Journal of Nursing
Revista de Enfermagem
UFPE On Line
ISSN: 1981-8963

ORIGINAL ARTICLE

EXPERIENCES OF ACCESS TO PRIMARY CARE OF CHILDREN AND ADOLESCENTS WITH DISABILITIES

EXPERIÊNCIAS DE ACESSO À ATENÇÃO PRIMÁRIA DE CRIANÇAS E ADOLESCENTES COM DEFICIÊNCIAS

EXPERIENCIAS DE ACCESO A LA ATENCIÓN PRIMARIA DE NIÑOS Y ADOLESCENTES CON DEFICIENCIAS

Sarah Vieira Figueiredo[1], Lívia Lopes Custódio[2], Aline Mayra Lopes Silva[3], Roselene Soares de Oliveira[4], Juliana Vieira Figueiredo[5], Ilvana Lima Verde Gomes[6]

ABSTRACT

Objective: to understand the access of children and adolescents with disabilities to Primary Health Care services based on family experience. ***Method***: this is a qualitative, descriptive, exploratory study, developed from semi-structured interviews, performed in a pediatric referral hospital. The data were analyzed by the Thematic Categorical Analysis Technique. ***Results***: The findings revealed an underutilization of these services as a result of their weaknesses in the care and access of children and adolescents with disabilities, such as the lack of structural adaptations for these people and qualified health professionals. ***Conclusion***: primary Care needs to undergo restructuring, both in its physical conditions and the training of its human resources and the creation of strategies that contribute to the access of infants with special health needs. ***Descriptors:*** Child; Adolescent; Health Services Accessibility; Primary Health Care; Disabled Persons.

RESUMO

Objetivo: compreender o acesso de crianças e adolescentes com deficiências aos serviços de Atenção Primária em Saúde a partir da experiência de familiares. ***Método:*** estudo qualitativo, descritivo, exploratório, desenvolvido a partir de entrevistas semiestruturadas, realizadas em hospital de referência pediátrica. Os dados foram analisados pela Técnica de Análise categorial temática. ***Resultados:*** os achados revelaram uma subutilização desses serviços em consequência das suas fragilidades em relação à assistência e ao acesso de crianças e adolescentes com deficiências, como ausência de adaptações estruturais para essas pessoas e de profissionais de saúde qualificados. ***Conclusão:*** a Atenção Primária precisa passar por reestruturações, tanto em relação às suas condições físicas quanto à capacitação dos seus recursos humanos e criação de estratégias que contribuem para o acesso de infantes com necessidades especiais de saúde. ***Descritores:*** Criança; Adolescente; Acesso aos Serviços de Saúde; Atenção Primária à Saúde; Pessoas com Deficiências.

RESUMEN

Objetivo: comprender el acceso de niños y adolescentes con deficiencias a los servicios de Atención Primaria en Salud a partir de la experiencia de familiares. ***Método:*** estudio cualitativo, descriptivo, exploratorio, desarrollado a partir de entrevistas semi-estructuradas, realizadas en hospital de referencia pediátrica. Los datos fueron analizados por la Técnica de Análise categorial temática. ***Resultados:*** los hallados revelaron una subutilización de esos servicios en consecuencia de sus fragilidades en relación a la asistencia y al acceso de niños y adolescentes con deficiencias, como ausencia de adaptaciones estructurales para esas personas y de profesionales de salud calificados. ***Conclusión:*** la Atención Primaria precisa pasar por reestructuraciones, tanto em sus condiciones físicas como en la capacitación de sus recursos humanos y creación de estrategias que contribuyen para el acceso de infantes con necesidades especiales de salud. ***Descriptores:*** Niño; Adolescente; Accesibilidad a los Servicios de Salud; Atención Primaria de Salud; Personas con Discapacidad.

[1]Nurse, Master´s degree Professor, State University of Ceará/UECE, Fortaleza (CE), Brazil. E-mail: sarahvfigueiredo@gmail.com; [2]Psychologist, Master in Collective Health, State University of Ceará/UECE, Fortaleza (CE), Brazil. E-mail: liviacustodio@yahoo.com.br; [3]Nurse, Master in Collective Health, State University of Ceará/UECE, Fortaleza (CE), Brazil. E-mail: line_mayra@yahoo.com.br; [4]Physiotherapist, Master in Child and Adolescent Health, State University of Ceará/UECE, Fortaleza (CE), Brazil. E-mail: rose.fisio@uol.com.br; [5]Nurse, Ph.D. in Clinical Care and Nursing, Universidade Estadual do Ceará/UECE, Fortaleza (CE), Brasil. E-mail: ju_vfigueiredo@hotmail.com; [6]Enfermeira, Professora Doutora, Universidade Estadual do Ceará/UECE, Fortaleza (CE), Brasil. E-mail: ilverde@gmail.com

INTRODUCTION

The management of the health systems and services in Brazil is still a major challenge for the consolidation of the Unified Health System (SUS), mainly in the principle of integrality. Despite the expansion of the services offered, a continuum of necessary and indispensable care is still incipient so the different levels of care can be integrated.

Within the network of attention of the SUS Primary Care (PC) is its preferred gateway, characterized by a set of actions that involve individual and collective aspects aimed at the promotion, protection, maintenance and rehabilitation of health, diagnosis, treatment and prevention of diseases. Thus, it must employ technologies of high complexity and low density to solve the health problems of greater frequency in the territory where the population is attached.[1]

Thus, the PC should act in a joint and integrated manner with the other network services, through an interaction between the sectors of intermediate technological density (secondary care) and higher density (tertiary care), through a sharing of information about the patients, aiming to generate a length of service, tending to a comprehensive and qualified care to the population.

In the context of children and adolescents with disabilities coming from a chronic illness process, it is important to note that to provide comprehensive care to these patients it must be ensured throughout the public health services network at all levels of care, so besides receiving care in specialized services and tertiary care, they are also guaranteed adequate care for their low complexity health complaints in the primary and secondary services close to their residence.

According to the WHO, chronic diseases are the leading causes of death and disability in the world, defined as those that have a long permanence, a slow evolution, usually recurrent and that, consequently, contribute to the suffering of individuals, families and society, requiring continuous care and efforts from a set of public policies and equipment.[2]

Some of these diseases can lead to disabilities in affected children and adolescents. Thus, this study considered the concept of deficiency as "any loss or abnormality of a psychological, physiological or anatomical structure or function that generates incapacity for the performance of activity, within the standard considered normal", being considered with disability that individual presenting one or more of the following changes: physical, hearing, visual or mental impairment.[3]

However, it should be noted that the contemporary crisis in the Brazilian health system and in other countries has reflected a disharmony between the health situation of the population, permeated by an accelerated demographic transition and an epidemiological context with a predominance of chronic conditions, and a system based on the search for developing services and actions responsive to acute conditions of illness.[4]

Among the obstacles that exist for these children and adolescents with disabilities and specific health needs to achieve a continuity of their treatment and receive health care in all levels of attention they need, the difficulty of access and consequent receipt of care in health that considers the chronicity of their illness can be an obstacle to the continuity of this assistance, revealing the need for a greater discussion on the subject, in search of possible strategies to facilitate this access and in healthcare.

The concept of access is very broad and complex. For some authors, it is the first step to be overcome by patients in the search for health care and it is related to five dimensions: availability of services against patient demand, accessibility (location, distance and forms of displacement), functional adequacy (how the service is organized by patients), financial capacity (relation of costs and supply) and acceptability (related to the attitudes of health professionals, patients and the practices of these services).[5]

Based on these authors, this study considered access in its relationship with the supply or non-availability of services, distance to them, form of care, available resources, training of health professionals and the way in which responsibility for health problems has occurred to the population.[5]

OBJECTIVE

- To understand the access of children and adolescents with disabilities to Primary Health Care services based on family experience.

METHOD

This is a qualitative, descriptive and exploratory study. The scenario was a tertiary public hospital of pediatric referral in the state of Ceará/CE, Brazil, due to the great demand of patients under 18, chronically ill, assisted in this service, through the Ambulatory of Specialties, which provides

different people with special health needs, by a multi-professional team.

Regarding these children and adolescents, the study focused on those who have a defect in the formation of the neural tube called spinal bifida, being delimited to the most prevalent type and considered more serious, the myelomeningocele, by expressing components of the marrow spinal cord and generate neurological impairments, such as deformities and physical deficiencies, sensitivity deficit, changes in the urinary tract and intestinal functioning.[6]

As a consequence of its complications, myelomeningocele is considered a relevant public health problem, and it is necessary to support children and adolescents with this pathology, as well as their families, with public policies that actually implement their rights, increasing their access to health services and contributing to their better quality of life.[7]

Fifteen family members responsible for infants suffering from myelomeningocele from 14 municipalities in the state of Ceará, two from Fortaleza, five from the Metropolitan Region and seven from the interior of the state, participated in the study. The delimitation of the end of data collection occurred based on the degree of deepening of the information provided.

The inclusion criteria were: the responsible family member; be present during follow-up and treatment at the hospital; be the routine companion to health services, including those of PC to share information with greater detail regarding the subject under study; and present time to participate in the research. The exclusion criteria were: people with some mental deficit, previously diagnosed, who impaired their participation in the interviews, and who had little knowledge about the daily life of the child or adolescent.

The information was collected from September 2013 to February 2014 and a semi-structured interview was used with two items, the first item characterizes the child/adolescent and the accompanying family member; and the second consists of the following guiding question: talk about your experience in the search for Primary Health Care services since the birth of the child/adolescent, and how your access has occurred. All the interviews were recorded and transcribed only by the researchers.

For the analysis of the findings, the stages established by the thematic categorical analysis were followed, which works by means of operations of the dismemberment of a text in units and categories, according to analog regroupings. Among the different forms of categorization, the investigation through themes is considered effective and fast from the perspective of applying simple and direct speeches. The following steps were followed: pre-analysis; exploitation of the material; treatment of results; the inference; and interpretation. At the end, the thematic categories were delimited: Fragilities of Primary Health Care in the care of children and adolescents with disabilities; Distance and physical structure of Primary Health Care services.[8]

The research was approved by the Research Ethics Committee of the referred hospital (opinion 401,189) and had the consent of the management of the Ambulatory of Specialties. Also, all the norms of Resolution 466/12 of the National Health Council were followed. Therefore, some precautions were taken to protect the identity of the participants, replacing their true names with letters and other fictitious names, as well as health professionals and municipalities cited in the speeches.

RESULTS AND DISCUSSION

♦ Characterization of participants, children, and adolescents

Among the participants, only one was a father and the others were mothers. There was a predominance of people aged between 30 and 40 years old (10). As for education level, more than half had only had Complete or Incomplete Fundamental Education (8). Regarding marital status, most were married or lived in a stable union (11). People who did not exercise formal work activities predominated (10), only performing care services for the home and children with disabilities. The average income of the interviewees was one to two minimum wages, especially the Continuous Benefit (BPC) received (13), in the amount of a minimum salary, due to the physical deficiencies generated by the neural tube defect.

In this sense, a study carried out in Peru identified that 1.6 million Peruvians had at least one disability and that approximately 40% of them had dependency on a caregiver, which, similar to the findings of this study, was usually a female member of the family [9]

Regarding the children and adolescents, the age ranged from three months to 13 years old, of which nine were within the compulsory enrollment range in education, with only six attending school; relatives were justified by the non-education of the others due to the

sequels of myelomeningocele and absence of schools with adequate physical and structural support. In relation to complications of their illness, many children and adolescents with urinary incontinence were observed (13), requiring in some cases the need to perform the Vesical Home Remedy (VAS), as a therapy and strategy to improve urinary emptying; eight had fecal incontinence, requiring the use of diapers.

Four of them had not yet been diagnosed regarding motor changes due to age, eight did not walk and three had a non-functional gait, that is, they were moving with difficulty, requiring a wheelchair or other supports to meet their needs. Therefore, most of them depended on assistive technology equipment for ambulation and others on other types of therapeutic support to the sequels already demonstrated.

♦ Fragilities of Primary Health Care in the care of children and adolescents with disabilities

Through the experiences of family members, it has been shown that PC services have been underutilized to the care of children and adolescents with disabilities, with their search only for technical procedures such as vaccination, of materials and medications, as well as when they present health complaints considered by their caregivers as simpler.

It was also possible to observe that many families, through any complaints of the health of their children, preferentially and immediately sought the tertiary hospital service of pediatric referral located in the state capital and where they have accompanied ambulatorily from birth, greater confidence by the family members in this service:

> *It's difficult for me to go [PC service], because when he gets sick, I'll be here soon [HP], because here, there are the doctors (Sandra); I almost do not use the health center, it's just to receive material (Jane).*

Due to the fact that children and adolescents are continuously cared by professionals from this referral hospital and since the diagnosis of chronic illness, the formation of ties between family members and the health team has taken place. This establishment generates something positive for the caregivers since they often believe that their children have a chronic condition, all their complaints of health should be attended by those professionals who already know them, have specialized training and attend them in a service considered great quality and resolutive.

However, it is important to highlight the importance of the PC for presenting services with great potential to promote actions with these families, as well as the link between health professionals, considering the location in the same territory where they reside and having an entire organization based on the integrality and humanization between the team and the patients, being aspects considered differential, as well as being able to allow a closer approximation between them and the possibility of intervention by the professionals to promote the health of these people and children/adolescents with special health needs.[10]

Another aspect that also contributed to the low utilization of PC was related to the low level of knowledge of health professionals regarding the arrival of the child/adolescent in these institutions, besides the lack of resolution of their demands, with the referral to services of level independent of their health problem due to lack of knowledge about the chronic disease and its sequels, as the speech shows:

> *In the Municipality B, the health for Bejamim there is a mystery. Benjamin has hydrocephalus and mycelium, when I arrived at the healthcare there, My God, the health center is a mystery for the problem he had, "so there, no one here does not know what this is, a child different from the others and he cannot take care of him, he's going to have to go to Fortaleza, because that fever of him there. [...]". It has not been easy because of this prejudice because they did not know it in Municipality B, in the city where I live... everything has been only here in Fortaleza (Ezequias).*

The speech revealed that the principles of the universality of access and integrality of care were broken, inasmuch as the PC service imposed obstacles to the care of the child, refusing to receive it, presenting a response to their demands based only on the chronicity of his illness. Thus, one of the necessary changes in health care is a disease-centered, prescriptive model, for another centered on the person, on their singularities, on the socioeconomic context, making a connection between their objective and subjective illness issues.[4]

The access to health services fully by people with disabilities goes beyond the receipt of a care for their health needs, as it also concerns that they can enjoy their rights to integrality, equity, and universality in health.[11]

These aspects are the constitutional rights of all Brazilian citizens, regardless of their genetic characteristics, socioeconomic

conditions and whether or not to live with some pathology or disability, receiving a health care that is welcoming and free of any kind of discrimination aimed at promoting treatment with quality for all, while respecting their singularities.[12]

It should be noted that the failures and lack of resolution in PC, in situations of urgency and acute illness have led several times to a large search and overcrowded of people without urgencies or with moderate urgencies, in outpatient and large hospitals, overloading services and also reducing their resolution.[4,13]

On the other hand, it is important to highlight the distance these family members need to travel for their children to receive quality care of all their acute and chronic demands due to the pediatric referral service being located in Fortaleza and most residing in others municipalities in the state, which revealed deficits in the PC, becoming an obstacle in access to health care for these individuals.

Research in rural areas in South Africa has reaffirmed that people with disabilities have had fragile access to health services compared to people without disabilities, especially when talking about health care in interior regions.[14]

Regarding the lack of knowledge and qualification of these health professionals, it was noted the professional unpreparedness of the Family Health Strategy (ESF) teams, since, although it is not a specialized approach, it covers all the population, and should accept it regardless of their comorbidities. Also, higher education professionals, doctors, dentists and nurses need to be constantly updated, through a permanent education to provide better care to the entire community, including those who are chronically ill.

Thus, to achieve the principle of equity in the access to health of people with disabilities, it is necessary for PHC professionals to be better oriented and sensitized to this population profile and its specificities, to provide a differentiated, according to the needs of these people.[15]

The lack of activities offered to children and adolescents with special needs and their families and the deficit of medical professionals was added to these intervening factors in the use of basic health services, possibly indicating a poor quality of the PC located in different municipalities of the state of Ceará, which has not exercised in its entirety the functions to which it was fundamentally proposed.

> *Sometimes, there are days when I'll take her to the hospital. Because sometimes the center has almost nothing, does not have much to offer, does not have a doctor (Safira); There, it is so [...] there is a week with a doctor, there is a week without one (Marta).*

Other research developed with people with disabilities found similar results, insofar as it was seen that health services still have weaknesses regarding structural conditions and of professionals trained to assist these patients.[15]

It is important to point out that the research findings come from residents of several locations throughout the state of Ceará, which revealed the barriers to access for children and adolescents with disabilities and chronically ill to primary services, the way assistance has been offered, highlighting issues that revealed the poor quality of care, due to the lack of qualified human resources and low resolution of these services.

♦ Distance and physical structure of Primary Health Care services

From the perspective that access to health care within the network is a right of the entire population, it was evidenced that one of the children of this research resides in a rural location where there is no health service, occurring in an uncertain way visit of a health team in the region, coming from the municipality of which it is a part.

Therefore, when the child or his/her relatives need assistance, they need to seek it out in larger municipalities, which have a secondary hospital service and UBS. However, due to distance, the mother needs to get some private transportation to reach these health units, with neighbors and/or relatives:

> *There, is no health center for us. Sometimes, you go to a doctor there. When he [the child] needs it, we have to take him... it's far, it's far, we have to get a car, a motorcycle (Rebeca).*

Thus, it was observed the difficulty of access that this child needs to deal, through the necessity of any health care, even in the chronicity of his illness and sequels of neural tube defect. Thus, in small localities such as this, the support of health teams should be continuous and frequent, through home visits and/or transportation, in the most serious situations, when this possibility does not exist for the family, advocating Brazilian legislation, which guarantees access to all people with disabilities to health goods and services without discrimination.[16]

International study has shown similar results in addressing the existing barriers to

people with disabilities in access to health services in the city of Madwaleni in Africa, such as geographical barriers, failures in transport systems and road conditions, distances traveled, professionals that are sufficient for the demands, among others.[14]

From this perspective, it is emphasized that Decree 6,949 of 2009 calls for health care to be provided to people with disabilities as close as possible to their homes, including those living in rural areas, as in the situation of some study participants.[17]

Other relatives also spoke about the long distance from UBS to their residences, which generated the dependence of transportation to reach these services, being provided only by some municipalities. Thus, in regions where public transportation is not granted, family expenses increased due to the need to hire private cars to take the child and the adolescent to a basic health care when they did not have their own means of transport according to the speech:

> *It is far away, I'm going by car [...] we are forced to charter the car when it's time to go out with her (Naomi).*

For almost half of the participants, UBS was located with a certain proximity to their homes, with the possibility of walking to the service, taking the child and the teenager in their arms, or walking with their help, or with the support wheelchair.

It is about three blocks (Mara); It's close to home. I take the wheelchair (Samara).

Only one of the mothers spoke about the physical structure of the streets on the way to the UBS for not being paved, nor are there adequate sidewalks making the wheelchair unviable, making it difficult to access the health service. In this sense, it was possible to observe the importance of accessibility in the routes to the PC services, since many do not have private transport and they move by foot to these services.

Therefore, it is emphasized that for more than a decade, there has been a law that establishes standards for the promotion of accessibility for people with disabilities or reduced mobility by reducing obstacles in public streets and street furniture, among others. Thus, the planning and urbanization of these routes should be built with a view to the accessibility of these people, with emphasis on itineraries and pedestrian crossings, following the norms in the Brazilian Association of Technical Standards (ABNT).[18]

In a survey of students in New Zealand, participating adolescents who claimed to have some form of incapacitating illness reported having difficulty accessing health services.[19]

In this search to facilitate the access of these people to the basic health service, it is highlighted the home visits made by the health team as a strategy, when the family, due to the difficulties arising from deficiencies, other sequels, and socioeconomic conditions, is unable to take the child to the unit. However, a minority has had access to these visits, where there have been situations where family members had to position themselves in favor of their rights and demand them at UBS to finally reach the child's health care.

> *Today the doctor, the nurse, and the community agent go to my house, about since a year ago. It was only after my husband went there and complaint, he said that he had a special son and that no one in the house would visit (Jane).*

Home visits allow a closer approximation of health professionals with families, children, and adolescents with chronic illness and the environment in which they live, allowing a greater understanding of the realities of each patient, their difficulties and anxieties to favor a better identification of their needs and to develop a more particularized and higher-quality assistance.[10]

Therefore, the important role of home visits in the care of children and adolescents with special health needs was perceived by providing them with greater access to the health network at the primary level, better conditions for the interdisciplinary team of primary care, providing them with comprehensive, individualized and humanized care, as well as being a situation in which health professionals can exercise health education for these chronically ill people and their families, considering the socioeconomic, structural and relational conditions in which they live.

Regarding the physical structure of these health units, the presence of ramps, banisters, toilets adapted to wheelchair users and a suitable place for hygiene and exchange, is also an intrinsic part of the access to these services by users with deficiencies and special health needs, there were great structural variations in the different UBS of the municipalities and only a minority of relatives reported positive aspects regarding this structure.

Some health facilities were undergoing physical renovations and restructuring, and thereafter they began to present ramps, adapted toilets and larger places for the exchange of children/adolescents. In fact, Brazilian legislation requires that all public buildings must ensure accessibility for people

with disabilities or reduced mobility, emphasizing, since 2004, that the construction, remodeling, and extension of public buildings must guarantee minimum conditions of access.[20]

On the other hand, there was a predominance of the absence of these structures that facilitate the access of children and adolescents with physical disabilities and other special needs or only partial presence, for example, there were ramps, but there were no adapted toilets or the opposite. Circumstances that have revealed the still present omission of the public power regarding these people and Brazilian legislation that for more than a decade demands such changes.

> *It does not have [ramps], it does not have adapted chair for her, there is not an adapted bathroom (Penha); The health clinic center does not have an adaptation for the child of his type, who has to change diapers all the time, does not have a changing room, does not have a ramp to enter [...] the bathroom also does not have a wheelchair (Priscila).*

Even for those who have small difficulties walking, access to the UBS has been difficult, with the need for employees and family members to help them walk, hold them or carry them on their lap because of the absence of banisters and wheelchairs in these services. Also, when they go to these units, they are unable to use the toilets or use them with great difficulty because they have narrow entrances, lack of adaptations and places for exchange and hygiene.

Many performed VAS therapeutically because of urinary incontinence at predetermined times and there was a need for hygienic space and structures in the toilets so that the technique could be performed properly and safely. Without these conditions, the child and the adolescent do not follow the treatment when they need care in the UBS, besides having to be submitted to the use of diapers, being changed only in the return to their residences, a situation that can cause embarrassment to these patients.

Authors suggest that the structural precariousness of these institutions occurs in several municipalities, often due to their installation in inappropriate places, such as the use of residential houses for the operation of the health service, where there is no adequate and previously built environment with the objective of serving the population.[21]

Reaffirming the results found, a research verified the accessibility of people with physical disabilities in a UBS of Mato Grosso and also found the existence of much fragility in the structure of this service, preventing the patients´ passability. There were no handrails, despite the existence of ramps, or adapted restrooms and with free passage for wheelchair users.[22]

For some authors, disability is constituted through interactions between personal and contextual factors, that is, this is the result of having some kind of limitation based on their intrinsic conditions and if they experience barriers in the environment in which they coexist, by physical, social, cultural, economic and political aspects.[23]

Thus, the need for the development of projects for the construction and reform of these health services is reflected in the human particularities of people with disabilities and chronic diseases, including children and adolescents with special health needs such as those with neural tube defects, so there is a possibility of change in the current Brazilian and daily reality of these people, who routinely struggle to find affordable and quality health care for their demands.

CONCLUSION

The findings of this research allowed an understanding about the fragilities that exist in the PC health services in some municipalities of a state of Northeast Brazil, from the perspective of children and adolescents who have deficiencies, consequent to their chronic illness and special health needs.

Although the PC is the service with the highest degree of territorial proximity of these people, mainly because they reside in the interior of the state, it was underutilized by the participants, with priority being given to the receipt of vaccines, medications, and materials for home care. Also, it appeared to be poorly prepared to receive them due to the scarcity of activities directed at children and adolescents with disabilities and chronic diseases, lack of material resources and qualified health teams, functioning in a non-solving way for the demands of these users chronically sick

Therefore, it is believed that there is a need for discussion by managers and health teams about strategies that aim to promote a closer approximation of these families to these services, through an active search of the health professionals towards these children and these adolescents in their territory of assignment, aiming to accompany them also at the primary level, promoting rehabilitation

actions, social inclusion, a resolution to their health complaints that can be taken care of in that service, referencing them to other more appropriate sectors when necessary, being also a space of orientation and reception to the families, besides supporting the demands of this part of the population to act in an integrated way within the health care network.

It was also evidenced that the distance of the residences for some PC services, with the need of transportation to reach them, and their physical structure, lacking adaptations for people with physical disabilities and special needs, were aspects that constituted in obstacles to the access of children and adolescents to basic health care, essential for their integral care.

Thus, PC needs to undergo restructuring, both in its physical conditions to allow greater access to this part of the population, as well as the training of human resources, as well as the creation and expansion of strategies that contribute to its access such as home visits. Also, these services need to rethink their actions, including health promotion activities, which are part of their essence as localized services with greater proximity to the community, chronically ill people, through health education, among other strategies that consider the particularities of these individuals.

It should be noted that the study presented limitations since only the relatives of the children and adolescents were interviewed, without the involvement of managers and health professionals, which would contribute to a deeper discussion on the subject.

REFERENCES

1. Brasil. Portaria n°2.488 de 21 de outubro de 2011. Aprova a Política Nacional de Atenção Básica, estabelecendo a revisão de diretrizes e normas para a organização da Atenção Básica, para a Estratégia Saúde da Família (ESF) e o Programa de Agentes Comunitários de Saúde (PACS). Diário Oficial da República Federativa do Brasil [Internet]. 2011 [cited 2017 May 10]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2488_21_10_2011.html

2. World Health Organization (WHO). Preventing Chronic Diseases a vital investments [Internet]. 1ª. ed. Geneva: Organização Mundial de Saúde; 2005 [cited 2017 May 10]. Available from: http://apps.who.int/iris/bitstream/10665/43314/1/9241563001_eng.pdf

3. Brasil. Decreto nº 3.298, de 20 de dezembro de 1999. Política Nacional para Integração da Pessoa Portadora de Deficiência [Internet]. Brasília: Ministério da Saúde; 1999 [cited 2017 May 10]. Available from: http://www.planalto.gov.br/ccivil_03/decreto/d3298.htm

4. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da estratégia da saúde da família [Internet]. Brasília: Organização Pan-Americana da Saúde; 2012 [cited 2017 May 10]. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/cuidado_condicoes_atencao_primaria_saude.pdf

5. Assis MMA, Jesus WLA. Access to health services: approaches, concepts, policies and analysis model. Ciênc. Saúde coletiva [Internet]. 2012 [cited 2017 May 10];17(11):2865-875. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232012001100002&lng=en. http://dx.doi.org/10.1590/S1413-81232012001100002.

6. Cornegé-blokland E, Jasen HE, Jong-de Vos van Steenwijk CC, Poenaru D. Quality of life of children with spina bifida in Kenya is not related to the degree of the spinal defects. Trop Med Int Health [Internet]. 2011 [cited 2017 May 10];16(1):30-6. Available from: https://www.ncbi.nlm.nih.gov/pubmed/21070514

7. Figueiredo SV, Gomes ILV, Caetano R, Sousa ACC. Desafios enfrentados por crianças e adolescentes com mielomeningocele e suas famílias. IN: Gomes ILV, Pinto FJM, Figueiredo SV (org.) Temáticas de dissertações no âmbito da Saúde Pública: concepção de orientadores e estudantes. Fortaleza: EdUECE; 2014. p.131-52.

8. Bardin L. Análise de conteúdo. Tradução Luís Antero Reto, Augusto Pinheiro. São Paulo: Edições 70; 2011.

9. Bernabe-Ortiz A, Diez-Canseco F, Vásquez A, Miranda JJ. Disability, caregiver's dependency and patterns of access to rehabilitation care: results from a national representative study in Peru. Disabil Rehabil [Internet]. 2016 [cited 2017 May 10];38(6):582-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/26017542

10. Sousa EFR, Costa EAO, Dupas G, Wernet M. Continued care for families of children with chronic diseases: perceptions of Family Health Program teams. Rev Esc Enferm USP [Internet]. 2013 [cited 2017 May 10];47(6):1367-72. Available from:

http://www.scielo.br/pdf/reeusp/v47n6/en_0080-6234-reeusp-47-6-01367.pdf

11. Massula DR, Soares LMCA, Ribas E. Acessibilidade de pessoas com deficiência e mobilidade reduzida nos Serviços de Saúde da Secretaria de Estado da Saúde. BEPA [Internet]. 2016 [cited 2017 May 10];13(156):31-38. Available from:

http://portal.saude.sp.gov.br/resources/ses/perfil/gestor/homepage/gais-informa/bepa_156_gais_20_saude_e_protocolos_de_qualidade.pdf

12. Brasil. Ministério da Saúde. Carta dos direitos dos usuários da saúde [Internet]. Brasília: Ministério da Saúde; 2011 [cited 2017 May 10]. Available from: http://www.use.ufscar.br/direitos-e-deveres-dos-usuarios/carta-direitos-usuarios

13. Aguilera SLVU, França BHS, Moysés ST, Moysés SJ. Articulação entre os níveis de atenção dos serviços de saúde na Região Metropolitana de Curitiba: desafios para os gestores. Rev Adm Pública [Internet]. 2013 [cited 2017 May 10];47(4):1021-39. Available from:
http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-76122013000400010

14. Vergunst R, Swartz L, Mji G, MacLachlan M, Mannan H. 'You must carry your wheelchair'- barriers to accessing healthcare in a South African rural área. Glob Health Action [Internet]. 2015 [cited 2017 May 10];8:[about 8 screens]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4592846/pdf/GHA-8-29003.pdf

15. Pessalacia JDR, Ribeiro IKS, Rates CMP, Azevedo C, Braga PP. Experiências de acesso a serviços primários de saúde por pessoas com síndrome de down. R. Enferm. Cent. O. Min. [Internet]. 2015 set/dez [cited 2017 May 10];5(3):1752-367. Available from: http://www.seer.ufsj.edu.br/index.php/recom/article/view/1275/936

16. Deficiência. Viver sem Limite - Plano Nacional dos Direitos da Pessoa com Deficiência [Internet]. Viver sem limite – Plano Nacional dos Direitos da Pessoa com Deficiência: SDH-PR/SNPD; 2013 [cited 2017 May 10]. Available from:
http://www.pessoacomdeficiencia.gov.br/app/sites/default/files/arquivos/%5Bfield_generico_imagens-filefield-description%5D_0.pdf

17. Brasil. Decreto n°6.949 de 25 de agosto de 2009. Promulga a Convenção Internacional sobre os Direitos das Pessoas com Deficiência e seu Protocolo Facultativo, assinados em Nova York, em 30 de março de 2007. Diário Oficial da República Federativa do Brasil [Internet]. 2009 [cited 2017 May 10]. Available from:

http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2009/decreto/d6949.htm

18. Brasil. Lei n° 10.098 de 19 de dezembro de 2000. Estabelece normas gerais e critérios básicos para a promoção da acessibilidade das pessoas portadoras de deficiência ou com mobilidade reduzida, e dá outras providências. Diário Oficial da República Federativa do Brasil [Internet]. 2000 [cited 2017 May 10]. Available from: http://www2.camara.leg.br/legin/fed/lei/2000/lei-10098-19-dezembro-2000-377651-publicacaooriginal-1-pl.html

19. Peiris-John R et al. Adolescents with disability report higher rates of injury but lower rates of receiving care: findings from a national school-based survey in New Zealand. Inj Prev. [Internet]. 2016 [cited 2017 May 10];22:40–45. Available from:

https://www.ncbi.nlm.nih.gov/pubmed/26130733

20.Brasil. Decreto nº 5.296 de 2 de dezembro de 2004. Regulamenta as Leis n° 10.048, de 8 de novembro de 2000 e a 10.098, de 19 de dezembro de 2000, e dá outras providências. Diário Oficial da República Federativa do Brasil [Internet]. 2004 [cited 2017 May 10]. Available from: http://www.planalto.gov.br/ccivil_03/_ato2004-2006/2004/decreto/d5296.htm

21. Amaral FLJS, Holanda CMA, Quirino MAB, Nascimento JPS, Neves RF, Ribeiro KSQS et al. Acessibilidade de pessoas com deficiência ou restrição permanente de mobilidade ao SUS. Ciênc. Saúde coletiva [Internet]. 2012 [cited 2017 May 10];17(7):1833-40. Available from: http://www.scielo.br/pdf/csc/v17n7/22.pdf

22. Nascimento VF. Acessibilidade de deficientes físicos em uma unidade de saúde da família. Revista Eletrônica Gestão & Saúde [Internet]. 2012 [cited 2017 May 10];3(3):1031-44. Available from: http://periodicos.unb.br/index.php/rgs/article/view/23058/16580

23. Krahn GL, Walker DK, Correa-De-Araujo R. Persons With Disabilities as an Unrecognized Health Disparity Population. American Journal of Public Health [Internet]. 2015 [cited 2017 May 10];105 (Suppl 2):198-206. Available from:
https://www.ncbi.nlm.nih.gov/pubmed/25689212

Submission: 2017/06/17
Accepted: 2017/11/23
Publishing: 2017/12/15

Corresponding Address

Sarah Vieira Figueiredo
Universidade Estadual do Ceará
Curso de Enfermagem
Av. Dr. Silas Munguba, 1700 - Campus do Itaperi
CEP: 60714-903 – Fortaleza (CE), Brazil