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Understanding the experiences of caregivers of children with tuberculosis in directly observed therapy

COMPREENDENDO A EXPERIÊNCIA DE CUIDADORES DE CRIANÇAS COM TUBERCULOSE EM TRATAMENTO DIRETAMENTE OBSERVADO

COMPRENDIENDO LA EXPERIENCIA DE CUIDADORES DE NIÑOS CON TUBERCULOSIS EN TRATAMIENTO DIRECTAMENTE OBSERVADO

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ABSTRACT

Objective: To understand the situations and communications experienced by caregivers of children with tuberculosis (TB) with regard to directly observed therapy (DOT). Method: A descriptive exploratory study with a qualitative approach was applied and developed in the ambulatory of *Programa Einstein na Comunidade de Paraisópolis* (PECP). The data were collected using semi-structured interviews of 13 caregivers of children with TB in DOT. The Collective Subject Discourse (CSD) method was used to analyze the data. Results: Seven CSDs were identified and grouped into four categories: “Living in a difficult situation”, “Changing the family routine”, “Responsibility almost always fall son the mother”, and “Adapting to the DOT”. Conclusions: The difficulties faced by the caregiver of the child at the beginning of DOT significantly changed the familiar routine. The responsibility for its continuity was assigned to the mother, who must adapt to the demands of the treatment and face the situation.

DESCRIPTORS

Tuberculosis
Child
Pediatric nursing
Public healthy

RESUMO

Objetivo: Compreender a experiência vivenciada por cuidadores de crianças com tuberculose ou comunicantes em relação ao Tratamento Diretamente Observado (TDO). Método: Pesquisa descritiva exploratória, de abordagem qualitativa, desenvolvida no ambulatório do Programa Einstein na Comunidade de Paraisópolis (PECP). Os dados foram coletados por meio de entrevistas semiestruturadas com 13 cuidadores de crianças em TDO para tuberculose, utilizando-se o Discurso do Sujeito Coletivo (DSC) para analisá-los. Resultados: Foram identificados sete DCSs, agrupados em quatro categorias: “Vivendo uma situação difícil”, “Mudando a rotina da família”, “A responsabilidade é quase sempre da mãe” e “Buscando-se adaptar-se ao tratamento diretamente observado”. Conclusão: As dificuldades enfrentadas pelo cuidador da criança ao iniciar o TDO modificam significativamente a rotina familiar. A responsabilidade pela sua continuidade é principalmente da mãe, que busca adaptar-se às exigências do tratamento e enfrentar a situação.

DESCRITORES

Tuberculose
Criança
Enfermagem pediátrica
Saúde pública

RESUMEN

Objetivo: Comprender la experiencia vivida por los cuidadores de niños con tuberculosis o la comunicación en relación a el Tratamiento Directamente Observado *(*TDO). Método: investigación descriptiva exploratoria, con enfoque cualitativo desarrollado en el dispensario del “*Programa Einstein na Comunidade de Paraisópolis*” (PECP). Los datos fueron recogidos por medio de entrevistas semiestructuradas con 13 cuidadores de niños en TDO para tuberculosis, utilizando el Discurso del Sujeto Colectivo (DCS) para analizarlos. Resultados: fueron identificados siete DCSs, agrupados en cuatro categorías: “Viviendo una situación difícil”, “Cambiando la rutina de la familia”, “La responsabilidad es casi siempre de la madre” y “Buscando la adaptación al tratamiento directamente observado”. Conclusión: las dificultades enfrentadas por los cuidadores del niño para empezar el TDO cambian significativamente la rutina familiar. La responsabilidad por la continuidad en el tratamiento es principalmente de la madre, que busca adaptarse a las exigencias del tratamiento y hacerle frente a la situación.

DESCRIPTORES

Tuberculosis
Niños
Enfermeria Pediátrica
Salud Pública

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INTRODUCTION

Approximately 64 million people are estimated to be infected with the tuberculosis bacillus (TB), and approximately 70,000 new cases were reported in 2012(1) Developing countries account for 80% of all global cases, and this disease predominates among the economically active population aged 15 to 54 years(2-4).

Children often acquire the infection by living with contagious adults; however, they do not always become sick(3,4). When ill, the recommended treatment is conducted in two stages. Rifampin (RIF), isoniazid (H), and pyrazinamide (Z) are administered for 2 months during the attack phase and only rifampin and isoniazid are used for 4 months during the maintenance phase(4).

Children who have had contact with patients with TB but who are not ill (carriers) typically receive isoniazid (chemoprophylaxis) for 6 months when tuberculin test reactivity is present(4).

Because TB treatment is often prolonged, patients frequently discontinue it when a general improvement occurs. To increase treatment adherence and cure rates, as well as reduce the risk of disease transmission within a community, the "Directly Observed Treatment (DOT) strategy" was created(4).

DOT consists of observing the ingestion of drugs on all working days during the attack phase and at least three times per week during the maintenance phase of treatment. The drugs are administered by health professionals or any duly qualified person under nurse supervision(5).

A study on patient adherence to long-term treatment published by the World Health Organization (WHO) found that the quality of the therapeutic relationship predicts adherence. Flexibility is essential so that alternatives and therapeutic means can be explored with the patient(6).

Because children depend on adults to treat them, it is necessary that health professionals work together with guardians to secure their commitment to treatment adherence.

The Brazilian Ministry of Health's TB treatment program provides specific benefits, such as the right to basic food and free transportation during the treatment period. However, these actions are not sufficient in isolation because the caregivers of these children face other difficulties with regard to continuing treatment.

With that in mind, the authors of the current study seek to understand the experiences of caregivers of children diagnosed with or carriers of TB with regard to DOT.

METHODS

This field study was descriptive, exploratory, and qualitative. It was performed in the clinic of the Programa Einstein na Comunidade de Paraisópolis (PECP) located in the municipality of São Paulo.

The study included 13 caregivers of children with TB in DOT treated at the clinic between September and November 2013. All caregivers agreed to participate in the study by signing an informed consent form according to Resolution CNS 466/2012(7).

Data collection was performed after the Research Ethics Committee approved the project (CAAE: 17931213.8.0000.0071) by conducting semi-structured interviews based on a script consisting of questions regarding the participant's identification information, the child's current treatment, and two open-ended questions concerning the experience of the caregiver in accompanying a child with TB in DOT.

The interviews, conducted during the participant's stay at the clinic, were recorded and later transcribed verbatim. The collective subject discourse (CSD) technique, which tabulates and organizes qualitative data and is based on social representation theory and its sociological assumptions, was used for data analysis(8).

The technique is composed of analyzing the verbal material collected as well as extracting the central ideas or anchors and their corresponding key expressions. Based on the similarities between these expressions, one or several discourses are created that reflect the opinions of the community from a first-person perspective(9).

RESULTS

The majority of respondents were mothers of children in DOT (11, 84.6%) who were between 24 and 48 years old (mean = 34.2 years). Seven (58.3%) mothers had incomplete primary education levels, and five (38.4%) were unemployed.

Regarding the children's treatment, ten received chemoprophylaxis (76.9%), and three (23.1%) received the basic treatment scheme for TB.

The data analysis identified seven CSDs, which were grouped into the four categories listed below.

1 Living in a difficult situation

1.1 The effect of the diagnosis (CSD1)

When speaking about the time when the disease was diagnosed, the children's caregivers expressed feelings of insecurity and guilt because of their unawareness regarding the development of the disease and its treatment.

> I had it [TB] first. I found out [that] I had TB because I was coughing. It is very difficult having this thing, not knowing you have it and suddenly passing it [on]to your child.... When I found out [that the child had TB], I was really upset... well, you know… so to speak.... The day I came[to the clinic], they said she'd have to take [medication]; I lost my bag, I missed the exam, [and] I left here disheveled.... I lost my head, I cried [and] felt devastated…. I didn't know, I felt groundless, [like] I had nothing. I didn't know what to expect.

1.2 Fear of losing the child and having to address prejudices (CSD2)

To compensate for the feelings of guilt, the caregivers adopted a posture of overprotection. The caregivers tended to alienate the children from the rest of the family, especially when an existing case of TB existed among the family members, out of fear that the child's clinical situation would worsen. Depending on the disease, the caregiver believed that the children's health was more fragile than usual and that they were more vulnerable to other infections.

> At first I was like, sort of neurotic. When she [the child] showered, I'd put a cap on her... it was crazy. She didn't go out on the street; I waited approximately 3 hours to go with her on the porch....I'd close everything. I also prevented her from getting too close to other children. Because before, she was always at her grandmother's house.... Her cousin was also in treatment [for TB]. Because her cousin would stay at her grandmother's house, we had to stop her from going there so she didn't get any worse.

Caregivers reported noticing that certain symptoms, such as fever, cough, and sweating, deteriorated after the treatment began, rather than improving. Therefore, they were concerned that the child's condition might have been worsening. Treatment was also associated with adverse effects related to the metabolism and excretion of drugs, such as hepatic and renal changes, which increased the parents' fears of losing their children.

> It's a nightmare for me. After she started taking it [the medication], I noticed that the symptoms seemed to increase; I don't know... then I got a little desperate. She had a fever, [and was] sweating....She sweated a lot, [and] her cough got worse....Also, a liver problem caused her to throw up. She had high enzymes, [and] her kidney was kind of overloaded....The doctor said that the bacilli, or something like that, were too high.... She was crying a lot, [and] I saw that the medicine was causing her pain, so she had to take the medication and then take [additional] medicine for the pain. Then, she [the doctor] had to reduce treatment. She ordered blood tests.... Now, let's see.

The need for the children to take medication and there for ego to the health service each day deterred the caregivers from wanting to continue their children's treatments. However, they recognized that this attitude might seriously compromise their children's health and even lead to death.

> She was taking only one [medication], and then, we had to increase the dosage. She was almost at the last stage and had to start all over again.[The child was a carrier, but tuberculosis was later diagnosed.] You feel like giving up, but you want the best for your children... so what do you do? It is not easy. However, you have to do it, so the worst doesn't happen because the worst is what's difficult, isn't it? [The researcher asks what the worst is] Death.

Prejudice was another difficult issue with which the caregivers had to cope. Specifically, they dealt with the lack of knowledge concerning TB and the stigma that this disease has carried since the days when nothing effectively treated those with TB. This prejudice often extends to those who no longer transmit the disease (i.e., abacillary TB) and to those who have only had contact with sick people (carriers) who are still taking the medication.

> *Also, people don't always want to talk to people they know who are taking these medications. Not everyone understands. Because the people we are in contact with think we are all infected with the disease.... In her [the child's]father's family they're afraid just because they didn't take the test.... Prejudice, because they don't know [if she has the disease]... not even I know. I thought[that] you could pick it up just by being near someone [with TB]. Everyone thinks that, right? They don't want to come into the house.... They avoid us.... We suffer from prejudice....*

1.3 Dealing with financial difficulties during treatment (CSD3)

The need to be present at the health service several times a week interfered with some of the caregivers' work when they did not have someone to share the task of accompanying the child. This fact directly affected the family's financial situation because only one parent generally worked.

> The financial situation…it's very complicated. I'm pretty much tied up for 6 months... 6 months with only my husband working. We've got two others [children] besides her. Have you thought about that situation? I have to help my husband....There are bills to pay, there's this and that... there is shopping to do.... I know it's a situation that caught us off guard.

In addition, the non-receipt of the basic food basket that is provided to children with chemoprophylaxis caused discontent. Caregivers stated that the fact that they did not work because they accompanied the child on daily medication visits negatively affected the family income. The Brazilian Ministry of Health's National TB Control Program (Programa Nacional do Controle da tuberculose - PNCT) provides a monthly food basket for patients with TB during treatment; however, this right does not extend to carriers(2).

> What I don't understand is why they don't give me the [food]basket. The doctor said that she[the child] couldn't have the basket because she's not sick [rather, she was a carrier]... but I didn't understand... because she hasn't got the disease, she just has the bacteria, so she doesn't get the same benefits as a person with the disease. Because I know if a person has the disease, they are entitled to a basket of food every month.

2 Changing the family routine (CSD4)

The "DOT strategy" means that the families of the children in treatment must modify their routines because of the requirement that one family member be present at the treatment unit to accompany the child each day.

> For me, much has changed. Almost everything has changed. First, it's added a load to our routine, you know. It wasn't just her [the child]who was under treatment... she had another sister who was also [being treated]. In the beginning, I had to come every day. It was a rush because I couldn't not come. Now, she only comes on Mondays, Wednesdays, and Fridays; in other words, we have to come here every other day....Today, she's already had a blood test, and she needs to have another at the end of the month and then have another.

Because of their need to keep their jobs as heads of the households, some caregivers adopted strategies to prioritize the treatment of the child, such as hiring people to accompany the child to the service to receive the treatment and conduct routine examinations.

> Because her [the child's]father worked in the morning, he couldn't come with her, so I had to pay for her to be able to come for 5 months... so, someone else came with her. When she [the person hired]didn't bring her, I asked if someone else could bring her.... Right now, I'm going to work. However, it is tiring because today I have to bring her, work, [and] do the housework.

The caregiver also sought to protect the child from situations that could worsen her health or, in the case of carriers, lead to developing the disease.

> My sister-in-law told me that she got it [TB] from my brother-in-law who was in prison. When he came out [of prison], he went to his mother's house, and there he passed it on to her [the child] and to two more nephews. The two nephews were treated here [at the PECP]too, and the uncle was treated at another service... at the BCU (basic care unit). Others [family members] said [that] they were treated, but they did not take the test to see if they are ok. So, I don't want it to be like the old days... when she spent more time inside that house.

Depending on the status of the disease, the caregivers strove to adopt new routines, mainly those related to hygiene, preventing transmission to other members, and preventing the worsening of those already affected.

> At home, the only care I take [with hygiene] is to wash my hands like they tell you on television... after going to the bathroom... [and I] brush my teeth. I also separated the cutlery, changed the bedroom around because it had to be more airy... because of her and the other girls who have asthma.

3 The mother is (almost always) responsible (CSD5)

The majority of children were accompanied by their mothers. Their discourses make it clear that the responsibility for childcare usually falls on them. The mother takes full responsibility for the treatment, delegating it to others only when she is unable to accompany the child.

> Now, I spend the whole day doing things, running around and thinking [about] medicine, medicine, medicine....Medicine never leaves my head. She [the child]has to take the medicine; I can't forget, I can't not come. If I don't come, and she doesn't take the medicine for one day, [then] she will get worse. You just worry all the time, and now, bringing her here to take the medicine is a bit hard, you know.... I am pregnant. Coming here every day is a bit tiring for me. I live down this big hill. It's tiring because I have to walk up it, you see. My belly is already big...it's heavy... the baby already started moving, so I take her[the sick child] to school, and I try to give her the medication quickly before time passes. Only when there's no way [that] I can do it, I ask my mom to bring her. But that's only sometimes.

Although some caregivers hired people to take their children to the service, these employees often failed to meet their commitments; once again, it falls on the mother to take responsibility for the child's attendance.

> *There have been three times that she [the child]didn't received the medication when I left it in the hands of other people. When I asked people to come, they didn't show up to take her.... Because if you pay, as I've already tried, it's hard to find responsible people... even in kindergarten they [the educators] won't give it [the medication]. From the point of view of others, even if you're paying them, people think, "Ah, I didn't have time" because it's not their child....They are so irresponsible. They don't feel the same responsibility that I do as a mother. Sometimes I have [my] two granddaughters with me, and I have to take them to school…. They already lost 3 days of school because I was waiting for a person to take them to school, but she never showed up.*

The above discourses show that the mother is the individual most involved with treatment, and she cannot always count on the father who faces the situation in a "more relaxed" way. Specifically, the mothers believed that the fathers should prioritize the health of their children, even before their own health.

> *It's different for the father....Men are always more relaxed. My husband is confused; he doesn't know... and so, he thinks [that] everything is easier. Also, he can't bring her because he is being treated too, so he goes to take the medicine, then goes directly to work. Anyway, the mother has to really sacrifice....The mother has to think about the health of the child first.... I think about the health of my children. When I get tired... I sit and rest later.*

4 Adapting to the demands imposed by DOT

4.1 Understanding the child's situation better (CSD6)

As an understanding grows regarding why the child is receiving treatment, the caregivers become more resigned to the situation. It is noteworthy that, in most cases, the children were only carriers and not sick. By understanding this difference and through knowing that TB is currently curable when treatment is applied correctly, the caregivers felt more confident in the performance of the team and might rely on the faith they have in God.

> The way it was explained to me, I understood that she is not sick, she's just at risk. The virus [Koch's bacillus] that's in her body is asleep, and the medication [chemoprophylaxis] is trying to kill it, and because I understood that the treatment is preventive... I became less concerned, mainly because I saw that she was in the hands of a good doctor.... I saw that she [the doctor]was doing her job well, so when I told her about a case in the family, she immediately requested exams, and before the results came out, she was supportive.... Thank God there is a cure, and with faith in God, she [the child] will get better.

4.2 Moving on, despite difficulties (CSD7)

By committing to treatment, the caregiver can seek, together with the team, for alternatives to facilitate its continuity.

> *Before I was bringing her [the child]every day, but because sometimes I work every other day, it became more difficult, so I spoke to nurse Luana.... I said, "Luana, I can't... I need a break... I need to rest, otherwise I can't do it." Thank God, we managed....She[the nurse] gave me two days off, so I'd come [on]Mondays, Wednesdays, and Fridays, and she [the nurse] would take [the medication to the caregiver's home] on Tuesdays, Thursdays, Saturdays, and Sundays.*

The medication regimen generated some undesirable reactions and might have contributed to treatment withdrawal. Nevertheless, the caregivers understood the importance of continued treatment, and they encouraged the child to take the medication.

> *She [the child]was telling the doctor that she had a lot of pain in her belly and legs [as well as] headaches and weakness. She was vomiting a lot, but she's not vomiting any more. She never refused [to take the medication].... She always took it; she always followed the treatment, and I always said to her every day, "We'll go, take it [the medication]quickly, and come right back," so we come here, she takes it, and then I go and take mine [at the UBS]. In this respect, it's something [that] I try not only to tell her, but with the others [the other children who are also being treated]... I say [that] it's for their own good. I don't like to threaten. If you see her taking the medication, it's as though she took a cup of something tasty, that she wants... in this respect, she is not a burden.*

The caregivers also took care not to treat their children receiving TB treatment differently than their other children, showing concern for their emotional wellbeing.

> *I'm not going to treat her differently…. That gives the child a reason to think, "Ah, I'm sick, I'm really sick, I can die," so now I try to let her know [that] she's just like the others.*

Despite all the difficulties encountered during treatment, the caregivers considered the importance of the support that they received from other family members, from the health service team, and from the government.

> I have to thank my mom because she helps me with the kids. With her help, it's still difficult. Imagine doing it alone with two children to care for; it is very difficult, but here we are, thank God; we are almost at the end, after 9 months of treatment. We only missed one day....Also, I get a basic food basket, and that helps a lot; it's very good.

DISCUSSION

A study that examined the potential for and limits of the DOT strategy among people with TB from the perspectives of treatment recipients and healthcare professionals(10) found data similar to those of the present study regarding the difficulties faced by caregivers during their children's treatments and the changes to their family routines.

Treatment affected the everyday lives of the recipients in the aforementioned study(10) because of prejudice and rejection, isolated the caregivers from society and their families, and caused feelings of worthlessness and financial dependence because of the need to stop work-related activities and the fear of transmitting the disease to nearby individuals.

Children commonly acquire TB from their caregivers because of their close relationship. This fact is likely a major reason for the caregivers' guilt.

The caregivers' fears of transmitting the disease to their children and families, even during the final phase of treatment when they are no longer in the transmission phase, were also cited in a study conducted on the outskirts of the southern region of the municipality of São Paulo. That study focused on healthcare needs from the perspective of individuals with pulmonary TB(11).

Because caregivers feel guilty about their dependent children contracting TB, they tend to adopt overprotective child-rearing attitudes, even when their children's clinical statuses do not require complex treatments.

This behavior was also observed in a study conducted with the parents of children with heart disease, who redoubled their attention to and vigilance over their children, overprotecting them because of their constant concern for their health conditions. That study also revealed the difficulty that these parents feel in freeing themselves from the stigmatized image of a sick child, even after successful surgical correction(12).

Another concern that caregivers have with regard to childhood treatments for TB are the adverse effects of medications, which add unwanted discomfort for the children. According to the Brazilian Ministry of Health, the most common side effects are nausea, vomiting, and abdominal pain(4).

The discomforts generated by the use of medications are a risk factor for discontinuing TB treatment. However, they can be circumvented when children and their caregivers are instructed to ingest the drugs along with breakfast(4).

The importance of establishing a meaningful connection between the caregiver and the healthcare team to reduce treatment discontinuation has been demonstrated. Caregivers must be informed about the occurrence of major side effects(4) because, as indicated in the caregivers' discourses, knowledge of the treatment promotes adherence to it.

The fact that the children must be present at the health service unit every day affects the family's financial situation because the primary caregiver, usually the mother, must leave her job to accompany the child.

This DOT strategy was established for all patients being treated for TB to ensure treatment adherence. However, other modalities exist, such as home and shared treatment, when the individual cannot go to the health service; rather, they take their medication at home or another shared location more accessible to the family. The choice should be made jointly between the healthcare team and the patient given the reality and structure of healthcare(4).

These alternatives might contribute to the reduction of the financial effect that families experience when the primary caregiver stops working or when they need to hire someone to ensure that their children are treated.

A study conducted in the municipality of Diadema, São Paulo state, Brazil that identified the health beliefs and adherence capacity of mothers with children suffering from chronic and severe diseases concluded that a rational understanding of the disease was insufficient for treatment adherence. As the child's primary caregiver, the mother is responsible for treatment adherence, and she must have more contact with the disease treatment(13).

This finding was also observed in the present study: some mothers reported preferring to accompany the child to the health service so that they can have concerns regarding the disease and treatment clarified, thereby demonstrating their commitment to the health of their children.

In a previously mentioned study(13), parents' perceptions about the disease changed and their fears subsided when they acquired more accurate information about the disease and planned treatment. These effects helped them to cope with the situation. This effect was also found among the caregivers of children treated for TB.

Faith in God was another factor that helped caregivers to cope with the disease; they clung to the possibility of having divine support for their children's healing. Another study found that people attribute solutions to personal health problems to God(14).

Caregivers also emphasized the importance of support from others in coping with difficulties, and this support helped them to continue treatment until its conclusion. A study addressing the personal and social conflicts of patients with TB suggested that the presence of individuals who can share in coping with the disease and the difficulties of treatment is crucial for healing(15).

The desire to occasionally stop treatment was also evident among caregivers of children undergoing treatment for TB, although treatment was not stopped because of family encouragement.

Therefore, it appears that knowledge about TB and its treatment, as well as the support of the healthcare team and family, contributes greatly to the treatment adherence of the child and their family via the DOT strategy, despite the difficulties faced in their daily lives.

This result indicates the social representation of the children's caregivers, who face the challenge of routinely accompanying them to the health facility to receive treatment for TB.

Social representation studies represent knowledge built from the relationships between humans and their environment. Therefore, the theory of social representations allows us to investigate how the reference systems used by individuals to classify people and groups and interpret the events of everyday reality are formed and to examine how they function(16,17).

FINAL CONSIDERATIONS

Children's caregivers face many difficulties when beginning supervised treatment for TB. These difficulties trigger feelings of guilt that they infected their children. The fear of losing a child is prominent because of the severity of the disease. Other concerns include suffering from prejudice because of people's ignorance regarding TB and financial difficulties because the parent must almost always stop working to accompany the child to treatment.

The need to take the child to a health service several times per week significantly changes the family routine, which is reorganized to continue the treatment. The major responsibility for continuity of care rests with the child's mother, who often fails to meet her own needs because she must prioritize the child's.

Ultimately, the caregiver seeks to adapt to the demands of treatment and cope with the situation with the support of family members, professionals, and God.

Understanding the complex situation experienced by caregivers offers important insights to healthcare professionals involved in the treatment of these children. The healthcare team must reassess their approach toward these caregivers; this reassessment is critical to contributing significantly to continued treatment until completion.

Establishing a bond of trust with the caregiver is a valuable strategy that emphasizes the professional as a partner in treatment. Furthermore, he or she not only helps the child and caregiver through the system but also seeks, along with the caregiver, the best solution to circumvent the difficulties faced.

Healthcare professionals must motivate caregivers and recognize their efforts, always reinforcing what the caregiver can do to ensure the most successful treatment.

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