

(In)accessibility experienced by people with spinal cord injury*

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ABSTRACT

The aim was to apprehend the (in) accessibility experiences of people with spinal cord injury. Descriptive exploratory research with a qualitative approach. Data collection occurred from January to June 2016, through interviews with 23 people with spinal cord injury, identified from the Family Health Strategy teams and from the Support to Adapted Sports Association and analyzed by thematic content. Two categories emerged, which show that people with spinal cord injury face difficulties in conducting their daily activities with autonomy, insufficiency and/or deficiency in accessibility and family and social support. The sports practice and an active family action can be an effective incentive to social and equal conviviality. The adequate implementation of public policies for inclusion and accessibility that are existing would facilitate and allow people with spinal cord injury to have greater socialization and participation in health-related activities and adapted sports.

Descriptors: Disabled Persons; Social Support; Paraplegia; Community Health Nursing.

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INTRODUCTION

The spinal cord injury (SCI) is responsible for triggering chronic disease and physical deficiency, implicating in significant neurological changes⁽¹⁾. Every year, up to half a million people around the world are affected, being more frequent in young male adults due to trauma⁽²⁾.

Thus, SCI affects the person's life in many aspects, especially in the social, psychoemotional elements, in the acceptance of body self-image, as it involves a great load of incapacity and decrease of quality of life⁽¹⁻²⁾. Affected people usually face greater health needs than other individuals, as they have conditions and/or illnesses that are influenced by the social adaptation process and accessibility⁽¹⁾.

Most people with SCI live in an excluding society and in a social context that oppresses one's specificities, once the lack of accessibility impairs well-being, the adaptation and the self-esteem of these people⁽³⁾. Thus, it becomes indispensable to develop collective actions from the public power and community to decrease the architectural barriers and social segregation⁽¹⁾.

The Brazilian Health Ministry, attentive to questions permeating and conditioning social exclusion of people with SCI, formulated about a decade ago a guide "Health attention to the person with Disability", highlighting the need to favor the autonomy and mobility of people with SCI so they can move safely, with confidence, and more convenience. It also emphasizes that accessibility as a way of respect and aims to decrease barriers faced daily, noting prejudice and discrimination⁽⁴⁾.

The Brazilian legislation guarantees many rights to the person with SCI, including accessibility promotion and social security. But empirically, these rights are not yet sufficient for the equal integration of people with SCI to the civil society. The possible awareness of the population about the challenges faced by these people in their daily reality can trigger in medium- and long-term more concern with aspects related to accessibility of public and private places coming from the civil and organized society, therefore complying rights which were already guaranteed⁽⁵⁾.

However, the accessibility of people with SCI has not constituted the focus of nursing research, which is concerning because the nurse is part of the health team, therefore, he/she should search for knowledge and scientific evidence and from them, propose favorable strategies to the adaptation of the physical environment, aiming to promote safe access to these people⁽⁶⁾.

To investigate the perception of people with SCI regarding architectural accessibility and how they feel regarding life in society, within the family and friends, is a way to give voice and visibility to them. Thus, the aim of this study was to apprehend the (in)accessibility experiences of people with spinal cord injury.

METHODS

An exploratory, descriptive study with a qualitative approach conducted with people with SCI, residing in a medium-size city in the northwest region of Paraná state. At the time of the study, the population size was 403,000 inhabitants; there were 74 groups of the Family Health Strategy (FHS) located in 34 Basic Health Units, with 63.3% of the population covered by the FHS⁽⁷⁾.

The data was collected from January to June of 2016, through interviews. Participants were 23 people with SCI identified with the help from FHS teams (11) and Support to Adapted Sports Association of the State University

(12). The inclusion criteria were: to have SCI for more than two years and to be 18 years or older, and participants not located after three trials were excluded.

The first contact with the users of Basic Health Units was intermediated by the community health agent and conducted in person or by telephone. With the athletes, the first contact was held in person when visiting the sports court. The interviews were previously scheduled and performed at home or in a private location close to the sports court. Interviews lasted on average one and a half hour, and they were recorded with a digital device. They were guided by the question: Tell me about the changes in your life since the SCI. The search for information occurred until the moment that data started to be repetitive and the research objective was answered.

All interviews were fully transcribed and submitted to content analysis, thematic modality, following three proposed steps⁽⁸⁾. In the pre-analysis, fluctuating reading of the interviews was conducted, followed by an exploration of the material with a careful and exhaustive reading of the printed content. After, a codification of the messages was performed using colors, apprehending the nucleus of meaning, grouping them according to their similarities⁽⁸⁾. From this analytical process, two thematic categories emerged: Difficulties to move and to be integrated; and Social segregation x integration over time, which were discussed enlightened by the scientific literature.

All ethical precepts from the Resolution 466/12 were respected, and the project was approved by the Ethics Committee of the University (Protocol nº 1.328.940/2015). The segments of participant's speeches are identified with the letter "P" ("Participant"), followed by the Arabic number indicating the order of the interviews, the letters "W" (woman) or "M" (man), another number indicative of age and the last, the time since SCI.

RESULTS

The 23 interviewed participants were 23 to 28 years, 16 were male, eight were single, nine were married, five were separated, and one was widowed. Seven had more than eight years of education. Regarding their work activity, five had a job, while 18 received benefits from the government. The time since the lesion varied from 2.7 to 33 years. Regarding etiology, 11 were in an automobile accident (eight with motorcycles), a firearm harmed eight, two fell from a height, one was a victim of a run over, and another had a tumor in the cervical region.

All interviewed referred to at least, one hospitalization due to SCI. The leading causes of admissions were urinary and pulmonary infections, pressure injuries and treatment of complications, as the Charcot's spine. Few participants had concomitant diseases, such as Diabetes mellitus (two people), Hypertension, Charcot's spine, Chronic kidney failure, Viral hepatitis, Adhesive Capsulitis, and kidney stone. Fifteen participants did not refer to any health issue.

The two emerging thematic categories are described below:

Difficulties in moving and in integrating

When using the wheelchair in public and private spaces, people with SCI referred to limited accessibility that still is extensive in society, as the difficulty to move in streets and buildings and to use ways of collective transportations, like airplanes and buses. This impact their actions and interactions.

The lack of accessibility within their homes or in environments commonly used, as the houses of friends and family members, additionally to other devices of social conviviality, results in participants having a meaningful experience of embarrassment. It occurs because of the impossibility meaning in performing their independence and autonomy in simple activities as using the bathroom or the kitchen, or even when enjoying interactions in happy and festive moments.

There is no adaptation in churches [...] One time that I was really embarrassed was at my sister's house on my father's birthday, and there was no accessibility, I was carried, they set me in the couch [...] At the university is hard, the sidewalks are all broken! (P5-W, 52y, SCI-32y).

It is difficult when I am in other people's houses; the bathroom door is small, the wheelchair doesn't pass, someone has to pick me up [...] to build a ramp here at home would take space [...]. I count on the neighbor's help to go up and down the ramp to take a shower (P3-M, 29y, SCI-2y).

Another issue was the lack of accessibility in the streets, as the sidewalks are considered steep and the access ramps are inadequate. It impaired mainly women who transit alone, considering that six of them referred difficulty, imposing the family support. It is important to highlight that in the poor areas the sidewalk and streets were worse. The reports also demonstrated that parking spots designated to people with disabilities are not respected by society.

I don't do anything alone. We (daughter) went in a store by the sidewalk, one car parked in the sidewalk, it disturbs! I don't walk alone; I can't go up on a ramp, they are too inclined, the chair steers. The asphalt is full of holes (P6-W, 48y, SCI-8y).

Talking about accessibility, all segments leave a lot to be desired! In the neighborhoods, in the streets, even in the health units, because accessibility is only central. (P5-W, 52y, SCI-32y).

Another aspect pointed was the poor conditions to move with the wheelchair in airports, or to board in an airplane or bus.

In the airplane, the flight attendant said: "Sir, I think you cannot enter the bathroom". A chair does not move in the plane, and not all airports have special chairs (P13-M, 35y, SCI-18y)

I used to take a blanket inside the bus, I threw it over myself, I used to pee inside a water bottle) (P11-W, 34y, SCI-7y).

It was possible to note with the reports that public places and ways of transportation also do not provide the adequate mobility, besides not allowing privacy to perform daily and needed procedures for the physical well-being, as the relief vesical catheterization. This, in a few cases, was considered by the interviewed as a limitation to travel, and the meaning of traveling over time changed considering the experience of many difficulties while in travel.

Social segregation X integration over time

There were situations when people with SCI felt excluded or suffered discrimination by society in general, worsening the feeling of sadness in their experience. On the other hand, few people reported moments/situations where they felt welcomed, included and incentivized, which favored to recover their autonomy.

The exclusion situations are perceived by the interviewed in peoples' eyes, that in some cases express rejection and prejudice, and in others, curiosity, causing discomfort and inconvenience. Situations were also reported where actions and social interactions resulted in excluding treatment, where the individuals steered to the companion of the person with SCI because they signified the fact of being in a wheelchair as affecting their intellectual and cognitive capacities.

*The sight is bad, seems like I'm sick, poor one, what a pity! It is strange, a child comes, and the dad says "Don't touch!" seems like I'm a leper [...] it's the worst sensation because everyone is staring (P9-M, 29y, SCI-10y).
People are curious; they stare. And when you are on the street, and people say "hi" (without enthusiasm), they think you are mentally disabled! And when they go to talk to the person who is pushing me?! (P11-W, 34y, SCI-7y).*

Exclusion perceptions involved the most varied environments and people, like the bus, salespeople, friends, and the general population. The prejudice included, for example, the disconnection and the abandonment by family members. Social exclusion actions entail symbolically negative experiences to people with SCI that awaken feelings of abandonment, as not being invited to family parties and even to be hidden by their family members or spouse.

*I stopped doing many things. Until this day I cannot travel, the bus has a wheelchair sticker, but where is the adaptation? I think this is a crime! It is so much embarrassment; the bus ticket collector doesn't want to put us inside, says that has spine issues (P5-W, 52y, SCI-32y).
In the beginning, there was so much prejudice in the family. I was hidden for a long time in a room. Because of people's vision that there was a spell in the family (P5-W, 52y, SCI-32y).
I love the pool. My aunt has one, never invited me. I know she thinks I'm a problem. People don't invite you anymore; they withdraw (P11-W, 34y, SCI-7y).
He (spouse) started to lose love. Love was there when I walked, worked, danced. Suddenly, to see me in that situation, helped with the separation (P10-W, 38y, SCI-18y).*

There were also reports of difficulty to be in the job market. In this aspect, two situations happen to impair people with SCI to be integrated into society: the prejudice and the lack of accessibility in workplaces.

*They were going to hire me; I was approved in the tests. Change of manager. He called me to meet me, said that he liked me very much, but the spot was canceled. I thought there was prejudice when the manager saw me in the wheelchair (P2-M, 26y, SCI-7y)
Every place that I got an internship, or they said it wasn't possible because of the wheelchair, or it was impossible because it was tight and I couldn't pass by the doors. The spot was for disables, but they want who can walk, that is missing only a finger (P11-W, 34y, SCI-7y).*

Despite the distinct treatment received when they formally enter the job market, there was also a situation where the interviewed themselves, when assuming the role of the other – in this case, the excluding society, prejudiced and unprepared – were self-excluding, letting go participation in collective activities or even leaving the house.

He (husband) used to take me to fishing places, and I stayed in the car crying! [...] I didn't want to go out in the street at the beginning (P8-W, 35y, SCI-23y).

In the second year with the wheelchair, I only stayed at home, laying down, without life. I was embarrassed of me, it wasn't even the chair [...] I used to do the physical therapy, used to leave the house very quickly so no one could see me. I lost ten years of life repressing myself (P17-M, 40y, SCI-20y).

However, there were reports of inclusion situations, where the community, family members and the sports practice incentivized them and were present. These interactions changed the meanings that the SCI entails on people, as the prejudice, facilitating social interactions and the return to activities of daily living. The sport itself helped to minimize difficulties to socialize at the beginning, overall during the first stages after the SCI.

Every place where my husband is, I am there too. Even if people don't want me there, he puts me in. In the boat! At the beach! (P7-W, 46y, SCI-33y).

When I started to seat in the wheelchair, they took me to pubs, all the places (friends and family) (P12-M, 28y, SCI-5y). I don't feel embarrassed anymore; it was by practicing sports that helped me (P19-M, 36y, SCI-12y).

According to most reports, the symbols of prejudice and discrimination were present in the daily lives of these people. But over time, the socialization and inclusion through interaction with family members, friends, and sports practice provided the overcoming of changes resulted from the lesion.

DISCUSSION

The inefficient or inexistent accessibility in different places made people with SCI to feel excluded and to stop socially participating/interacting in inaccessible and little inclusive environments. A study conducted in Portugal with 28 people with SCI also showed that their mobility capacity was limited, caused by the absence of accessibility in diverse settings and/or even in their homes. Thus, the physical adequacy to new necessities is fundamental considering the conviviality with the SCI, to allow maximum mobility⁽³⁾.

Besides holes in the streets, steps, uneven sidewalks, and steep ramps; people, especially women dealt with trash, cars on sidewalks, objects impairing them to move with autonomy and alone. A study conducted in Santa Catarina with 13 individuals who had SCI also showed the lack of accessibility; inadequate sidewalks and ramps with inappropriate angles, noticed by people of both sexes⁽⁵⁾. The Health Ministry emphasizes that accessibility means to allow autonomy and more independence to these people, facilitating the rescue of their identity⁽⁴⁾.

Besides physical barriers, the reports point to the existence of prejudice and discrimination coped daily. A study conducted with people with SCI in São Paulo identified that the lack of accessibility and prejudice were the most dominant factors to overcome for social integration⁽⁹⁾. Thus, in respect to human dignity, the community needs to promote accessibility and to guarantee the applicability of equity rights, because all individuals deserve to develop their life projects with equal conditions, and with respect of their peers⁽¹⁰⁾.

The sigh and few attitudes – as withdrawing or treating the person with SCI as if she/he had a mental disability – characterize, in the participants' opinion, social symbols that represent pity and incapability towards society. But, over time, when putting themselves in others' role, they started to comprehend the social positioning and, even, got used to such situations. However, they continued to feel socially excluded. A study of the social representations revealed that the stigma surrounding not to walk is reflected in society, as it can confuse the need

of a wheelchair with another mental disorder/disability, and it leads to discriminatory treatments to people with SCI⁽¹¹⁾.

In this sense, a review study found that people with SCI face a little inclusive society⁽¹²⁾. Unfortunately, many people do not put themselves in others' position, and they use parking spots designated to wheelchair users, violating the legal right of these people. On the other hand, the Brazilian Constitution reinforces the importance of actions to facilitate and adapt physical environments to people with special needs; thus implicating in better accessibility conditions⁽¹³⁾.

These data reinforce the gap mentioned in the study conducted in Santa Catarina, where people with SCI highlighted the inefficient accessibility in commercial establishments and difficulty to use public transportation like buses and airplanes⁽⁵⁾. Therefore, there is still a generalized lack of awareness of society regarding unique needs and, at times, more elementary as to have mobility by using public transportation, which can trigger in social isolation, overall at the beginning of the SCI⁽⁵⁾.

In this direction, a study conducted in João Pessoa-PB with 120 people showed that 80% of individuals with disabilities did not participate in social groups, like religious ones, meeting with friends and community parties. As a consequence of the restriction to family conviviality, there was an aggravation of limitations caused by the disability, as their active social participation incentivizes the re-start of healthy daily activities⁽¹⁴⁾. According to the literature, since the first hospitalization, it should exist clarity to questions and incentive to the adaptation to ones' new health condition. The social and family support have essential meanings to overcome difficulties resulting from the SCI, especially at the start of this process⁽¹⁵⁻¹⁷⁾.

A study developed with 210 people with SCI found, already at the first hospitalization for rehabilitation, positive changes in the body image of participants, as the decrease of levels of depression and anxiety. These results led the authors to recommend that all health team members should be concerned to develop interventions that can collaborate to improving the body image of these people⁽¹⁵⁾.

Thus, to promote the social inclusion of these people in public, private, community and familiar level, it seems fitting and necessary to raise awareness in the population through social projects and inclusion policies that will benefit them directly and their families. These actions should be multi-disciplinaries, and the Health Ministry proposes network care to the person with disability aiming to broaden the access and to quality the attention in the Unified Health Care System⁽¹⁾.

On the other hand, there are inappropriate work environments to wheelchairs⁽¹⁸⁾; thus, the Brazilian government created specific legislation and instituted the National Council for the Rights of the Person with Disability (*Conselho Nacional dos Direitos da Pessoa Portadora de Deficiência –CONADE*) to supervise its implementation⁽¹⁹⁾. But despite the advances, there are a lot to be done, as the presence of these individuals in the job market does not mean, as a rule, social inclusion, but following the legislation. A study in Australia with 250 individuals with SCI showed that they suffered prejudice and discrimination at their workplace and, in few cases, were paid less, although they performed the same functions as other people⁽²⁰⁾.

Still, in this direction, a study with employees and managers of the University of São Paulo assessed the effects of an intervention that aimed to promote critical reflection about the inclusion of people with disabilities in the job market. The results showed that after the course, participants manifested more favorable conceptions

to this participation, leading the authors to conclude that these reflections can produce changes in the social attitudes of employees and administrative team, favoring the inclusion of people with disability in the work environment⁽²¹⁾.

The family members and friends with whom they interacted and enjoyed leisure activities withdrew, and in a few cases, there was separation from the spouse/boy(girl)friend. However, the presence of these people, offering care, providing support in the rehabilitation process and social re-insertion, incentivizing the adaptation and the attribution of another meaning to the new condition is indispensable^(5,17,22). In this direction, the sport arises as a facilitator in the adaptation process, with an improvement of the functional capacity and quality of life, as it promotes physical, psychological and socialization benefits⁽²³⁻²⁴⁾.

FINAL CONSIDERATIONS

The results show that people with SCI have difficulties in returning to their daily life activities with autonomy, due to lack of accessibility and support in the home and/or social environments, causing limitations to move in streets or sidewalks, to enter in establishments previously frequented or to use public transportation. Besides feeling excluded by their family members, friends and community.

However, over time, these limitations were minimized by the social inclusion and welcoming of the community, as well as the conviviality with family members and friends. This, in turn, allowed new activities, as sports practice, as well as, activities previously performed, became part of the routine of the person with SCI.

Therefore, the adequate implementation of inclusion and accessibility public policies already existing would allow the community socialization, participation in activities related to health and adapted sport. The results highlight the importance of nursing as social practice, to take in the responsibility of acting with these people, to incentivize them to fight for their rights as citizens and quality of life in their home and social level.

However, the study presents few limitations, within them the fact that participants were predominantly male, which demonstrates the need of studies involving a higher number of women, to understand better the specificities of the perception of this public.

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