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ORIGINAL ARTICLE

FAMILY COPING: LIVING WITH THE CHILD AFFECTED BY CHRONIC DISEASE

ENFRENTAMENTO FAMILIAR: CONVIVENDO COM CRIANÇA PORTADORA DE DOENÇA CRÔNICA

ENFRENTAMIENTO FAMILIAR: CONVIVIENDO CON EL NIÑO PORTADOR DE ENFERMEDAD CRÓNICA

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ABSTRACT

Objective: to identify the main difficulties of families/caregivers of coping with children's chronic condition. ***Method***: descriptive and exploratory study with qualitative approach, conducted with 22 caregivers of children affected by chronic diseases living in municipalities of the rural arid zone of Pernambuco State. Data were produced through semi-structured individual interviews and analyzed with the content analysis technique. ***Results***: the main difficulties faced by caregivers were related to changes in routine imposed by the disease and include increased attention to the child and the caregiver burden. To help in coping with the situation and keeping the hope for the future, caregivers rely on social support, especially from the family. ***Conclusion***: it is essential to know the difficulties experienced by caregivers in order to create strategies that help in coping with the chronic condition in childhood. ***Descriptors***: Chronic Disease; Child; Public Health.

RESUMO

Objetivo: identificar as principais dificuldades das famílias/cuidadores no enfrentamento da condição crônica infantil. ***Método***: estudo descritivo e exploratório, com abordagem qualitativa, realizado com 22 cuidadores de crianças portadoras de doenças crônicas residentes em municípios do Agreste Pernambucano. Os dados foram produzidos a partir de entrevistas individuais com roteiro semiestruturado e analisados pela técnica de Análise de Conteúdo. ***Resultados***: as principais dificuldades enfrentadas pelos cuidadores foram referentes às mudanças na rotina impostas pela doença e incluem atenção redobrada à criança e sobrecarga da cuidadora. Para ajudar no enfrentamento e manter acesa a esperança em relação ao futuro, as cuidadoras contam com o apoio social, principalmente, o familiar. ***Conclusão***: torna-se imprescindível conhecer as dificuldades vivenciadas pelas cuidadoras para a criação de estratégias que auxiliem no enfrentamento da condição crônica na infância. ***Descritores***: Doença Crônica; Criança; Saúde Pública.

RESUMEN

Objetivo: identificar las principales dificultades de las familias/cuidadores en el enfrentamiento de la condición crónica infantil. ***Método***: estudio descriptivo y exploratorio, con enfoque cualitativo, realizado con 22 cuidadores de niños portadores de enfermedades crónicas residentes en municipios del Agreste Pernambucano. Los datos fueron producidos a partir de entrevistas individuales con guía semi-estructurada y analizados por la técnica de Análisis de Contenido. ***Resultados***: las principales dificultades enfrentadas por los cuidadores fueron referentes a los cambios en la rutina impuestas por la enfermedad e incluyen atención redoblada al niño y sobrecarga de la cuidadora. Para ayudar en el enfrentamiento y mantener asesa la esperanza en relación al futuro, las cuidadoras cuentan con el apoyo social, principalmente por el familiar. ***Conclusión***: se torna imprescindible conocer las dificultades vividas por las cuidadoras para crear estrategias que auxilien en el enfrentamiento de la condición crónica en la infancia. ***Descriptores***: Enfermedad Crónica; Niño; Salud Pública.

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INTRODUCTION

The Brazilian epidemiological scenario has been changing since the 1980s. Before this period, infectious diseases were the predominant cause for morbidity and mortality. However, chronic diseases now assume the place of infectious diseases and have become a public health problem and this is due to urbanization, access to health services, technological advances, cultural changes, increasing life expectancy and demographic transformation.[1]

Contrary to what is usually expected, chronic non-communicable diseases (CNCDs) occur not only among the richest population nor affect only older people and the elderly, but the increase in chronic health conditions is present even in childhood. However, despite the difficulty of national indicators on the prevalence of chronic diseases in childhood, some researchers point out that, among the various chronic diseases that arise during this period of life, cystic fibrosis, liver disease, congenital heart diseases, cerebral palsy and cancer stand out.[2, 3]

Chronicity in childhood compromises not only the child but also its family which usually does not expect that the child's diagnosis results to be a long-term illness that requires constant care and for long periods. However, the need for hospitalization and special care ends up causing pain and changes in the daily lives of all family members, especially the primary caregiver, which is close to the child's suffering. In this context, everyone tries to adapt to changes and new requirements of routine.[4]

It is vitally important that families understand that most chronic diseases have prolonged, complex and constant care-demanding treatments, requiring the inclusion of family members in the process. Therefore, knowledge about the disease, its manifestations and implications is necessary. Also, they need incentive to develop ability to care and, therefore, need to rely on the support and backing from social networks in which both children and family are inserted. Thus, the family will be able to develop a daily care with quality and autonomy, preventing relapses and health problems of children with chronic disease.[1,5-6]

Based on the foregoing and on the need to direct/guide the care of children with chronic illnesses and their family in accordance with the lived reality and considering its uniqueness, this study aimed to identify the main difficulties experienced by the families/caregivers in coping with the chronic condition of the child, tracing the changes in post-diagnosis familiar routine and the existence and role of support networks in this process.

METHOD

Descriptive and exploratory study with qualitative approach developed in Alagoinha, Pesqueira and Sanharó, cities located in the rural arid zone of Pernambuco. The survey took place between August and October 2015 and involved 22 caregivers of children aged from one to nine years who met the following inclusion criteria: be the primary caregiver of a child with chronic disease treated at the Association of Holders of Special Rights -PODE (non-governmental organization that serves children and adolescents of Pesqueira and neighboring municipalities) and/or treatment outside the residence of domicile; reside in the municipalities of Alagoinha, Pesqueira and Sanharó. Subjects who were not present at the time of collection or who refused to participate were excluded from the sample.

Data were produced through individual interviews, operationalized through a semi-structured script with questions about family care for the child with chronic disease, the main difficulties in carrying out this type of care and the support that these families receive. These interviews, recorded and transcribed in full-length, were held in a private and quiet place in the PODE Association - Association of Holders of Special Rights, or at the home of the interviewees.

Data were analyzed based on the Bardin's content analysis technique, organized in categories and discussed along with the literature.

Research subjects had their confidentiality assured with respect to identity and information provided, and were told that they had the right to refuse to participate in the study or to leave it at any moment. Thus, subjects of this research are identified as I1, I2 and so on.

As for the ethical and legal responsibilities, because this research involves human beings, the principles set out in Resolution nº 466/2012 of the National Health Council were complied. The present protocol of research was approved by the Research Ethics Committee (CAAE: 44358815.0.0000.5666).

RESULTS AND DISCUSSION

During the period of this study, caregivers of 22 children aged between one and nine years and suffering from disease/chronic condition, residents in the municipalities of

Alagoinha, Pesqueira and Sanharó, were interviewed in order to identify the main difficulties experienced by families/caregivers in coping with the disease/chronic condition of the child. These data are shown below.

Table 1. Sociodemographic characteristics of caregivers of children suffering from diseases/chronic conditions living in the municipalities of Alagoinha, Pesqueira and Sanharó, PE, 2015.

Variables	n = 22	%
Age		
<30 years	8	36.4
30 years or over	14	63.6
SEX		
Female	22	100
Male	0	0
Degree of kinship with the child		
Mother	19	86.5
Grandmother	1	4.5
Cousin	1	4.5
Not a family member	1	4.5
Marital status		
Single	9	40.9
Married	8	36.4
Common-law marriage	5	22.7
Level of education		
Illiterate	1	4.5
Incomplete primary school	9	40.9
Complete high school	9	40.9
Complete higher education	1	4.5
Others	2	9.2
Exerts other profession besides caregiver		
No	11	50
Yes	11	50
Has children		
No	1	4.5
Yes	21	95.5
1-2 children	11	52.4
3-4 children	10	47.6
Monthly Income		
< 1 minimum wage	7	31.9
1-2 minimum wages	14	63.6
3-4 minimum wages	1	4.5
Dependents		
No	1	4.5
Yes	21	95.5
1-2 dependents	8	38.1
3-4 dependents	7	33.3
5 dependents	6	28.6
Affected by a chronic disease		
No	17	77.3
Yes	5	22.7
Leukemia	1	20
Gastritis	1	20
Depression	1	20
Hypertension	1	20
Epilepsy	1	20

Note: numerical data are approximated numbers.

The data in Table 1 show the woman as the primary caregiver of a child with disease/chronic condition (100%). This is, in most cases, the child's mother (86.4%), which has also been observed in other studies.[3,6-10] Among these women, 40.9% said they were single; 36.4% were legally married; and 22.7% lived a common-law marriage.

Among respondents, 50% reported exercising other profession besides cargiver. However, all caregivers are overwhelmed to carry out the activities relating to the child and household chores. They are caregivers, mothers, housewives, entrepreneurs, all in full time. They accumulate tasks, but as for the socio-economic aspect, remain with low family income - a fact also been observed in another study.[11]

The family income ranges from less than one minimum wage up to four salaries, and

63.6% have a monthly income of one to two wages. Moreover, it was found that 95.5% of respondents have dependents and 22.7% of caregivers reported having chronic diseases.

As for education, 40.9% said they have not completed elementary education; 40.9% completed high school; 4.5%, completed superior education; and 4.5% said they did not have any schooling. That is, a small percentage have no schooling, thus, considered illiterate, and the same percentage has higher education, as revealed earlier research.[11] The same was observed in relation to incomplete primary school and complete high school, both with the same percentage.

Regarding the health of the caregiver, different from what is presented in the literature, few reported some health problems, as shown by another study.[12] Also, in relation to children with diseases/chronic conditions, the socio-demographic profile was drawn and presented in Table 2.

Table 2. Socio-demographic profile of children with diseases/chronic conditions living in the municipalities of Alagoinha, Pesqueira and Sanharó, PE, 2015.

Characteristics	n = 22	%
Total	22	100
Age		
< 5 years	10	45.5
Between 5 and 9 years	12	54.5
Gender		
Female	9	40.9
Male	13	59.1
Attend school		
Yes	16	72.7
No	6	27.3
Vaccination days		
Yes	21	95.5
No	1	4.5

Note: numerical data are approximated numbers.

It is observed in Table 2 that 59.1% of children are male and 40.9% female. It is also seen that most have between 5 and 9 years (54.5%); 72.7% attend school and 95.5% are on time with the vaccination schedule.

The rise of chronic diseases in childhood is a growing phenomenon that has called attention.[3,13] It is important to note that, according to results found in the study, rthere was an increase in mortality from NCDs in Latin America and the Caribbean in the age group from 1 to 9 years.[14]

Considering that chronic diseases compromise the routine of the child because they have limitations, mainly physical limitations, due to its signs and symptoms,[6] this study also investigated the clinical situation of children with disease/chronic condition that are residents in the municipalities of Alagoinha, Pesqueira and Sanharó. The collected data are recorded in Table 3.

Table 3. Clinical situation of children with disease/chronic condition residents in the municipalities of Alagoinha, Pesqueira and Sanharó, PE, 2015

Clinical diagnosis of the child	n = 22	%
Phenylketonuria	1	4.5
Thrombosis	1	4.5
Hearing disability	2	9.2
Hydrocephaly	2	9.2
Meningocele	1	4.5
Down syndrome	3	13.7
Autism	4	18.2
Hyperactivity	2	9.2
Congenital malformation	1	4.5
Myelomeningocele	1	4.5
Epilepsy	1	4.5
Convergent strabismus	1	4.5
Cerebral palsy	3	13.7
Mental retardation	1	4.5
Disintegrative syndrome of childhood	1	4.5
Microcephaly	1	4.5
TOTAL	26	118.2
It has already needed hospitalization		
No	8	36.4
Yes	14	63.6
Total	22	100

Note: numerical data are approximated numbers.

The data of Table 3 reveal that among the diseases/chronic conditions that affect these children, the most common are Autism (18.2%), Down syndrome (13.6%) and Cerebral palsy (13.6%). Some children are affected by more than one pathology and 63.6% of caregivers reported that the child has required hospitalization because of the disease/chronic condition. However, it is important to remember that the child's disease/chronic condition does not change only its routine, but the routine of the whole family. The changes may include physical, psychological and financial limitations and require continuous care.[1,5]

The child with disease/chronic condition requires an extended care and this must be fully and equitably carried out. To plan this care, the existence of a social support network that support and backs both the child and the family up regarding the care of their daily needs is required.[15]

For the social network have a positive effect, it is necessary that their relations are perceived by its members as significant or differentiated[16]. Thus, social network (which brings social support) functions as a key resource to help families cope with the chronic condition in childhood.[7] Thus, we sought to find out what kind of support families received to help them to cope with the situation of illness of their children. As a source of social support, caregivers mentioned family members, health professionals from local treatment of children, children's teachers and the government financial aid.

Knowing, then, that chronic disease in childhood affects not only the child but the whole family, it is important the family to (re)organize itself to minimize the effects of these changes and to avoid overwhelming the primary caregiver. This is because the family represents the main source of social support in coping with the disease/chronic condition in childhood[1,15], as can be seen in the interview recorded clippings below.

> *The family is involved, contributing to her development, helping out in what I need, as far as their abilities and time allow. (I7, I13, I17, I20)*
>
> *The help I have is from the immediate family, the help comes from the ones living here with me, the rest of the family is busy with their own lives. (I6, I12, I14, I21)*

Health professionals support is also present in the networks of caregivers. This support comes mainly from health professionals of locals where children make their treatments, including PODE Association and referral hospitals for specific treatment for the disease. This is observed in portions of interviews transcribed below.

> *They guide me about her illness, the cautions that I should have and the difficulties that I may face [...] they alert me to what will happen to her and always ask how is her behavior at home. (I4, I7, I22)*
>
> *They are always available to [...] when I need to, schedule a consultation, they get me a car. (I3, I5, I19)*

This type of support is guided by listening and helps to reduce the caregiver's burden, providing support to physical health and training to develop home care.[1,17]

Another source of support mentioned by the caregivers are teachers. The interviewees point out that these professionals, even facing obstacles, strive to meet the demands imposed by the limitations caused by the child's illness. This information can be found in the following portions of interviews:

> *The teacher helps a lot [...] I like it because she reads a lot about his problem and she talks to me a lot about what she reads [...] She does everything for making him learn. (I6-I7, I18)*
>
> *[...] it is very good because they understand his problem and that helps a lot. (I19)*

This data found in this study shows how important is that the school be inserted in the life of the child and the family, because, from the moment they know the limitations imposed on the child by the disease and the effects of drugs in its life, may help the family to cope with the difficulties in this respect.[7]

Another important support is financial, since, with the disease they have to spend money with medicines, consultations, transportation, among others. This financial resource is granted by the State and, for many families, is the only source of income, which serves both to assist in childcare as to keep the expenses of the house. It is what can be seen in clippings of the transcribed interviews that follow.

> *This financial aid has improved the food [...] I can give her a toy, clothing [...] now I can do something for her. (I3, I9)*
>
> *The financial aid helped [...] is helping a lot. It helps to cope with the extra spending on medicines, diapers and take to the doctor. (I8, I21)*

For many of these families, the sick-pay called "benefit" by participants is the only income and they make their best to meet their needs with it.[10] The sickness allowance is granted to people who can not sustain themselves and can not depend on the family. To earn it, they must meet certain criteria established by Law nº 8742/93, and after granted, this is paid by the National Social Security Institute (INSS) and revised every two years.[1,7]

Despite knowing about the benefits of social support, it is known that this support is not always offered continuously, that is, the quality of relationships of support network do not address the needs of families[1,5,15], as can be observed in the following interview quote:

> *I have no support [...] anyone. I do everything by myself. (I1)*

This lack of support ends up overloading the caregiver and making difficult to cope with the disease.[1]

Another issue examined in this study was the change in the life of the caregiver and the family routine, because of the diagnosis of the child's chronic disease. These changes involve financial, social, emotional, time for self-care and professional aspects.

The financial and professional aspects can be considered together, since the professional life of the caregiver is often interrupted for her to track/run the care of child with chronic illness, whats ultimately affects directly or indirectly the family budget . In such cases, the main caregiver is usually the child's mother. This is noted in the following interviews clippings:

> *I prefer to stay out of work and care for her until she reaches a certain age, she is very small and needs a lot of care. (I1-I4, I6, I7, I9, I11, I14)*
>
> *I had to quit work in order to care for her [...] You can not conciliate work, travellings, consultation, treatment. (I5, I8, I12, I20)*
>
> *I slowed my workload and his father left the job to be able to take care of him while I'm not at home. (I17)*

The job abandonment by one of the parents appears in another study as one of the major changes in family reorganization to meet the needs of children with chronic disease. This usually causes changes in the family's financial standard, since there will be lower income and higher expenses, increasing child care costs.[8,18] However, if it is only the financial side is taking into consideration, many families will have their situation improved by the fact that the child is the beneficiary of the sickness allowance, which is often the only source of income.[7] There are also professional caregivers that increase their income by taking care of these children, as can be seen in the following interview clipping:

> *My financial situation has changed for the better, because before I had no job, but now I take care of her. (I16, I19)*

In addition to the above changes recorded, the caregivers interviewed reported that the social lives were quite struck by the child's illness, as can be seen in clippings of interviews transcribed below.

> *Before that, we used to go out more frequently [...] now we go out depending on which places she can go [...] and she can not go anywhere, then our life is more restricted to the domestic environment. (I4, I6, I10, I13, I15)*

> *I have no social life, no longer, all possibilities are gone, since I have no one to take care of her and I can not take her to any place. (I9, I11)*

It is very important that the social life not only of the caregiver, but of the whole family, be preserved. Leisure time with family and friends are needed to renew the forces and strengthen families, helping to overcome the difficulties imposed by the disease,[8,19] However, the fact is that, not only the social life of caregivers changes but also the affective life. Although most participants said that the problem of the child did not interfere with their emotional life, those who affirmed the existence of this change showed both positive and negative aspects. This is seen in the following interview clippings:

> *I spend a lot of time with my son who needs my care all day, so I have no time for him [her husband], as I had before. (I7)*
>
> *My husband does not give much attention to our son, then complain a lot with him to see if things change and he comes closer to our son. (I20)*
>
> *Changed for the better [...] her problem drew us even closer, we became more united. (I10, I17, I19, I21)*

As seen in the speech I7, the dedication of caregivers may affect their marriage, because they usually exclude the man from the care for the sick child, causing the rupture of the couple's ties.[8] However, the data from this survey reveal that changes, mostly, caused more union between the couple, as stated I10, I17, I19, I21.

This dedication from the caregiver also ends up interfering with her self-care, as she is so often very involved with child care that she simply forgets to take care of herself. This is what can be seen in the following interview clippings:

> *We forget to care of ourselves to take care of them [...] The mother always forget herself, because it is indispensable to take care of the child. (I3, I7, I12)*
>
> *I will give priority to him [...] I have no time to take care of myself, even my vanity, it's gone. (I10, I20)*

Most caregivers, as previously reported, are the mothers. Thus, this ends up as a double demand for exclusive dedication throughout the day.[20] This is because the caregiver/mother believes that there is no one else to perform the care of the child and that no one else will take care better than her. This excess of care leads to a work overload that ends up not only harming the health of the caregiver/mother, but may compromise the care of the child.[5,18,21]

In the face of changes in family life and the perception of support networks, the interviews indicate their difficulties, as can be seen in the following interview clippings:

> *I have problem because I cannot work and help with the expenses of the house, because I have to take care of her. (I1- I2, I5, I7, I12, I14, I20)*
>
> *She needs a lot of attention. You have to be all the time with her because she has no concept of things, so needs company full time, but there are other things to do, house, husband, other children [...] (I1, I3, I5, I9, I12, I15)*
>
> *I had a lot of trouble at first, because I did not know how to take care of her right, I did not know what to do or how to do, but in time I was gaining experience. (I3-I4)*
>
> *Even having transportation to take us to places of treatment, it is very difficult [...] You have to wake up very early to schedule, sometimes the car is broken or they provide inadequate transportation [...] We would need a small car to stay at our disposal, but we often have only the bus and we have to wait all be assisted in order to return, and the child who is already sick is obliged to go through this. (I1, I3, I6, I11, I14, I21)*

It is common that in the beginning, caregivers feel difficult to play their role in child care, after all, it is all new and they often have to perform medical procedures, continuing the treatment at home by themselves.[22-3]

When analyzing the speeches, it noticeable that all the difficulties faced by caregivers fall in workload. The chronic disease of the child is not the only concern, because living with other problems and needs is part of the daily lives of caregivers.[24]

The logistics about the child's treatment also appears to be difficult for caregivers. Because the treatment of the child is done often outside the municipality of residence, it is necessary to move several times and not always the trip is made in proper transportation, and this ends up negatively impacting on the child's treatment[6,18]. Because of this, it is clear that the caregiver is constantly exposed to complex tests, suffered, lonely and with many unforeseen events, uncertainties and discoveries.[3]

With so many changes and difficulties in the routine of caregivers, we sought to know how is their relationship with the public health service, particularly with primary care in supporting the health needs of children with chronic disease. Primary care is the entrance door of public health services, with activities guided in the family. It should, then, be used as a tool for family coping in cases of chronic condition in childhood.[25] In this regard, interviewees had the following stance:

> *I don't have a good impression of the care in the Family Health Strategy, that's why I do not take her there. When I need to, I use other services. (I6, I13, I17-I18, I20)*
>
> *Her consultation is normal, I take her there only to weigh, vaccinate, and when she gets sick, take her to the doctor, but they do not follow the course of disease, let alone how her treatment and her evolution is going. (I1-I3, I5, I7-I9, I11, I14-I16)*
>
> *The service is very good [...] I take her to weigh, vaccinate, consultation. They seek to know how she is responding to treatment and every month I receive the visit from the Community Health Agent. (I4, I10, I12, I19, I21-I22)*

The care adopted by professionals of the Family Health Strategy (FHS) are still guided by a technical model. Because of such, the host, the bond and accountability remain bellow expectation.[26]

In Brazil, the Secretariat of Attention to Health proposed in 2012 the construction of the Care Network for People with Chronic Diseases in order to disburse practices and health services to better serve the population. The regulation of this network involves basically the capacity of Primary Health Care (PHC) to organize the other network levels.[27]

Thus, the dialogue between specialized care services and primary care teams must be guaranteed and facilitated. The flows and conditions for referrals should be defined according to the construction of lines of care, that is, with the primary care entryway, mainly represented by the Family Health Strategy. However, even while monitoring continues in specialized care, the PHC should remain informed of the patient's health status, as well as monitor the development of the care plan, constituting what we call reference and counter reference.[27]

As already reported, chronic diseases bring several changes to the life and routine of people. Each disease affects in specific manner each individual but, in most cases, it imposes limitations of various types. With the child is no different, because its routine is intrinsically modified because of the illness. Even with these imposed limitations, the caregiver/family does everything for the child to have a life as normal as possible. This is noted in the following interview clippings:

> *Even though she had the slower learning and could not eat everything not alone and even needing supervision to play, she does it all! Studies, plays [...] You have to encourage her for her to be able to develop. (I1-I3, I5, I10, I16-I17)*
>
> *Her behavior sometimes prevents her from having a normal life [...] She gets very agitated and aggressive and people turn away, then she ends up isolating herself. (I6-I9)*
>
> *She is totally dependent, she does not do anything by herlself, do not walk, do not talk, do not eat or take bath alone, does not play [...] (I4, I15)*

As we could see in the above quoted words, the caregiver/family usually tries to prevent the sick child to be defined by her/his condition. Thus, they encourage the child to develop coping strategies to seize the opportunities of life, that is, stimulate the child so that there is a balance between the demands of the disease and the demands of everyday life. So, they let the sick child do (or try to do) things that every child does.[19,28]

Moreover, it is also necessary that the family understands that overprotection may cause problems in the development of the child and that the best thing to do is stimulate the child to create new friendships. This will encourage her/his independence.[8]

When it comes to the future, the speech of caregivers is full of faith and hope, as can be seen in clippings transcribed below.

> *God can do anything! And I have faith that everything will be OK, that she will be able to overcome all difficulties and even if she does not reach the cure, that she may live well. (I3-I4, I6-I8, I12)*
>
> *I do not know [...] No one knows what will happen, but I hope she gets better. (I2, I9)*
>
> *I hope she may evolve, develop [...] study, graduate, work, raise a family. I hope that society accepts and receives her with open arms, without prejudice. (I1, I5, I10, I16-I18, I21)*

In the above quotes, we see that faith and spirituality are phenomena present in the lives of people facing difficult situations, because they help to overcome obstacles and keep hopeful.[15,18,29] The caregiver/family has the perspective that the child will be able to have a better future, free from the disease or at least adapted to the limitations imposed by it. Hope for healing, either through medical advancement or by a miracle, being strengthened through faith and hope.[24]

FINAL REMARKS

In this study, it was found that caregivers face daily difficulties in the care of children with chronic disease. The challenges arise from changes in routine imposed by the disease, which are present in their speeches and associated to workload. But the existence of social support is also evident, in a way, as it helps to enhance the strength of the caregiver so that she may minimize the negative effects caused by the child's illness in his/her life. This support takes various forms, but it is in the family that he is more present.

Based on the foregoing, it is essential to know the difficulties experienced by caregivers in order to implement strategies that help in facing the disease and also realize the importance of social support networks in the face of chronic diseases in childhood and their strengthening, especially with respect to the sphere of health services, which should work more actively in this process.

Thus, new studies in this area are recommended to address not only the point of view of the caregivers but also the point of view of the children and the professionals involved in the treatment. It is suggested, also, that an effort to deepen studies on the relationship between the Family Health Strategy and families living with the chronic condition in childhood be made, because this is the health service that is closer to the population, and may be configured as the unique support for families.

In this sense, this study allowed greater knowledge of the subject and can be used for planning programs that help in coping with the chronic illnesses in childhood by the family in a working set of permanent education of families and children both in schools and in health services.

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