Abstract

Objective: To understand the difficulties experienced by fathers of children with chronic illnesses in terms of day-to-day childcare.

Methodology: A descriptive, qualitative study conducted between June and August 2014 by means of semi-structured interviews with 10 participants who were fathers of children with chronic illnesses. The data were subjected to thematic analysis.

Results: The fathers experienced many difficulties in terms of day-to-day care: emotional burden, trying to balance work with caring for their child, administering medication, hospitalisation, and sharing the child’s care with the mother. Because the fathers assumed financial responsibility for their homes, they lacked time to better serve their children and to foster the emotional structure needed to support the duties and constraints that arise because of their absence.

Conclusion: The fathers needed guidance and support from the health team to overcome the difficulties experienced in day-to-day life and become better prepared to understand and fulfill their roles in caring for children with chronic illness effectively.

Introduction

The family is the primary social institution linked directly to a child’s development, especially in the first years of life. Marked change in how the mother’s position in childcare is appreciated has been historically evident. As women have increased their presence in the labour
market, a reorganisation of the family structure has occurred. Consequently, the man/father has become more clearly regarded in childcare, and his participation has increased [1-3].

When exercising the role of fatherhood, a man completes a social cycle that is important to his development. The process of paternity demands profound changes in a man and is one of the most challenging times of his social and family life [4].

The social role of men in the family has changed significantly. Previously, the man was responsible for supporting the household, leaving the woman responsible for raising the children and fostering affective ties. Today, we see a “new fathering” movement in which the man is more interested, participatory, affectionate, and caring. Studies [4-5] show that, from their partner’s pregnancy onward, fathers are increasingly trying to become part of the child’s world. They are present, forming expectations and hopes in relation to the child.

A child’s diagnosis of chronic illness has a significant impact on the family, especially the parents. However, the focus is still predominantly on the maternal figure when identifying the person regarded as being most responsible for the care of a child with a chronic illness. Such care includes routine consultations, treatment, and constant hospitalisations, which require an intense remodelling of family life in order to meet the needs of the affected child [6].

Studies [7-9] have drawn attention to the need to include the man/father in the context of care for a chronically ill child insofar as he affects and is affected by his direct relationship with the child. In this regard, a man’s priorities change when he needs to care for a child with a chronic health problem: his working hours are reduced, he tries to establish a stronger bond with his child in stressful routines, and he tries to know the specifics of the diagnosed illness.

However, fathers must confront many difficulties in providing effective care. Studies have revealed difficulties related to communication, authority issues, defining roles, division of labour, skills in performing therapeutic activities or administration of medication, and decision-making. There remains a distinction between fathers who are focused on their roles as household providers and those who more strongly emphasise moral, educational, and emotional issues. It is therefore necessary that the health team supporting the child be familiar with and receptive to the family, including the father figure [2, 6, 8].

This study therefore poses the following question: What are the difficulties experienced by fathers in the day-to-day care of children with chronic illnesses? This question stresses the importance of the father’s direct involvement in the care of the chronically ill child and the importance of the multidisciplinary team’s, including the nurse’s, ability to understand and know how to deal with his difficulties. Therefore, the aim of this study was to understand the difficulties experienced by fathers in the day-to-day care of children with chronic illnesses.

Methods
This was a descriptive qualitative study developed in two public hospitals in a Northeast Brazilian capital in the period from June to August 2014. The study included 10 fathers of children aged 0-12 years who had confirmed diagnoses of chronic illnesses and who were being treated in the participating hospitals. Fathers with difficulties in verbal communication and those for whom telephone contact to arrange the interview was not possible were excluded. Documents relating to the hospital admission of children with confirmed diagnoses of chronic illnesses in the specified age group were used to recruit participants. Contact was then established with the father in order to schedule the interview at a place of his choosing, which included hospitals and/or the father’s home, according to his availability.
Data collection occurred via interview with semi-structured script, which enabled the participants to express themselves comprehensively on the subject in question. The interview was guided by the following question: What are the difficulties you experience in caring for your child with a chronic illness? The interviews were recorded on digital audio media (mean duration: 60 minutes) after prior authorisation by the fathers participating in the study. These interviews were fully transcribed.

Empirical data analysis followed three stages of thematic analysis. The first stage, or pre-analysis, began after transcription of the interviews. This stage consisted of an active and thorough reading of the transcripts, followed by organisation of the material (constitution of the corpus) so that the information collected could be analysed thoroughly and data interpretation could begin. The second stage, exploration of the material, comprised “a classificatory operation to reach the core of understanding of the text” [10]. This process sought to find significant expressions by which the content of the statements could be organised. These cores of meaning were then organised and grouped by similarities and differences, with the main objective being to compare them. Following this reorganisation, the results were interpreted in light of the pre-established theoretical framework.

According to ethical principles, the guidelines of Resolution 466/12 of the Brazilian National Health Council (Conselho Nacional de Saúde do Brasil) and the Declaration of Helsinki were followed. The study was approved by the Ethics Committee (protocol 83/2011 CAAE No. 0466.0.000.126-11). All study participants signed terms of free and informed consent.

Results
The age of the children whose fathers participated in the study ranged from 4 to 12. They had the following diagnoses: cystic fibrosis (1), mucopolysaccharidosis (1), cerebral palsy (2), sickle cell anaemia (3), diabetes (1), and asthma (2). Time since the child’s diagnosis ranged from 3 to 10 years, which was relevant in terms of analysing the fathers’ different experiences. The fathers’ ages ranged from 25 to 56 years, and their education ranged from 3 to 13 years of completed study. Only one father was unemployed at the time of the interview. Family income ranged from approximately R$ 1,000.00 (US$ 300.00) to R$ 3,000.00 (US$ 900.00). Two fathers owned their own homes, and there was a minimum of 4 and maximum of 6 rooms and an average of 3 people living in the fathers’ households.

The results were analysed to establish the core meaning underlying the difficulties the fathers faced in caring for their children with chronic illnesses. These difficulties are discussed below, along with subtopics.

Difficulties in the father’s day-to-day care of a child with a chronic illness
Many challenges and difficulties emerge when caring for a child with a chronic illness. One of the difficulties reported by the fathers in this study was combining work with caring for the child.

Because, so, I work all day, I can’t give all this care [that] I want to, but someone has to put money on the table, and there’s no one here to help [...]. If I’m a father who’s not around much today, it’s because my priority is to ensure they have good things and the best; this is my role as a father.

E6.

[...] The worst thing is just fatigue: I come home tired, but then there is so much to do that by the time I feel on top of things, it’s time to go to work again.

E8.

The household provider function is very important, but it does not go hand-in-hand with satisfaction related to fathering. A study of fathers
of children with cancer has shown finances to be the greatest difficulty reported by fathers, who attempt not to appear fragile with regard to their role as the household provider. The little time that fathers have to devote to their children proves to be a problem in terms of exercising the paternal role and generates intense frustration and feelings of guilt. Fathers are torn between care activities and work, triggering negative feelings in regard to self-evaluation [11].

For some fathers, work can sometimes provide a means of escape that eases the anguish and pain associated with a situation they cannot control and the perception that they cannot protect their family. [12] Fathers try to appear strong, which is consistent with the principles of a patriarchal model and the male stereotype. However, this way of interpreting fatherhood can cause harm to the relationship with the child and put the father at a distance from her.

Nevertheless, the need to work makes it very difficult for the father to take part in the child’s treatment. He does not always know how to deal with this feeling of concern that occupies his thoughts [11].

Although some fathers describe work as being an impediment to spending more time with their children, studies [13-15] have shown that it is not the amount of time that fathers spend with their children that qualify the relationship and care activities, but the quality of the time that is available. When the father and mother work, the maternal figure remains the one who provides more care to the child, and the father continues to maintain a more peripheral position in this regard. It should be noted that even when the father exercises few care activities compared to the mother, his participation is seen as positive and important in this process. Thus, the care provided by the father, whether simple or systemic, is in itself seen as positive.

Chronic illness in a family member can trigger changes in marital relations. The demands, responsibilities, worries, and anxieties can cause couples to become distant. In this sense, other issues are experienced by fathers, such as social isolation and financial difficulties. These challenges increase stress and induce a tendency toward depression. Financial difficulty is seen as the main limiting factor in a father’s satisfaction level, as it causes profound stress.

Food today is becoming a luxury item, and the food the nutritionist recommends is expensive; it’s around BRL 150 a week in the supermarket. [...] One hundred and fifty is a lot of money, at least for poor people already living on a monthly budget. [...] And on the weekends, I have to do odd jobs to make ends meet, because he has to buy clothes, the materials that the teacher makes us buy for school; there is already a lot to provide.

We do our damnedest to pay the rent, purchase from the farmer’s market, buy medicine, pay for tutoring [...]. If we could stay at home all the time and still earn money, it would be good. If the wife were working, I think it would ease things even more. [...] I say, “my work,” because today I’m the one who’s responsible for everything in the house.

These difficulties were also highlighted in a study [16] in which fathers reported anxiety in the pursuit of financial stability and the need to maintain their child’s cancer treatment without having to compromise in other areas of the family’s life.

The family accumulates financial expenses in meeting all the care and treatment needs of a child with a chronic illness. The health worker should advise them on how to minimise the financial burden [12]. Treatment of chronic illnesses, even in specialised and state-subsidised centres, still leads to other expenses, such as food, recreation, and alternative treatments.
Another situation, classified in the statements of the fathers in this study as one of the main difficulties encountered, is related to the perception of the father in relation to his partner’s care. Many feel resentful and see that maternal attitudes form a barrier against the paternal care role.

In fact, to this day, she does not let me touch him much, and when he couldn’t hold his head up at all, that’s when she wouldn’t let me do anything [...] because she doesn’t believe I can take care of him [...]. She thinks only she knows how to look after him.

E2.

I don’t do more simply because his mother doesn’t let me. [...] She is very suspicious; she won’t even leave him with me. [...] She thinks I don’t know how to do what she does, [...] that I can’t do it.

E10.

This inability of the father to develop care activities may arise from his partner’s and the health team’s neglecting to provide him with information to enable him to care [12]. The mother “takes care of (the child)” and the father “takes care of (the mother)”. Fathers do not understand how they can play their part because they do not know how to divide activities, share actions, or make decisions. Fathers feel displaced because they do not know exactly what their role is in the care of children with chronic illnesses. Increased pressure and being called upon by the mother to take responsibility for this care causes distance between the parents, which can lead to conflict.

To avoid such conflict, fathers prefer to leave complex care activities to the mother. They fear that the mother will criticise their unskilled efforts in caring for the child. [12]

One study [17] has shown that the distance assumed by the father in the care of children with chronic illnesses is directly related to gender differences with the child’s mother. This difference, which is socially rooted, causes fathers to not take responsibility for certain care activities because they believe them to be inherent to the maternal figure. The main difficulty is to overcome these differences, as they prevent the man/father from taking over and sharing care actions. Furthermore, fathers cannot cope with the pressure of having to care for a sick child, as they do not know how or cannot express their emotions and frustrations.

The fatigue and exhaustion that accompany caring for a child with chronic illness were seen in all the fathers’ statements. They reported a physical and emotional burden in addition to problems with work and constant worries about the sick child.

Look, [...] this way, [...] nothing is easy. I arrive home exhausted, tired, but I don’t feel like sleeping. There is so much heartache that I have neither the will nor the peace to sleep [...]. It’s not easy to have a special child. You have to pay careful attention, more than you would with a normal child [...]. I can’t sleep because I think he may have a crisis and I’ll not see it. Can you imagine? He dies and I don’t notice?.

E3.

I am always very tired, I don’t know whether it’s because of work, or things at home. [...] I’m constantly sleepy, tired even. It’s bad, but we can’t stop.

E10.

The rearing and education of a child with a chronic illness requires much more careful attention from parents than those of a child with no health problems. As a result of the additional responsibilities relating to the control of illness symptoms, there is a need for complex technical care for, protection for, and defence of the child. In addition, there is the responsibility of searching for and coordinating the health and social services that the sick child needs. [12]
The fathers reported burdens in their day-to-day lives and emphasised the importance of overcoming adversity and facing the problems that may appear throughout the course of a life with a sick child. A study showed that the burden faced by caregivers of children with chronic illnesses is associated with variables relating to sleep quality, mental health, stress, anxiety, depressive symptoms, perception of the child’s illness, the effects of coping strategies and self-efficacy, ethnic and regional differences, and demographic data. [18]

In this study, the burden reported by fathers related not only to the day-to-day routines at work and at home but also to the responsibilities and feelings that arise when living with a sick child. There is also a relationship between the caregiver’s burden and the degree of dependence of the sick child and time spent on care activities, which can even cause the caregiver to become ill himself. While not constantly voiced by fathers, a physical and emotional burden exists and accompanies feelings such as sadness and concern.

Studies [8, 13, 19] corroborate the existence of a physical and emotional burden in parents of children with chronic illness. This burden can be directly related to the losses that parents witness daily in contact with their children, who sometimes cannot feed themselves or perform everyday tasks without assistance.

The literature shows that the burden of caregivers of children with chronic illness affects various areas. Several instruments have therefore been used to evaluate this burden, including the Zarit Burden Interview and Montgomery-Borgatta Caregiver Burden Scale Revised [19]. These scales have been applied in studies evaluating the burden of caregivers of children and adolescents with different chronic illnesses (sickle cell anaemia, haemophilia, inborn metabolic errors, and cancer) [17-20].

Another difficulty often mentioned by the fathers was related to administering medication. It was observed that all the fathers had this experience, as it is part of the day-to-day life of a child with a chronic illness. However, the fathers’ reports showed a certain resentment, either because they believed that they were unable to carry out such activity or because they feared forgetting the schedule or dosage of medication to be administered.

**When he gets sick, I’m nervous. ...I’m not good with medication, I don’t know how to do these things ... because his mother usually does it.**

E6.

**I’m afraid. And what if something happens, what do you do? It causes a fight (with the child’s mother).**

E10.

The fathers interviewed felt insecure about providing care. This insecurity triggers a fear of performing an activity unsatisfactorily and causing harm to the health of the child.

As a result, the father sees himself as a possible threat to the protection and safety of the child insofar as he does not know what to do and how to do it when helping his family care for the child. He responds by withdrawing, which causes feelings of guilt, failure, helplessness, sadness, shame, and anger. [12]

Fear is a common reaction to the unknown. The role of the health team is to enable the father to acquire the skills needed for childcare. This process includes the following: listening to the father; encouraging shared caregiving; training him to perform technical care duties with skill; and informing him about the illness, its development, and the care necessary for his child. The health professional’s role is key to providing safety and reducing the stress and anxiety associated with caring for his child.

Difficulties are even greater when the child needs to be hospitalised. Fathers monitoring their children participate in their direct care and are vigilant to ensure that no symptoms go unnoticed and that there are no signs of the child’s health worsening:
I’m in despair when he needs to be hospitalised; I think about it a lot ... at work. ... I think about it all the time. What if something happens? I just want him not to need to come here (hospital) again.

Even tonight, if I had not paid attention, the nursing technician wouldn’t have seen he was in crisis. That is how a crisis is—you have to pay close attention.

The hospitalisation process triggers various changes in the family dynamic. The father is forced to change his entire routine in order to monitor the child. This situation can cause discomfort and stress. Studies [4-6] show that the hospital environment is hostile because it promotes discomfort and causes the patient to become depersonalised. Just as all of the child’s routines are changed and others are imposed, those of the parents are also affected.

It should be noted that the concerns of fathers regarding the care of children with chronic illnesses during hospitalisation are linked to possible changes in the clinical picture. However, one study emphasises that these children have diverse needs that transcend the biological dimension. Health professionals and families must recognise and value the individuality inherent in such cases to successfully and satisfactorily manage childcare [21].

The empowerment of fathers consists of a process of recognition, promotion, and improvement in care-providing skills. Health professionals should form a partnership with fathers of children with chronic illnesses to help them through this process [12]. From this perspective, health professionals should encourage fathers to enhance recognition of their child’s needs and to notice areas where fathers can contribute to care, both in the hospital and at home-areas in which they already have the skills necessary to do so.

In addition to the fear of worsening the child’s clinical condition, fathers face fears around their absence from work due to caring for the child in the hospital.

You have to miss work, and it becomes a mess. ... I’m afraid of losing my job, but I’m here (in the hospital) whenever I can, because I’m concerned.

Often, the family needs to restructure financially because, in general, one parent leaves his or her job to care for the sick child, which sometimes results in the father having to get a second job. [22]

The father is concerned about his ability to manage the family’s growing financial burden when his child is diagnosed with a chronic illness. [12] He thinks about the possibility of losing his job, the only source of family income, and this concern causes repercussions in his family’s life. Being the source of income makes the father experience this responsibility as a stressful burden that permeates his thoughts and that can affect his relationship with his family.

The paradox between the need to be working and the desire to be present with his hospitalised child is unsettling for the father. This conflict regarding his role can contribute to a stressful situation for the family and cause negative feelings. Having more flexible hours for hospital visits, when he cannot always monitor his son, helps the father feel more collaborative and satisfied to be with his child during this time, thereby minimising the negative aspects presented in this study. Additionally, visitation makes the father-child relationship closer, helping to bring him closer to the reality of the situation and the care that the child needs.

According to the statements and perception of the fathers, the difficulties they encounter in caring for children with chronic illnesses reflect intrinsic aspects that are related to the process of diagnosis, care of, and treatment of affected children. One can
observe feelings of responsibility, dedication, and commitment permeating the father’s role as a social member and as an active participant in the care of a child with a chronic illness. On the other hand, one can observe the limitations that permeate this experience, which also generate negative emotional and physical consequences that can compromise the father’s health and his role as a participant in the care that is being given to the child.

Conclusion
The main difficulties encountered by fathers in day-to-day childcare relate to economic problems, the man’s ability (or inability) to reconcile this care with work, household chores, and obligations to the household and his children, and insecurities about the direct care of the sick child.

Social responsibilities, especially in the family environment, that necessitate greater involvement of the father with the child’s care could be clearly observed in the fathers’ statements. They feel frustrated because they do not know how to deal with the specifics of the child’s illness—an experience that generates negative feelings of self-evaluation regarding their paternal role.

The father’s relentless efforts to provide economic support to the household complicates the time he has to relate to the child, making the care process more difficult. On the other hand, there is a need for financial support throughout the treatment period of a chronic illness, which causes concern about the permanence of employment contracts that, although indispensable, compromise his participation in care.

The family, especially the child’s mother, also needs to open up space and share her experiences with the child’s father. She will thereby be meeting her child’s needs as well as her own. In doing so, both the father and the mother can take care of the child with a chronic illness in an effective and shared way.

Understanding the father’s difficulties, providing support, and guiding him in relation to childcare will give him the opportunity to learn how to care for the child. This role is key to his involvement in the effective care of the child with a chronic illness, and the health team must assume this responsibility when developing actions during the child’s hospitalisation. The team attending to the child with a chronic illness and everyone in the immediate family must see the impact of the father’s participation as a positive feature.

Assisting fathers with their difficulties and understanding them to be a part of the care process are challenges to be carefully studied and unravelled. The idiosyncrasies of the fathers studied here represent a limitation of the research; thus, there is a need to further explore this issue. The results offer the possibility of developing other research that can contribute to broadening the field’s understanding of the difficulties and needs of fathers of children with chronic illnesses in the process of caring for their child. The goal is to provide greater empowerment and autonomy to the father when faced with chronic childhood illness.

References


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