revista de pesquisa ISSN 2175-5361

CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

RESEARCH DOI: 10.9789/2175-5361.rpcfo.v15.11945

PERCEPTION OF PHYSICAL REHABILITATION CENTER USERS ABOUT ACCESSIBILITY BARRIERS AND URBAN MOBILITY

Percepção dos usuários de centro especializado em reabilitação física sobre barreiras de acessibilidade e mobilidade urbana

Percepción de los usuarios de centros de rehabilitación física sobre las barreras de accesibilidad y movilidad urbana

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ABSTRACT

Objective: to understand the perception of users of a physical rehabilitation program about their experiences in facing barriers to accessibility and urban mobility to attend consultations at a Specialized Rehabilitation Center. **Method:** descriptive study, qualitative approach, in the Metropolitan Region I of Rio de Janeiro, Brazil. Data collected through semi-structured interviews, analyzed in the light of content analysis, thematic approach. **Results:** from the analysis, four categories emerged that showed repeated challenging experiences in the course of their residences for scheduling in the rehabilitation program, facing urban mobility environments unsuitable for the circulation of people with some type of disability or reduced mobility. **Final Considerations:** participants experience embarrassing situations that make them feel powerless, unmotivated, frustrated and with low self-esteem, requiring rehabilitation teams to adopt welcoming strategies for care so that they do not compromise the achievement of goals planned in the rehabilitation program.

DESCRIPTORS: Barriers to access of health services; Rehabilitation centers; Disabled person; Mobility limitation; Social discrimination.

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Received: 06/21/2022; Accepted: 01/03/2023; Published online: 05/22/2023

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How cited: Cruz VV, Sé ACS, Machado WCA, Figueiredo NMA, Pereira RSS, Monteiro RS. Perception of physical rehabilitation center users about accessibility barriers and urban mobility. *R Pesq Cuid Fundam* [Internet]. 2023 [cited year mouth day];15:e11945. Available from: https://doi.org/10.9789/2175-5361.rpcfo.v15.11945

RESUMO

Objetivo: compreender a percepção dos usuários de programa de reabilitação física sobre suas experiências no enfrentamento de barreiras de acessibilidade e mobilidade urbana para comparecer nos atendimentos em Centro Especializado de Reabilitação. **Método:** estudo descritivo, abordagem qualitativa, realizado na região Metropolitana I do Rio de Janeiro, Brasil. Dados coletados através de entrevistas semiestruturadas, analisados à luz da análise de conteúdo, abordagem temática. **Resultados:** da análise emergiram quatro categorias que evidenciaram reiteradas experiências desafiadoras no percurso de suas residências para agendamentos no programa de reabilitação, se deparando com ambientes de mobilidade urbana inadequados à circulação de pessoas com algum tipo de deficiência ou mobilidade reduzida. **Considerações Finais:** os participantes experimentam situações constrangedoras que os fazem se sentir impotentes, desmotivados, frustrados e com baixa autoestima, requerendo das equipes de reabilitadoras a adoção de estratégias acolhedoras de atendimentos para que não comprometam o alcance de metas planejadas no programa de reabilitação.

DESCRITORES: Barreiras ao acesso aos cuidados de saúde; Centros de reabilitação; Pessoas com deficiência; Limitação da mobilidade; Discriminação social.

RESUMEN

Objetivo: comprender la percepción de los usuarios de un programa de rehabilitación física sobre sus experiencias frente a las barreras de accesibilidad y movilidad urbana para asistir a consultas en un Centro Especializado de Rehabilitación. **Método:** estudio descriptivo, abordaje cualitativo, realizado en la Región Metropolitana I de Río de Janeiro, Brasil. Datos recolectados a través de entrevistas semiestructuradas, analizados a la luz del análisis de contenido, abordaje temático. **Resultados:** del análisis surgieron cuatro categorías que evidenciaron reiteradas experiencias desafiantes en el transcurso de sus residencias para la inserción en el programa de rehabilitación, frente a ambientes de movilidad urbana no aptos para la circulación de personas con algún tipo de discapacidad o movilidad reducida. **Consideraciones Finales:** los participantes viven situaciones bochornosas que los hacen sentir impotentes, desmotivados, frustrados y con baja autoestima, requiriendo que los equipos de rehabilitación adopten estrategias acogedoras de atención para que no comprometan el logro de las metas previstas en el programa de rehabilitación.

DESCRIPTORES: Barreras de acceso a los servicios de salud; Centros de rehabilitación; Personas con discapacidad; Limitación de la movilidad; Discriminación social.

INTRODUCTION

The World Health Organization (WHO) estimates that over one billion of the global population have some type of disability, and with this number increasing, has stated the need for more qualitative research to better understand the experiences lived by people with disabilities. As noted by WHO, accessibility encompasses physical, economic, and information affordability, as well as non-discrimination, as one of the four elements of the right to health, along with availability, acceptability, and quality of services provided.[1]

A variety of obstacles arranged at various points along the routes used by people heading for health care and rehabilitation settings, posing nothing less than imminent accident risks and reproducing social inequality, restrict accessibility for many individuals and groups around the world. These obstacles or barriers especially hinder regular access for people with disabilities (PwD) or reduced mobility (RM) to be met in their health care and rehabilitation needs, compromising their well-being, quality of life and social inclusion.[2-3]

Regarding barriers, we can mention objective, subjective, and attitudinal types. The objective barriers consist of materiality, they have identification potential so they can be questioned, criticized and eliminated. The subjective barriers subsist in discriminatory gestures, attitudes and discriminatory behavior of some unenlightened people, directed to minor groups in society, such as PwD or RM. The attitudinal barriers arise from pre-judgmental and inappropriate attitudes, preventing people's access to some environment, equipment, services and essential information.[3,5]

Such barriers persist and are highlighted in numerous situations in everyday life, consciously or unconsciously reproducing historical social behaviors, cultivated by part of humanity that refused to accept that human diversity has multiple ways of manifesting itself, but all of them feel, suffer, cry, love, and can be happy, depending on how they are respected and included among the others in society.[3,6-7]. The lack of social connection has become a major factor influencing social isolation and ultimately social exclusion,[8] providing significant impacts on people's health, resilience, self-esteem, recovery, rehabilitation, and life.[4]

The participation in social activities, community and social interaction with peers is a determining indicator of disability or reduced mobility and is linked to experiences of motivation, competence and self-efficacy. The users of health services or physical rehabilitation are among the people most affected by accessibility barriers and urban mobility, that are located at various points along the route when they go to their treatments.[1,3,8,11]

In this context, urban mobility has an indirect but significant influence on the well-being of all members of society.[5,11] Meanwhile, accessibility implies making public places accessible to all individuals, regardless of their disability or special needs, ensuring the integration of these citizens in society and thus giving them the right, ability and capacity to participate in activities of

a fulfilling life in the communities where they live and circulate, just like other people.[12]

That said, it is necessary to consider the urgent need for professionals working in physical rehabilitation teams to know the experiences resulting from lack of accessibility and urban mobility faced by users of these services, to promote encouraging and welcoming care strategies, focused on their potential to promote functional autonomy. The objective of this study was to understand the perception of physical rehabilitation program users about their experiences in facing accessibility and urban mobility barriers to come to the services in a Specialized Rehabilitation Center. This study is justified by the need to expand the understanding of health professionals working in teams from specialized centers for physical rehabilitation and the Disability Care Network (RCPCD), about how their users perceive the facing of various barriers to be present in the treatment. Being essential encouraging and fraternal welcoming, empathetic actions to minimize the anxiety of these people, motivating them to persist in achieving self-improvement goals and a more independent life.

METHOD

This is a descriptive study with a qualitative approach, conducted and structured in line with the Consolidation Criteria for Qualitative Research Reports (COREQ).

The participants were 90 users of the Physical Rehabilitation Specialized Center of the Brazilian Rehabilitation Beneficent Association – ABBR, located in the city of Rio de Janeiro (RJ), which, according to Ordinance 793 of April 24, 2012, establishes the Disability Care Network within the Brazilian Unified Health System (SUS).[13]

As inclusion criteria, the participants had to be users of the physical rehabilitation programs of the institution, of both genders, older than 18 years old, regularly assisted by the multi-professional team, and living in the Metropolitan Region I of Rio de Janeiro. Cognitive deficit or other disability that would make it impossible to understand were the exclusion criteria.

The data production was carried out between April and May 2019, through individual interviews with a semi-structured script containing sociodemographic, clinical characterization and open questions about accessibility barriers and urban mobility. The open questions that guided this study were: What are the biggest barriers to be faced to get to the Rehabilitation Service? How do you feel when you cannot reach your goals because of accessibility barriers and for experiencing the condition of a person with disability and/or reduced mobility?

The invitation to participate in the interviews was made in the reception to the users in the waiting room for the appointments in the rehabilitation program, with subsequent scheduling according to their availability. All participants were given explanations about the research as described in its free and informed consent form, which they all signed. The completion of the interviews was based on the saturation criteria, considering a sufficient number of interlocutors to provide recurrence and information completion.[14]

The interviews were recorded using a cell phone application, with an average length of 30 minutes. The content of the interviews was transcribed by one of the researchers, and later validated by another researcher.

To preserve the anonymity of the participants, we used the abbreviation M/F for gender, followed by a cardinal number, according to the order of the interviews, and the age range of the users.

The data analysis procedures were based on thematic analysis technique, following its three phases: pre-analysis, material exploration and treatment of results/inference/interpretation. In the first stage, a comprehensive reading of the selected material is made, in an exhaustive way, reaching deeper levels, with the objective of the author impregnating himself in the material. The second stage is the exploration of the selected material, the analysis itself, also known as categorization, which comprises cutting the texts into units of records, for later classification and union of the units into thematic categories, with the objective of identifying the nucleus of senses. In the third stage of results treatment/inference/interpretation, the aim is to highlight the information provided by the analysis, by means of simple quantification. Thus, inference is made in an intermediate phase, between the analytical treatment and the interpretation of results.[15]

The research protocol was approved by the Ethics Committee in Research under CAAE nº 97122818.6.0000.5285, complying with the current Resolutions of the National Health Council.

RESULTS

The categorization of the participants in this study showed that most of them are men, aged between 44 and 56 years, single, with elementary school education and family income between R$ 1,000.00 and R$ 1,999.99. They present RM or disability due to disease, accident, congenital malformation and violence. They receive treatment 1 to 2 times a week, traveling mainly by bus, cab or Uber, with a companion, as described in Table 1.

The data from the participants' statements in this study were analyzed and organized into four thematic categories, namely: Negative feelings due to risks and difficulties to get around on public roads; Inaccessibility at home, lack of support network or dependence on family members; Discrimination, exclusion and judgments by appearance and; Feelings of impotence and inferiority that impact self-esteem.

Category 1: Negative feelings due to risks and difficulties to get around on public roads

The physical confrontation with the architectural barriers exposes the participants to risks of being run over and dependence on others due to the impossibility or difficulty of movement and accessibility during the displacement to the assistance in the

Table 1 – Sociodemographic profile of users of a Specialized Physical Rehabilitation Center regarding accessibility barriers in Metropolitan Region 1. Rio de Janeiro, RJ, Brazil, 2019

Variables	N	%
Gender		
Male	53	58,9
Female	37	41,1
Age range		
18 to 30 years	9	10,0
31 to 43 years	5	6,0
44 to 56 years	26	29,0
57 to 65 years	25	28,0
> 65 years	25	28,0
Marital status		
Single	37	41,1
Married	27	30,0
Divorced	9	10,0
Widower	17	18,9
Education		
Elementary	43	47,8
High School	30	33,3
Higher Education	14	15,6
No education	3	3,3
Family income		
< R$1.000,00	12	13,3
Between R$1.000,00 and R$1.999,99	47	52,2
Between R$2.000,00 and R$5.000,00	23	25,6
> R$5.000,00	7	7,8
Not informed	1	1,1
Disability	77	85,5
By illness	57	74,0
By accident	17	22,0
By congenital malformation	2	3,0
By violence	1	1,0
Reduced mobility	13	14,4
Treatment frequency		
1 to 2 times per week	90	100,0
3 times a week or more	0	0
Means of transportation to treatment		
Private car	14	15,5
Bus	23	25,7
Cab or Uber	25	27,8
Subway	2	2,2
Train	0	0
Motorcycle	3	3,3
Ambulance	6	6,7
City van	17	18,9
Travel to treatment with companion		
Yes	57	63,3
No	23	25,6
Sometimes	10	11,1
Total	90	100,0

Source: The authors

rehabilitation service, triggering negative sentiments by feeling disrespected, humiliated and ashamed.

> *My biggest difficulty is the disrespect because people don't respect the disabled. There are places designated for the disabled that they don't respect. If you doubt, they run over the disabled people.* (M28, between 44-56 years old).

> *I feel very embarrassed. There is no way we can get around by ourselves, always with the help of family members, it is very bad because we don't have our independence.* (F52, between 31-43 years old).

I was devastated, I couldn't pass. I found it humiliating that a person picked me up and put me up there, I stayed without treatment. I didn't know what to do, I'm going to complain to whom? (M84, over 65 years old).

It kills me to let them carry me in their laps. I am very embarrassed (F3, > 65 years).

It seems that we have no place in our world. Everyone can come and go, but not us. (F4, between 57-65 years years old).

Category 2. Inaccessibility at home, lack of support network or dependence on family members

Living in distant neighborhoods, or in low-income communities, with fewer resources for urban mobility and linear ground swings increases the obstacles for users of physical rehabilitation programs, making their journeys even more challenging, as recounted in the following.

I live alone, I live in a very distant neighborhood, my sister takes care of me, but she has to work [...] *I feel alone.* (F24, between 44-56 years old)

I feel difficulty in terms of access, because I don't have conditions to do everything by myself, see? I live in a place that is a hill, right? So I have to ask people to carry me.... (M45, between 57-65 years old).

The worst problem for me here is going down the stairs where I live, there are one hundred and seventy-eight steps, I live alone and God. (M2, between 57-65 years old).

The dependence on family members for help when leaving home is present in most of the narratives, some of them even miss the rehabilitation appointments, which makes them give up on leaving home.

It is so difficult to get out, that I prefer not to leave the house, I am afraid because I need help from someone else. (M7, between 44.56 years old).

Very sad, because in the old days we used to manage, but now with this type of disability it is complicated. We depend on people to help. (M65, between 31-43 years old).

There is no one to take me, and alone it is impossible. The way is to accept it, right, so what, I've had depression, I've tried to kill myself, but now I've accepted it. (F19, > 65 years).

Very complicated! Just this week I had to come with a wheelchair, when I got to the bus station there was no ramp to get up the chair, so I had to depend on the help of a guy who took the chair to get through (M10, between 31-43 years old).

I wish it had, everybody, had the ability to circulate, to have the freedom to come and go, but unfortunately it is not like that. I don't leave home much, only to come to the therapies. I even feel like it, but when I think of all that I have to go through... I give up. (M15, between 18-30 years old).

Category 3. Discrimination, exclusion and judgments by appearance

The participants' narratives express situations of discrimination, exclusion and judgments by employers, employees of public service companies and the general population, associated with appearance and physical disability.

I was a secretary, I speak three languages. After the accident, I had to have my legs amputated, they didn't want me anymore. They pulled me over. I think it was because it became ugly, right? There they give a lot of value to appearance (F3. > 65 years old).

Because the people themselves don't respect (...) at last, there is a lot of discrimination against elderly people with disabilities". (F17, between 57-65 years old).

It is a lack of respect for us. I feel humiliated, and despised in the eyes of the authorities of Rio! (F64, between 44-56 years old).

Sometimes we are so discriminated for being disabled. I've been insulted several times, I've been thrown out of the bus and I've been very embarrassed. (M17, between 57-65 years old).

Category 4. Feelings of impotence and inferiority that impact self-esteem

Stories of feeling inferior to other people due to the condition of being deficient, mark the experiences of the participants, who report sadness, crying, depression, feeling incapable, or feeling like they can't live. A reality that shows deep emotional suffering, impact on self-esteem, resulting from the non-fulfillment of their fundamental rights.

I feel a great sadness and I feel inferior to other people, ok! (F49, between 57-65 years old).

I cry a lot, a lot, but a lot really. (F35, between 57-65 years old).

I feel incapable. (F33, between 57-65 years old).

We feel like nobody, no?! We want to do things, we can't, we have to depend on others, right? (F48, > 65 years old).

I feel very bad. It seems that I don't live. (F90, between 44-56 years old).

Look, I feel very upset. I get depressed, I don't feel like leaving home. I feel that we are not worth anything. (M22, between 44-56 years old).

It is difficult, excuse the expression, we become animals, animals in this country, I worked so hard, I lost my legs, depending, begging to have a right that is mine, I can't, it's ridiculous. (M42, between 57-65 years old).

On the other hand, even in the face of so many difficulties to get around due to architectural barriers, there are some among the participants who do not give up and resort to resilience.

It is very difficult. I live in an apartment, I live on the second floor, there is no elevator, and I have to get off the chair, climb stairs and there are those barriers, the difficulties, but I don't give in to this right, I overcome it right, and doing the best way I can, doing my part. (M13, between 31-43 years old).

DISCUSSION

Independent mobility constitutes a fundamental right of people with or without disabilities and should ensure the right to full access to urban spaces and equipment for collective use, as a way to prevent embarrassing situations of dependence on others on public roads.[4] However, studies carried out in Indonesia,[16] Poland,[17] India,[18] Mexico,[3] Brazil[7] and United States,[6] demonstrate antagonistic realities and reveal that barriers to accessibility and urban mobility persist, curtailing the fundamental rights of movement of PwD or RM around the world, causing them constraints in their experiences in the transportation system, public roads and buildings of collective use.

As narrated by the participants of this study, the repeated perception of being disrespected in their fundamental rights to come and go is corroborated by both the international literature on the subject, highlighting the demotivation to leave home and the fear of the barriers that they will face on the way to the Specialized Rehabilitation Center. A reality present both in low--income countries[19-20] and rich and developed ones [6,21], attesting that the respect or disrespect for the fundamental rights of the human being is independent of the technological and economic resources of nations, but rather of the humanitarian and brotherly sense that permeates people's relations with one another.

It is important to emphasize that urban public spaces are part of the circulation environment of their users and, therefore, need to be properly designed to meet their needs. Despite the prejudiced reactions and judgments due to the appearance of what is different, giving up one's own emotions for fear that the cost will be high means moving away from the fight for inclusion, which is essential to the greater achievement of real meaning and significance to life.[4,22]. Facing the various structural barriers in public environments associated with acts of prejudice and judgments by appearance narrated by the participants of this study, increases the perception of not belonging in society, depression and serious impacts on self-esteem, confirmed in a study conducted in Iran in 2014 and 2015,[23] increased by the indifference of others.

Regarding the reports of the participants in this study about being carried on the lap due to lack of accessibility options on the way from their homes to rehabilitation care, it should be noted that the episode itself makes them feel excluded, although there are those who are willing to help.[22] By the way, the idea of being carried on the lap of strangers, due to lack of accessibility, makes any adult human being feel uncomfortable, insecure, afraid of falling and acquiring greater functional complications.[21,23] The fear of falling is an important health concern among dependent adults and elderly people, related to previous experience or to the likelihood of a future fall. favoring restricted activities, functional declines, social isolation, depression, and institutionalization.[23]

The feelings of impotence and inferiority that affect the self--esteem of the participants of this study relate to the perception of indifference of the authorities regarding compliance with legislation. Although the United Nations Convention on the Rights of People with Disabilities establishes as essential the right to come and go for PwD.[24] The implementation of public policies for the dispensation of assistive technologies, orthoses, prostheses, materials and equipment, is fundamental to make the life of these people dignified, however, its achievement is still difficult in low and middle income countries, mainly due to lack of financial support.[25-26]

The fact of feeling undervalued, discriminated, excluded, can lead to suicidal ideation, as mentioned by the participants of this study, triggered by a symptom of major depressive disorder. As depressive disorders occur at a high rate among individuals with acquired disabilities (particularly in the first 2 years after disabling neurological injury or amputation), becoming a portion of the population at risk for suicidal ideation.[27]

Similar narratives of the participants in this study were identified in a study focused on the same object, conducted in Cambodia, concluding that the intersection between health, disability and accessibility presents significant practical challenges for people with disabilities living in low – and middle-income countries, where urban infrastructure is poor and mobility is unsafe.[26] Moreover, the lack of access to health, rehabilitation, education, employment and other services hinders the achievement of sustainable development goals and affects the quality of life of these citizens, even in rich countries.[28]

In Brazil, the deficient level of knowledge of public managers and health professionals about the implementation and operationalization of the Network of Care for People with Disabilities,[15] based on the precarious conditions of accessibility and urban mobility in their metropolitan regions,[4,15,27] have a major influence on the life, health and recovery of minorities, including people who need regular rehabilitation services.

The results of this study contribute to broaden the understanding of health professionals working in teams of specialized centers for physical rehabilitation and points of attention of the Care Network for People with Disabilities, about how their users perceive the confrontation of various barriers to be present in the treatment. Being indispensable encouraging and fraternal welcome, acting with empathy to minimize the anxiety of these

people, encouraging them to persevere to achieve goals of overcoming and living with more functional independence.

CONCLUSIONS

Even though we have identified mostly negative experiences in facing accessibility barriers lived by the participants of this study, on the way to their treatment in a specialized center for physical rehabilitation, it is relevant to invest in awakening resilience to overcome their own vulnerabilities, aiming gradual functional progress in the program. Situations of disrespect, frustration, loneliness, fear, dependence on others, prejudice, exclusion, judgment, feeling of powerlessness, inferiority, and low self-esteem, which require the members of professional teams to adopt welcoming care and emotional support.

The limitation of this study is that it was conducted only with users of a specialized physical rehabilitation center in the Southeast Region of Brazil, not allowing the generalization of the results obtained from the analysis of the statements collected, being necessary studies in other scenarios.

It is essential to deepen the discussions about how accessibility barriers can provide advances for practice, teaching, and research in the areas of physical rehabilitation and collective health, demonstrating how social adversities should influence the therapeutic behaviors of rehabilitation teams, particularly nurses for their uninterrupted presence in institutionalized care settings extended to contexts of primary health care. Likewise, by offering relevant subsidies for public managers to comply with the legislation and promote the adequacy of urban mobility equipment, ensuring the right to accessibility for all people.

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