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SOCIAL REPRESENTATIONS OF WHEELCHAIR USERS

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ABSTRACT: The use of a wheelchair can come loaded with peculiar meanings that pass around the world or who use assistive technology. This study aimed to know how social representations of people with physical disabilities about the use of a wheelchair. A survey was conducted with a qualitative approach through semi-structured interviews with 10 people with physical disabilities who used assisted technology and who frequently practiced a Physiotherapy clinic and a Specialized Rehabilitation Center. From the analysis of the emerging results or the thematic block Social representations of the use of the wheelchair and as categories: a dependence on the chair and functional independence and social exclusion when using the chair. The ways of seeing the use of assistive technologies such as the wheelchair are surrounded by concepts and relationships that demarcate the importance of comprehensive health care with a view to social inclusion.

KEY WORDS: Comprehensive health care; Social inclusion; Social representations; Self-help devices.

REPRESENTAÇÕES SOCIAIS DOS USUÁRIOS DE CADEIRA DE RODAS

RESUMO: O uso da cadeira de rodas pode vir carregado de significados peculiares que passam a circundar o mundo de quem necessita de tal tecnologia assistiva. Este estudo objetivou conhecer as representações sociais de pessoas com deficiência física sobre o uso da cadeira de rodas. A pesquisa foi de abordagem qualitativa por meio de entrevista semiestruturada com 10 pessoas com deficiência física que utilizavam tecnologia assistiva e que frequentavam uma clínica de Fisioterapia e um Centro Especializado de Reabilitação. A partir da análise dos resultados emergiu o bloco temático Representações sociais do uso da cadeira de rodas e as categorias: a dependência da cadeira e a independência funcional e a exclusão social diante do uso da cadeira. As formas de ver a utilização de tecnologias assistivas como a cadeira de rodas estão cercadas por conceitos e relações que demarcam a importância da atenção integral à saúde com vistas à inclusão social.

PALAVRAS-CHAVE: Atenção integral à saúde; Inclusão social; Representações sociais; Tecnologia assistiva.

INTRODUCTION

Historically, disability has been strongly understood as a phenomenon of the body, in which the absence of some of its parts or functional limitations are defining elements. This understanding is often reinforced by the definition of disability advocated by the World

Health Organization (WHO), in which physical disability is defined and understood as the loss or abnormality of a body structure or function. It may be the result of a congenital condition, that is, when the child is born with a disability, or of an acquired condition, which is so called when the person develops the disability at some stage of life due to the most varied factors, such as accidents or other condition, which was not expected during the life cycle[1].

Both in congenital and acquired disability, the person undergoes an assessment of their functionality. In the International Classification of Functionality (ICF), this term is used in the positive aspect of disability, and is related to body components, functions and structures, activities performed, and social participation. Thus, it is understood that developing a disability at any stage of life can impact people's daily life with regard to the structures and functions of the body, the performance of activities, and social participation[2].

To reduce this impact and enhance functionality, technological development has influenced the field of rehabilitation and there is an increasing investment in the production of resources that have become part of the list of therapeutic actions aimed at meeting the needs of people with disabilities. Data from the National Health Survey indicated that, of the 200.6 million people living in permanent private households, 6.2% had at least one of the four disabilities investigated (intellectual, physical, hearing, and visual), and 1.3% stated having a physical disability (0.3% were born with a physical disability, while 1.0% acquired it due to illness or accidents). Another important fact is the estimation that approximately 10% of the world population has a disability, and 10% of this part of the population requires a wheelchair because of their limited walking capacity[3].

With regard to limitations in activities, it can be said that physical disability causes radical changes in a person's life, due to changes in body dynamics and abrupt transformations that they, their family, and their closest social environment undergo. This often leads to the need to adopt another lifestyle to adapt to the new situation. There are several physical changes interfering with urinary and gastrointestinal excretion; skin and soft tissues; joints; expression of sexuality, nutritional requirements, in addition to those changes in affective, social, and professional life and consequent productivity of all the individuals involved[4].

Furthermore, the physical changes and the functional limitations that affect people with physical disabilities cause different social and psychological reactions in the life cycle of the affected individual. To increase their functionality, people with physical disabilities use assistive technologies under the guidance of a professional. Among these technologies wheelchairs stand out; they have been widely used by people with limited mobility. The use of a wheelchair can carry peculiar meanings that come to surround the world of those who need such technology. Users are involved in ideas, images, and concepts both individually and collectively. The form of adherence to this proposal will also depend on such meanings and concepts socially developed and shared[5]. Therefore, knowing the social representations involved in this process is important for society and also for the health professionals involved in the rehabilitation and promotion of health and quality of life for people with disabilities and users of wheelchairs.

Social Representations (SRs) are defined as the way in which a person understands, gives meaning, and relates to the world. In the context of wheelchair users, it can be said that this relationship involves the meaning or concept that the person has built and shares with others in society regarding a signifier or object. Such understandings, beliefs, and values surrounding this phenomenon are active, interpreted, and used in decision making and in the way of being in the world[6]. In this way, it can be said that action and problem-solving strategies are permeated by people's representations of their condition, and these representations are related to behaviors that reflect on the life and health of the person as a whole.

The social representation of people with disabilities who use a manual wheelchair are the glasses through which they will be seen by the world and, at the same time, they will see the world. These perceptions can be full of stereotypes and preconceptions, on both sides. The functional disabilities and disadvantages that people can have in the face of physical, sensory, and psychosocial aspects reinforce segregation and discriminatory feelings by society[2]. The need for a wheelchair can increase the symbolic arsenal of the person's disability.

Still with regard to the aspects that involve social representations of wheelchair users, it can be said that the meanings created and socially shared permeate the representations of the human body, which are also a reflection of individual and social creations and can undergo changes over time. This process depends on how each individual perceives, uses, and transforms their body[7]. In this sense, it can be said that physical disabilities that require the use of some technology can cause a change in the conception of the body and it is necessary, therefore, that people, professionals, and society can reflect and get to know this process[8].

The concern of how the physically disabled person and wheelchair user perceives the world and is perceived by the world is not widespread in the area of scientific knowledge production and is directly related to body changes and to the limitations of functional actions that happen to the body. To this end, this study aimed to know the social representations of people with physical disabilities on the use of a wheelchair.

METHODOLOGY

This paper is the result of a qualitative and exploratory research that encourages the interviewees to think freely about a topic, object or concept. It was based on the theory of social representations, in order to understand the phenomenon about the social representation of wheelchair users. The Theory of Social Representations (TSR), adopted as the theoretical option of this study, provides for the discussion of data based on socially constructed and shared common sense knowledge or experiences[6]. Thus, it is intended to know the meanings shared by a specific group or the representations that constitute the reality of people who use wheelchairs[7].

The study participants were selected by purposeful sampling. The participants in the research had physical disabilities, used assistive technology, and attended a Physiotherapy Clinic and a Specialized Rehabilitation Center in a city in the Vale do Itajaí region, state of Santa Catarina (SC). The inclusion criteria were being disabled and using assistive technology, receiving care in specialized centers or clinics, being over 18 years old and having no communication disabilities that made it impossible to answer the interview.

For data collection, semi-structured interviews were conducted with people with physical disabilities who used assistive technology. The guiding questions of the interviews were about the aspects related to the time using the wheelchair, the adaptation to the use of the chair, barriers in daily life, and with regard to social and family exclusion. The interviews were conducted in the Physiotherapy Clinic from March 2017 to December 2017, at a previously scheduled time and location, in a room where only the interviewer and the interviewee were present. The interviews were recorded on a voice recorder and later transcribed in full.

Data collection only started after submission and approval by the Ethics and Research Committee under opinion No. 2,015,431 and followed the ethical precepts of Resolution No. 466/12. Therefore, the research started only after the participants accepted and signed the Free and Informed Consent Form. In order to maintain anonymity, the participants were given code names.

After data collection, the results were analyzed through content analysis proposed by Bardin, following the stages of pre-analysis, analytical description, and referential interpretation. In the pre-analysis, the transcribed interviews were skimmed[9]. In the analytical description, the raw data from the interviews were transformed into categories to achieve the research goal of understanding the reasons that trigger the use and non-use of assistive technologies by people with physical disabilities.

Therefore, in this stage, the classification and aggregation of data was carried out through theoretical or empirical categories. Dialog occurs in the interpretation, which is made from a synthesis text in each category and expresses the meanings present in the different units of analysis included in each one. Social Representations (SRs) were used to interpret the perceptions, concepts, and meanings expressed by the participants in their statements. The project was supported by article 170 of a Community University in the Vale do Itajaí region, state of Santa Catarina (SC).

RESULTS AND DISCUSSION

Ten wheelchair users participated in the research. Among them, six were women and four were men. Regarding the interviewees' age, a mean of 38.3 years old was found, where the youngest interviewee was 19 and the oldest was 63. The participants had different medical diagnoses; however, three had the same diagnosis of spinal cord injury and, of these, two were involved in traffic accidents. Chart 1 shows the characterization of the wheelchair users.

After in-depth reading of the transcripts, the Social Representations of the use of wheelchairs were attained and divided into two categories: 1) Dependence on wheelchair and functional independence, and 2) Social and family exclusion when using the chair.

SOCIAL REPRESENTATIONS OF THE USE OF WHEELCHAIRS: DEPENDENCE ON WHEELCHAIR AND FUNCTIONAL INDEPENDENCE

The social representation of the body involves different levels of perceptions and conceptualizations. The physical, emotional, and mental levels are taken into account for each person and, together, will express the representation or significance of the body as a whole[10]. The presence of a physical disability and the need to use technology such as a wheelchair can modify the previously established body image or representation. Such transformation is part of a process that involves continuous constructions between the person and the concepts of the social environment[11].

Although manual wheelchairs are used to increase the functionality and independence of the individuals both at home and in the community, users see them as an assistive technology that favors independence but needs adaptation because, at the same time wheelchairs promote independence, they can make people dependent on them to perform activities of daily living, as showed in the following statements of the interviewees. While P6 and P4 raise the question of independence, P5 and P1 report, on the other hand, the possible dependence on technology to perform daily activities.

Chart 1. Characterization of the wheelchair users in a Physiotherapy Clinic and a Specialized Rehabilitation Center in 2017

Participant	Age	Diagnosis	Etiology	Profession	Gender	How the wheelchair was acquired
P1	29	Spinal cord injury	Traffic accident	Bank clerk	M	Bought it
P2	21	Acute motor-sensory axonal polyneuropathy	Congenital	Student	F	Won it
P3	61	Tetraplegia	Spinal infection caused by bacteria	Retired	F	Bought it
P4	19	Cerebral palsy	Premature birth	Unemployed	M	Won it
P5	26	Spinal cord injury	Spinal anesthesia during childbirth	Unemployed	F	Won it
P6	20	Hemiplegia	Firearm accident	Unemployed	F	Won it
P7	58	Poliomyelitis	Poliomyelitis sequelae	Retired	F	Bought it
P8	30	Spinal cord injury	Traffic accident	Paralympic athlete "target shooting"	M	Bought it
P9	63	Lower-limb paralysis	Spine surgery (herniated disc)	Retired	M	Won it
P10	56	Amputation of the LLs	Infection after insect bite	Disability benefit	F	Won it

Reference: M (Male); F (Female); LLs (Lower Limbs)

> If I didn't have the wheelchair at home, there was no way for me to be alone when my husband went to work, there was no way for me to do the housework (P6).

> I didn't need a chair until I started to be unable to move around in the traditional way, because I usually needed help from others to keep me from falling; then, as I grew and my size increased, my grandfather, who you must have seen outside, he is a 78-year old man, he is very tired by now (emotional). Then we saw the need to use the wheelchair, even for my independence (P4).

> It's because I need it, but so, today I'm 80% dependent on it, because the wheelchair helps me. But so, it's a normal life, I only have to adapt to it, to live with it; if it's not for the wheelchair, I don't walk, I can't go out (P5).

> In fact, the wheelchair makes you both dependent and independent because, while I depend on it, it makes also me independent (P1).

Used as assistive technology to increase functionality, wheelchairs are often an unwanted object of mandatory visibility, which can provide a better user experience and less stigmatization, as it allows the user an image that focus on their abilities and skills, instead of the usual association with lost functions and dependence. The possibility of changing the perception of the meaning of the product and the user's image encourages their self-esteem, providing greater social and work inclusion[12].

The adaptation to the new condition can be a difficult process which requires coping by the individual. This coping is given by the establishment of concrete goals that can be achieved, as well as the attainment of autonomy and the ability to self-govern. This is only possible with the proper equipment and early, supervised training[12].

Wheelchairs are symbolically associated with disability. Despite the changes in recent years, these individuals have their freedom of choice and preferences subjugated in view of the constant association with dependence on other people, especially in places of medical assistance[13]. They are also associated with states of ill health, as well as helplessness and heteronomy[14]. Therefore, users tend to feel diminished regarding their preserved skills, being regarded only by the lost functions, condemning them to a status of inferiority.

This fact is also related to the history of wheelchairs, which initially had shapes similar to furniture objects; the changes in their presentation started in the second half of the 20th century. However, since its conception, the shape has undergone little changes, and the model was stagnated in design lines that associate this product with medical concepts, characterized by the association of those who use them with the pathologies, causing functional reductions and increased dependence[15].

Although assistive technologies help people to resume their daily routines and activities, there is a dichotomy in the representation by those who use them[12]. If, on the one hand, there are positive impressions of keeping independence, the idea of freedom and the perception of security in carrying out activities, activities that would not be possible without assistive technologies; on the other hand, the association with the limitation and the social barrier that many devices cause were mentioned as negative aspects[16].

From this understanding of independence versus dependence in the use of wheelchairs, it can be understood that the creation of meaning for life involves more than giving meaning, but also reorganizing the world view, inclusion of the users themselves and of society, since human beings are gifted with the ability to review the concepts and to interpret the events. When creating meaning for the loss, users have the task of finding benefits from the loss and transforming themselves. It is often necessary that they find themselves capable of facing challenges and overcoming imposed situations, with the support of family members and their participation in physical rehabilitation. The three components (creation of meaning, presumed world, and life project) are communicated at all times in the lives of people with disabilities. This triad is like a cog, which works concomitantly whenever a new event occurs and a new view is required by the circumstances[17]. This new view will involve subjective aspects that are socially and culturally shared and represented[5].

SOCIAL REPRESENTATIONS OF THE USE OF WHEELCHAIRS: SOCIAL EXCLUSION WHEN USING THE CHAIR

As mentioned earlier, physical disabilities can indicate important limitations in people's life. If their needs are not taken into account and the applicable and appropriate measures are not achieved, people's functionality can be compromised[2].

In addition to the meaning of the use of wheelchairs, social representations of disability are also relevant and can indicate ways of understanding that underlie the practices and actions of both the individuals themselves and the society in which they live. In this sense, the perspective of social inclusion and the way the family is organized and works to adapt the person to their new condition and needs are essential to contribute to this problem[18].

Although wheelchairs are used to increase the functionality and independence of individuals, both at home and in the community, users see them as the main factor that prevents them from moving more easily and effectively, more limiting than their own paralysis. The reported causes of this limitation are environmental barriers and poor adjustments of the wheelchairs themselves[19].

Indications like these, which can signal social exclusion due to physical barriers in view of the need to use technology, are found in the participants' statements, as mentioned by P4 and P1.

> I spend most of my week, my month, my year at home. Brazil itself is not for people with physical disabilities; deaf people can move around the streets of Brazil despite traffic issues, blind people too; but for wheelchair users it's very complicated, for example: **my city** *[name of the city] has a horrible sidewalk to move in a wheelchair* (P4).

> So, before the car I had difficulties getting out and I avoided leaving the house; the bus is terrible, the ramp is damaged, some people have no patience… so accessibility in cities is very bad, you can't go out in a wheelchair; I could often go to the bakery, the supermarket, but there is always a step, a hole (P1).

Unfortunately, there is a marked distance in Brazil for mobility and accessibility to be effectively carried out. Despite this, much has already been done for the benefit of people with special needs. An example of this is the creation of laws that govern the rules and criteria for accessibility for the physically disabled, such as the standards from the Brazilian Technical Standards Association (*Associação Brasileira de Normas Técnicas*, ABNT), the accessibility law (Law No. 10,098/2000), and the parameters of Brazilian Standard NBR-9050, among others. In the physically disabled person's view, there are still many architectural barriers in household settings and in society that do not favor them, hindering locomotion, preventing the person from having autonomy and thus being able to fully exercise their right to "come and go" expressed in the current legislation[20].

In a survey conducted with 164 people with acquired physical disabilities it was verified that, when the accessible items present at home were analyzed by people with physical disabilities, it was found that "access ramps" was the most marked item (26.83%), followed by anti-slip mats (18.9%), and by "toilet and shower support bars" and "enlarged doors" with 17%; however, "pillows" and "special beds" were identified by 3.05% of the total respondents as the least accessible items at home. When analyzing the items accessible in collective use by people with physical disabilities, it was found that "access ramps" was the most marked item (35.4%), followed by reserved parking spaces (32.9%) and adapted public transportation (26.2%); however, "shower support bars" and "adapted taps" were identified by 6.1% of the total respondents as the least accessible items[20].

One of the many examples of physical barriers that prevent people with disabilities' effective participation in society, on an equal basis with other people, is the absence of access ramps for wheelchair users on Brazilian streets. The IBGE census in the survey on the urban characteristics of the surroundings of the cities informs that, while almost 100% of the streets have public lighting, way less than 10% have access ramps. Also with regard to mobility, the lack of maintenance of adapted buses should be noted, as well as the lack of training of drivers and collectors to operate the equipment[3].

Nowadays there are more people using wheelchairs who are exposed to the most variable barriers in their daily lives, which are related to their daily routine, indoors, on the street, at work, at leisure, even in the family and from other people. Thus, it is not only physical barriers that can indicate a representation of social exclusion. There are also social barriers that culminate in a cultural and social difficulty for inclusion, in the full sense of the person with disabilities. There is also the physical world, created by man for the so-called "normal" people, where the environment is the barrier. The other barrier is people, with their customs, values, attitudes, and social expectations that exclude due to preconception, ignorance or inconsideration the person with a disability from the social interaction and the benefits offered by society[21]. These barriers at the social and family level were also found in the participants' notes.

> My nail stylist, for example, lives very close to my house, she doesn't come anymore, she said she doesn't want to see me anymore, she can't see me like this, she met me walking, working. Since I had the accident she didn't see me anymore, if she saw me it was from a distance, she doesn't do my nails anymore, so I had to find another (P10).

> At the beginning, I was even ashamed to leave home, you know, I used to walk, right, when he (son) invited me to go out I was even kind of angry, I thought about how they would look at us, but there is nothing to do, right, I have faith that I will soon be better (P9).

> Yes, my family and friends. But I still have that problem of going out on the street, so I even had appointments with a psychologist, but nowadays I go out; some time ago I didn't because I got angry when others kept looking at me. Many keep looking, but not nowadays. Nowadays I go out and stare, I guess they think I'm pretty (P5).

> So… I think that people really want to help, all of them, even if they know or don't know me; they are really trying to help, even though sometimes they get in the way more than they help. Sometimes you don't want to cross the street and they come and move you. They think people in wheelchairs are blind, deaf, everything, so they don't ask (P10).

> Yes, they keep treating you like a child, they want to give you everything by themselves, they don't even let you take a glass of water from the sink. It's bad, it's embarrassing, because it looks like we're dead. Like we are undead (P6).

People outside of normal standards were always seen as a "dead weight" and left on the margins of society, without this being seen as something wrong. It is true natural selection based on the view that the disabled are necessarily incapable, unproductive, inefficient. This attitude has led to the systematic exclusion of disabled people, who gradually lose the status of citizens, at the same time that all their expectations of recognition are frustrated, which makes it difficult for a significant portion of the population to live respectfully[21].

Thoughts like these are sometimes considered harsh, but they reflect the still very contemporary reality. While professionals in the areas of health, education and social assistance, and society as a whole, do not reflect and discuss effective interventions in search of all kinds of accessibility considering activities of daily life of wheelchair users in terms of overcoming physical, social, psychological and family barriers, full social inclusion will not be possible and social representations like the ones discussed in this study will continue to exist[22].

FINAL CONSIDERATIONS

This study made it possible to better understand the social representations that surround people living in a certain reality regarding the use of the wheelchair. Despite the variations in terms of gender, age, etiology of the disability and diagnosis, the participants seem to represent cores of common sense with regard to the use of wheelchairs. The categories in the study highlighted such common meanings that are based on perceptions of society as a whole, from the closest, familiar interactions to the macro-level interactions, represented by the physical barriers of the places where they live.

Therefore, the participants indicated different barriers and challenges encountered in daily life due to the disability and the use of assistive technology, represented both in the use of the chair in terms of the search for functional independence, which ends up causing dependence on technology, and in the feeling of exclusion due to their physical and social limitations.

Results like these can make it possible for caregivers (family members and health, education, and care professionals) to approach the real senses and meanings, as well as the weaknesses and potentials present in the lives of wheelchair users. From this approach to the reality of these individuals, the professionals specialized in meeting the needs of people with disabilities will be able to promote practices to change the representations of the use of the wheelchair both for the people themselves and for society as a whole, especially the family setting. These representations need to be recognized and changed as contemporary scientific, social, and economic advances occur. Likewise, data also provide information for Inclusive Public Policies for people with disabilities and increase the need for discussions about the meanings and cores of meaning revealed in these participants' statements, especially with regard to the physical barriers signaled in this research.

Among the limitations of this study are the small number of participants and the variations in their socio-demographic characteristics. Among the methodological limitations is the use of the Theory of Social Representations as a theoretical and not as a methodological tool. For future research studies, these issues should be further discussed with a larger social segment and with the use of a collection and analysis methodology that contemplate the TSR as a whole, thus seeking to discuss all the individuals' evocations from such phenomenon. It is also suggested that information about family functioning, quality of life, stress and anxiety levels and overload indicators, as well as greater indicators of the physical mobility of users and activities of daily living, be included in the analyses.

Hopefully, this study can serve as a basis for practical clinical and psycho-educational actions and interventions for health promotion for users and their families. These actions can be developed in specialized centers, as well as in Primary Health Care. Physical and social barriers of all kinds must be recognized, monitored by people and their families and resignified on various occasions to increase people's daily functionality, as well as their independence and autonomy. Assistive technologies such as the wheelchair will only be fulfilling their ultimate end if the barriers are progressively reduced. Steps like these may finally make it possible to achieve the longed-for social inclusion.

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