

SOCIALIZATION OF CHILDREN AND ADOLESCENTS WITH CYSTIC FIBROSIS: SUPPORT FOR NURSING CARE¹

Tainá Maués Pelúcio Pizzignacco²
Regina Aparecida Garcia de Lima³

Pizzignacco TMP, Lima RAG. Socialization of children and adolescents with cystic fibrosis: support for nursing care. Rev Latino-am Enfermagem 2006 julho-agosto; 14(4):569-77.

The aim of this paper is to identify the routine (school, work, free time activities and relationships with friends and family) of children and adolescents with Cystic Fibrosis (CF) through their experiences and identify situations that can affect these routines. The objects of analysis of this research are children and adolescents with CF who attend a teaching hospital in a city of the State of São Paulo - Brazil. It is a qualitative research, with data collection based on open interviews and patient charts. The data brought the following themes: misleading knowledge about the disease, concern with self-image, search for self-care and hope of improvement in the future. The results evidence the repercussion of CF in those patients' socialization process, evidencing the importance of health professionals knowing about these demands and incorporating them into the care plan, with a view to effective interventions to promote infant-juvenile growth and development.

DESCRIPTORS: cystic fibrosis; child; adolescent; nursing care; pediatric nursing

EL PROCESO DE SOCIALIZACIÓN DE NIÑOS Y ADOLESCENTES CON FIBROSIS QUÍSTICA: APOYO PARA LA ATENCIÓN DE ENFERMERÍA

La finalidad de este estudio es conocer el día a día (escuela, trabajo, actividades de ocio e interacciones con la familia y amigos) del niño y del adolescente con Fibrosis Quística (FQ) a partir de sus propias vivencias e identificar situaciones que puedan interferir en esa cotidianidad. Los sujetos de la investigación son niños y adolescentes portadores de Fibrosis Quística bajo seguimiento en un hospital-escuela del interior del Estado de São Paulo, Brasil, con edad entre 7 y 18 años. Efectuamos una investigación con aproximación cualitativa. Los datos empíricos fueron recopilados mediante el análisis de registros médicos y entrevistas abiertas, revelando los siguientes temas: conocimiento equivocado sobre la enfermedad; preocupación con el autoimagen; búsqueda por autocuidado y esperanza de mejoras en el futuro. Los resultados evidencian las repercusiones de la Fibrosis Quística en el proceso de socialización de esos pacientes, es importante que los profesionales de salud conozcan esas demandas y las incorporen al plan de cuidados, con vistas a intervenciones efectivas que promuevan el crecimiento y desarrollo infanto-juvenil.

DESCRIPTORES: fibrosis quística; niño; adolescente; atención de enfermería; enfermería pediátrica

O PROCESSO DE SOCIALIZAÇÃO DE CRIANÇAS E ADOLESCENTES COM FIBROSE CÍSTICA: SUBSÍDIOS PARA O CUIDADO DE ENFERMAGEM

O presente estudo tem por objetivo conhecer o dia-a-dia (escola, trabalho, atividades de lazer e interações com a família e amigos) da criança e do adolescente com Fibrose Cística (FC), a partir de suas próprias vivências, bem como identificar situações que possam interferir nesse cotidiano. Os sujeitos da pesquisa são crianças e adolescentes portadores de Fibrose Cística em acompanhamento num hospital-escola do interior do estado de São Paulo. Trata-se de pesquisa com abordagem qualitativa, com coleta de dados empíricos realizada mediante análise de prontuários e entrevista aberta. Dos dados, emergiram os seguintes temas: conhecimento equivocado sobre a doença; preocupação com a auto-imagem; busca pelo autocuidado e esperança de melhorias no futuro. Os resultados evidenciam as repercussões da Fibrose Cística no processo de socialização desses pacientes, salientando a importância dos profissionais de saúde conhecerem essas demandas e incorporarem-nas ao plano de cuidados, visando a intervenções efetivas que promovam o crescimento e o desenvolvimento infanto-juvenil.

DESCRIPTORES: fibrose cística; criança; adolescente; cuidados de enfermagem; enfermagem pediátrica

¹ Research inserted in the integrated project CNPq (Process No 550713/2002-6) and FAPESP (Process No 01/10764-0); ² Undergraduate Student, Scientific Initiation Grant Holder, e-mail: tatapizzi@hotmail.com; ³ Advisor, Associate Professor, e-mail: limare@eerp.usp.br. University of São Paulo at Ribeirão Preto College of Nursing, WHO Collaborating Centre for Nursing Research Development

INTRODUCTION

Cystic Fibrosis (CF), also known as Mucoviscidosis, is a chronic, autosomal, recessive, hereditary and still incurable disease. The gene of Cystic Fibrosis is located on the long arm of chromosome 7 and is responsible for producing the CFTR membrane protein, which conducts ions between intra and extracellular domains. Incidence levels of the disease amount to 1 in every 1,500/2,000 in the south of Brazil. This is similar to levels in the European Caucasian population. Rates decrease in other Brazilian regions, that is, 1 case for every 10,000 births⁽¹⁾.

As a result of deficient ion transport in cellular membranes, thick secretions are produced from the exocrine glands, which end up obstructing the canaliculi and ducts through which they are secreted, preventing their arrival at their place of action⁽¹⁾. As there are various mutations in the CF gene, signs and symptoms can be more or less intense, although the upper airways and pancreas are always affected⁽²⁾.

Nowadays, lung symptomatology manifestations represent the highest morbidity and mortality rates. The thick mucus clogs the lungs and becomes a culture medium for bacteria and microorganisms, causing repeated pneumonias, bronchiectasis, pneumothorax, among other complications. One other big complication of Cystic Fibrosis is that it affects the digestive tract, especially causing pancreatic insufficiency, which impedes the production and/or sending of digestive enzymes to the digestive tract, causing poor digestion. This problem is mainly due to the non-absorption of fats, which causes steatorrhea and protein-caloric malnutrition in children and, thus, affects their weight and stature development. Reproductive organs and liver can also be affected⁽¹⁾.

Cystic Fibrosis can be diagnosed through different methods. The most common one is the Sweat Test. It is confirmed by two measurements with chloride concentrations superior to 60mEq/l⁽¹⁾. In general, the mother suggests the probable diagnosis to doctors by mentioning that, when she kisses the baby's forehead, the kiss "tastes salty"⁽²⁾.

In Brazil, Decree GM/MS No 822 by the Health Ministry, issued on June 6th 2001, established that neonatal screening, better known as the "Heel Prick", which was only used to detect congenital diseases like Hypothyroidism and Phenylketonuria, would also

allow for the early detection of other diseases, including Cystic Fibrosis⁽³⁾. Although this Decree has been in force since its publication, many health institutions still do not perform complete neonatal screening because they have not been qualified by the Single Health System (SUS). This qualification requires compliance with all steps of the process, ranging from neonatal screening until the follow-up of detected cases, as well as the availability of a multidisciplinary team. Nowadays, only few private and public hospitals, considered to be centers of excellence for diagnosing and treating these diseases, perform complete screening. A complementary Decree⁽⁴⁾ also determines on free outpatient, hospital and medication treatment for CF patients.

Treatment of CF is aimed at minimizing the signs and symptoms of the disease and impeding its progression. It mainly involves maintaining airways clean and humidifying the mucus to make it more fluid and facilitate expectoration; respiratory physiotherapy and using corticosteroids and antibiotics to avoid infections. Moreover, nutritional supplements with vitamins, salts, liquids, extra calories and digestive enzymes, before meals and snacks, have contributed to keep patients healthy⁽¹⁾.

In 1938, 70% of children diagnosed with CF died before their first anniversary. As a result, the disease was classified as a potentially lethal pediatric pathology. In recent years, countless studies have produced broader knowledge about the disease and have led to the use of a treatment more coherent with physiopathology, which has provided an increase in these patients' life expectancy. Mean life expectancy, as documented by the Epidemiological Cystic Fibrosis Records in 1998, corresponded to 32 years, although this varies according to the country's socioeconomic and scientific development levels, treatment conditions and patients' age at the moment of diagnosis⁽⁵⁾.

Nowadays, a global epidemiological transition is in course, due to technological advances in the health area as a whole, allowing chronic diseases, including CF, to be controlled more easily. This fact, particularly CF, is evidenced by the growing number of adolescents, young adults and even married adults living with the disease.

Socialization process

According to development theories by Erikson and Piaget, child development depends on children's

interaction with their environment through repeated and varied actions, which allows them to get familiar with it and explore it better; in this process, a preceding phase is needed for the development of the next one. In the case of children with chronic disease, depending on which phase of life symptoms start to appear in, the impact on their cognitive, emotional and social development will happen in a particular way, thus impeding future developments⁽⁶⁾.

Socialization is defined as "a broad and consistent introduction of an individual into the objective world of a society or a sector of it". It can be ranked as primary and secondary socialization. The primary type is what the individual experiences during childhood and through which (s)he becomes a member of a society; the secondary type is any subsequent process that introduces the already socialized individual into new sectors of society. The family is responsible for the child's first insertion into the objective social world, to the extent that it offers the learning of cultural elements, such as language, habits, uses, customs, values, standards, behavioral standards and attitudes and, mainly, promotes the formation of basic personality and identity structures⁽⁷⁾.

With respect to the socialization of children and adolescents of school age who suffer from chronic diseases, these are at the intersection of the health and education systems, in view of the separation between both in most countries' teaching institutions. Hence, there needs are not integrated, creating a deficiency in one of the sectors, usually the educational side, as health is urgent. The lack of communication between these two sectors and educators' lack of knowledge are the main educational constraints for these students⁽⁸⁾.

The problems these children experience in school are directly related to the collateral effects of treatment, to signs and symptoms of the disease and to feelings like rejection, stress and isolation out of shame from their colleagues⁽⁸⁾. During crisis periods of the disease and due to constant hospitalizations, children and adolescents with CF miss school and often cannot pass to the next year because of their absences, which discourages them so study⁽²⁾.

To the extent that the life expectancy of children and adolescents with CF increases, issues related to choosing a profession, relationships and reproduction become more intense and expectations for the future start to appear, which can create anguish, depression and often treatment abandonment. It is

during this transition period from childhood to adult age that feelings of self-control, immortality and freedom of choice come up. Treatment abandonment occurs because health care, which used to be attributed to another person, like the mother for example, is not attributed to the patient him-/herself⁽²⁾. Furthermore, during this phase, new social attributions emerge, such as work or the continuity of school commitments which, together with therapeutic commitments, lead to a full agenda and exhaustion to perform self-care, which may become less frequent or relegated to the background⁽⁹⁾.

In spite of their turbulent life and constant changes in their health state which, in turn, require changes in the structure of care and in the family nucleus, most relatives of children and adolescents with CF and these patients themselves consider their lives as normal. This phenomenon is known as normalization and occurs in stigmatized groups like the chronically ill⁽⁹⁾.

In this sense, concern about these children and adolescents' quality of life has also been a focus of interest for researchers in the area. Thus, the *Cystic Fibrosis Questionnaire* was developed in 1997. In Brazil, the validation of this instrument is being conducted by Prof. Tatiana Rosov, from the Department of Pediatrics and Rehabilitation of the Federal University of São Paulo - Paulista Medical School. This questionnaire will make it possible to analyze the impact of treatment and the disease itself on the quality of life of Brazilian CF patients⁽¹⁰⁾.

The **aim** of this study is to investigate how the socialization process of children and adolescents with CF is occurring, based on their own experiences. This research is justified by the possibility to identify, in the daily lives of these patients, aspects that need nursing interventions, with a view to improving their quality of life.

METHOD

This is a descriptive and exploratory study⁽¹¹⁾. The answers to the research questions were sought in the qualitative approach, due to the characteristics of the study object and the proposed objective. We believe this approach is particularly valuable, as it permits discovering the meaning of events, social practices, individual perceptions and actions⁽¹²⁾.

The research project was approved by the Research Ethics Committee of the study institution. The submitted protocol contained the free and informed consent term, which described the research in simple language⁽¹³⁾. Before the interview, this term was read and discussed with the parents, children and adolescents. On this occasion, any doubts were clarified and, after the children and adolescents had agreed to participate, both parents and participants signed the term.

The study institution is a teaching hospital and reference for care delivery to children and adolescents with CF, located in the interior of the state of São Paulo. Study participants were eight (8) children or adolescents with a diagnosis of CF, in the age range from 7 to 18 years, male and female, who were under clinical and hospital follow-up at the study hospital. The choice of this age range was due to the fact that these patients are in the phase of logical thinking, and can therefore communicate their ideas verbally and give meaning to the experiences⁽⁶⁾. We defined the number of participants when data provided us with sufficient support to understand the study phenomenon.

We used open interviews as a data collection strategy, due to the fact that this technique gives access to descriptive data in the subjects' language and because it allows the researcher to interactively develop an idea about how subjects interpret aspects of the world⁽¹²⁾.

The interview was held at the participants' homes (6) or at the clinic (2) and consisted of two parts: the first part, for identification, gave us information about sex, age, education level, profession/occupation, work place and origin. The second contained two guiding questions: 1. *Tell me what you know about your disease*; 2. *Do you think you are different from your friends / acquaintances who do not have Cystic Fibrosis?* We looked for complementary data on the patient charts, when we examined the diagnosis data and therapeutic scheme. Moreover, we used a field diary, where we registered the impressions obtained from each interview, giving special attention to non-verbal communication and family relations.

Data interpretation started on the basis of the fully transcribed tapes. We analyzed each set of data (interview, field diary notes and patient chart data) per part, seeking the codes, that is, phrases or words that give meaning to the information contained

in empirical data⁽¹²⁾. Next, we grouped the codes according to their similarities, which resulted in the themes. The children's and adolescents' reports were identified according to the order of the interviews (E.1 to E.8). For each situation, we indicated the age because we believe this is an important indicator (E.1, 18 years).

RESULTS

Data analysis allowed us to identify 4 themes, which are directly or indirectly reflected in the socialization process. These are:

Mistaken knowledge about the disease

Most interviewees could not explain exactly what Cystic Fibrosis is. Many of them mixed up information, like in the following examples: *It's genetic. I know more or less, I don't know very much. I know it's more or less similar to Down's Syndrome. It's from the same chromosome, I think it is, but I really don't know for sure. (E.1, 18 years). I know it's without organ there and that you need drugs for digestion... (E.3, 17 years).*

Other participants associated the disease with prevailing signs and symptoms, as well as with specific drugs: *The disease I have...I cough a little when I have quite a lot of catarrh.... (E.4, 10 years). Cystic Fibrosis is a thing in the lungs. Then, each time you're going to eat you have to take the enzyme, but then you have to do the PULMOZYME® [inhalation medication], if not it turns into pneumonia. (E.6, 10 years).*

Data evidenced that scientific words like genetics, chromosome and hereditary appeared in the reports quite frequently, although without any actual meaning, emphasizing the technician language of the information they received. For example: *I explained that it's a genetic disease...they asked what it was and I said it was a genetic disease! (E.4, 7 years).*

A communication barrier is created between professionals and patients, due to the use of technical and abstract language. In many situations, health professionals overestimate patients and family members' knowledge, based on the premise that they master their scientific universe.

Many CF patients prefer to maintain the disease a secret because they have insufficient knowledge. By ignoring it, they cannot develop positive coping strategies and then start to hide it as a form of self-protection. Examples are: *Oh, no, I don't like to keep*

on telling to friends, not like that; it's just that, like that, I only tell it to the closest ones, more close like that, you know? (E.3, 17 years). Nobody suspects. Yes, and they will not know, I'm never gonna tell (E.1, 18 years).

Then often hide the disease because they do not know the transmission mechanisms and, thus, seek to avoid people stigmatizing them because of the possibility of contagion, like in the following examples: *So, I think that people around should become aware of what it is, you know? I think it's a bit similar to AIDS, like, you say you have AIDS everybody immediately...does not want to sit down (E.1, 18 years).*

Concern about self-image

It is when they start school that children and adolescents with CF start to perceive they are different from their colleagues⁽²⁾. Sometimes, these differences are evidenced by their own colleagues, causing constraint and shame in patients, according to the following reports: *Two girls keep making fun of me because I'm short! I say, so what? So what if I'm short? (E.4, 7 years) I'm a bit shorter than my classmates... (E.5, 10 years).*

In patients who are still going to school, differences go beyond physical changes; there are also restrictions the disease imposes and the continuously present treatment, as mentioned: *They don't have it, but I do, I can't run because I'm gonna cough. And if I run a lot, jump a lot, then I'm gonna get tired, feel bad (E.6, 10 years). I cough a lot and take a lot of drugs, the others [children] only take them when they are ill, I take them all the time (E. 4, 7 years).*

In the situations the children experienced, we observed they felt uncomfortable about the image, although as something that cannot be changed. Adolescent participants, on the other hand, revealed to be more concerned about their body image with respect to changes and their possible interventions: *I practiced swimming for 7 years. I chose this sport to develop the lung, so that I wouldn't get barrel chest and hunchback and short with more or less 1.50 m...[ironic]. (E.2, 18 years).*

Concern about self-image is also a strategy to fight the stigma, since it is an attempt to minimize the physical symptoms of the disease and be equal to other persons: *I was thin, it bothered me, I couldn't take my shirt of close to friends... Then, I started to buy supplements from a supplement shop... So, I don't know if it's true, I saw it on the Internet that, over time, the muscles of Cystic Fibrosis gradually atrophy, I don't know, I don't know if this is true. But*

I didn't stick to this either to do it [weight lifting] no, it's more to have, how do you say, to have a better physique actually. (E.1, 18 years).

Body alteration due to the progress of the disease is one of the few complication children and adolescents may have some control over, whether by exercising or by preventing complications after treatment. This mechanism can be classified as a directed coping strategy, that is, oriented towards a specific stressor.

Search for self-care

We found that most interviewed patients performed self-care in their search for independence: *Yes, so, since about two years, I took hold, you know? I started to cope with things alone. I go to the hospital alone, I take the prescriptions, if a prescription is missing I say this, I solve it myself. (E.1, 18 years). No...my mother, lately, and my father just say: 'you have to do this, you have to do that, do that other thing'... I cannot keep depending on them my whole life, I have to learn to find my way, go out and arrange my life. (E.2, 18 years).*

The interviewed children and adolescents mentioned that the disease crossed their daily lives, especially because care took a lot of time. Treatment for Cystic Fibrosis is constant, happens every day and several times per day, thus taking a lot of time. This affects the realization of other activities, like working or playing for example: *I don't have a lot of time for other things. Because, until I started to do the TOBI® [inhalation antibiotic], I had to do 4 inhalations per day. Then I had to, what is it like, I had to do the PULMOZYME® first, wait a while...then, I only had to do the PULMOZYME®, spit, all of this took one hour. Then I had to wait for at least 3 hours to do the TOBI®, because I had to do it with clean lungs. So together that's 3 hours already, so, that means, if you have to do something like working, there is no way. Soon afterwards, you had to do everything again. Just with the machine on that's 40 minutes straight. So I only finish at night really. (E.1, 18 years). After I do the PULMOZYME®, I feel light to be able to play! (E.4, 7 years).*

Although they considered the therapy intense and exhausting, children and adolescents in this study turned to self-care as a strategy to control their activities, since this allows them to plan their daily life better and minimize the impact of the disease, especially in the school environment, as mentioned below: *So, we try, seeing the possibilities and the time I have available during the day to do it. I don't live in favor of Cystic Fibrosis, it lives with me and I take it along. If I stop my life to live it, I'll become completely ill! (E.2, 18 years). I control the*

drugs myself, because I know my times, so I don't get confused. But I don't take the drug in school, I don't eat when I'm there... I'm ashamed! (E.3, 17 years). I don't take medication in school, there's no reason why, because sometimes I have a snack, so I'd have to take it with the pancrease, you know? But I don't take it, no, just a snack, a juice, I don't think it's really necessary to take it. (E.1, 18 years).

Hope for improvements in the future

As CF is a genetic disease, the only viable cure is gene therapy⁽¹⁾. Nevertheless, the interviewees' hopes were more directed at new drugs and therapies. The dissemination of new treatments in the media has contributed to keep up these hopes, for example: *Because my mom said that, in Europe, they are making a drug to cure...they're going to cure it. (E.5, 10 years). There's that vaccine [against Pseudomonas], which is not available in Brazil yet. (E.4, 7 years). Yes, the trend is for things to get better and better, it's better already! Over here, in Brazil, mucoviscidosis patients used to be 30 years old at most. (E.2, 18 years). Yes, I hope it improves because of the drug, which is evolving. (E.3, 17 years).*

Children and adolescents in this study mentioned another form of hope that their condition will improve in the future, and desire to have the disease recognized by the population in general. They suggested strengthening the Brazilian Association in Support of Mucoviscidosis (ABRAM), campaigns to disseminate the disease and greater media involvement in knowledge dissemination. In this respect, they reported: *I think that, if the disease were well explained, there would be less prejudice... (E.1, 18 years). Look, in Brazil, it only works when you go to the media...AIDS, Diabetes, Cholesterol, Cancer, all of these things worked out, people accept it, because it's in the media. Cystic Fibrosis is not in the media, I also think it won't be until some daughter of a famous person is born with this disease... (E.2, 18 years). Ah, nobody really knows what Cystic Fibrosis actually is! (E.4, 7 years). I think that it's missing [information], in my city I'm the only one who has it. No one understands it well! (E.7, 12 years).*

DISCUSSION

In relation to the theme of *mistaken knowledge about the disease*, communication between the health team, patients and family members is fundamental to understand the observed phenomenon. The professionals' world is based on

science and technology and their language is basically constructed in this rationality. Families, children and adolescents, on the other hand, are immersed in changes in their daily lives as a result of the disease and their interactions are supported by their affective life. As language is one symbolic communication form, symbols do not always have the same meaning for families and professionals⁽¹⁴⁾. Hence, as mentioned above, words whose meanings seem to be understandable in the eyes of professionals may be empty, or have an obscure sense for children, adolescents and their relatives.

The individuals' disease and development cross several times during the lives of chronic patients and the cognitive domain, that is, how they understand and assess the disease and its stressors, will determine how they will handle things when the disease is interfering in their lives. When these individuals are children, the meaning of the disease will depend on what is said to them, on what they experienced and their developmental abilities⁽¹⁵⁾. Thus, the children's and adolescents' knowledge about the disease will be determinant for them to develop positive coping strategies, which will minimize the stressors that will naturally come up in their lives as chronic patients.

Concern with self-image reflects social processes; one older one, called *normalization*, and the other, contemporary, called the *cult of the body*. Although distinct, in the case of children and adolescents with Cystic Fibrosis, both are used with the same purpose, the search for normality.

In spite of individual manifestations, stigma and discrimination are social constructions. Stigma is defined as "an attribute that is deeply depreciative and that, in the eyes of society, serves to discredit the person who has it". Stigmatized persons are seen as possessing an unwanted difference, thus, stigma appears in society through differences, deviations. Discrimination, on the other hand, is an act of ethnocentrism in society and means not liking what is different⁽¹⁶⁾. Hence, *normalization* appears as a strategy to cope with the stigma, to the extent that, through actions, people attempt to mitigate the difference and turn its existence closer to what is normal⁽⁹⁾.

Before they went to school, many CF children of school age did not have an idea about the exact dimension of their differences in relation to other children with the same age. In school, they perceive

that they are shorter, that they cough and expectorate more and that they take drugs frequently and in greater quantities than most of their colleagues⁽²⁾. Children of school age need to feel equal to their colleagues. In this age range, they perceive the physical differences and distinguish deviations from normality. Children considered "normal" indicate the defects of others who are "different" from them, causing shame and constraints⁽¹⁷⁾. When problems related to the disease and treatment appear during childhood or adolescence, social adjustment problems are expected. When children and adolescents with chronic disease do not know the meaning of their disease and are different from the others, their acceptance by their colleagues is put at risk⁽⁸⁾. Even if school appears as an obstacle for children and adolescents with CF, it can help, providing experiences that can increase their self-esteem, such as the development of skills and insertion into a healthy environment⁽²⁾.

The normalization process permeates all phases in the lives of families and patients with CF, although the strategy used to maintain it varies according to the phase of the disease. Besides this coping mechanism, due to the trajectory of the disease, routine care and the fact that it is a congenital disease, families and patients do not have any experience with another type of life and consider their life as normal⁽⁹⁾.

The *normalization* process also includes so-called *problem-solving* coping strategies, which use specific actions to solve stressors, which are also specific for the disease. Normalization is observed by defining the child and adolescent as normal, not different from its healthy peers, when they establish routines with the treatment and self-care. The normality attribute indicates the formation of a cognitive scheme, through which the child starts to interpret his/her disease-related experiences as something natural and familiar⁽¹⁵⁾.

The biggest stigmas in CF are related to the fact that these children and adolescents are physically different from others in the same age range. The fact that they are thinner and, sometimes, present corporal changes like clubbing of the fingers and barrel chest, accentuates this difference, and this makes them increasingly turn to normalization processes. The body-related stigma is also present in other diseases, and is determined by the way society classifies physical normality and values corporal attributes.

Since the 1980's, the world has been observing the growing valuation of muscles and healthy appearance, encouraged by the industrial increase in products that indicate beauty and health at the same time. As a result, this stimulates the cult of the body and healthy appearance and excludes people who do not follow these standards. This may occur with Cystic Fibrosis patients, whose disease is physically visible.

When they *search for self-care*, children and adolescents with CF once again may be recurring to normalization, through the *problem-solving* strategy, which also promotes the search for knowledge and treatment adherence. This strategy is based on the organization of care to decrease the disease's impact on their daily lives⁽¹⁵⁾. In a study of adults with CF, many patients mentioned that they did not like to perform self-care every day or many times during the day as, this way, the disease becomes increasingly present in their lives, filling their agenda more than they would like to. However, they performed self-care because they were afraid of the disease's evolution⁽⁹⁾. Particularly for adolescents, self-care is a crucial component in the transition from pediatric to adult care, constituting a fundamental instrument to develop self-esteem, mainly for patients who depended on their parents' care for a long time⁽¹⁵⁾.

In reporting their *hopes for improvement in the future*, related to therapeutic measures, the children and adolescents who participated in this study restricted their anxieties to less complex issues and did not quote the cure of the disease, perhaps due to a lack of knowledge about the implications of a genetic disease. However, participants' greatest hope was related to the dissemination of the disease by communication channels, school and associations. This result is especially important for this study, as it emphasizes the need for better structured social support to this clientele.

One of the coping strategies for children and adolescents with chronic disease is the search for social support from friends, family and professionals, as they consider this is one of the most significant ways to control stressors caused by the disease. Social support can be of help in different phases in chronic patients' lives, whether by providing emotional support, solving disease-related questions and giving care and distraction in difficult periods. In most cases, this support is provided by the parents. However, when friends give support, the range of socialization

increases, which is especially important for school-age children and adolescents. The search for social support from friends varies according to the children's and adolescents' ages and contexts. The stigma of the disease influences the choice of support, making them turn to people who have demonstrated loyalty and sensitivity, seek persons who experience similar situations or simply hide the disease from their friends⁽¹⁵⁾. The search for people who experience the same situation, that is, other CF patients, is a type of social support based on normalization since, in contacts with people who share the same experiences, children and adolescents identify themselves and become equal to their peers. This is an important support, as it allows for the exchange of experiences related to the disease, coping strategies and socialization.

CONCLUSIONS AND IMPLICATIONS

We believe that this study offers considerable contributions to understand how Cystic Fibrosis can interfere in the socialization process of children and adolescents with this disease. Recommendations emerged from the participants' experiences and suggest: elaboration of educative folders; lectures in schools; propaganda and subjects on television and strengthening leagues and associations that fight for the cause, so that patients, relatives and society get to know the disease and start to cope with CF and its patients in a comprehensive and respectful way.

REFERENCES

1. Ribeiro DJ, Ribeiro G, Ribeiro FA. Controvérsias na fibrose cística: do pediatra ao especialista. *J Pediatr* 2002; 78(2): 171-86.
2. Anfenson M. The school-age child with cystic fibrosis. *J Sch Health* 1980; 26-8.
3. Ministério da Saúde (BR). Portaria GM/MS nº 822/GM. Brasília(DF): Ministério da Saúde; 2001.
4. Ministério da Saúde (BR). Portaria GM/MS nº 1069/GM. Brasília(DF): Ministério da Saúde; 2002.
5. Cowlard J. The role of the cystic fibrosis nurse specialist. *Nurs Times* 2002; 12(98):52-3.
6. Perrin CE, Gerrity PS. Desenvolvimento das crianças portadoras de enfermidades crônicas. *Clín Pediatr Am Norte* 1984; 1: 21-34.
7. Berger P, Luckmann T. A construção social da realidade. 12ª ed., Petrópolis (RJ): Vozes; 1995.

We also consider that these patients' relation with school, work, friends and family is impaired, not because of the disease in itself but due to the lack of positive coping strategies. Mistaken knowledge about Cystic Fibrosis unchains non-positive coping strategies, which lead to distancing from colleagues, increased family problems and difficulties to attend environment with greater socialization, such as school and work.

With a view to putting participants' suggestions in practice, there is a need for articulation among health professionals, civil society and the State. The latter should develop health and education policies aimed at training professionals who are capable of dealing with these demands; establish greater articulation between health and education sectors to deliver integral care to these citizens. Professionals should provide clear information about the disease, not only to patients, but also to relatives. And society needs to welcome these children and adolescents without any stigma, as this is the only way to intensify their relation with school, work and friends and, thus, to guarantee a better quality of life.

ACKNOWLEDGEMENTS

Thanks to the multidisciplinary Cystic Fibrosis team at the Ribeirão Preto Medical School Hospital das Clínicas and to the Support Group for Cystic Fibrosis Patients and Relatives.

8. Brook U, Galili A. Knowledge and attitudes of high school teachers towards pupils suffering from chronic disease. *Patient Educ Couns* 2001; 43:37-42.
9. Gjengedal E, Rustøen T, Walh A, Hanestad BR. Growing up and living with cystic fibrosis. *ANS Adv Nurs Sci* 2003; 26(2):149-59.
10. Rosov T. Questionário de qualidade de vida para os pacientes e pais em Fibrose Cística no Brasil. São Paulo (SP): Laboratório Roche; 2003.
11. Polit DF, Hungler BP. Fundamentos da pesquisa em enfermagem. 3ª ed. Porto Alegre (RS): Artes Médicas; 1995.
12. Bogdan R, Biklen S. Investigação qualitativa em educação: uma introdução à teoria e aos métodos. Porto (Portugal): Porto; 1994.
13. Ministério da Saúde (BR). Diretrizes e normas reguladoras de pesquisas envolvendo seres humanos. Brasília (DF): Ministério da Saúde; 1997.

14. Lima RAG. Experiências de pais e de outros familiares de crianças e adolescentes com câncer: Bases para os cuidados de enfermagem [Livre-Docência]. Ribeirão Preto (SP): Escola de Enfermagem de Ribeirão Preto/USP; 2002.
15. Stewart JL. Children living with chronic illness: an examination of their stressors, coping responses, and health outcomes. *Ann Rev Nurs Res; Research on Child Health and Pediatric Issues*; 2003; 21:203-43.
16. Parker R, Aggleton P. Estigma, discriminação e AIDS. *Cidadania e Direitos - Associação Brasileira Interdisciplinar em AIDS*. Rio de Janeiro (RJ) 2001; 1: 9-17.
17. Anders JC. Crescer como transplantado de medula óssea: repercussões na qualidade de vida de crianças e adolescentes. *Rev Latino Am Enfermagem* 2004 novembro/dezembro; 12(6) 866-74.