

Urban accessibility barriers: daily life of families of children with neurological disabilities**Barreiras de acessibilidade urbana: cotidiano das famílias de crianças com deficiências neurológicas****Barreras de accesibilidad urbana: vida cotidiana de las familias de niños con discapacidades neurológicas****Received: 01/05/2020****Approved: 20/07/2020****Published: 22/07/2020****Gisélia Gonçalves de Castro¹****Adriana Santos Camargos²****Marilurdes Silva Farias³**

This study aims to understand accessibility barriers from the perspective of mothers of children with neurological disabilities. This is a cross-sectional, qualitative study carried out with 20 mothers of children being cared for in an outpatient clinic in a city in the state of Minas Gerais from February to September of 2019. Of those mothers, 15 were between 31 to 45 years of age and 12 were married. Regarding children, 70% were male, and 95% were 17 months or older. According to the topography, there was a predominance of quadriplegia, representing 95% of children. Two categories were elaborated based on the mothers' statements: "*Transportation Barriers*" and "*Urban Barriers*", thus pointing out disregard for adaptations for the disabled, especially with regard to the functioning of urban devices and public transportation. Accessibility barriers not only hamper mobility, but also hamper inclusion and increase the demand and concern of family members.

Descriptors: Architectural Accessibility; Family; Disabled Children.

Este estudo tem como objetivo compreender as barreiras de acessibilidades a partir da visão das mães de crianças com deficiências neurológicas. Trata-se de uma pesquisa transversal, qualitativa, realizada com 20 mães de crianças em acompanhamento em ambulatório de um município mineiro de fevereiro a setembro de 2019. Constatou-se que 15 delas pertenciam à faixa etária de 31 a 45 anos e 12 eram casadas. Em relação às crianças, 70% eram do sexo masculino, e 95% tinham 17 meses ou mais. De acordo com a topografia, houve predomínio da quadriplegia, somando 95% das crianças. Duas categorias foram construídas a partir das falas das mães: "*Barreiras nos Transportes*" e "*Barreiras Urbanísticas*", apontando assim, descaso com as adaptações para deficientes, principalmente no que diz respeito ao funcionamento dos dispositivos urbanísticos e transporte coletivo. As barreiras de acessibilidade não apenas dificultam a locomoção, mas também prejudicam a inclusão e aumentam a demanda e preocupação dos familiares.

Descritores: Acessibilidade Arquitetônica; Família; Crianças com Deficiências.

Este estudio tiene como objetivo comprender las barreras de accesibilidad desde la perspectiva de las madres de niños con discapacidades neurológicas. Se trata de una encuesta transversal y cualitativa, realizada con 20 madres de niños en régimen de atención ambulatoria en una ciudad de Minas Gerais de febrero a septiembre de 2019. Se descubrió que 15 de ellas pertenecían al grupo de edad de 31 a 45 años y 12 eran casadas. En relación con los niños, el 70% eran hombres y el 95% tenían 17 meses o más. Según la topografía, predominaba la cuadriplejía en el 95% de los niños. A partir de los discursos de las madres se construyeron dos categorías: "*Barreras de Transportes*" y "*Barreras Urbanísticas*", señalando así el descuido en las adaptaciones para los discapacitados, principalmente en lo que se refiere al funcionamiento de los dispositivos urbanísticos y de transporte público. Las barreras de accesibilidad no sólo dificultan la locomoción, sino que también perjudican la inclusión y aumentan la demanda y la preocupación de los familiares.

Descritores: Accesibilidad Arquitectónica; Familia; Niños con Discapacidad.

1. Physiotherapist. Specialist in Public Health. Master, Doctor and Post Doctor in Health Promotion. Professor at Centro Universitário do Cerrado Patrocínio (UNICERP), Patrocínio, MG, Brazil. ORCID: 0000-0003-1132-5647 E-mail: giseliacastro@unicerp.edu.br

2. Physiotherapist. Patrocínio, MG, Brazil. ORCID: 0000-0001-5993-2329 E-mail: didicaptc@hotmail.com

3. Nurse. Master in Health Sciences. PhD in Sciences. Professor at Faculdade São Luís de Jaboticabal, SP, Brazil. ORCID: 0000-0002-3827-2568 E-mail: malufariasbr@yahoo.com.br

INTRODUCTION

The environment has a strong influence on the growth and development of children, since it is through it that the development of skills, abilities and children's learning occurs. Therefore, children, especially those with disabilities, must grow up in an environment rich in motor and sensory stimuli, offering them information about the environment and the body itself¹.

A child born with a disability or an adult disabled by an accident is more limited by society than by the disability itself². One of the main causes of social exclusion of the disabled is the precarious availability of accessibility to public means in cities, which end up reducing mobility and ability of the individual making them prefer isolation³.

Accessibility to the environment can be understood as the possibility that the individual has of using, in a safe and autonomous way, buildings, furniture, spaces and urban equipment. It should be borne in mind that accessibility does not have a specific focus only on those who have some type of disability, contrary to this; it aims to serve all users of the service⁴. In view of this, the Brazilian Association of Technical Standards (*Associação Brasileira de Normas Técnicas - ABNT*) has implemented, through NBR 9050/2004, standards and technical specifications that must be considered in the elaboration of constructions and installation projects and also in the adaptation of buildings, furniture, urban spaces and equipment, in order to make them more accessible⁵.

Public space constructions and projects must be designed, adapted and executed in such a way as to be accessible to people with disabilities or reduced mobility⁵. However, even though the law guarantees the right of accessibility and mobility to the disabled, what is often perceived is that municipalities have not met the parameters established by NBR9050/2004. It is not uncommon to find, for example, buildings that do not have at least one accessible route in environments, equipment and furniture adapted for people with disabilities or reduced mobility⁶.

The Brazilian Law no. 10,098, of December 19, 2000, establishes general rules and basic criteria for promoting accessibility for people with disabilities or with reduced mobility. According to this law, barriers are obstacles and prevent or limit the individual's social participation, safe circulation, access to information, understanding and freedom of movement. These barriers can be divided into: urban, architectural, transport and communication and information barriers⁷.

Caregiving mothers of children with disabilities face different obstacles in their daily lives to provide quality of life for their children and also to maintain the routine of care⁸.

The importance of this investigation resides in the fact that the number of children with some type of disability grows more and more and it is noticed that, frequently, the accessibility norms are not respected. Also, based on this information, it is possible to provide subsidies so that, at some point, it is possible to evaluate strategies and plan actions to solve the main problems encountered.

Thus, this study aims to understand accessibility barriers from the perspective of mothers of children with neurological disabilities.

METHOD

This is a cross-sectional study with a qualitative approach carried out from February to September of 2019, and approved by the Research Ethics Committee, under Protocol CAAE 62623416.9.0000.5495. The study was carried out in an outpatient clinic in the interior of a city in the state of Minas Gerais.

This study was aimed at mothers of children with neurological disabilities monitored at a specialized outpatient clinic. After identifying the children in medical records, the mothers were invited to participate in the research. The medical records also collected the following

information: gender, gestational age at birth, type of delivery, current age, topography, as well as some data from the mothers. Subsequently, scheduling was carried out according to the availability of each participating mother for the interview.

On the days and times scheduled, the Informed Consent Form was read. To guarantee confidentiality, mothers were identified by the letter M followed by numbers (M1, M2, M3 ...). In the interview with the mothers, the following question was asked: "*How do you perceive the issue of accessibility for your child?*". For recording the mothers' reports, a digital recorder, Sony brand, model ICD-PX440 was used.

To analyze the characterization of the profile of children and their mothers, means and standard deviations were used. The data were compiled in Epi Info and tabulated in Excel and analyzed using the Statistical Package for Social Sciences (SPSS) version 18.0 for Windows.

Descriptive analysis of the cross between the variables analysis of qualitative data was also made based on Content Analysis by Minayo⁹ and Gomes¹⁰, in which the collection and analysis of data occurred simultaneously, performing the open coding and its categorization. Open coding is the part of the analysis that concerns naming and classifying the phenomenon through exhaustive examination of the data.

During open coding, data is "broken" into short sentences, examined, compared for similarities and differences. Through this process, the content is explored, allowing for new discoveries. The encoded data is grouped by similarity. The process of grouping concepts related to the same phenomenon is called categorization. Each category is considered saturated, when it is not possible to add new data. After this stage, readings of the obtained results were carried out, in order to apprehend particularities and determine the discussion with the literature of the area.

RESULTS

Twenty mothers participated, of which 15 were in the age group from 31 to 45 years old, 11 were married, 12 were housewives by occupation and had no income and eight worked in paid jobs.

Characterizing the children, the male gender predominated (70%), in which 60% were carried to term, 85% were born by cesarean delivery and in a public hospital. Regarding the age of the participants, most of the children (95%) were aged 17 months or more and 1 between 0 and 17 months. According to the topography, 19 were classified as pyramidal, with quadriplegia predominating, with only 1 extrapyramidal, classified as Athetosis.

In the qualitative data, two categories were formed: "*Transportation Barriers*" and "*Urban Barriers*".

Transportation Barriers

In regards to public transport, mothers reported that these are adapted to serve people with disabilities, but they complained about flaws in their functioning, because, many times, the population itself damages the accessories, such as seat belts, for example. Such complaints can be verified below:

The bus ramps are not always working, right? And another one they don't wait for us to put the belt on, right? ... you get the chair up in the bus... we're putting the belt on and the bus is going... it's very distressing... [M20]

The passengers themselves destroy that place where it is for the child to stay... I've never been in a bus that had the belt to pass my child in the seat ... and the bus ramps are not always working [M13]

Urban Barriers

Regarding the places for wheelchair users in parking lots, the mothers reported that they are insufficient and that they are often occupied by people without any type of disability, as expressed by the following reports:

There is also little space for the disabled... very little. It is very difficult for you to find a place for the disabled that is actually occupied by a disabled person. [M3]

Sometimes you still can't do it, right? Because there are a lot of people who are normal and take vacancies from those in need, right? [M15]

The population is kind of complicated to deal with. There are days when you arrive at the wheelchair parking lot and an able-bodied person's car is parked and they think they are in the right place. [M17]

According to the participants, access ramps are not yet available throughout the city and, when they are accessible, sidewalks are full of holes or have configurations that make it difficult to get around. According to some interviewees:

The sidewalks are very complicated.... The ramp and the sidewalk are full of holes and the wheels of the chairs fall and puncture. And sometimes there is that black stone sidewalk, those that are a little bit bigger, it's very hard to walk. [M17]

These ramps on the sidewalks, it is not every place you find them and when there is only the ramp, right? Because the entire sidewalk is bumpy... so you have to walk on the street. [M10]

DISCUSSION

A study with children with cerebral palsy and their caregivers, similarly to the present study, the children presented important changes in the motor level, in addition, it was found that caregivers are their own family members, especially mothers, so that the task of taking care causes family members to undergo a continuous process of physical, emotional and social adaptation¹¹.

The interviews conducted with participants of this study showed that families face different setbacks, such as the non-inclusive attitude of other citizens, little investment in accessibility in peripheral regions of the city, and the existence of barriers that hinder the mobility of disabled people. The lack of accessibility profoundly intensifies the demands for the families of children with disabilities¹¹.

With Law No. 10,098, public companies and public transport concessionaires now have a reserved and identified place for individuals with disabilities, the elderly, pregnant women and people with infants. In addition, vehicles produced one year after the enactment of the law must be planned for easy access by people to its interior⁷.

Public transportation allows individuals to access numerous places, such as stores, home, work and leisure, thus guaranteeing a right to "come and go" established by the Brazilian constitution¹². The use of these vehicles by people with disabilities or reduced mobility can be a great challenge, since the design of cars consists of high steps, unfavorable handrail layout, seats and turnstiles¹³.

In order to reduce barriers in public transport, alternative technologies can be adopted, such as low floors that allow access to the interior of buses at the same level as the sidewalk or from any other stopping point¹³. ABNT, through NBR 14022/06, institutes parameters and technical criteria for accessibility to public transport according to indications of the universal design, in order to guarantee accessibility in a safe and autonomous way¹².

In a survey conducted with disabled people, users of public transportation in the city of Uberaba, in the state of Minas Gerais, reports were found similar to those of the mothers of the present study. The testimonials of bus users showed that adequate accessibility to the bus depends on variables such as the conservation of equipment and the technical skills of drivers and collectors. It is known that only laws related to equipment and furniture are not sufficient to guarantee accessible transport, and continuous training and preparation of drivers and collectors is also necessary¹².

A survey carried out in 2010 in the city of Manaus, in the state of Amazonas, with wheelchair users showed that 80% of the participants use public transport. The interviewees denounced the population's neglect, as the space reserved for wheelchair users are often occupied by able-bodied people, who act with indifference towards the disabled; in addition, the lack of training to lift disabled people to buses can make the activity take an average of 30 minutes¹⁴.

Urban barriers are those that hinder access or mobility of the disabled or those with reduced mobility to spaces. These barriers exist in public and private places and prevent the exercise of citizenship in its fullness, due to the difficulty of displacement. Examples of urban barriers are: stairs, sidewalks with steps, ramps with exaggerated inclinations, narrow doors, among others.

With regard to special spaces for people with disabilities, Article 7 of Law No. 10,098 guarantees that, in all vehicle parking lots and on roads or public spaces, there are reserved and signposted spaces for the disabled. Such spaces must be located close to pedestrian circulation accesses and must be present in a number equivalent to 2% of the total number of spaces⁷.

A study investigated physical facilities of public hospitals in João Pessoa, in the state of Paraíba, seeking to verify accessibility for the disabled and individuals with reduced mobility. It was found that only one of the hospitals had a reserved space marked with the International Access Symbol (SIA)¹⁵. In another study, carried out again in João Pessoa, it was found that 97.8% of Family Health Units did not have parking facilities for people with disabilities¹⁶. Such results corroborate with the exposures of this study, since the mothers report the existence of few parking spots.

Still regarding parking spots for the disabled, a survey conducted with 29 bank branches identified that 20 did not have parking spots for the disabled. Thus, in 10 public agencies, only five had special spots, and of the 19 private agencies, only four provided spots for the disabled¹⁷. Another investigation, carried out in libraries in Portugal, found that half of the 25 libraries studied did not have their own parking in the vicinity and no signage for people with disabilities or reduced mobility¹⁸.

With regard to sidewalks, NBR 9050 determines that these must remain unobstructed and free from interpositions, such as holes, unevenness and obstacles that prevent or hinder people's mobility. With regard to ramps, the inclination must be in accordance with the limits established by NBR 9050, and the width must be established in accordance with the flow of people; also, fixed stairs and steps must be associated with ramps or vertical transport equipment. In addition, it is important to remember that, next to the parking space, there must be a total lowering of the sidewalk that coincides with the projection of the vehicle door opening¹⁹.

In an investigation carried out in 157 Primary Health Care Units (PHCU), located in 16 municipalities in the Maciço de Baturité region, located in the state of Ceará, it was observed that 39% of stairs and 74% of access ramps were if inaccessible to the disabled²⁰. In order for accessibility and inclusion to occur effectively, it is extremely important that health units offer physical access and appropriate environmental adaptations to people with disabilities²¹.

Another investigation revealed that 63.9% of users of the public health system with disabilities or mobility restrictions face barriers such as ramps and sidewalks on the way from their homes to the service location²². These findings are in agreement with the reports exposed in the present study.

Another survey of four public hospitals found that sidewalks had obstacles such as rubble and holes. It was also possible to observe that only two sidewalks had lower curbs at strategic points¹⁵.

CONCLUSION

Urban and transport adaptations, although present, have imperfections or do not work properly. It is known that adaptations need to be in accordance with the rules, because only then will people with disabilities or difficulty in locomotion be able to use them safely.

Thus, it is necessary that the maintenance of public transport is done regularly so that the adaptation equipment works properly. It is also necessary that drivers and collectors are instructed on how to operate elevators, and the population must be made aware of the importance of conserving adaptation devices.

The awareness of the population is also extremely relevant, together with a strict inspection, with a view to educating citizens about the importance of adaptations and conservation of accessibility equipment for those who have mobility difficulties.

The inadequacies of accessibility not only disrespect the laws, but also hinder mobility of the disabled and individuals with reduced mobility, impairing inclusion and increasing the demand and concern of family members. In view of this, it is important that public authorities participate more actively in issues related to accessibility, ensuring that, in fact, the law is complied with.

The limitations of the study are related to the fact that it was developed in a single city and with a reduced sample size, preventing generalizations, so that similar studies with larger sample sizes and in several different locations are suggested. On the other hand, this research points to a context possibly similar to other realities and may, in the case of the studied city, point out clues to review spaces and accessibility.

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CONTRIBUTIONS

Adriana Santos Camargos contributed with data analysis and writing. **Gisélia Gonçalves de Castro** participated in planning, conception and data retrieving. **Marilurdes Silva Farias** worked with writing and revision.

How to cite this article (Vancouver)

Castro, GG, Camargos AS, Farias MS. Urban accessibility barriers: daily life of families of children with neurological disabilities. REFACS [Internet]. 2020 [cited in *insert day, month and year of access*]; 8(Suppl. 2):694-701. Available from: *insert access link*. DOI: *insert DOI link*.

How to cite this article (ABNT)

CASTRO, G. G.; CAMARGOS, A. S.; FARIAS, M. S. Urban accessibility barriers: daily life of families of children with neurological disabilities. **REFACS**, Uberaba, MG, v. 8, p. 694-701, 2020. Suppl. 2. Available from: *insert access link*. Access in: *insert day, month and year of access*. DOI: *insert DOI link*.

How to cite this article (APA)

Castro, G.G., Camargos, A.S., & Farias, M.S. (2020). Urban accessibility barriers: daily life of families of children with neurological disabilities. *REFACS*, 8 (Suppl. 2), 694-701. Retrieved in: *insert day, month and year of access* from *insert access link*. DOI: *insert DOI link*.