

Narratives of the parents' experience of children with cystic fibrosis

Selene Beviláqua Chaves Afonso(a)

Romeu Gomes(b)

Rosa Maria de Araujo Mitre(c)

(a,b,c) Instituto Nacional de Saúde da Mulher da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz. Avenida Rui Barbosa 716. Flamengo, RJ, Brasil. 22250-020. selene@iff.fiocruz.br; romeu@iff.fiocruz.br; rmitre@iff.fiocruz.br

This study analyses the parents' experience of children with cystic fibrosis. From the perspective of social anthropology, the experience of disease changes the perception of the world. Ten narratives were analyzed over a two-month period in 2010, at a public hospital in Rio de Janeiro, Brazil. The results, considering scenarios, characters and plots, highlighted: difficulties in obtaining diagnoses and understanding of the disease; exchange of information with other families; absence of paternal affection; maternal emotional overload and the role of 'health technician'; distress among siblings; school as a place of life; constant presence of death; and difficulties with healthcare professionals. Important issues surrounding family members may be poorly known by the professionals but need to be taken into account in decision-making and in drawing up therapeutic plans.

Keywords: Cystic fibrosis. Chronic disease. Child. Family

Introduction

Chronic diseases are regarded as incurable persistent or otherwise long-lasting conditions whose sequels affect life in various dimensions: they change the relationships with family, society, health institutions, caregivers and with other groups, as well as modify personal beliefs and values of the individuals who live with it ^{1, 2, 3, 4, 5}.

As reported by Canesqui⁶, common sense views of different social groups on diseases may influence the particular ways of incorporating chronic disease concept. Furthermore, the experience lived by chronic patients is influenced by external aspects, such as health and social policies that shape the access to services, diagnosis and treatment.

Good⁷ contributes to the discussion on experience and representation of illnesses in general and particularly on chronic illnesses. Good and Kleinman⁸ are aligned to the main representatives of the interpretive medical anthropology, discussing the interaction between meaning and interpretive practices with social, psychological, and physiological processes in order to produce distinctive forms of illness and illness trajectories. Hence, biology, social practices and subjectivity interact in the organization and lived experience of the illness.

This experience changes the perception of common meanings that are intersubjectively shared. Sureness are modified: the supposition of having control on happenings; the concept that we live in the same world as persons around us; the relevance and speed of time; the focus of attention of the person; the perception of placing priorities, as well as the confidence on the own body and life⁷.

Regarding the body as a creative source of illness experience, Good⁷ analyses theoretical and phenomenologically oriented philosophers and social scientists – particularly Merleau-Ponty and Schultz – focusing on the relationships among the body as the medium of experience, intersubjective meanings, the narrative strategies that reflect upon and reconstruct the illness experience, and the social practices which guide illness behavior.

Good⁷ discusses the analysis of semantic networks, which provides a means of systematically recording the domains of meaning associated with core symbols and symptoms in a medical lexicon. These domains influence experiences and social relations, constituting illness as a syndrome of meaning and experience. The set of meanings associating illness to fundamental cultural values of civilization are old and resistant, serving as an anchor to new illnesses or medical classifications.

In line with Good⁷, experiencing pain and other chronic illnesses systematically threatens subverting, deconstructing or rebuilding the vital world in search for meaning. This idea is also related to Bury's⁹ biographical disruption. Bury⁹ stated that chronic illness – for involving pain and suffering, possibly even death – can lead individuals, their families, and wider social networks to disrupt normal rules of reciprocity and mutual support, making them reevaluate their plans for the future. Thus, face to face with disrupting the structures of everyday life, its meanings and the forms of knowledge provoked by chronic illness and resources for coping with the new situation, they involve rethinking of a person's biography and self-concept⁶.

These changes also take place with families living with children with chronic diseases and are linked to several reasons, such as uncertainty of the future; being conditioned to health institution rules; adaptation to changes in personal and family routines; treatment and care recommendations; social and professional life; fear of losing affective partners by physical and emotional detachment due to caring for the chronically ill child; and suffering arising from intense physical and mental strain they undergo¹⁰. In this scenario, this paper looks at the experience of parents with chronically ill children suffering from cystic fibrosis.

Cystic fibrosis (CF), also known as mucoviscidosis, is an autosomal recessive genetic disorder that chronically affects exocrine glands leading to substantial mucosal thickening and side effects as chronic suppurative lung diseases, intestinal malabsorption and increased sweat chloride concentration. Clinical manifestations of cystic fibrosis occur in different forms, the range extending from early childhood – the most common form – to adulthood. It is an evolutive disease and can result in death in infancy or when children reach adulthood. Its incidence in Latin America is estimated in

1/4,000–10,000 in newborns¹¹. The amount of CF diagnosis has increased by the acknowledgement of the illness manifestations; positive family history; and neonatal screening or Guthrie test. Nevertheless, the disease still needs to be better known and disclosed, given it has been underdiagnosed in developing countries¹², thus affecting the course and experience of the disease.

The dynamic and organization of families whose children are CF patients are compromised by a routine of care. Mothers often leave their home, work, other children and husband in order to dedicate themselves to outpatient procedures and hospitalizations demanded by the CF disease¹³.

The anticipated feeling of loss makes pain constant to these families. The child's life is quantified, the body is measured, and lifetime is unconsciously calculated every clinical complication. In addition to the constant fear of failing, the parents have many doubts concerning the course of the disease, as it can lead to the death of their child despite their efforts. For some parents, it will not matter how strict they are in caring for and treating their child because sooner or later the illness will be stronger and kill their child, meaning, in this manner, that they have failed to provide appropriate childcare¹³.

Listening to family experience will provide other families going through the same problem learn how to deal with themselves in order to withstand the chronic conditions of their children; and to health professionals, a better understanding of the world in which those families live. Hence, lines of care can be outlined, triangulating the available technology, children's subjectivity and the experience of their direct caregivers.

From this perspective, this paper analyses the experience of parents with chronically ill children suffering from cystic fibrosis, aiming at constructs that contribute to promoting a better health care assistance.

Methodology

This study is part of a larger research addressing the meanings attributed by families to the hard news they were getting along while living with and treating their chronically ill children suffering from cystic fibrosis. Notwithstanding, other results showed aspects regarding parental experience towards coping with it. This paper is based on the study of narratives about problematizing “the relationship between cultural or symbolic forms and the experience”⁷.

Bury³ understands narrating and storytelling on oneself or on others as universal and permeated by an endless reservoir of meanings, weaving universal, cultural and individual narrative threads of human experience. The experiences are reported in a meaningful sequence, articulating past, present and future. Therefore, not only past events can be presented under the gaze of the present, but also experiences can be projected into the future¹⁴.

In addition to describing people’s experience, the narratives show an effort seeking the standardization of their lives while confronted with ongoing threats. The narrativization looks for meanings that nominate and give shape to the source of suffering. This process permeates experience throughout the timeline of the person’s life attempting to locate the events in his own life history, and placing them into a meaningful order by means of a reflexive, therapeutic and transformative mechanism⁷. As the illness experience can be extensive and complex, the focus of this study, whose methodology was based on Gomes and Mendonça¹⁴, was mainly on either the way the research participants assumed being the parents of a chronically ill child suffering from cystic fibrosis or on how they situated themselves in that framework.

The fieldwork was the Pulmonary Ambulatory Center of a public hospital in Rio de Janeiro city – a reference for treating CF disease, providing care services for 129 children from several regions of the state of Rio de Janeiro at the time the survey was conducted. That Center is integrated with other multiprofessional services for cystic fibrosis, such as nutrition and respiratory physiotherapy care. Usually, the patients receive monthly hospital services, although changes can occur depending upon disease severity. Research participants were mothers and fathers of children aged 2–12 years old with cystic fibrosis (for at least two years) without comorbidities.

A survey of ten participants was carried out. The sample size was evaluated according to the saturation point meaning. Research participants were approached in the hospital waiting room and previously selected from the hospital attendance sheet. Participation in the survey was voluntary, and the respondents who agreed to take part in the survey were led in the same day to a reserved hospital room. The interviewer was concerned to not overload the respondents' routine, ensuring that user data was kept secure. Furthermore, the respondents were previously informed about the research objectives and provided with an informed consent form.

Open interviews were held with the previously selected 10 research participants, who were requested to share their experiences with their children. The participants' reports were freely and voluntarily made. However, there were interruptions when the researcher either needed to encourage respondents to talk or asked them clarifications on some subject matter.

The participants' narratives were transcribed and analysed using as theoretical methodological framework the systematized principles of Good⁵ and Gomes and Mendonça¹⁴. The analysis departed from repeated readings of the collected data in order to understand the meanings attributed to CF and the experience of being a father/mother of a child with this disease, as well as aiming at getting a general perception about the participants' reports. Six additional steps were followed: (a) identifying reports excerpts related to narrative components (scenarios, characters and plots); (b) identifying the main ideas of every part in each category; (c) comparing reports ideas in each category for establishing similarities and differences; (d) describing the findings of each narrative component; (e) articulating our research data with other research findings on the subject, when that articulation proved to be necessary; and (f) preparing a synthetic interpretation of results, articulating narrative components and theoretical principles of the study.

Research participants

Interviews were conducted with nine mothers and a father of CF children (Table 1). The ten collected narratives were enough to answer the original research questions, reaching a saturation point meaning.

Table 1. Children with cystic fibrosis

Narrative	Position of the child in the family/ Child's age	Time of diagnosis
N1	middle / 3.11 years old	2 months
N2	youngest / 9 years old	1 year
N3	oldest / 11 years old	6 months
N4	youngest / 6 years old	2 years
N5	youngest / 8 years old	4 years
N6	youngest / 9 years old	2 years
N7	an only child / 4.11 years old	6 months
N8	youngest / 10.11 years old	1 year
N9	oldest and youngest / 8 years old and 1 year old respectively	2 years
N10	youngest / 10 years old	4 years

From the set of respondents, eight had more than one child with CF whereas 2 had an only child; two respondents had already lost a child with CF whereas another one had a second child who had also been diagnosed with the disease. Furthermore, one interviewee had already lost an older child from cancer whereas another one had a child with cancer.

Nine of ten respondents were born in Rio de Janeiro and one was born in Santa Catarina. With regard to housing, three interviewees reported living in the northern part of the municipality of Rio de Janeiro, one in the western part and six in other cities, giving the group, therefore, an urban socio-cultural profile, in addition to two respondents reported living in slums.

With reference to the educational status of the ten respondents, three reported they had a high school education; one had not completed high school; one was an undergraduate student; and five reported having an elementary school level. As for the

subject health care, all 10 respondents reported being dependent on the Unified Health System for the treatment of their children, given our research was carried out in a public health institution specialized in CF treatment. Nevertheless, two of the interviewed families relied on supplementary health insurance coverage.

Regarding their participation in the labor market, seven of the nine mothers had no formal work; five relied exclusively on their partner's income; and two relied on the social welfare child benefit granted for their ill children. As for the two working mothers, one was self-employed whereas the other one worked for the public service sector besides being self-employed. The only father interviewed was self-employed, but living from unskilled labor.

Scenarios of experiences

The scenarios, understood in this context as a place where the meanings of experience were created, also inform us about the spaciality where “the narrative reinvents the experience in its uniqueness, sharing it by introducing it in the world of meaning between partners”¹⁵.

Health care service centers play a key role in the research participants' narratives as part of their lives occurred in those environments, in addition to the fact that the narratives were also produced there – and, for a professional of the health area, that fact favored the narrativization process.

Searching for care service, diagnosis and treatment, the route followed by those families involved a long journey to a great number of health care services and health professionals. Difficulties in accessing these services often resulted in the worsening of the children's clinical condition. Apart from the reference service center where this study was conducted, there was difficulty in articulating the necessary specialized multidisciplinary team even when an accurate diagnosis was made.

“And then I cried very much because I had to go under a pulmonary treatment and I had to do a nutritional balancing. And people didn't

know how the disease was! People don't know, doctor. It's very bad!
You know that people don't know how to treat it!". (N8)

Professional unpreparedness and health care services fragmentation represent an additional suffering to families searching for accurate diagnosis and treatment. This situation is therefore dehumanizing for providing substandard quality of care and selecting the individuals' access to the best technologies available according to their status¹⁶.

Regarding the experience for dealing with chronicity, it led to consequences to children's school life. The school is such an important agent of childhood socialization that, for those CF children, it was seen as their reason for living. Some of them resented when they needed skipping school, as it was the place where they had the opportunity to feel like the other children.

"Last year she was in hospital from March to August. At the end of the year, she was reading, writing, and she was the valedictorian who thrilled everyone. The school psychologist said: 'She holds herself to school as a way of life'". (N2).

On the other hand, the school was also the place where differences between the CF children and other children were evident, as, for example, the case of a CF child who sought among classmates one that had his disease, but found none. It is worth noting that the school was only mentioned in the narratives as a locus where reflections of CF disease may be observed, but without presenting several elements to be outlined as a scenario of experiences of having a CF child. Perhaps, if children were the narrative subjects, rather than their parents, the school would be better configured as a scenario of experiences.

Characters mentioned

Different characters composed the narrative plot: the child itself; the child's siblings; CF disease; the father; the mother; health professionals and death. The relationships established among them demarcated narrative moments that interfered in the illness experience.

The child was the lead character of parental narratives and their major theme, even when mentioned in implied form. Difficult dialogues were established with the child, such as when one of the mothers insisted upon her daughter taking medicine and received the following answer: "Oh, Mom, I'll die anyway!" (N3).

Other times, creativity was necessary to overcome dilemmas and conflicts towards treatment requirements and for the sake of the child:

"I had to find a way for him to accept [artificial] milk. I had to stop breastfeeding, but he wanted to suck my breast all the time. I give him [artificial] milk and he vomited. He wouldn't take a bottle. Mother is this animal with unconditional love [she cries]. Then, I spread the [artificial] milk on me [on my body] for him to accept the milk and forget my breast [she was very moved]". (N8).

In some narratives, the child emerged as someone to be protected from public exposure; nevertheless, routine and necessary care for the child needed to be accepted. One mother reported that her husband did not want to give several pills to his two year-old son in public for not exposing him to the curiosity of others, while she, on the contrary, was of the opinion that her son needed to take medicine anywhere because, she ponders, "It's his reality. He needs to deal with that and it isn't nice to hide it" (N9).

Sometimes, the centrality played by the CF child led to its siblings being relegated, causing, therefore, more suffering, grief and guilt to the mothers, as it can be seen in one of the reports: "I ask my eldest [healthy son] to forgive me until today. He shows understanding, but his need is clear" (N8).

Under the circumstances, some of the research participant's children had to be cared for either by ex-partners or their grandparents, which means not living under the same

roof as their parents. On the other hand, those who remained with the nuclear family received less attention from their mothers and were more exposed to the risks of living in violent slums.

Studies on the relationship between family and CF children have shown physical and emotional distress¹⁷; changes in the family life¹⁸; lack of attention and feeling guilty regarding the healthy children¹⁰; and need for complete family life reorganization¹⁹.

The CF disease was also personified and emerged as unknown in the narratives, even to family members coping with it for years: “I don’t know anything about cystic fibrosis! It’s a search for answers, because we need to get answers” (N2).

Aiming at a deeper understanding of the CF disease and its consequences, as well as at exchanging experiences, the research participants turned to other families that were going through the same problem. However, on account of each case being unique and the different clinical expressions of the disease, those exchanges worked as an emotional support and to give them a picture of the illness stages that were to come, leaving them with several doubts about the organic causes and the dynamics of CF disease.

“I didn’t know [the disease], but to this day I don’t quite know what awful illness is that! What I know is what I’ve been hearing in the hospital, that is, what mothers find out and talk about”. (N3)

Notwithstanding, even the knowledge about the CF disease – what is held as appropriate by the biomedicine – does not nullify the presence of uncertainty, since this is the essence of chronic illness experience, affecting both the medical performance and the patients’ and their family lives²⁰.

Thus, the prevalence of experience on knowledge does not imply a decrease in the importance of such exchanges, given that solidarity and parents’ identifying themselves with the ones who face the same problem generates in the parents the feeling of belonging that empowers them; therefore, helping them to withstand challenges in the treatment process²⁰.

The father was another character present in the narratives and mentioned by all female respondents. When present in family life, he was quoted as a good father and husband. On the other hand, his emotional absence was the most frequent complaint. Even when the male partners belonged to the health care area, they delegated to women to take important decisions referring to the disease, bringing, in this way, more consequences to their state of mind.

“The father, in the first year – I don’t know if out of fear or desperation – was completely emotionally absent, and his absence hurt me a lot”.
(N8)

Mothers played a central role in the activities related to the CF child. They dealt with all the commitments regarding health services, such as medical appointments, hospitalizations, and everything else that entailed CF disease.

“And, again, I feel I take part of a struggle that seems to be only mine, that seems not to be related to the father, that seems not to be related to the best man. It seems that I’m the only one who has to go after medical reports, or seek once more a public advocate”. (N8)

Complete dedication and commitment to the CF treatment, seeking to prolong and maintain the child’s life, was a role that was played by the respondent mothers. They were the ones who needed to learn and supervise procedures and/or apply them to their children. The more specialized in childcare they were, the more they became indispensable to the CF treatment, thus increasing their physical and emotional burden resulting from the physical and emotional handling of their CF child²⁰.

“He didn’t accept that someone else touched him... Then, I had to deal with that [the gastrostomy]! And it was hard for me because he was my son and I didn’t want to touch that. I had to go over it slowly, but we’ve adapted ourselves. I didn’t feel confident someone else touched

him. He was also going through a moment he needed me. I wouldn't leave his care in the hands of someone else". (N9)

Coping with and taking care of a chronically ill child can be a lonely experience, as many commitments fall on the mother, thus nullifying, for most of them, other roles previously played. The narrative of the only interviewed father – although it points toward his commitment and care for the child – was more helpful, perhaps due to the reduced exposure to many of the activities imposed by CF disease, as they are usually performed by the mothers, as shown and reinforced in other studies^{18, 10, 19}.

Women's centrality in childcare comprises gender issues built from cultural and subjective meanings with space–time variations. Stereotypes created around these meanings influence the creation of generalized beliefs surrounding traditional stereotypic gender roles of men and women^{22, 23}, therefore influencing care concept as typically female²⁴ – an understanding that can both strengthen women's symbolic power in the family environment and naturalize traditional gender patterns.

In spite of several categories of health professionals being mentioned in the narratives, the doctors, who were characterized in different forms, were the main protagonists. The findings also showed that doctors played a dual role for the research participants. On the one hand, there was the recognition of their domain of expertise, as they had diagnosed the disease, recommended prescription treatments, determined the critical moments that required either hospitalization or the onset of new therapeutic measures for the CF child; and, on the other hand, they were expected to show understanding on the lived experience of the families as to the child's illness, as well as sensitivity to break the news about CF patients' status.

"When I arrived, I remember as if it were today... I entered the room and they even asked me to sit down... And the doctor said: 'Mom, your daughter has a very serious incurable disease and she must be urgently hospitalized.' It was like a hard impact! And when you get the news, you feel like vanishing. The ground seems to open up!". (N4)

Communication problems resulting from the lack of clear, accessible or inadequately conveyed information by health professionals undermine mutual trust and understanding that families may have on the disease dynamics; retention and understanding of information; ability to overcome the impasse of CF disease; and ability of patients and their families acting towards improving the patients' health^{25, 26, 27}.

Costa et al (2010) note that the patients' family members not always understand what the doctors explain. Moreover, the shortened life expectancy prognosis of their children may trigger fear, anger, and rejection of reality. Finally, death implicitly or explicitly acts as a character due to the incurable genetic condition of the disease. As reported by one of the interviewed mothers, "You have to live 24 hours with death hanging around you all the time" (N2).

For some research respondents, that perspective brought the idea that they were facing an inglorious war against disease. The reports presented the existence of a strong struggle, being the only certainty the fact that there would be no victory if the narrators considered healing as such. Regarding this issue, literature review shows that families whose children are diagnosed with CF experience feelings of fearing the child's death, certainty that death will come prematurely causing an anticipated regret. They highlighted their fright of failing to care, as it would shorten the child's life¹³.

Plots

According to Good⁷, plot is the meaningful order of history, giving a certain direction, design and intention of meaning-making in narratives. Clinical events in plots are the starting point of a sequence of events that produce a dramatic change in the world of everyday life, culminating initially in the diagnosis of the disease.

In this sense, CF patients' family members, as a response upon first learning the diagnosis of CF and its chronic condition, had ambiguous feelings: on the one hand, disease awareness provided the control of symptoms and improvement in the clinical status of their children; and, on the other hand, it also changed their everyday

lives due to the restricted prognosis and therapeutic prescriptions, causing them fear, uncertainty and setting up a new routine. With respect to this issue, N8 reports: “And then came the news [the diagnosis] and the [awareness of] disease. [She cries] That was the worst moment for me.”

After receiving diagnosis and establishing a care routine, there were other challenges to be faced even for those with financial resources. The interviewed parents struggled hard to comply with medical prescriptions in order to live as close to the “normal” life as possible.

“Everyday life is tiring. Sometimes respiratory physiotherapies are tiring. He feels sick. He is a child! They are playing, the physiotherapist arrives and he has to stop, sit down and do respiratory therapy. But it’s bad; it isn’t something good to get along. That isn’t what I’ve planned to my life, but that’s what I’ve got”. (N9)

At the same time that the families tried to live in as close as possible of the way the alleged healthy people live, they could perceive huge differences between their routines and the ones lived by the others. The probability of healthy people understanding the limitations caused by CF disease was quite low, and the families that had to undergo the process had a “syndrome of experience” that only those who live with a chronic disease can assess⁷.

The plots of mothers in particular have as unanimous outcome abnegating their own lives, as they give up their personal projects and needs to provide intense care for their children – exactly what the common sense would expect from a “good” mother.

“I had to give up my work. I knew I had to get that treatment to save the life of my son, and I gave up everything for him!”. (N7)

For some, the way to cope with the lack of control over the CF disease progression in the child’s body and its consequences was to accept that fight as a

personal challenge, buying time until new biotechnological resources could arise²⁷, changing and adjusting priorities in their lives.

The unfolding plots after diagnosis of CF disease also suggest disruptions in everyday life.

“I’m not the mother of [mentioning the name of the daughter] now. I’m not the secretary I used to be, I’m not the mother anymore. I don’t even feel I’m a mother anymore. I feel I’m the nurse, the nanny... If she’s at school I also have to be at school, because she won a scholarship and the school expects I’m always around. So, this means I don’t live anymore”. (N2)

Living with chronically ill children can lead to undergoing a disruptive experience, promoting a biographical disruption⁹ in parents’ lives. In this sense, other social roles played by the parents run the risk of being discarded to make room for necessary care that must be provided to the disease. This type of disruption can both reach the everyday life structures and the ways of thinking sustaining them⁹.

On the other hand, ruptures do not always remain. For coping with the ongoing illness of the child, parents can change their way of thinking, experiencing an adaptation or resignification towards the disease, or even – using Bury’s³ expression – a biographical reconstruction.

“When I found out [that my son had CF], I didn’t want to have children anymore because there are chances and so forth. Over time, I learned to deal with [she mentions the child’s name]. I saw that was no pain... it was not rocket science, and that I was able [to deal with that situation]! I said to myself: If I’m capable of one [caring for a CF child], I can take the risk of being able to have another [child with CF]”. (N9)

Although this is a real possibility, grief of not knowing how long the child would live prevailed in the narrative plots, and that doubt may be understood as a possible rupture.

Some of the analysed narratives showed that there seemed to be a double parental effort: fighting against death and, simultaneously, leading a life closer to the ordinary.

“[It’s] sad, but I’m taking life. Oh, I take it so normally, but only I know what I’ve to go through!”. (N3)

Therefore, cystic fibrosis disease has changed the lives of those families, making them face a reality to which most of them, until now, were barely aware of: the finitude and fragility of human life. Although stating that they were “taking life”, the narrators seemed to be rather taken by it, hence reversing the logic of common sense according to which we control our body and destiny⁷.

Interpretive Synthesis

Parental narratives about living with their children with CF – a long, life-threatening disease – reveal scenarios, plots and characters with specific characteristics. The health care services play a central role in the scenarios of experiences of this disease because of successive medical appointments or hospitalizations of patients. In these services, it is developed meanings and ways of dealing with the disease, which advances in the spatiality of chronic illness experienced in other environments of the everyday life of the patients and their families.

According to Good⁷, although in such services there are various health professionals providing care to the chronically ill patient, doctors can be seen as the main protagonists in the narratives. Their explanations on the disease are often used as part of the natural order. Furthermore, their actions, in many experiences of chronicity, increasingly shape the everyday life. As a consequence, the world of health clinics, medical examinations and laboratory tests dominate social relations.

With reference to the fact that health care services and doctors respectively play a central role in the narrative scenarios and between characters, it should not be overlooked that this situation may have occurred due to the narratives of this study have taken place in a health care service environment and the listener was a professional of medicine, given the narratives must be produced in the context of interpersonal relations, involving authors and audiences⁷. In such relation, the power of the narrator also lies in the ability to tell the type of story that is important for whom it is directed²⁷.

Death, despite being perceived as a supporting character, can also emerge among the characters of the chronic disease plots. As reported by Good⁷, death is an omnipresent character and background of the everyday life, being more evident to chronically ill persons than it usually is for those who do not live with a disease, as death turns the world of chronically ill patients into a world that is different from that in which others live. With reference to children, death acquires a differentiated symbolic, since it interrupts their expectation of having a future ahead for being regarded as a break in the “natural” order of life²⁸.

Finally, still on the issue plots, it is worth noting a relativization on the fact that we hold the struggle for the childlife as the outcome in this study. Nevertheless, this does not mean that there was completeness in all narratives because the reports were usually inconclusive, in the same way as in Good’s study⁷. The complexity of the chronic disease faced in the present not always open space so there is a clear outcome referring the future. The reports, in a way, using Good’s words, seemed to refer to people who are in the middle of a story⁷.

Final Remarks

The findings of our study showed a number of peculiarities of parents living with the chronic condition of their CF children that may go unnoticed for health professionals, suggesting that they can be sensitized beyond biomedical issues.

Together with the etiologies and nosologies of diseases, the experience of the surveyed families may serve as a reference for a clinical approach.

Different realities determine a great variety of values, behaviors, reactions, and choices. Knowing and respecting them is an important part of the health professionals' commitment to the lives of families/patients who are cared for by health care services, without distinction of any kind, assisting them within the limits of biomedicine and human dignity. As for the chronically ill children, particularly the ones with cystic fibrosis, the quality of care provided to them needs to go through a continuous and dynamic review.

According to the surveyed scenarios, increasing information disclosure on cystic fibrosis and preparing new reference health centers with the proper articulation of key specialities for the treatment of the disease could facilitate and accelerate both diagnosis and accurate treatment. Nearing health services to schools could make them partners. Moreover, clarification, information and effective communication on CF disease to educators help creating a network, which would facilitate the inclusion of children and help them changing both their lives and their family lives in a more autonomous and complete way.

All characters evidenced by narratives in general, including those collected for this study, comprise the fabric of relationships that make up the world of chronic diseases, organized by plots tied to the pursuit of accurate diagnosis and proper treatment, having as driving force the struggle for the life of the chronically ill child. Both a deeper knowledge about the interdependence of these factors and their influence concerning the disease experience suggest that the dialogue between all actors, added to emotional support, can alleviate physical and emotional wear, therefore strengthening bonds favoring agreements both in family relationships and between the patients and multidisciplinary professional teams, thereby promoting nearness between those who live with a chronic disease and those who run an ordinary life, even if it takes place under the shadow of death.

Finally, it is worth adding that innumerable aspects emerged in the narratives on cystic fibrosis can be found in other chronic childhood diseases, suggesting the need

of further studies leading to reflections and actions expressing the intertwining of biopsychosocial factors in the context of public health facing challenges posed by the new epidemiological profile of chronic diseases.

Collaborators

All authors have participated in the preparation and writing of this paper.

References

1. Kleinman A. The meaning of symptoms and disorders. In: The illness narratives, suffering, healing and the human condition. Edição . Cidade: Lexington – USA: Basic Books; 1988. p. 3 – 30.
2. Uchôa E, Vidal JM. Antropologia médica: elementos conceituais e metodológicos para uma abordagem da saúde e da doença. Cad Saude Publica. 1994; 10 (4).
3. Bury M. Illness narratives: fact or fiction. Sociol Health Illn. 2001; 23(3): 263–285. Acessado em mar/2010: disponível em: <http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.00252/abstract>.
4. Herzlich C. Health and illness on the eve of 21st century: from private experience to the public sphere and back. Physis. 2004; 14 (2).
5. Good BJ. The body, illness experience, and the life world: a phenomenological account of chronic pain. In: Medicine, rationality, and experience An anthropological perspective. 10. New York: Cambridge University Press; 2008. p.116 – 134.
6. Canesqui AM. Estudos socioantropológicos sobre os adoecidos crônicos. In: Canesqui AM, organizadora. Olhares socioantropológicos sobre os adoecidos crônicos. São Paulo: HUCITEC/Fapesp; 2007. p.19–51.
7. Good BJ. Medicina, racionalidad y experiencia. Una perspectiva antropológica. Barcelona: Edicions Bellaterra; 2003. p. 375.
8. Kleinman, A. Concepts and a model for the comparison of medical systems as cultural systems. Soc. Sci Med. 1978; 12: 85–93.
9. Bury M. Chronic illness as biographical disruption. In: Sociology of Health and Illness. 1982; 4(2):167–182.
10. Santos, MER. Crianças e doença crônica: a vida possível. [tese]. Rio de Janeiro (RJ). Universidade Estadual do Rio de Janeiro; 2003
11. O’Sullivan BP, Freedman SD. Cystic fibrosis. Lancet. 2009; 373 (9678): p.1891–1904.

12. Firmida M, Lopes AJ. Aspectos epidemiológicos da FC. *Revista Hospital Universitário Pedro Ernesto*. 2011; 10(4).
13. Jussep M, Parkinson C. "All at sea: the experience of living with cystic fibrosis. *Qual Health Res*. 2010; 20(3): p. 235–264.
14. Gomes R, Mendonça EA. A representação e a experiência da doença: princípios para a pesquisa qualitativa em saúde. In: Minayo MCS, Deslandes SF, organizadoras. *Caminhos do pensamento: epistemologia e método*. Rio de Janeiro: Editora Fiocruz; 2002. p. 109–132.
15. Deslandes SF, organizadora. Humanização: revisitando o conceito a partir das contribuições da sociologia médica. In: *Humanização dos cuidados em saúde: conceitos, dilemas e práticas*. Rio de Janeiro: Fiocruz; 2006. p. 33–47.
16. Furtado MCC, Lima RAG. O cotidiano da família com filhos portadores de FC: subsídios para a enfermagem pediátrica. *Rev Lat Am Enfermagem*. 2003; 11(1).
17. Nóbrega VM, Collet N, Silva KL, Coutinho SED. Rede e apoio social das famílias de crianças em condição crônica [Internet]. Goiânia: *Rev. Eletr. Enf*; 2010;12(3):431–40. Disponível em: <http://www.fen.ufg.br/revista/v12/n3/v12n3a03.htm>.
18. Tavares KO, Carvalho MDB, Pelloso SM. O que é ser mãe de uma criança com FC. *Rev Gaúcha Enferm*. Porto Alegre (RS). 2010; 31(4): 723–729.
19. Adam P, Herzlich C. *Sociologia da doença e da Medicina*. Bauru (SP): EDUSC; 2001.
20. Aragão PM. A criança com mucoviscidose e seu campo de possibilidades. Uma perspectiva etnográfica de dois estudos de caso [Dissertação de Mestrado]. Rio de Janeiro (RJ): Instituto de Medicina Social, Universidade Estadual do Rio de Janeiro; 2004.
21. Courtenay WH. Construction of Masculinity and Their Influence on Men's Well-Being: A Theory of Gender and Health. *Soc Sci Med*. 2000; 50(10):1385–1401.
22. Machin R et al. Concepções de gênero, masculinidade e cuidados em saúde: estudo com profissionais de saúde da atenção primária. *Cien Saude Colet*. 2011; 16 (11): 4503–4512.
23. Gomes R, Nascimento EF, Araújo FC. Por que os homens buscam menos os serviços de saúde do que as mulheres? As explicações de homens com baixa escolaridade e homens com ensino superior. *Cad Saude Publica*. 2007; 23(3):565–574
24. Caprara A, Rodrigues J. Relação assimétrica médico-paciente: repensando o vínculo terapêutico. *Cienc Saude Colet*; 2004; 9 (1).
25. Gouveia GC; Souza WV; Luna CF; Souza-Júnior PRB; Szwarcwald CL. Satisfação dos usuários com a assistência de saúde no Brasil. *Cienc Saude Colet*; 2011; 16(3): 1849–1861.
26. Damião EBC. *Crenças das famílias da criança com FC [tese]*. São Paulo (SP). Escola de Enfermagem da Universidade de São Paulo; 2002.

27. Cardoso VZ. Narrar o mundo: estórias do “povo da rua” e a narração do imprevisível. *Mana*; 2007; 13(2): 317–345.

28. Nehmy RMQ, Brito AC, Mota JAC, Oliveira BM. A perspectiva dos pais sobre a obtenção do diagnóstico de leucemia linfóide aguda em crianças e adolescentes: uma experiência no Brasil. *Rev. Bras. Saúde Matern. Infant.*; 2011; 11 (3): 293–299.

Translated by Riyadh Weyersbach