

All the interviewees lived in houses, 15 of them in the urban area and two in the rural area. The number of individuals per household ranged between three and six, with three individuals in eight of the households, five individuals in four of the households, three individuals in five of the households, and six individuals in one household.

The number of rooms per household ranged between three and ten, and seven of the respondents lived in households with four rooms, three with five rooms, three with three rooms, two with six rooms, one with nine rooms, and one with ten rooms.

The housing conditions related to ventilation and the presence of infiltrations/mold on the walls and floors were questioned, considering the relationship with the manifestation of respiratory diseases, especially allergic diseases.12 It was observed that 12 houses were ventilated, three were not ventilated, and two were little ventilated. There was presence of infiltration and mold in six houses and the number of houses without infiltration was the same. Regarding the houses with ventilation, two had infiltrations, one house was undergoing alterations, and one had rugs and curtains, which is a condition of exposure of infants to the causative agents of allergic respiratory diseases, such as mold, dust, and other odors from products used in the construction. This situation is contrary to the recommendations of the Brazilian Consensus of Immunology for prevention of respiratory diseases.12

With respect to the presence of domestic animals, 11 of the interviewees mentioned having animals in their houses and six of them...
stated that they did not have animals at home. According to the mothers, the majority of the animals were kept in the backyards, but some infants had contact with them. There was a predominance of dogs in eight of the houses. There was a dog in one of those houses, in addition to birds, rabbits, and chickens.

As for the water supply source, 14 of the interviewees stated that they had water supplied by the general distribution network and three of them used well water. With respect to the availability of sanitation, 14 houses had treated sewage, and three did not have it. Of these houses, two had septic tanks and the waste produced by one house was thrown in the river that flowed beside the house. All the respondents reported that their garbage was collected between two and three times per week.

Regarding the use of other health services, all mothers reported taking their children to basic care units, family health strategy units, or family medical programs for immunization. According to the mothers’ reports, these were not always physicians in these units and, when there were physicians, they were pediatricians and, in many units, the service was carried out by nurses. In addition for immunization purposes, two of the interviewees also attended these services because they were benefited from the “Bolsa Família Program” (A social welfare program of the Brazilian government that provides financial aid to poor families). It was also found that 15 interviewees had already taken their infants to emergency services due to respiratory problems and others. Besides the services mentioned above, it was found that five interviewees had their infants followed up by other specialties, such as: genetics; cardiology; pneumology; nephrology; neurology; and immunology, followed by four mothers who, in addition to using the basic care, emergency, and specialties, also took their infants regularly for rehabilitation activities, such as: physical therapy; speech therapy; and occupational therapy in other institutions.

With respect to hospitalization, ten interviewees stated that their children had never been hospitalized; however, seven mentioned prior hospitalization of their infants, whose diagnoses for admission had been bronchiolitis, pneumonia, cellulitis, and pulmonary aspiration.

As for the use of medicines for respiratory diseases, the interviewees reported that 11 of the infants had already used antibiotics and steroids, followed by three that had only used antibiotics and two undergoing continuous drug treatment due to the frequency of respiratory diseases.

Most of the interviewees were not smokers, making a total of 11 out of the 17 mothers interviewed. Smoking was confirmed by six interviewees, and half that amount did not correspond to the mothers or fathers, but the grandparents who often had contact with the infants.

**DISCUSSION**

Historically, the tendency of care provided to ensure life and continue the human species is limited to woman, considered a symbol of fecundity and responsible for the conception, development, and maintenance of life.\(^{13}\) The present study corroborates the millennial tradition of women responsible for care provision, since the figure of the mother is regarded as the main provider of care for infants. Other studies on caring for children at home show the mothers as responsible for the integral care of their children.\(^{14,15}\)

Some of the interviewees worked and shared care provided to their infants with the fathers, grandmothers, aunts, and the day care. This finding confirms the practice of gender-related care when grandmothers, aunts and the day care—a place where care provided to infants is attributed to women—are part of the support network for women who work. Only one of the mothers shared the task of caring for the infant with the father.

The sociohistorical context produces the division of labor including the gender. Women performed care activities in private—the family space—accepting full responsibility for activities with children, older adults, sick family members, and the environment, among others. The men performed the activities of assurance of necessary resources to support their family and defend the territory.\(^{13}\) This feature of man as the main source of family income was confirmed in the present study since most of the mothers had no labor activities out of their homes. Thereby, the activity of women providing care to the home, the infant and the companion became clear. The absence of labor activities performed by the mothers can be explained on the grounds of some diagnoses of the infants, since they require follow-up performed by other specialists and stimulating activities. A research on cultural practices of care provided to infants with respiratory diseases showed that most mothers that participated in the study did not perform labor activities.\(^{16}\)
The family income interferes in the possibilities the family has to provide appropriate care to infants. In the present study, the family income ranged between one and three minimum wages. Low family income interferes with living conditions and this economic factor has an impact on housing and nutritional conditions, causing growth deficit. Therefore, health care professionals, the educators, cannot be oblivious to the economic conditions of their students in order to be able to identify one of their limitations for care practice.

Despite all the cultural and historical changes that encouraged women's education in the 1930s, the appreciation of their intelligence and competence, and their insertion in the labor market, direct care provided to their children is still under the maternal responsibility. The mothers still regard themselves as the main responsible individuals for care provided to their children. Their dedication, affection, and attention play a significant role in the healthy growth and development of their children.

The predominant education of the mothers in the present study was complete secondary education achieved by ten of the respondents, which may have favored the obtention of the necessary information on the part of the mothers in order to identify symptoms. Some authors have related mothers' education with knowledge to identify signs of respiratory diseases and their prevalence. They stated that mothers' education was inversely proportional to the prevalence of cases, i.e., the highest the mothers' education the lowest emergence of cases of respiratory diseases and the greatest chance of identifying the signs of diseases. A prospective study on the morbidity of respiratory diseases in children under one year of age related this morbidity with the precariousness of family knowledge about the disease and the recognition of signs of diseases affecting the quality of care received by the children in their homes, especially in the management of severe cases.

With respect to hospitalization, it was observed that in 2009 respiratory diseases accounted for the second most common cause of hospitalization in the UHS of the metropolitan region of Rio de Janeiro, RJ. The indexes were 36.63% for children under one year of age, and 42.65% for children between one and four years of age.

This study found that hospitalization due to respiratory diseases was observed in three of the infants under one year of age and in one infant between one and two years of age, representing a reduced number in relation to the epidemiological data presented previously. These data can represent the impact of regular follow-up of these infants in the outpatient clinic with multidisciplinary care, contributing to improve care provided to the dyad infant-family.

Unfavorable housing conditions, with little or no ventilation and infiltrations and mold on the walls and wardrobes, were cited by the mothers as difficulties encountered for care provided. The environmental conditions are one of the risk factors for the emergence of allergic respiratory diseases. Allergic rhinitis, for example, is triggered by several factors, like the sensibility and exposure to aeroallergens, such as mites in the home dust and fungi. Mites are found in curtains, rugs, blankets, etc. and fungi are found in the infiltrations present in the environment. Allergic rhinitis is triggered by exposure to strong odors. This fact was perceived by one of the mothers who related the cold of the infant to the use of perfume by individuals living in her home. One of the mothers cited the difficulty in keeping the house clean, because she lived in a street with heavy car traffic. This situation is confirmed in the literature regarding the environmental pollution caused by car smoke as another triggering factor for allergic respiratory diseases.

Some studies regarded environmental conditions as triggering factors for respiratory diseases. The present study found favorable conditions of the houses regarding ventilation, since 12 of them were ventilated. However, in spite of this number, two houses had infiltrations, one was undergoing alterations, and one had rugs and curtains, increasing the risk for infants' exposure to aeroallergens. Still, regarding the housing conditions, it was found that ten interviewees lived in houses with three to four rooms and with four to six members per household, contributing to the agglomeration of individuals in the same environment, thus predisposing the emergence of respiratory diseases. This situation was also confirmed as a risk factor for triggering respiratory diseases in a study conducted in the city of in Pelotas, State of Rio Grande do Sul, since the majority of the infants under one year of age slept in the same room with their parents.

It is important to highlight that the exposure of infants to smoking was little observed in this study, unlike other studies, one in the city of Rio Grande, State of Rio Grande do Sul, one in the city of Rio de Janeiro, State of Rio de Janeiro, and one in
the city of Pelotas, State of Rio Grande do Sul, where children were exposed to smoking in greater proportion. Smoking is considered the largest household inhalable pollutant since it harms the nasal epithelium, triggering and aggravating respiratory problems.

All of the houses had electric light, thus avoiding the use of other means to produce lighting and heating of water for sanitizing, preventing the burning of some organic materials whose pollutants irritate the respiratory mucosa.

The presence of domestic animals in the houses was unimpressive, representing a relevant finding in this study, because the direct contact of infants with animals causes or exacerbates allergic respiratory diseases. Domestic animals such as dogs and cats excrete allergenic substances by the sebaceous glands and secrete them by the skin.

The absence of basic sanitation found in three houses represents a public health problem and a potential for development of respiratory diseases. In one of the houses, the garbage generated was thrown to the river that flowed beside the house. This situation entails the appearance of insects such as cockroaches, whose proteins from renewal and body decomposition are part of the home dust and responsible for respiratory allergies.

With respect to the continuous use of prescribed allopathic medicines, there were two infants being followed up in the Pediatric Pneumology Service of the hospital. The mothers reported that they had received medical advice to change the dose of the medication of continuous use or administer the specific medicine when their infants exhibited wheezing and dyspnoea. This prior guidance on how to perform in cases of destabilization of respiratory condition undoubtedly made the mothers feel secure, avoiding "pilgrimage" in search of care and resolving the instability of the moment. On the other hand, it brings concern to the nurses with respect to delaying professional assessment due to the medicalization for cases of wheezing or dyspnoea, since these signs can be related to bronchitis or pneumonia.

**CONCLUSION**

The sociodemographic data brought to the fore the barriers faced by family caregivers of infants with respiratory diseases that hindered care provided to reduce the recurrence of those diseases. The housing conditions—whether in the structural or location aspects—the number of individuals and rooms per households, and low family income represent the main difficulties for the provision of proper care. In addition to the conditions of life, there is restriction of access and completeness of care provided in the basic health services, forcing the family members to seek emergency services and exposing these infants to other aggravations.

It is essential that nurses and other health professionals know the reality of life of users under their responsibility, since the social, economic, and cultural conditions of these users cannot be dissociated from the health-disease process. Furthermore, this knowledge favors the approach of the nurses to the users in accordance with their reality in order to stimulate their care autonomy.

The educational activity performed in the nursing consultation must propose a reflection on the part of the family members about the relationship between health and its determinants. This procedure will promote health and the improvement of living conditions, as well as the exercise of the right to citizenship through users’ co-participation in individual and/or collective decisions for solving problems that interfere with the maintenance of their health and that are not exclusively dependent of their care.

**REFERENCES**


