SUPPORT NETWORKS IN THE CONTINUUM REHABILITATION PROCESS IN THE DAILY LIFE OF PEOPLE WITH SPINAL CORD INJURY

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ABSTRACT

Objective: to understand the support network in the continuum process of rehabilitation in the daily life of people with spinal cord injury. Methodology: a descriptive study of a qualitative nature, based on Comprehensive Sociology and Everyday Life, with 23 people with spinal cord injury, accompanied by a Nursing and Rehabilitation Service in southern Brazil. For data collection, we used the medical record, genogram, ecomap and individual interview. Content Analysis was used to analyze the interview. Results: when entering the Rehabilitation Program, the support networks were configured as a weak link when inaccessibility was a barrier, specifically, work/school; hobby/leisure. Strong bonds consider the main caregiver networks, health center, friends, religious orientation and family. Final thoughts: the support networks that surround each individual with spinal cord injury and the family and how they relate, help to cope with the new rhythm of life, collaborating to achieve the goals of rehabilitation and resocialization.

Keywords: Rehabilitation Nursing, Social Support, Spinal cord injury. Activities of Daily Living, Family Health.

INTRODUCTION

Spinal cord injury (SCI) involves severe physical, social and psychological consequences, which limit significant changes in the physical domain and functional independence, requiring a continuum rehabilitation process. Experiencing the chronic condition implies the protagonism of sick people and their families in the process of daily management(1).

Faced with changes and impacts caused by SCI, the support network in the rehabilitation process becomes fundamental in all post-injury phases, contributing to the individual strengthening, giving emotional and instrumental support, helping the individual in coping and/or adaptation to the new rhythm of life. The support network helps people with SCI overcome the difficulties of their new reality(2).

One study identified, in view of the perspectives of individuals with SCI in relation to physical rehabilitation interventions, that there is a need for support from health professionals, family members, friends and participation of other people with SCI during the rehabilitation process(3).

Considering that the rehabilitation process is a continuum in the life of a person with SCI, that is, it begins with the diagnosis of the injury and continues throughout life, it is necessary that health professionals understand the support network of these individuals at different moments of the process of living.

Successful rehabilitation contributes to physical and emotional restoration, avoids or minimizes possible complications and, consequently, reduces the incidence of readmissions. It is also understood that adherence to rehabilitation transitions through integration between people with SCI, their families, society...
and health professionals, with emphasis on nurses for spending more time with the person with SCI, for their holistic ability to care for although it is poorly developed in practice, due to lack of contextualized training for the care of these people\(^4\).

Nursing professionals and family members of people with SCI need to understand how support and care networks interact, in order to provide means of teaching and learning for self-care throughout life at home, in order to prevent preventable sequelae promoting the rehabilitation process\(^4\).

This process of understanding involves generosity of spirit, closeness, correspondence when apprehending or sensing the subtleties, nuances and discontinuities of this or that social situation\(^5\). In this thinking, the understanding of the dynamics of support networks at different times of living with SCI in everyday life may indicate more effective care practices at different levels of health care.

For this, the present research brings as a question: how is the support network of people with SCI presented in the admission of the rehabilitation program and in the daily home post-rehabilitation program? This study aimed to understand the support network in the continuum process of rehabilitation in the daily lives of people with spinal cord injury.

**METHOD**

This is a descriptive study with a qualitative approach developed with 23 people with spinal cord injury, in a Specialized Center for Physical and Intellectual Rehabilitation, in Southern Brazil, from October 2019 to January 2020. The study was conducted according to the Consolidated criteria for Reporting Qualitative research (COREQ)\(^6\).

The invitation to participate in the research was made by the head of the Nursing Sector and by the researchers through the messaging application WhatsApp, as well as in-person meetings of the Support Group for People with Spinal Cord Injury (GALEME), carried out monthly at the institution.

Inclusion criteria for the participants were: adults with traumatic and non-traumatic SCI, having participated in a Rehabilitation Program for at least one year and having a complete genogram record and admission ecomap. People with associated cognitive impairment, aged over 18 years, were excluded.

Data collection was developed in two stages: data collection in physical/electronic medical records and genogram/ecomap and, later, the interview, lasting approximately 40 minutes, in private locations in the institution. The interview of people living in the state of Santa Catarina was conducted by telephone. The collection instrument is used for nine years by the institution, scenario of this study and constantly updated by the nurses of the CER, therefore, validated by them. The inclusion of new participants was suspended when the possibilities of finding complete records of Genograms and ecomaps in the admission evaluation were exhausted, and confirmation of data saturation\(^7\).

Clinical and sociodemographic data were presented descriptively. Genogram/ecomap data were composed of: school/work; primary caregiver; hobby/leisure; social group/social network; Health Center/rehabilitation center/hospital; friends; belief/religion and family. Social networks and participation of groups/associations were added to the data collection instrument, in the second stage of the research, post-rehabilitation program, since the instrument underwent updates.

Genogram/ecomap data was released in Genopro Software, version 2020. For the analysis of the interview, the Content Analysis technique was adopted\(^8\). Data interpretation was based on the theoretical framework of Comprehensive Sociology and Everyday Life\(^9\).

The research was developed after approval by the Ethics and Research Committee, according to Protocol n. 2,841,165. To guarantee the anonymity of the participants, the initial letters of Genogram and Ecomap (GE) were used, followed by the Arabic number in the order in which the interviews took place.

**RESULTS**

The participants were 23 people with SCI, of which 15 were male and eight female, and the average age of the participants in the admission to the rehabilitation program was 38 years and 40 years after the rehabilitation program.
As for the profession/occupation, before the SCI, all participants developed paid activities, 13 people with employment and 10 autonomously. After the SCI, 20 people were retired due to disability, two receiving Continuing Benefit of Social Assistance – BPC/LOAS and one was active, and four participants associated retirement or benefit to other informal labor activities to supplement income. With regard to schooling, when entering the rehabilitation program, ten participants had incomplete elementary school, two, complete elementary school, seven, incomplete high school, two, complete high school, one with incomplete higher education and one with complete higher education. After the SCI, four participants returned to the studies, stating that the return to schooling occurred among the youngest, with a mean age of 26 years. After the rehabilitation program, it was observed that four participants returned to schooling, three completing high school and one completing higher education. The average family income of the participants on entry, or before SCI, was approximately two minimum wages.

As for marital status, in entering the rehabilitation program, nine participants were single, twelve were married or in a stable union, one was a widow and one was divorced. Four participants changed their marital status after the rehabilitation program, with one marriage and three divorces. Most of the participants were from the interior of Santa Catarina (14).

According to the characteristics of SCI, SCI stands out for traumatic etiology (16), caused by automobile accidents (09), followed by fall (04), gunshot injuries (02) and diving (01). Of these, (12) participants had complete lesions (AIS A) and the other AIS B and C, respectively, according to the American Impairment Scale (AIS). The non-traumatic spinal cord injuries were due to discopathy (06) and medullary tumor (01). Regarding the level of injury, 20 participants presented paraplegia and three participants were quadriplegic.

In order to understand the support networks of people with SCI in the entry of the rehabilitation program and in everyday life, 23 Genograms were analyzed, considering two generations, in addition to 23 structured ecomaps, in the categories: school/work; main caregiver; hobby/leisure; Group/social network; Health Center/Rehabilitation center/hospital; friends; belief/religion and family. The quality of the bonds was evaluated as strong, when there was an ease/close relationship, weak, when it showed a distant and conflicting difficulty/relationship, when there was a tumultuous relationship. The results will be presented according to each category.

School/work

For the most part, when entering the rehabilitation program, participants were already retired or receiving the BPC/LOAS, or depending on the time between the SCI and the admission to the rehabilitation program, are already retired due to disability, weak attachment due to the break with the work. In the post-rehabilitation program, lack of accessibility and distance contribute to a weak link in the return to work and/or schooling, but the desire to continue the studies is still frequent among participants, as the reports show:

I want to finish high school (GE09). I didn't go back to school because of the distance (GE10). I want to go back to school, go to college (GE21). I want to go back to school, but poor accessibility prevents me from going back. There are almost no buses (GE22).

The completion of the upper level and the desire to continue the career was reported by one of the participants after the rehabilitation program:

I finished college, I intend to do a graduate degree. (GE20)

Regarding work, after the rehabilitation program, most participants (20) were retired due to disability. However, in order to improve the monthly family income, some participants turned to informal work, sometimes linked to their profession or crafts. Only two participants received benefits, and one was active performing automotive painting. The quality of the link with this support network at home is very diverse, dividing between weak and strong, with only three participants who considered this conflicting network.

Main caregiver

The relationship between the primary
caregiver and the person with SCI is identified as a strong link in the admission of the rehabilitation program and also in the household, post-program. At the entrance, care is provided by the mother, daughter, grandmother, father and grandparents. It is evident that the female family figure occupies a prominent place in care.

After the rehabilitation program, the care provided by the family is no longer a routine, since during the rehabilitation, the person with SCI acquired independence and can manage his self-care. During this process, contradictory feelings are pointed out by the participants:

Gratitude for the care provided to me (GE08). Many times I felt that it was automatic [...] an obligation (GE10).

**Hobby/leisure**

The link with the hobby and leisure, before entering the rehabilitation program, was considered strong for most participants. Work and sport occupied important space in the participants' lives:

Gratitude for the care provided to me (GE08). Many times I felt that it was automatic [...] an obligation (GE10). Gratitude for the care provided to me (GE08). Many times I felt that it was automatic [...] an obligation (GE10).

Post-rehabilitation program, it was found that the quality of the link with hobby/leisure depends on the process of elaboration and individual transfiguration by loss of physical integrity after SCI. By re-signifying the lived, we see strong bonds associated with new learning possibilities, even adapted as:


The weak or conflicting bond with the hobby/leisure was characterized by the research participants in situations where the lack of functional ability compromised the development of the activity; when the subject did not express interest or allowed himself to develop other potentialities, staying at home, dedicated to online games, due to architectural barriers; for not having a hobby/leisure since work was his hobby and also for not enjoying leaving home.

I don't like to leave the house (GE02). Barbecue, I ran out of hands (GE11). Previously it was work (GE12). Cycling (GE14). Lack of accessibility (GE17).

**Social group/social network**

There is emphasis on the use of social networks among young people, such as:

WhatsApp and Facebook (GE02, GE18, GE17, GE13, GE09, GE22).

Older people reported not liking or having difficulty accessing the technology:

I don't like social networks (GE15). I'm very poor in this area (GE11).

In addition, participation in social action and self-help groups, as a support network, showed a strong link, especially in the activities carried out in GALEME:

(GE18, GE22, GE09, GE03, GE19, GE20, GE16).

**Health care networks**

It was observed in the analysis of the ecomaps that the participants considered Primary Health Care as a support in the network, with a strong link related to the availability of materials and medications for continuous use, good relationship with the team and home visits.

Nurse comes to the house to do the dressing 3x a week (GE02). I receive visits and if I ask, I receive material (GE09). I am well attended, I do dressings, exams (GE22).

However, attachment is weakened when their needs are not met, due to lack of material, difficulty in service or lack of professional.

Difficulty getting material (GE05; GE23). Difficulty to get an appointment, I have to go very early and when I can, they cancel (GE07). Material is missing, I can't get exams (GE10), There is no doctor (GE14).

The strong quality of the bond with the Specialized Centers in Rehabilitation stands out for the specialized, systematized and multidisciplinary care, the theoretical and
practical learning incorporated in everyday life, the supply of materials and auxiliary means of locomotion, and also for the welcome and good service.

The moment I joined was not the best, but I learned a lot (GE03). Very good, I get material (GE04). Great, specific care (GE16). Everything to me! Very good service (GE18). I received the best information (GE19). I love! Note 10 (GE22).

However, the link with the CER may be conflicting or weak, in the perception of research participants, when access to rehabilitation is limited due to architectural and attitudinal barriers, social determinants that hinder their access to health goods and services, exposing them to social inequities.

Limitation in assistance (GE21). I can't go (GE06).

Hospital care, as a support network in the rehabilitation process, has a strong bond for people with SCI, when associated with good care and when the demands of people with SCI are met.

Good service (GE06; GE09; GE15; GE16; GE18; GE22).

Meets health needs (GE09; GE12; GE15; GE19; GE20; GE21).

And, weak and conflicting, when associated with the relationship of suffering, neglect, precariousness, forgetfulness/carelessness of professionals related to the emergence of pressure injury.

It sucks, we are forgotten by professionals. I had a pressure injury when I went to the hospital and it hasn't closed until today (GE11).

In private I was well attended, in public there was negligence (GE08).

Suffering relationship (GE13).

Precarious, they don't do tests, they don't solve my problem (GE14).

Friends

According to the participants of the research, the friends make visits soon after the spinal trauma, becoming more infrequent with the passing of the years, having a total rupture of the ties with the old friends:

Small group comes to visit me, most disappeared (GE01). They disappeared (GE09). Few visit (GE10). They don't visit anymore (GE16). I have no friends after the injury (GE17). Many visits were at the hospital, then... (GE21).

However, in this research, some participants verbalized a strong bond with the network of friends, characterized by the remarkable presence and the feeling of belonging to a tribe:

I keep my friends (GE04). I receive friends at home and I am very happy (GE05). I receive many friends, I feel that I am part of them (GE19). They are very close, work group, college (GE20).

In the post-rehabilitation program, there was also a bond with friends well divided, sometimes configured strong by maintaining old friendships or creating a new circle of friends after SCI, sometimes configured as weak by breaking friendships.

New friends (GE09). Good/true/strong friends (GE03; GE04; GE08; GE11; GE13; GE14; GE20; GE21). They moved away after the injury (GE01). Disappearance of friends (GE17). They had no friends (GE02; GE06; GE12; GE15).

Religious orientation

Belief, as a support network for the person with SCI, transcends the choice for a religion and the physical presence in a sacred temple. When entering the rehabilitation program, it was found that, regardless of religious belief, the bond was pointed out as strong by most participants and helps to cope with the new rhythm of life.

God was my safe harbor (GE08). Without my belief in I would not have endured (GE12). If I'm alive, it's because of my faith (GE17).

After the rehabilitation program, there was no significant change in the quality of the bond with the participants’ belief. Those who reported a strong bond in entering the rehabilitation program continued with their post-rehabilitation program beliefs as a necessary resource to move forward. In addition, as the participants who reported a weak bond, two participants reported improved bonding times after being rehabilitated and two others reported worsening of the bond.

My faith is unshakable, it accompanies me until
today (GE04). It makes no difference to me (GE09).

Family

The family, as far as it is concerned, stands out among the research participants as an important support network in the admission of the rehabilitation program. Only two interviewees reported a weak bond, and one reported a conflicting bond with the family.

I still have problems (GE15). Very conflicting family relationship (GE22).

After rehabilitation, it is observed in the ecomaps that strong, weak and conflicting bonds maintain the patterns reported by the research participants. Family conflicts are linked to:

Distance/abandonment (GE11; GE22). Little or no contact with the family (GE02; GE15). The difficulty of being cared for (GE03). Feeling of obligation of the family in care (GE10).

DISCUSSION

SCI is a disabling syndrome that affects the daily lives of people with families. Young, male adults are the most affected by this condition.(2)

The World Health Organization (WHO) has revealed that motor vehicle accidents are the most responsible for traumatic SCI in the three largest regions of the world: Africa, America and Europe(10). In Brazil(11), in a study with 618 people with spinal cord injury, most injuries were traumatic (78.5%), being caused by traffic accidents (40.8%) and weapons (17.5%).

The main cause of SCI identified in this study is of traumatic origin caused by automobile accidents, followed by falls and gunshot injury, corroborating other studies(11). The traumatic etiology of SCI caused the majority of participants to have complete paraplegia (ASIA A)(11,12).

With regard to the schooling of participants, most have low education when entering the rehabilitation program, which corresponds to incomplete elementary school, confirming other studies(12,13). Low family income was also identified before SCI, with an increase after the program(13).

Faced with the consequences of SCI, support networks, associated with rehabilitation, are fundamental pillars for the acceptance and transposition of the obstacles encountered on the route. Rehabilitation is presented as a possibility of return to life, which enables coexistence between equals, stimulates self-care and adaptation(4).

When analyzing the data of this research, it was observed that rehabilitation after SCI contributes substantially to the improvement of quality of life. When rehabilitation goals are achieved, in greater or lesser intensity, associated with the support network, rehabilitation evokes the power of wanting to live, which, in the words of Maffesoli(14), is the force that comes from within, which germinates another way of thinking, of transfiguring the rhythm of living(14).

In the early stages of SCI there is a break in the bond with work and/ or school. The return to work and schooling is conditioned to the functional gain arising from the rehabilitation process, the support network and accessibility. The lack of accessibility in public and private places significantly impacts the return to study and work, as was reported by the participants of this research and evidenced by the studies(12,15).

This impediment is a limit for the resocialization of people with SCI, since people with higher levels of education tend to have greater ease to enter the labor market and have higher remuneration and, consequently, better quality of life(12).

In a cross-sectional study with 121 people with spinal cord injury after a rehabilitation program conducted in Brazil, the labor market participation rate was 21.6% (24 individuals). Five respondents worked in formal work activities and the other 19 in informal (autonomous) activities. Since the beginning of the injury, shorter time was associated with non-participation in occupational work. Individuals with higher educational level were more likely to work(16).

With the abrupt change in the rhythm of life of people with SCI, especially in the first months after injury, home care is mostly provided by family members (mother, daughter, grandmother, father and grandparents), being of the order of organic solidarity, which is based on affective social ties, the instituting, the spontaneous way or the feeling of being with, because it makes one feel good(17). In this research, there was emphasis...
on the role of women as the main caregiver, represented by mothers, daughters and wives, noting a strong attachment. In contrast, in some families, whose bonds were conflicting, it was also found the mechanical solidarity that is of the order of the instituted, of obligation\(^\text{(17)}\).

In the study that analyzed the powers and limits in adherence to rehabilitation\(^\text{(4)}\), the support of the family to the person with SCI rescues the will to live, which stimulates and gives security, bringing a certain normality to life, adjustments so that the person adapts to the new rhythm of living, configuring a power in adherence to rehabilitation.

The hobby/leisure, highlighted by people with SCI as pleasant activities, arise as a great potential in the recovery and health promotion of these people, covering the physical, psychological, social and emotional aspects, providing a personal satisfaction with life\(^\text{(18)}\). However, not all people can have this access to sports or other leisure activity, this limit is once again linked to the lack of accessibility they find in society, generating social isolation\(^\text{(19)}\).

The beginning of post-injury life requires changes, struggles and mobilization to create paths and actions that strengthen the confrontation on a daily basis\(^\text{(4)}\). The lack of motivation, dissatisfaction, depression and the feeling of mourning experienced by the person with SCI interfere in this return to community participation\(^\text{(20)}\). The formation of support groups becomes vectors of communion, sharing, feelings, promoting the approximation of people, the development of societies, and accessibility to information. In this sense, technosociality offers people with SCI interaction with other people and translation of knowledge, providing social inclusion. It is evident, then, that technological development is a positive factor for health promotion\(^\text{(21)}\).

There are many factors that can influence the quality of life after trauma, with the quality of care offered by the health system\(^\text{(22)}\). The (dis)care of health professionals goes through the lack of early rehabilitation in the hospital environment, causing avoidable complications, due to the lack of guidance on reference services and health policies, as well as the nonspecific care in PHC. Studies reinforce that the preparation of hospital discharge of people with disabling neurological injuries needs to be more elaborate, planned, so that these people and families can be oriented to the continuity of care network, to obtain better quality of life\(^\text{(4,23)}\). In addition to the need for professional preparation in the multidisciplinary team for the employment of competent and satisfactory educational and assistance activities\(^\text{(24)}\).

The CER become a reference of care for people with SCI, as highlighted in our study, providing the development of basic and instrumental skills of daily life with maximum patient independence, family and other support networks as part of care. "Rehabilitation is a possibility of returning to life by the edifying way of teaching the "first steps", through the reuse of the body, continuous movement, challenge and independence in the activities of daily life\(^\text{(16)}\)."

Nursing is an integral part of the rehabilitation team, present in the different contexts of the health of the person with SCI and his family, standing out for the systematized action, evidenced by the Nursing Process, and humanizing care for these people during the process of rehabilitation and social inclusion.

**FINAL THOUGHTS**

The results of this study show that the support networks in the continuum rehabilitation process enhance the will to live of the person with SCI, collaborating for their rehabilitation and resocialization.

It was found that most participants had SCI of traumatic origin in a young population, meaning an economic-social problem, given the difficulty of these people return to the labor market or even to be retired.

Work/school and hobby/leisure support networks have weakened linkage, which is justified by the loss of functionality, social role and radical change in lifestyle, which associated with lack of accessibility, determining social isolation. Those who stand out for the quality of the bond in the entry of the rehabilitation program are the main caregiver and the family, signaling the need to be welcomed, guided and cared for at different levels of health care.

At home, after rehabilitation program, there is a more favorable scenario for social inclusion. In greater or lesser intensity of attachment,
rehabilitation is the way back to life for people with SCI.

The implementation of genogram and ecomap in health services enables professionals to understand the daily life and support networks that surround each individual with SCI and their family and how they relate to each other, that can thus be fully worked by the multidisciplinary team for the achievement of rehabilitation goals.

The nurse, as a member of this multidisciplinary team, needs to develop their actions in a targeted way both for recovery and adaptation to the limitations arising from disability, as the subjective needs of each individual and his family, psychosocial and spiritual dysfunctions, since SCI changes the dynamics of these people’s lives, interfering with the relationships with networks and the well-being of the person with SCI and their relatives.

The presentation of the results of this research contributes to the strengthening of support networks, based on the understanding of health professionals, at different levels of care, so that they can provide the rescue of physical functionality and the social role of people with spinal cord injury, through rehabilitation, according to the possibilities of each individual.

This study presents as a limitation the intentional population when selecting people with SCI linked to a scenario that was predetermined, but based on the results found, intentional sampling can be considered representative in populations and similar conditions. The realization of telephone interviews, too, can be characterized as a limit of the research, for not allowing the identification of non-verbal language, the guarantee of an adequate place for the realization of the interview, as well as the impossibility of ensuring privacy.

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