

ACTIONS OF THE SUPPORT NETWORK FOR PEOPLE WITH SPINAL CORD INJURY

ATUAÇÃO DA REDE DE APOIO ÀS PESSOAS COM LESÃO MEDULAR

ACTUACIÓN DE LA RED DE APOYO A LAS PERSONAS CON LESIÓN MEDULAR

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ABSTRACT

Objective: to analyze how is composed the support network for people with spinal cord injury and how it works. **Method:** descriptive, exploratory study of a qualitative nature, based on the theoretical framework of Symbolic Interactionism. The data were collected between January and June of 2016 from 23 people with spinal cord injury through a semi-structured interview and submitted to Content Analysis in the Thematic modality. **Results:** besides the presence of family and friends, the interviewees emphasized the importance of community, sport and rehabilitation and health centers as support resources in the adaptation to the condition of living with spinal cord injury. However, they showed that there were still some shortcomings related to obtaining greater knowledge about how to perform body care and improve daily life. Meeting other people with spinal cord injury and their experiences facilitated the learning and living with this condition. The practice of adapted sports represented a differentiated support network in the rehabilitation, recovery of autonomy and social reintegration of people with spinal cord injury. **Conclusion:** support networks are necessary in the process of rehabilitation, adaptation and overcoming in the lives of people with spinal cord injury. **Keywords:** Disabled Persons; Social Support; Socialization; Spinal Cord.

RESUMO

Objetivo: analisar como é constituída e como atua a rede de apoio à pessoa com lesão medular. **Método:** estudo descritivo, de natureza qualitativa, fundamentado no referencial teórico do interacionismo simbólico. Os dados foram coletados entre janeiro e junho de 2016 entre 23 pessoas com lesão medular, por meio de entrevista semiestruturada, submetidas à análise de conteúdo, modalidade temática. **Resultados:** além da presença da família e amigos, os entrevistados ressaltaram a importância da comunidade, do esporte e dos centros de reabilitação e de saúde como recursos de apoio na adaptação à condição de ter lesão medular. Evidenciaram, porém, que ainda permaneciam algumas lacunas impeditivas de alcançarem mais conhecimento sobre como realizar cuidados ao corpo e melhorias em seu cotidiano. Conhecer outras pessoas com lesão medular e suas experiências facilitava o aprendizado e a convivência com essa condição. A prática esportiva adaptada constituía-se em uma rede de apoio diferenciada na reabilitação, recuperação da autonomia e reinserção social da pessoa com lesão medular. **Conclusão:** as redes de apoio são necessárias no processo de reabilitação, adaptação e superação na vida de pessoas com lesão medular.

Palavras-chave: Pessoas com Deficiência; Apoio Social; Socialização; Medula Espinal.

RESUMEN

Objetivo: analizar cómo se constituye y cómo actúa la red de apoyo a la persona con lesión medular. **Método:** estudio descriptivo exploratorio de naturaleza cualitativa, en base al referente teórico del Interaccionismo Simbólico. Los datos fueron recogidos entre enero y junio de 2016, entre 23 personas con lesión medular, por medio de entrevistas semiestructuradas; los datos después fueron sometidos al análisis de contenido, modalidad temática. **Resultados:** además de la presencia de la familia y de amigos, los entrevistados realzaron la importancia de la comunidad, del deporte y de los centros de rehabilitación y de salud como recursos de apoyo en la adaptación a la lesión medular. Sin embargo, afirmaron que seguían existiendo obstáculos para alcanzar mayor conocimiento sobre cómo cuidar el cuerpo y mejorar su vida cotidiana. También mencionaron que conocer a otras personas con lesión medular y sus experiencias facilitaba el aprendizaje y la convivencia con la lesión. El deporte adaptado, según ellos, era otra red de apoyo diferente en la rehabilitación que ayudaba en la recuperación de la autonomía y en la reinserción social de la persona con lesión medular. **Conclusión:** las redes de apoyo son necesarias en el proceso de rehabilitación, adaptación y superación para las personas con lesión medular.

Palabras clave: Personas con Discapacidad; Apoyo Social; Socialización; Médula Espinal.

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INTRODUCTION

In the current national scenario, spinal cord injury (SCI) is an important public health problem, especially because it is related to urban violence, traffic accidents and firearm aggression. These external causes usually affect males and young people, who, in most cases, are at the peak of social and economic productivity. Thus, early retirements and expenditures for the public and/or private health sector are generated.¹

Because SCI affects the transmission of sensory and motor signals in the injured area, as well as the autonomic nervous system², it transforms the way of life and the routine of the affected person. Such transformations are well-known to be influenced by the individual personality, social interactions, and the support network involving people with SCI. It is, thus, evident that positive social support and family environment can promote better adaptation to the new life and health condition, since the perceived challenges faced daily can be minimized with the support of family members.³

The main challenges arising from this condition are related, in particular, to architectural, structural and environmental barriers of public and/or private physical space, and also involve social, psychological aspects, self-image and self-esteem. Thus, social support – understood as any information, whether spoken or not, and/or material aid, offered by groups and/or people who know each other and which results in positive emotional effects and/or behaviors⁴ – may favor coping with difficulties in the new life and improving the quality of care for people with disabilities.⁵

Given the above and considering the difficulties faced in the daily life by people with SCI, the following objective was adopted for the study: to analyze how is composed the support network for people with spinal cord injury and how it works.

METHOD

Descriptive research of a qualitative nature, based on the theoretical reference of symbolic interactionism, which seeks to understand the interpretations and meanings that people give to the situations they are experiencing.⁶

The study participants were 23 people with SCI living in Maringá-PR, located by indication of *Estratégia Saúde da Família* (ESF) teams (11 cases) and by registration in the *União Metropolitana Paradesportiva de Maringá* (UMPM) (12 cases). The inclusion criteria were: being 18 years old or older, diagnosed with paraplegia for at least two years caused by SCI and having integral communication capacity. People who could not be located after three attempts at different times and days were excluded.

Data were collected from January to June 2016, by means of a previously scheduled interview, recorded after consent and performed at the place of choice of the participant (residence

or room attached to the sports field). After completing a form with sociodemographic information and health profile, the interviews were conducted with the following guiding question: tell me about your life after the spinal cord injury, the changes that occurred in the personal, family and social environment. Information was surveyed until the data began to become repetitive and the purpose of the survey was achieved.

For the analysis, the recorded interviews were transcribed verbatim and then submitted to content analysis in the thematic modality, respecting its stages.⁷ In the pre-analysis, a quick reading of the printed interviews was made, highlighting the points of interest. Then, the material was explored with a thorough and exhaustive reading of all the content. Afterwards, the messages were codified by means of different colors, with detection of the nuclei of meanings, which were grouped to generate thematic categories. Finally, the inference was made based on the data obtained, which were analyzed and discussed with the literature.⁷ Three thematic categories emerged from this exhaustive analytical process, namely: support network for people with spinal cord injury – who they are and how they act; one helps the other and everyone helps - a support network under construction; and deficiency in the performance of the support network – implications for independence and autonomy.

All interviews were conducted by the first author. It should be noted that they were transcribed on the same day they were held, which allowed us to add to the registration and transcription process information about the reactions of participants when addressing certain aspects of their experience.

In the development of the study, the Resolution 466/12 of the *Conselho Nacional de Saúde* (BR) was respected and the project was approved by the Standing Committee on Ethics in Research with Human Beings of the *Universidade Estadual de Maringá* (Opinion nº 1,328,940). All participants signed two copies of the Informed Consent Term (ICT). And to preserve anonymity, their reports are identified with the letter P and a number corresponding to the order of interview, followed by the words BHU or sport, according to location source, M (man) or W (woman), age and how many years the person lives with SCI.

RESULTS

CHARACTERIZATION OF SUBJECTS

Twenty-three people aged 23-58 years, of which 16 were men, participated in this study. The time living with SCI ranged from 2.7 to 33 years. Regarding marital status, eight participants were single, nine married (five married after SCI), four separated (all after SCI) and one widower. As to the nature of the trauma, only one case was not due to external causes (tumor in the cervical region). The others were: 11 cases of automobile ac-

cident (eight with motorcycles), eight cases of firearm injuries, two cases due to a fall from a different level, and one due to hit-and-run accident.

Regarding occupation, 18 participants were retired due to disability or received pension, four worked and only one had no occupation. Of the total, 20 lived with a relative. Ten had bought wheelchairs with their own resources and the others with the help of government, religious groups and friends. Only four respondents had complete higher education, 11 had secondary education, and eight had not completed primary school. Regarding the economic condition, 14 of them had their own home, 12 had a car adapted for paraplegic people, six had car without such adaptation, and the other five were users of public transportation.

All the participants mentioned that they had undergone hospitalizations due to complications of the SCI, such as urinary or pulmonary infections and skin lesions due to pressure ulcers. Moreover, 15 participants reported having no health problems, two had diabetes *mellitus* and the other six reported a different problem: arterial hypertension, Charcot spine, chronic renal failure, adhesive capsulitis, renal calculi and viral hepatitis.

NETWORK OF SUPPORT FOR PEOPLE WITH SPINAL CORD INJURY: WHO THEY ARE AND HOW THEY ACT

In this category, in addition to family and friends, the participants identified the community, sport and rehabilitation and health centers as active support networks. This occurs in a more or less effective way, at different moments of their experience with SCI, that is, soon after the accident, during the period of adaptation and during the course of daily life.

According to reports, it was noted that family unity was strengthened in the face of the trauma. This was an important support for the SCI patients, especially in the first moments after the injury. Family closeness was also observed, in many cases, to persist over time.

Everyone got closer to each other in the beginning, my family is my father, my mother, a cousin who lives here on the side and her two sisters [...]. When the injury happened my family somehow got together (P11-BHU, W, 34 years old, SCI 7 years ago).

My parents, my siblings, my close relatives, uncles, cousins, these people, became more united, created affection, an even greater bond, until today this is cultivated (P13-sport, M, 35 years old, SCI 18 years ago).

Families also undergo a process of adaptation when SCI affects one of its loved members, and it was very present in the

daily routine of the interviewees in this study, assisting them to carry out everyday tasks which are understood as simple, such as washing clothes:

My sister always on my side, whenever I needed to help, wash my clothes, my nieces also helped (P19-sport, M, 36 years old, SCI 12 years ago).

They [family members] are adapting along with me [...] they have gradually accepted also, seeing my conditions and they have been helping me to adapt to the chair. Each day learning a different thing, improvising some things, the ones that support me are the ones who live with me in the house, they help me in this routine of the wheelchair (P3-BHU, M, 29 years old, SCI 2 years ago).

On the other hand, families sometimes also functioned as incentives for adaptation and autonomy:

One day I sat on the bed, it had been seven or eight months after the injury, I was arguing with my sister, I fell from the bed, my mother was lying on the sofa, I told her: "won't you help me get up?!" And she said to me "I won't, you have both arms still, you lean on the bed and go up", [...] it hurt, but it was a learning process for me, it was very good [...] I thought, it is truth, if my mother is telling me this, I can do it, so I can climb the bed, I can do things, so I can, this was very good (P18-sport, M, 34 years old, SCI 12 years ago).

In addition to the assistance offered by family members, the support network made up of friends and anonymous members of the community was also relevant for the reintegration and reinsertion of people with SCI into society.

I'm lucky to have friends who always help me, not everyone has that. I've always found people who are there by my side helping me (P9-BHU, H, 29 years old, SCI 10 years ago).

My friends made a raffle and bought a motorized chair. With that I would get on the bus and go to college alone, without needing anyone (P20-sport, M, 41 years old, SCI 15 years ago).

Inside the bus, some drivers are cool, they talk to you, help you to go up the ramp. On the street too, if I go down a ramp or some inaccessible place, some people pass by you and ask if you want help (P3-BHU, M, 29 years old, SCI 2 years ago).

It was also possible to identify in the speeches the importance of the spiritual background for some participants. The

community and church members were also present, helping financially or encouraging people with SCI to move forward:

My motivation to move forward is God, and my will to win (P2-BHU, M, 26 years old, SCI 7 years ago).

I used a medicine that was expensive, I could not buy it, the minister of the Eucharist and the priest helped me buying the medicine (P6-BHU, W, 48 years old, SCI 8 years ago).

I had a very strong support after the accident, from pastors and from friends of the church. I see that this was the key factor for me to never get discouraged (P13-sport, M, 35 years old, SCI 18 years ago).

Rehabilitation centers, in turn, played a significant role in the learning process about body care and re-education aiming at independence. And the practice of sports favored social interaction, learning, occupation and not only motor but also psychological rehabilitation.

It was at the Sarah (hospital-Brasília) that I learned to have coordination, they say that we have to educate, re-educate the bowel and reeducation of the urine. The nurses there say that your legs are now your arms, there's nothing you are unable to do, everything you can do [...] they've taught me a lot, so that I can be more independent (P6-BHU, W, 48 years old, SCI 8 years ago).

[...] When you see that there is no way out, you have to live like that, the idea of sports come. I always say that there should be more of entities like the CVI (Centro de Vida Independente), people who are willing to take these people out of their houses; the CVI helped me a lot (P14-sport, W, 50 years old, SCI 25 years ago).

How do I climb on the chair by myself? Then you will learn. I learned this at the Selma Foundation [...] take care not to have an ulcer (pressure injury) (P15-sport, M, 52 years old, SCI 24 years ago).

The sport meant everything to me, if it was not for the sport I do not think I would even leave the house. After I started practicing in sports, I lost the shame of going out of home (P16-sport, M, 35 years old, SCI 11 years ago).

Finally, other members of the support network mentioned by the participants were health professionals, especially community health agents, physiotherapists, nurses and social workers.

The role played by the basic health units, which provide medical and hospital supplies and medicines, was also highlighted.

In the survey, the nurse in the hospital helped me, she taught me, she showed how I had to do it (P21-sport, M, 23 years old, SCI 5 years ago).

The CHA [Community Health Agent] is always here at home. She helps a lot with the medicine, physiotherapy helps me a lot, they are always present in my daily life, they know what I'm going through (P3-BHU, M, 29 years old, SCI 2 years ago).

The health center helps me a lot, they give me the materials, the glove, the probe, the medicine, everything is the health center that gives me (P10-BHU, W, 38 years old, SCI 18 years ago).

It is the social worker who helps us to get the medicine (P6-BHU, W, 48 years old, SCI 8 years ago).

In summary, in this category, it was possible to observe that the support received by people with SCI comes from family, friends, religion, rehabilitation centers, sports and health services. These support networks were fundamental in the process of adaptation, rehabilitation and social reintegration after SCI.

ONE HELPS THE OTHER AND EVERYONE HELPS: A SUPPORT NETWORK UNDER CONSTRUCTION

In this category is emphasized the importance of the experience of another person with SCI over the emotional strengthening of affected individuals, especially in the first moments after the injury. In this sense, the interviewees reported that it was initially important to recognize the fact that they were not the only people experiencing this situation and needing a wheelchair and then that they sought to learn from the experience and knowledge of the others, so as to help others as well.

I had a hard time accepting that I could do things [...] one of the people in the CVI (Centro de Vida Independente) said that he worked with cleaning, he had a normal life. Until I had to see [...] I sell, I took some lessons with her, I adapted the broom, I adapted the squeegee. Today I do everything, we kind of imitate others, we learn, it helped a lot (P14-sport, W, 50 years old, SCI 25 years ago).

The major rehabilitation was with wheelchair friends, the older [more years living with SCI] would speak, give

tips. I've been learning. Seeing another person in the same situation helps a lot, it teaches us. The greatest rehabilitation was the [wheelchair] friends, it was a learning process. This interaction is needed; it is a life experience (P22-sport, M, 40 years old, SCI 10 years ago).

I started helping people who had just suffered an injury, telling my story, showing that I overcame, it being a good mirror (P15-sport, M, 52 years old, SCI for 24 years).

Interviewees also reported that practicing sports was an important means for mobility and social interaction, since this space was responsible for establishing affective ties with other individuals who already had SCI:

It is very good to practice sports; it helps a lot in mobility. I met a lot of people, many wheelchair users, it was good for everything. I made a lot of friendships (P20-sport, M, 41 years old, SCI 15 years ago).

I made friends, we formed a family, a very nice social relationship, there are many wheelchair users. Today I no longer see myself without sports. If I can't practice sports, I think I won't last long [laughs] (P23-sport, M, 23 years old, SCI 6 years ago).

The participants adapted to the new situation with support of their relationships with other wheelchair users; seeing others is something that helps with learning and rehabilitation. They reported that major rehabilitation happened interacting with colleagues, especially those friendships from the practice of sports.

DEFICIENCY IN THE PERFORMANCE OF THE SUPPORT NETWORK: IMPLICATIONS FOR INDEPENDENCE AND AUTONOMY

This category addresses the factors that interfere with the achievement of independence and autonomy of people with SCI, which includes the lack of support from the government, lack of guidance from professionals, and absence or excess of family attention.

In the family context, for example, the lack of support and attention aroused feelings of sadness and grudge against family members.

To put the chair in the car he [dad] does not take it and put it there, he throws it! It is a struggle with my father [...] I feel neglect of him, he never really cared, so in helping with something, it seems that I am bothering (P9-BHU, M, 29 years old, SCI 10 years ago).

My family did not give much importance, at that time, they had to have given me a better assistance and it was not given, staying in the wheelchair I don't think it is natural (P8-BHU, W, 35 years, SCI 23 years ago).

On the other hand, too much help was perceived as an impediment to the development of independence and autonomy. This is because family members often did the important tasks, making it difficult for people with SCI to learn.

When people want to help too much, they mess up. He [ex-husband] did everything, I did not do anything alone, it was a support, but a false support, he would spare me from everything, I felt more useless. When I went to live alone, I was able to say: "now I am living a life as a wheelchair user" (P10-BHU, W, 38 years old, SCI 18 years ago).

I had family support, but it was that, protection [...] it's kind of like overlooking. We cannot consider this as a good thing, because at this moment, I do not have my mother anymore, I do not have my father anymore, what would have been of me if I had not fought (P14-sport, W, 50 years old, SCI 25 years ago).

Although the people with SCI who performed sporting activities perceived that this practice promoted more independence and quality of life, they criticized the lack of help and encouragement, mainly from government agencies, which required them to be more committed and determined to initiate and/or continue to play sports.

It took me two, three years to start practicing sports. The hospital did not provide support, neither the university. We started with basketball for rehab, with our own chairs (P18-sport, M, 34 years old, SCI 12 years ago).

They registered us to play basketball; it was a private university that paid for it, but not any longer. Lack of sponsorship is a very bad thing, and that sucks, no one gives an incentive, nothing, you go with your own willpower (P23-sport, M, 23 years old, SCI 6 years ago).

It is important to highlight that the absence or limitation in the guidelines provided by primary and tertiary health professionals was perceived by people with SCI as a barrier to self-care.

Here in this town nobody teaches anything, and the little they taught was wrong; here I was taught to insert a probe with polyvidine. I also had wounds, because I left the hospital with a wound, after five days of hospitaliza-

tion, that caused a bedsore. Every time I was hospitalized I would get a wound, because they did not care (P11-BHU, W, 34 years old, SCI 7 years ago).

[...] there is no guidance, neurologist. I missed information. I could have gone to rehab somewhere, could be better. And everything I learned, I learned alone. In the leaps and bounds, I lost my kidneys, I have to do hemodialysis [...] the urologist, he did not come to me and said that if I did not have certain care measures I could lose kidney function. So it was only sinking [...] very precarious health for us (P20-sport, M, 41 years old, SCI 15 years ago).

It was noticed that the barriers are many and they compromise the autonomy, the self-care, the early rehabilitation and even the health of the people with SCI.

DISCUSSION

The results of this study showed that the support network helps people with SCI overcome the difficulties of their new reality. Activities often surrounded by insecurity and fear arising from the new context of life come to have another meaning when there is help from family and other social groups. The presence of family, friends, community and the spiritual background were complementary as sources of encouragement and support for the development of daily activities and re-adaptation. However, it is important to emphasize that in some moments family overprotection may happen and can disrupt this process.

Thus, the family should be prepared to receive the individual with SCI at home. Roles need to be redistributed and the family has to be reorganize in the structural, physical and psychological spheres, redefining routines and seeking to remedy/minimize the limitations inherent in living with SCI.⁸ Indeed, the family core may be the main support in these cases, acting as a source of care and incentive before this new condition. Therefore, there is no doubt that when families are well prepared and minimally structured, they play an essential role in the daily life and experiences of people with SCI.⁹

It is observed in the reports that the fact of having a family member with a recent SCI caused the family members to get closer and support each other, with the person affected by SCI as the central axis of this context. This finding corroborates the results of a qualitative study with seven individuals with SCI in the city of Rio de Janeiro which identified that the presence of a person with SCI in the home environment directly influences the family unity, which may favor the individuals' autonomy.¹⁰ Thus, the degree of dependence of the injured person does not affect the family relationship when it is already established. On the contrary, sometimes there is more unity between family

members when something like this happens, and the SCI works as a reinforcer of the family bond. This is a fundamental support, aid and reference for people with SCI.^{11,12}

It is verified in the present study that health professionals need to act in the sense of preparing the families to perform the care to be provided to the relative with SCI. In this sense, it is fundamental that professionals provide information to SCI patients and their family members.¹³ Adaptations of the physical environment where they live and the help of family members, when well guided by the health professionals, allow the recovery of more positive perspectives and a proper care.¹⁴

The family, therefore, must assist the individual with SCI until he gains autonomy to perform daily chores and self-care independently. This transition period is sometimes experienced by the family with negative feelings and uncertainties. Each family reflects, gives meanings, and reacts to the situation differently. However, it is expected that the family participate and, above all, support the person with SCI in the rehabilitation process, making the adaptation they face less painful.¹⁵

It was still possible to perceive that, in addition to the family, friends play an important role in encouraging the resumption of social interaction. Undoubtedly, reinsertion into society is laborious and requires individual effort, because everything before the injury was normally seen and now starts to have another symbolic meaning. The reports of the participants of this study reinforce what had already been identified in previous investigations with respect to the support of friends who become partners of the family in the care and, above all, in the stimulus for the affected individual to resume activities in society, which is considered salutary for recovery, particularly the psycho-emotional recovery.^{5,15}

Another important support after SCI comes from spirituality. In the view of the participants, clinging to a supernatural belief helped in coping with adversities such as loss of motor function. Similarly, a study carried out in Fortaleza-CE identified the influence of spirituality, religion and beliefs on the quality of life of people with SCI, favoring a better acceptance of the current condition.¹⁶ It is, thus, important that health and rehabilitation institutions create groups to assist and promote the emotional support they need.¹⁰

In the participants' reports, they showed to be satisfied when they received some help from the community, be it financial or emotional. The social support of the community, which involves friends, the church and others, is relevant in the adaptation process.¹⁷ It also influences and promotes health, preventing complications and diseases, helping social reintegration and community living, which is directly related to psychosocial rehabilitation and autonomy.¹⁸

Rehabilitation centers, in turn, in the view of those who could enjoy the service provided by them, played a fundamental role. They provided the necessary learning techniques for

the best use of wheelchairs (transfers and mobility) and self-care procedures such as intermittent bladder catheterization, for example. In addition, they also provided advice on body care, prevention of urinary infections, colds and pressure injuries.

The centers mentioned by the participants, such as the *Hospital Sarah Kubitschek* in Brasília, the *Centro de Vida Independente* (CVI) in Maringá, which has been inactive since 2013, and the *Fundação Selma* in São Paulo, promote not only physical rehabilitation but also social reintegration and psychological support. This is because in these places the individuals coexist with other wheelchair users and share doubts, teachings and experiences, which favors the development of autonomy.

The *Hospital Sarah Kubitschek* and the *Fundação Selma* provide people with SCI full rehabilitation, helping in the process of adaptation to the wheelchair and to the new state of the body. Among the 23 participants, however, only seven had had the opportunity to attend these centers (six attended the *Hospital Sarah Kubitschek* and one the *Fundação Selma*). In four cases, the care was sought based on the patients' own initiative; in two, the care resulted from intermediation of the BHU, and one from intermediation of the *Associação Norte Paranaense de Reabilitação* (ANPR). It should be noted that in Maringá, after the deactivation of the CVI, support for people with SCI has been restricted to BHUs and includes the distribution of materials and supplies for daily use (probes, gauzes for dressings and orthopedic equipment), and to provision of physiotherapy at the ANPR and/or at two private universities.

However, Ordinance nº 793 of the *Ministério da Saúde* (BR) of April 24, 2012, established the Network of Care for Persons with Disabilities under the Unified Health System, which considers the need to improve rehabilitation and prevention of disabilities through the articulation between the different services.¹⁹ It is therefore essential that this network carry out and promote the rehabilitation and clarification necessary to prepare people with SCI to develop basic and instrumental skills of daily living with the maximum possible independence.

In this aspect, the findings corroborate the results of a study carried out with 13 people with SCI in a rehabilitation center that is a reference in the state of SC, which showed that the follow-up that these people receive from the *Sistema Único de Saúde* (SUS) is limited to the supply of medicines and medical material such as procedure gloves, bladder catheter, and dressing supplies.²⁰ Health care institutions and rehabilitation centers, in turn, provide guidance and rehabilitation, especially in the first days after the injury.¹⁹

Besides the relationship with the community, friends and participation in rehabilitation centers, sports can also positively help in the social reintegration of people with SCI. This is because sports cause them to re-plan daily activities and feel active. According to the reports of this study, an adapted sport made

it possible to experience achievements, not only of sports titles, but also of personal accomplishment growth. Moreover, it was observed that for some, sports are the only daily activity performed outside the home. In these cases, reinsertion exists, although in a limited way, because the person interacts with other colleagues, travels to competitions, and finally, has a goal in life.

A study conducted in Londrina-PR evaluated the impact of sports training on people with SCI and verified a significant improvement in social relationships, psychological aspects and quality of life, favoring rehabilitation. These results led the authors to conclude that adapted sporting training complements the process of functional and emotional rehabilitation.²¹

In contrast to the support network, the lack of family support, the low incentive to social interaction and to sporting practices and the fragile clarification about the necessary care by health professionals characterize situations of lack of support. Regarding family functioning, it should be emphasized that the unexpected event of SCI can trigger an inappropriate climate for good family functioning, because individuals are generally unprepared to deal with disability.²² It should be noted that this lack of preparation can trigger inappropriate action to the physical and psychological needs of the individual, either immediately after the injury or over the years. In some cases, the family has an overprotecting attitude, which is also detrimental to rehabilitation.²³

The lack of information, guidance and specific care was perceived by the participants as a flaw in the health system, with serious and damaging consequences to the life of people with SCI. A study with 118 patients at a rehabilitation center in Goiás stated that the health team should provide accurate information so that the subjects and the family may give effective care to prevent health harms. It also showed, as in the present study, the dissatisfaction of SCI patients with respect to avoidable health complications such as pressure injuries that start in the hospital environment.

In relation to social interactions, this is essential for the mental health of individuals in any situation, especially injured people.⁵ In this context, sports for disabled people appears as a favorable option. Although the media has encouraged and promoted the dissemination of this practice through the transmission of the Paralympics, encouragement from health professionals and from the care network still falls short of the ideal. Therefore, more investment and government incentive to different sports modalities are necessary, to support strategies in different scenarios such as schools, universities, clinics, BHUs and rehabilitation centers, with the aim of developing potentialities, promoting physical benefits and providing opportunities for social integration and motor rehabilitation.²⁵

Thus, it is important for the family, the community and health professionals to adopt coping strategies to manage the various difficulties faced by people with SCI, especially with regard to the perception of themselves as different from others.

Strategies focused on the problem are facilitators to adapt to different situations. Example is the sharing of knowledge with other people who have experienced the same situation. Thus, the beginners in the process of rehabilitation receive mutual help, and this will affect the process of living.¹⁸

FINAL CONSIDERATIONS

The results of this study allowed identifying who is included in the support network of people with SCI and how this network acts. In general, this support comes from the family, religion, friends, community, health professionals, rehabilitation centers and sports associations. The family in general forms the basis of care and is the greatest incentive for re-adaptation. Therefore, health professionals need to prepare not only the people with SCI, but also their families, so that they may be able to act by encouraging participation and autonomy in daily tasks, thus favoring the quality of life and physical and mental health of these patients, as well as their social reintegration. However, in spite of family effort, the adaptation process requires or is facilitated by mediators, which, according to the participants of this study, are the coexistence with other individuals who experience the same condition, adapted sports, and rehabilitation centers.

On the other hand, the deficiencies of the support network were also present in the life of people with SCI. They often face difficulties without the support of the family or health professionals. There is also a considerable gap, and it is necessary that the support network proposed by the *Ministério da Saúde* (BR) put PHC in contact with rehabilitation centers so that more people have access to the rehabilitation process and receive the necessary guidelines that can favor them, thus guaranteeing a comprehensive care.

The present study has limitations. The first one is the fact that the interviews with the participants of the sport group were carried out on the university campus and sometimes they seemed concerned about returning to the training activities. Secondly, most individuals had SCI for more than 10 years, indicating a natural adaptation to the time of injury, which may have triggered the bias of forgetfulness with respect to problems in the beginning of the process of adaptation to SCI. Further studies with people newly diagnosed with SCI are recommended to investigate more deeply the presence or absence of support networks at this stage of the injury, allowing the creation of interventions focused on the demands of this group of people.

REFERENCES

1. Nogueira PC, Rabeh SAN, Caliri MHL, HAAS VJ. Cuidadores de indivíduos com lesão medular: sobrecarga do cuidado. *Rev Esc Enferm USP*. 2013[cited 2017 Jan 05];47(3):607-14. Available from: <http://www.scielo.br/pdf/reusp/v47n3/0080-6234-reusp-47-3-00607.pdf>

2. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, et al. International standards for neurological classification of spinal cord injury (Revised 2011). *J Spinal Cord Med*. 2011[cited 2017 June 15];34(6):535-46. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3232636/>
3. Ferreira M, Guerra MP. Adaptação à lesão vertebral-medular. *Psic Saúde Doenças*. 2014[cited 2017 Dec 18];15(2):380-95. Available from: <http://www.scielo.mec.pt/pdf/psd/v15n2/v15n2a05.pdf>
4. Amendola F, Oliveira MAC, Alvarenga MRM. Influência do apoio social na qualidade de vida do cuidador familiar de pessoas com dependência. *Rev Esc Enferm USP*. 2011[cited 2017 Mar 19];45(4):884-9. Available from: <http://www.scielo.br/pdf/reusp/v45n4/v45n4a13.pdf>
5. Holanda CMA, Andrade FLJP, Bezerra MA, Nascimento JPS, Neves RF, Alves SB, et al. Redes de apoio e pessoas com deficiência física: inserção social e acesso aos serviços de saúde. *Ciênc Saúde Coletiva*. 2015[cited 2017 Aug 19];20(1):175-84. Available from: http://www.scielo.br/pdf/csc/v20n1/pt_1413-8123-csc-20-01-00175.pdf
6. Blumer H. *Symbolic Interactionism: perspective and method*. London: University of California Press; 1969. 208p.
7. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 2011. 280p.
8. Alvarez AB, Teixeira MLO, Branco EMSC, Machado WCA. Sentimentos de clientes paraplégicos com lesão medular e cuidadores: implicações para o cuidado de enfermagem. *Ciênc Cuid Saúde*. 2013[cited 2017 Sept 19];12(4):654-61. Available from: http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/18107/pdf_64
9. Trierveiler KS, Ramos FRS, Schoeller S, Nogueira GC, Martins MMFPS, Schneider DG. Funcionalidade familiar da pessoa com lesão medular. *Texto Contexto Enferm*. 2015[cited 2017 Aug 30];24(4):993-1002. Available from: http://www.scielo.br/pdf/tce/v24n4/pt_0104-0707-tce-24-04-00993.pdf
10. Machado WCA, Alvarez AB, Teixeira MLO, Branco EMSC, Figueiredo NMA, Paiva RS. Imagem corporal de paraplégicos: o enfrentamento das mudanças na perspectiva de pessoas com lesão medular. *Rev Enferm UERJ*. 2016[cited 2017 Sept 28];24(1):e16125. Available from: <http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/16125/17872>
11. Cavalcante ES, Pessoa Jr JM, Freire ILS, Cavalcante CAA, Miranda FAN. Representações sociais de pescadores com lesão medular: repercussões e trajetória de vida. *Rev Bras Enferm*. 2017[cited 2017 Oct 12];70(1):132-8. Available from: <http://www.redalyc.org/html/2670/267049841019/>
12. Vivar CG. The family as a unit of analysis: a challenge for nursing. *Invest Educ Enferm*. 2013[cited 2017 Sept 15];31(3):339-40. Available from: <https://aprendeenlinea.udea.edu.co/revistas/index.php/iee/article/view/17493/15160>
13. Silva EC, Costa FJ, Ramos MC, Morita ABPS, Souza CJ. Expectativa de vida: após lesão medular: como recomendar, lidar com limitações e incertezas. *Rev Eletrônica Enferm Vale do Paraíba*. 2017[cited 2017 Oct 05];3(2):81-101. Available from: <http://publicacoes.fatea.br/index.php/reenvap/article/view/1847/1359>
14. Coura AS, Enders BC, Menezes RMP, França ISX. Análise contextual da consulta de enfermagem na visita domiciliar às pessoas com lesão medular. *REME - Rev Min Enferm*. 2013[cited 2017 Oct 20];17(4):1000-6. Available from: <http://www.reme.org.br/artigo/detalhes/901>
15. Schoeller SD, Zamprogna KM, Nascimento LRS. Compartilhando com a família o cuidado a pessoas com lesão medular. *Nursing*. 2015[cited 2017 Jan 05];1:1-11. Available from: <http://www.nursing.pt/compartilhando-com-a-familia-o-cuidado-a-pessoas-com-lesao-medular/>
16. Magalhaes SR, Carvalho ZMF, Andrade LM, Andrade LM, Pinheiro AKB, Studart RMB. Influência da espiritualidade, religião e crenças na qualidade de vida de pessoas com lesão medular. *Texto Contexto Enferm*. 2015[cited 2017 Jan 05];24(3):792-800. Available from: http://www.scielo.br/pdf/tce/2015nahead/pt_0104-0707-tce-2015000620014.pdf
17. Rattray N. Wheelchair basketball teams as "second families" in highland Ecuador. *RDS J*. 2013[cited 2017 Jan 05];9(2-3):92-103. Available from: <http://www.rdsjournal.org/index.php/journal/article/view/61>

18. Borges AMF, Brignol P, Schoeller SD, Albertina B. Percepção das pessoas com lesão medular sobre a sua condição. *Rev Gaúcha Enferm.* 2012[cited 2017 Feb 15];33(3):119-25. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472012000300016
 19. Ministério da Saúde (BR). Portaria N° 793, de 12 de Abril de 2012. Rede de Cuidados a Pessoa com Deficiência. Brasília: MS; 2012. [cited 2016 Sept 29]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2012/prt0793_24_04_2012.html.
 20. Cruz DM, Nascimento LRS, Silva DMGV, Nascimento JPS, Neves RF, Alves SB. Redes de apoio à pessoa com deficiência física. *Ciênc Enferm.* 2015[cited 2017 Mar 15];21(1):23-3. Available from: http://www.scielo.cl/pdf/cienf/v21n1/art_03.pdf
 21. Medola FO, Busto RM, Marçal AF, Achour Junior A, Dourado AC. O esporte na qualidade de vida de indivíduos com lesão da m espinhal: série de casos. *Rev Bras Med Esporte.* 2011[cited 2017 Jan 05];17(4):254-6. Available from: <http://www.scielo.br/pdf/rbme/v17n4/v17n4a08.pdf>
 22. Barbosa MAM, Balieiro MMFG, Pettengill MAM. Cuidado centrado na família no contexto da criança com deficiência e sua família: uma análise reflexiva. *Texto Contexto Enferm.* 2012 [cited 2017 Jan 05];21(1):194-9. Available from: <http://www.scielo.br/pdf/tce/v21n1/a22v21n1.pdf>
 23. Saurí J, Chamarro A, Gilabert A, Gifre M, Rodriguez N, Lopez-Blazquez R, et al. Depression in Individuals With Traumatic and Nontraumatic Spinal Cord Injury Living in the Community. *Arch Phys Med Rehabil.* 2017[cited 2017 Jan 15];98:1165-73. Available from: <http://www.sciencedirect.com/science/article/pii/S0003999316313053>
 24. Mota D, Ribeiro MB. Qualidade de vida em portadores de lesão medular com úlceras por pressão. *Enferm Glob.* 2016[cited 2017 Oct 05];15(42):13-21. Available from: http://scielo.isciii.es/pdf/eg/v15n42/pt_clinica2.pdf
 25. Cardoso VD. A reabilitação de pessoas com deficiência através do desporto adaptado. *Rev Bras Ciênc Esp.* 2011[cited 2017 Jan 05];33(2):529-39. Available from: <http://www.scielo.br/pdf/rbce/v33n2/17.pdf>
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