

## VIVER COM DEFICIÊNCIA FÍSICA E O PAPEL DA REDE DE APOIO

## LIVING WITH PHYSICAL DISABILITY AND THE ROLE OF THE SUPPORT NETWORK

## VIVIR CON DISCAPACIDAD FÍSICA Y EL PAPEL DE LA RED DE APOYO

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### RESUMO

**Objetivo:** Compreender o impacto da deficiência física na pessoa e a contribuição da rede de apoio. **Métodos:** Trata-se de um estudo exploratório descritivo de abordagem qualitativa. Foram entrevistadas 10 pessoas com deficiência física de um município localizado no Sul do Brasil. Os dados foram coletados no período de março de 2013 a fevereiro de 2015, por meio de entrevistas semiestruturada em profundidade e realizada análise de conteúdo. **Resultados:** os dados foram organizados em três categorias temáticas: perda da autonomia/independência; mudanças no cotidiano e no viver; e rede como apoio para superar/enfrentar as dificuldades. **Conclusão:** a deficiência física apresenta transformações na vida das pessoas, sendo a rede de apoio a elas, peça fundamental para o enfrentamento das dificuldades.

**Descritores:** Enfermagem; Apoio social; Pessoas com deficiência; Reabilitação.

### ABSTRACT

**Objective:** To understand the impact of physical disability on the person and the contribution of the support network. **Methods:** This is an exploratory descriptive study with a qualitative approach. Ten people with physical disabilities from a municipality located in the South of Brazil were interviewed. Data were collected from March 2013 to February 2015, through semi-structured in-depth interviews and content analysis. **Results:** data were organized into three thematic categories: loss of autonomy/independence; changes in daily life and living, and network as support to overcome/face difficulties. **Conclusion:** the physical disability presents changes in the lives of people, being the network of support to them, fundamental piece to face the difficulties.

**Descriptors:** Nursing; Social support; Disabled persons; Rehabilitation.

### RESUMEM

**Objetivo:** Para entender el impacto de la discapacidad física de la persona y la contribución de la red de apoyo. **Métodos:** Se trata de un estudio cualitativo descriptivo y exploratorio. Hemos entrevistado a 10 personas con discapacidad física en un municipio situado en el sur de Brasil. Los datos fueron recolectados a partir de marzo 2013 a febrero 2015, por medio de entrevistas semiestructuradas y análisis de contenido. **Resultados:** Los datos se organizan en tres categorías temáticas: la pérdida de la autonomía/independencia; cambios en la vida cotidiana y en el vivir; y la red como apoyo para superar/vencer las dificultades. **Conclusión:** la discapacidad física presenta cambios en la vida de las personas, la red de apoyo de las personas con discapacidad como una clave para hacer frente a las dificultades.

**Descriptor:** Enfermería; Apoyo social; Personas con discapacidad; Rehabilitación.

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## INTRODUCTION

Disability is a broad term that includes physical disabilities, activity limitations, and restriction of social participation. It includes factors that influence the interaction between a person and their environment (environment and personal factors). As such, it is a human rights issue that obeys the principle that every person has the right to enjoy all the necessary conditions for the development of their talents and aspirations without being subjected to any type of discrimination<sup>(1-2)</sup>. Persons with disabilities are those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may obstruct their full and effective participation in society on equal terms with others<sup>(1)</sup>.

For several years, disability has been understood only as biological dysfunction or as tragedy due to individual irresponsibility. It is only through the strengthening of the human rights framework, the politicization of social movements and the claiming of citizenship rights by this part of the population that several efforts have been made to guarantee acquired rights<sup>(3)</sup>.

According to the World Health Organization, there is a worldwide prevalence of over one billion people with some form of disability. Of these, about 200 million face significant functional disabilities and less than 50.0% have access to constitutionally acquired health care. In Brazil, there are approximately 46 million people with disabilities, 13 million people with motor or physical disability, which corresponds to 6.9% of the population of the country. The prevalence of physical disability is higher in females, with about three million more in females than in males<sup>(1,4)</sup>.

The transformations that occur in the lives of people with disabilities are perceived at a global level, insofar as they are seen in some way less as independent, and can cause or increase the difficulties that will be proportional to the limitations they present. Disability also entails profound changes in the functioning of the organism and the person needs a period of intense learning, in which he/she has to deal with acquired limitations. These changes demand physical, emotional and social adaptations that determine the emergence of new living standards<sup>(5-7)</sup>.

The person with a physical disability needs an environment that provides conditions that are conducive to their state, so that they can exercise

their activities, despite their limitations. This process of adaptation requires the contribution and support of the support network, since the person feels more loved and esteemed and with a sense of self-control. The support network allows for the acquisition of information, development and maintenance of self-concept, as well as regulation of emotions<sup>(8)</sup>.

Although there are a large number of people with disabilities in the world, there are few health studies on nursing care for this population<sup>7</sup>, mainly correlating the support network that people with disabilities receive in their lives. Therefore, people who are part of the support network lack information about their role, support and contribution to care and the reduction of stressors caused by changes in health and living with disabilities. This study deals precisely with this knowledge gap in order to understand the impact of the disability on the person and the contribution of the support network.

## METHODS

This is a qualitative study carried out in a municipality in the South of Brazil from March 2013 to February 2015. The study participants were ten people with physical disabilities, selected intentionally from a list provided by a non-governmental entity which provides assistance to this population. The number of participants was defined by the researchers from the theoretical saturation. Inclusion criteria were: being a person with a physical disability for more than one year; older than 18 years; with the ability to communicate verbally. As exclusion criteria: Have some cognitive, hearing or multiple associated disabilities.

Data collection was carried out through in-depth, semi-structured interviews, on the day and at the pre-scheduled time by the participants, who were contacted by telephone through the list provided. The questions asked were: What has changed in your life after disability? What needs has disability brought to your life (medication, diet/food, physical activities/physiotherapy, emotional/affective/religious support, specialist consultations, work adaptations, transportation, materials/equipment, home adaptations, school environment adaptations, leisure, others)? Who supported you to meet these needs (family, friends, neighbors, church, community center, health institution, specific groups, commercial

institutions, spiritist center, community therapists, folk healer, others)? The interviews were carried out at home, with a mean duration of 40 minutes and with participants' consent, recorded in digital format and later transcribed.

For data analysis, Minayo's assumptions were used, which unfold in three moments: the pre-analysis, which consisted of in-depth readings of the interviews; in the second moment the exploration of the material through pre-codification of the data and the apprehension and interpretation of the results, propitiating the categorization of the results <sup>(9)</sup>.

In addition, in order to check the anonymity of the participants, their identities were replaced by the letter P followed by sequential numbers from one to ten. The study complied with the formal requirements contained in the national and international standards regulating research involving human beings under the number 216.396.

## RESULTS AND DISCUSSION

Among the study participants, eight of them were male and two female, among them, three had paraplegia caused by a car accident or chronic disease; three had tetraplegia caused by iatrogeny or shallow water diving; four had amputation, three in a lower limb and one in an upper limb. Of these, four were married, five were single and one did not report; among the occupations, seven were retired, one was a secretary, one was a print clerk and one para-athlete.

Regarding education levels, one has completed higher education, three have incomplete higher education, three have completed high school, two have incomplete high school and one has incomplete elementary education. The time spent living with the disability was seven years (SD: 4.29).

Regarding the findings of the research, among important issues related to living with physical disability, we highlight: loss of autonomy/independence; changes in daily life and living; and network as support to overcome/face the difficulties that are described below.

### Loss of autonomy/independence

In this category, the participants reported the loss of autonomy as they relate to the individual activities of daily life that include: dressing, personal hygiene care, domestic

activities. They are the actions of mastery of the body itself, in the daily exercise of previously performed activities with ease. Execution in daily activities is an essential part of human living and it is through this that we improve our competences, interact with others and with our networks, and give life to our expectations and meanings. The following statements demonstrate such needs:

"And everything for me was difficult, to wash a dish, to wash clothes, to make a meal, today if it is for him to make a meal or to curt something he does it, he leaves everything ready for me, just me". (P 03)

" At first it was all difficult, they would pick me up on their lap, give me food practically in my mouth". (P 07)

" They did everything for me, actually. To go to the doctor, they had to get me on their lap, put me in the chair, get the chair put in the car, because I had no strength. I used to go on a stretcher at the beginning". (P 06)

"I try to be the as independent as I can, but I am not, no use. I depend, but I do not give up easily, many people in my place would have given up, I would get food in my mouth, I'd rather not, I'd rather have a little bit of work, but I try to solve my problems". (P 09)

We realize that autonomy is something that becomes impaired in people with disabilities, precisely because of the need for support that they need, being evidenced that the support network offered by family members has contributed to overcoming and coping with difficulties. In this context, we can observe the loss of autonomy related to the feeling of dependence and the fact that it requires other people to perform daily activities. The person with a physical disability feels incapable due to loss of independence and lack of self-control<sup>(10-11)</sup>.

The loss of autonomy is also expressed by the changes that have taken place. Among them, we highlight: coexistence with bodily changes, reduced mobility and, often, physical and even psychological dependence are overwhelming effects that people with physical disabilities come to experience after finding their current condition. We realize that disability makes people more vulnerable to social discrimination and socio-environmental barriers, corroborating with the findings highlighted in this study<sup>(12)</sup>.

Autonomy involves everyday activities. In this way, physical disability establishes difficulties that require planning based on goals and

strategies so that the person can face their acquired limitations, relying on his network, in order to become able to overcome limits and take a position of control over their own life in an autonomous way. This is one of the tasks of health professionals working in rehabilitation.

### Changes in daily life and in living

In this category, the need for adaptations was revealed in the environment in which people with disabilities live. The changes in living from the physical disability are the main reports of this category. These modifications can be from a variety of sources, among them: the use of medication, work leave, hospital admissions, necessary adaptations in the environment intrinsic to their home, as well as in collective circulation spaces, which means resignifying their life to adapt to this new physical condition resuming daily activities.

"Everything changed! Everything! Everything! Because I worked two jobs and still studied at night." (P 05)

"Yes, yes, medicine that I did not take any, I started to take three, four types of medicine". (P 03)

"As he was a carpenter, he realized that it was difficult for me in the house, he went and researched with the company's friends, so he managed, raised the floor, tidied up the roof". (P 07)

"Everything has changed, so much that I fell into depression. I was doing physiotherapy with Dr. P., since I had an eschar, so I had to stop, to be hospitalized for a year and four months in one hospital, then another 15 days in another". (P 08)

The changes arising from the new physical condition imply adaptations in the displacement and access to external environments, as well as in the person's home, discoveries being necessary for resuming social life. As explained in the above reports, these people carry out new actions regarding their health care, for example, the use of continuous medications, recurrent hospitalizations and the help of health professionals to adapt the environment to their new condition. In this way, as a result of the changes generated by the disability, the person feels incapable of living as before, since several changes are experienced in the daily life<sup>(6)</sup>. Thus, the support network presents itself as a fundamental piece for the aid in adopting adaptations and acquiring new skills to continue following its life. That is, their support network is

fundamental in the process of reintegration and resumption of the lives of people with disabilities<sup>(13)</sup>.

### Network as support to overcome/face difficulties

The majority of the study participants had support from relatives and health professionals, with different degrees of proximity and different types of support provided.

In this category, the presence of the support network and the need of this to face the acquired condition was evidenced, besides bringing as main actors the family members and health professionals and services, evidenced by the statements:

"It was the family ... the doctors, especially from XXX, that I treat them to this day (...). The nursing staff, XXX, XXX. At the beginning my family was more, in those moments the friends are gone (...) So, my mother, my brothers and sisters". (P 06)

"I was lucky to have my family who supported me a lot. By the time I got into the wheelchair, my mother was building, she built the whole house, thinking about it later, she would say: my son will not stay in the wheelchair, but if one day it happens I want him to be very welcome in my house. ". (P 07)

"My husband was my base, he was everything, he was looking for me, he would take me, he would shower me, he would change me, he would give me medicine, he would give me food when I could not ". (P 07)

"The health center, they went there and did the dressing, when I was bad I took antibiotics and medication, and they helped me a lot ... my children also helped ". (P 08)

A counterpoint is necessary to emphasize, since not all the participants of this research had in their network of support the family and the health services. "Now, I have to make do with my aunt. Because, my family, my mother, my brothers, no one gives any support, they did not know how to understand me". (P 08)

"I had my mother-in-law, but my mother-in-law almost destroyed me, almost killed me. It was necessary for my father to die, now two months I was in the hospital, to my father's family, who did not know the way I was, to come and support me". (P 08)

"Some things they gave me in the health service, but something a little like that, sometimes gloves that they need to do

procedures like that, they gave me, but, they gave me nothing, it's complicated. Today they give because they were forced to give". (P 06)

"The public service has nothing. Even a simple drug, dipyrone, the health office sometimes does not give, it says it does not have it because it's very cheap, then I need a more expensive medicine for the bladder, to control the bladder, then they say it's expensive. So they do not give anything in fact, everything so I get today's health post was because I filed a lawsuit, to be able to receive, because they give nothing, it's complicated. They do not come to visit me, I do not receive anything from the public agency, nothing, nothing". (P 06)

The network is seen as a way to overcome the difficulties imposed by the physical disability. The reports bring the family as the main support, but professionals and health environments appear as part of the network of people with disabilities, since the frequency and duration of rehabilitation therapy make this contact possible. It should be noted that the absence of an effective support network possibly ends up hampering the facing of the condition.

In this context, the Netherlands and collaborators<sup>(14)</sup>, in a cross-sectional study carried out in primary care, sought to identify the social support networks of people with physical disabilities and facilities for access to health services and social inclusion. The study showed that the networks are constituted mainly by the components of the family dimension, where support contributes to access to services and participation in social groups. Being locomotion, the main barrier to social interaction.

Physical disability includes factors that influence the interaction between an individual and his/her environment (personal and environmental factors) and, as such, is a human rights issue that obeys the principle that everyone has the right to enjoy all the necessary conditions for the development of their talents and aspirations, without being subjected to any type of discrimination<sup>(1-2)</sup>. In practice, guaranteeing the rights of people with disabilities requires action on both fronts, that of universal and specific groups, always aiming at minimizing or eliminating the gap between the conditions of people with disabilities and the rights of persons with disabilities and of people without disabilities.

In our study, the family presented itself as the main support for people in this condition, however, health professionals were also cited as

influencers in coping with people with physical disabilities, favoring the search for new strategies that enable better adaptation to this condition. When analyzing the work process at a State Rehabilitation Center in southern Brazil, Schoeller et al.<sup>(15)</sup> demonstrated that multiprofessional work facilitates the process of rehabilitation of people with disabilities, bringing unique benefits to the target users of this approach, and that nursing work is an essential part of this process. The performance of health professionals is perceived as extremely important for people with disabilities, since it is capable of providing a new way of recovering individual autonomy, while at the same time assisting in the necessary environmental changes<sup>(16-17)</sup>.

Physical impairment places the individual in the face of a multiplicity of physical, psychological and social challenges, which can lead to impairments in these aspects, as well as changes in body image and self-concept. However, it is necessary to consider that there is variation in the psychosocial perception of people with physical disability. Many are able to face, in a positive way, the condition experienced, especially when they feel supported by a support network; however, for others, the network does not provide adequate support, which makes it difficult to create coping strategies<sup>(15-17)</sup>.

This research points to important issues related to the support network for people with disabilities, listing the main elements of it and their contribution to the health of these people. However, the reduced number of participants constitutes its limitation, a fact that places the need for other studies with the same theme. Added to this is the small number of investigations into the support network for this population.

The present study points out relevant aspects related to living with a physical disability. Nursing becomes responsible for a practical and theoretical contribution, which provides different visions, that assists disabled people in their confrontation. Thus, health professionals should assume their role as a reinforcer of the supportive links and the support network, becoming active participants of this, seeking to know the nature of the relationships and how this tends to assist in the rehabilitation and reintegration of these people in society.

The reduced number of participants was a limitation of the study, a fact that places the need for other studies with the same theme. Added to

this is the small number of investigations into living with disabilities, as well as the support network of this population. New investigations are indispensable regarding the physical disability and the support received for the search for autonomy and the confrontation of the condition. And we also point to the need for studies that relate the conditions of life with the confrontation and the possibilities of adaptation to living with a disability.

## CONCLUSION

Understanding how people with physical disabilities live exceeds biological limits, because we need to consider psychological, social and cultural aspects, that is, transcend the clinical question, since the person is the reflection of several factors that influence them and that are part of their daily life.

Physical disability presents immeasurable transformations in the lives of those who acquire it, and it is on this path that the findings of this study pass. Among the most visible needs, previously unknown to the people and their conviviality with their condition, is the adaptation of the external and internal environment, generally inappropriate to receive them, which makes it difficult to reintegrate into society and to cope with their new condition.

The action of the support network, both family and professional, with people with disabilities is of paramount importance, since it presents several demands, both therapeutic care and psychological support, promoting improvement in the quality of life, besides helping significantly throughout the rehabilitation process.

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