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Cultural meanings of the infantile asthma

ABSTRACT

OBJECTIVE: To analyze the cultural meanings of infantile asthma from the perspective of the mother/carer of the child.

METHODOLOGICAL PROCEDURES: Qualitative research conducted in 2004, in the city of Fortaleza (Northeastern Brazil). An ethnographic approach was utilized, consisting of participant observation and interviews with seven mothers, accompanying their children in a hospital emergency ward. Thematic analysis was the technique employed when identifying the meanings of mothers' discourse.

ANALYSIS OF RESULTS: Two discussion categories were identified: "disinformation on illness" in which it was possible to perceive that the mothers were not informed with respect to their children's illness; and "cultural care" in which they relate information on caretaking and they use resources of popular knowledge to prevent their children's asthma, such as environmental care and the use of popular remedies, based on medicinal plants.

CONCLUSIONS: The disinformation and lack of maternal knowledge on infantile asthma among the mothers indicate the need for an intense educational program, problematizing in nature and based on dialogue, conducted in close collaboration with the treatment aimed at improving the prognosis of the disease.

DESCRIPTORS: Asthma, ethnology. Child Welfare. Mother-Child Relations. Anthropology, Cultural. Qualitative Research.

INTRODUCTION

Asthma affects both the child and his/her family, for reasons such as: the hereditary character of the disease, which leaves parents with a feeling of guilt for having provoked their child's disease; the distortion of family relations, due to the frustration of having a sick child and the anxiety resulting from not knowing how to deal with the disease; and the unpredictable character of the occurrence of acute episodes, leading to setbacks in family and social life.

Furthermore, there is the need to adapt the house, removing rugs, plants, curtains and domestic animals, for domestic hygiene is a measure of preventive care. Asthma may also give rise to problems with the healthy siblings, for they might feel neglected due to the asthmatic brother or sister, or they may exclude him from leisure activities and treat him as a weakling. Financial problems also occur, resulting from the need for treatment, with a high frequency at the emergency services, causing professional absenteeism on the part of the parents, and a risk of dismissal.¹

There was an increase in the number of hospitalizations due to asthma between 1993 and 1999. Data suggests that the prevalence of this disease is also on the

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rise throughout the world. In 1996, the costs of hospitalization due to asthma in the Brazilian Unified Health System were 76 million reais (US\$ 133 million dollars), 2.8% of the total annual budget and the third largest health expenditure with a single disease.⁴

It has been noted that in hospital emergency wards children presented hyperthermias of diverse origins, such as infections of the upper and lower airways, amongst others. In the majority of cases, children received interventions and did not return, at least not for the same reason. However, there are cases, prevalent among children under five years of age, in which the mother seeks the service significantly, whenever the child is panting and dyspneic, as if it were part of her daily routine. This fact is an alert as to the importance of the cultural reality of the mother/carer, since the child is not autonomous with respect to his/her own daily routine care within this age bracket.

Life does not always ensue in a normal manner among asthmatic children. They are sometimes submitted to excessive care, being impeded by their mothers from playing outdoor games, riding bicycles, walking bare-footed, eating frozen foods, exposing themselves to sun and wind.^{1,5}

The preventive phase is relevant because of recurring asthmatic crises. The need to intervene is recognized, but difficulties emerge due to the fact that little is known about the mother's or carers' cultural background, and that this issue involves various different social groups. The health professional is responsible for caring for human beings during a phase of physical, mental, psychological and social development. This is a formative phase, yet the focus is still on a traditional pedagogy. The dynamic, experimentally based characteristic of this phase seems to be forgotten.^{2,3,6} More years of schooling would propitiate knowledge of preventive health measures that reduce morbidity due to respiratory disease as well as a set of more appropriate actions with respect to child care.⁷ Given that one of the principal foundations of prevention and control of asthma is the educational process, it is necessary to become familiar with the social and cultural characteristics of the asthmatic child's mother /carer that seeks the emergency ward of the hospital during a crisis. Questions arise as to whether the recurring crisis are related to the mothers' cultural background and to her knowledge with respect to the disease as well as to what preventive measures are adopted by the mother to avoid these crisis, once her role as caregiver is acknowledged.

Given the perspective mentioned above, the objective of the present study was to analyze the cultural meanings of infantile asthma, from the mother's or carers' point of view.

METHODOLOGICAL PROCEDURES

A qualitative study was conducted at an emergency pediatric ward of a public hospital, located in the municipality of Fortaleza, Northeastern Brazil, in 2004.

Field research was based on ethnographic practice, with particular emphasis on the cultural theme of infantile asthma. The cultural meanings of this disease for a specific group were described, based on the central idea of culture as composed of knowledge, beliefs, arts, moral values, laws, costumes as well as any and all capacities and habits acquired by man as a member of a society.^{11,13,15}

The object of research consisted of discourses concerning infantile asthma, elaborated by different social agents, according to opinions, sentiments, attitudes and different world views, associated to the experience of the phenomenon – fundamental issues in medical anthropological research. Criteria for inclusion were: mothers of children between two and five years of age, given the greater significance of the clinical diagnosis within this age bracket, for children under one year old may have several viral respiratory infections (viral bronchiolitis) that may conceal or confound the differential diagnosis of asthma; children had to be cared for by the mother and did not frequent school or sports activities outside the household, so that asthma crises would not involve the interference of people other than the mother or carer. Seven biological or adoptive mothers of children with a clinical history of asthma and/or with hospital files that registered more than four visits to the institution with a diagnosis of asthma, weariness or difficulty breathing in the 12 months prior to the beginning of field work participated in this study. Mothers were named from M1 to M7.

Household visits in which data were collected were scheduled ahead of time with mothers' consent. The family household was the site where individual, semi-structured interviews were conducted with the mothers. These were based on three fundamental questions: "What do you know about your child's disease?"; "What do you do in order to try to prevent the asthma crisis?"; "What would you like to know about your child's asthma?". The encounters lasted from two to three hours.

During the interviews, an attempt was made to establish and maintain a calm and informal atmosphere, thus facilitating the involvement between researchers and informants. Interviewers also took notes in their field books during this visit.¹³ Through participant and reflexive observation, feelings were identified and interpreted.

Analysis of the set of data that expresses each mother's particular experiences, sought to explicit the meanings and notions associated with infantile asthma. The internal logic of each discourse was revealed and possible

relations were established between the diverse forms of expressing different realities.

Participant observation permitted researchers to become involved with their informants, making descriptive and exploratory notes in their field books, concerning mother's attitudes and behaviors with respect to their child and in relation to the state of emergency with which they were confronted while caring for them. This experience emerged in the reality of the subjects interviewed as if it were part of a "continuum".⁸

Data collected in the field books was later analyzed in conjunction with the interviews. The material from the interview that was recorded and transcribed was classified in terms of narrative excerpts. Recurrent phrases as well as those that were unusual were identified in the mother's narratives and were analyzed according to specific themes.⁹ Data was systematically organized in classificatory categories, which were considered as conceptual tools.

All interviews and observations were conducted once informed consent was granted by the mothers, all of which signed informed consent forms. The voluntary and anonymous character of participation in this research was guaranteed, thus attending to the norms of the Research Ethics Committee of the Universidade de Fortaleza.

ANALYSIS OF RESULTS

Popular knowledge concerning asthma

In the informants' community, mothers consistently referred to asthma as something that is extenuating and weariness. This information should be validated in the clinical history of patients given the cultural and linguistic characteristics of the community. There is a strong relation between the name attributed to asthma by the mothers and the clinical characteristics associated with its diagnosis. In addition, it must be noted that diagnosis of asthma among children under seven years of age is based almost exclusively on clinical criteria, since, during this phase, no laboratory based or functional diagnosis is reliable.¹⁰

A lack of understanding of the child's disease was observed in the mothers' statements. This may be due to the lack of information or explanations on the part of the professional team responsible for attending mother and child at the hospital; mothers' limited schooling; lack of access to services specialized in accompanying such cases, that would include health promotion and asthma prevention strategies.

"I don't even know how to explain it, I just know that people get asthma from contact with heat and fur; no one ever explained what it is to me". (M2)

The lack of coherent explanations concerning the disease, that sometimes plagued the mothers, may be caused in many cases by the lack of involvement or experience in health education on the part of the professionals attending them. Furthermore, current health policies tend to be directed towards technicism.

"They never explained anything about the disease to me; as to how it emerged, they tell me she inherited it from me because I was asthmatic". (M5)

The need for health education is urgent. Health professionals must be made aware of this so that they can collaborate towards greater effectiveness in the prevention of asthma. Technical assistance alone does not produce autonomy and, if the quality of care is not good, it may even produce irreversible dependence.

On the other hand, the delays in diagnosis of asthma should be observed. New diagnosis should be accompanied by a detailed clinical history of the child that makes early diagnosis possible and leads to more efficient treatment.¹²

Cultural care

Mothers statements concerning infantile asthma indicated they had other sources of knowledge with respect to their child's' disease. They utilized resources of popular knowledge or folk culture in order to prevent the asthma, such as some forms of environmental care and homemade remedies, based on medicinal plants.

"I make homemade medicine with tonkabean and other herbs". (M4)

Mothers care for their asthmatic child by developing actions, attitudes and behaviors based on different sources of knowledge – scientific in nature or oriented by experience, intuition, and/or critical thinking, in order to promote, maintain or recuperate their dignity and human integrity.¹⁶ By means of their care, the community prevents disease and promotes health even if this is undertaken by means of a conjunction of heterogeneous cultural propositions.

"I don't let him walk barefooted (...) But when he starts coughing, I run to the hospital with him, because if I wait a while to take him he goes into crisis". (M6)

The meaning of this expression is that mothers feel perplexed when confronted with the mystery that involves the onset of their child's crisis, and often feel insecure or dissatisfied as well with the explanations and orientations that they receive. Consequently, they try to prevent the problem from occurring, believing in a source of knowledge originating from a culture or belief that will justify their impotence when they are faced with the situation. Belief is explained by the mothers when they attempt to use teas to cure or prevent asthma. At present it is easier to establish a dialogue concerning

values and beliefs, although some health professionals adopt inconsiderate or disrespectful attitudes, at times without even being aware of this.

As to the recipes for helping to cure asthma, health professionals should become aware of those remedies that are based on scientific evidence and appreciate their value, attempting to show the client what should be maintained and what should be avoided. Many mothers believe that their child's contact with hot or cold weather and with strong winds may aggravate the asthma, relating past episodes of the illness with such climatic conditions. Since asthma is a multifactorial disease, in which diverse allergens are responsible for unleashing the process, rigorous observation on the part of the family is often required in order to identify the individuals' specific allergic reactions to determined factors.

"I don't let him expose himself to sun, dust, or ventilators and avoid his contact with hot water or earth". (M1)

Mothers' accounts of cultural care were similar, but did not always present an association with the specific reality or needs of each child. Attaining the singular, specific and active care that each child needs can only be accomplished by educating his/her mother. A mother's manner of caring for her children is drawn from a culture concerning what may cause her children's asthmatic episodes, being related to and esteemed by her beliefs. That is, only a mother that believes that inhaling allergics may develop asthma will understand the effects of physical environmental hygiene on controlling the disease.

"(...) I don't bathe him in hot water and I don't allow anyone who's body is hot or who is smoking to come near him". (M7)

A change in lifestyle may take place mainly through the mother's mediation and frequently they need to stop working outside the home in order for this to occur. On the other hand, when a mother stops working, she sacrifices the family income, precisely when financial needs are greater due to the expenses generated by certain aspects of care, such as, for example, substituting a wood fueled stove by a gas stove. Thus, the father's responsibility increases as he must carry the burden for both the family's income and his child's health.

"Here in my house we sometimes cook on a wood fueled stove, and it seems that this isn't good for him, right?". (M1)

Mothers who only have access to the emergency wards with their children elaborate a discourse on the disease with the means they have at their disposal, sustaining it with information transmitted to them by the health professionals who attended them in the past. They thus reconstitute a culture based on fragmentary information, words they did not fully understand and phrases they recall from past visits to the emergency ward.

Thus, an effective dialogue between health professional and client, which values cultural knowledge is indispensable. The health professional must adapt his/her discourse in order to promote an exchange of experiences with the parents so that the latter can learn to take care of their asthmatic children in a conscience and effective manner.^{14,17}

CONCLUSIONS

The cultural meanings of infantile asthma, from the perspective of the mother or carer, are related to lack of knowledge, schooling or sufficient information. Knowledge must be socialized and citizens' learning processes must become more democratic in nature so as to support health professionals' interdisciplinary and transdisciplinary assistance.

According to information gathered from mothers concerning how they care for their children, specific forms of caring were observed, within the community's culture, when they were confronted with their children's health problems. A reflexive form of care becomes relevant, one that is simultaneously critical and intentional, emphasizing the need to reorganize health practices.

Therefore, an intense dialogical educational endeavor is recommended in close collaboration with ongoing treatment, geared towards a better prognosis of the disease. In this manner, health professionals and mother/ carers should become jointly responsible for the prevention and elimination of the child's disease, as well as for health promotion.

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