

## **STRENGTHS AND LIMITS IN THE DAILY LIFE OF THE ADHERENCE TO REHABILITATION OF PEOPLE WITH SPINAL CORD INJURY AND THEIR FAMILIES**

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### **ABSTRACT**

**Objective:** to understand the strengths and limits in the daily life of the adherence to rehabilitation of people with spinal cord injury and their families.

**Method:** an interpretive study of a qualitative nature, based on Comprehensive and Everyday Life Sociology, involving 21 participants, 12 individuals with spinal cord injury and 9 family members, in a Specialized Rehabilitation Center in southern Brazil. The sources of evidence were individual and collective interviews, adopting the strategy of workshops for data validation. The Atlas.ti software was used for data collation and organization. Data analysis involved the following stages: preliminary analysis, ordering, key links, coding, and categorization.

**Results:** the following categories and subcategories were found: Strengths in the adherence to rehabilitation - welcoming and walking side by side; rehabilitation: a return to life; coexistence that brings the family together, as well as practicing faith. Limits on the adherence to rehabilitation - (d)efficiency of the health professionals in health care.

**Conclusion:** rehabilitation was evidenced as a possibility of returning to life, which enables coexistence among equals and stimulates self-care and adaptation. The family rescues the desire to live, and faith is a mechanism of hope and optimism. It is noteworthy that the welcoming deficit in Primary Health Care and the scarcity of rehabilitation care services in the hospital determine the onset of avoidable complications, in addition to the lack of guidance and/or referrals, characterizing a gap in the Referral and Counter-Referral System.

**DESCRIPTORS:** Spinal cord injuries. Daily activities. Rehabilitation. Families. Rehabilitation Nursing.

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# POTÊNCIAS-LIMITES NO QUOTIDIANO DA ADESÃO À REABILITAÇÃO DE PESSOAS COM LESÃO MEDULAR E SUAS FAMÍLIAS

## RESUMO

**Objetivo:** compreender as potências e os limites no cotidiano da adesão à reabilitação de pessoas com lesão medular e suas famílias.

**Método:** estudo interpretativo de natureza qualitativa, fundamentado na Sociologia Compreensiva e do Quotidiano, envolvendo 21 participantes, sendo 12 pessoas com lesão medular e 09 familiares, em um Centro Especializado de Reabilitação no sul do Brasil. As fontes de evidências foram entrevistas individuais e coletivas, adotando-se, para estas, a estratégia de oficinas para validação dos dados. Para o agrupamento e organização dos dados, utilizou-se o *software* Atlas.ti. A análise dos dados envolveu: análise preliminar, ordenação, ligações-chave, codificação e categorização.

**Resultados:** evidenciaram as categorias e subcategorias: Potências na adesão à reabilitação - acolher e caminhar junto; reabilitação: um retorno à vida; a convivência que aproxima a família, bem como praticar a fé. Limites na adesão à reabilitação - (d)eficiência dos profissionais de saúde no cuidado.

**Conclusão:** evidenciou-se a reabilitação como uma possibilidade de retorno à vida, que possibilita a convivência entre iguais, estimula o autocuidado e a adaptação. A família resgata o querer viver, e a fé é um mecanismo de esperança e otimismo. Ressalta-se que o déficit de acolhimento na Atenção Primária à Saúde e a escassez de cuidados de reabilitação no âmbito hospitalar determinam o aparecimento de complicações evitáveis, além da falta da orientação e/ou encaminhamentos, caracterizando uma falha no Sistema de Referência e Contrarreferência.

**DESCRITORES:** Traumatismos da medula espinhal. Atividades cotidianas. Reabilitação. Famílias. Enfermagem em reabilitação.

# PUNTOS FAVORABLES-LÍMITES EN EL DÍA A DÍA DE LA ADHESIÓN A LA REHABILITACIÓN DE PERSONAS CON LESIÓN MEDULAR Y SUS FAMILIAS

## RESUMEN

**Objetivo:** comprender los puntos favorables y los límites en el día a día de la adhesión a la rehabilitación de personas con lesión medular y sus familias.

**Método:** estudio interpretativo de carácter cualitativo, fundamentado en la Sociología Compreensiva y de lo Cotidiano y realizado con 21 participantes, 12 de ellos personas con lesión medular y 09 familiares, en un Centro Especializado de Rehabilitación del sur de Brasil. Las fuentes de evidencias fueron entrevistas individuales y colectivas, para las cuales se adoptó la estrategia de talleres para validar los datos. Para el agrupamiento y la organización de los datos se utilizó el *software* Atlas.ti. El análisis de los datos abarcó las siguientes etapas: análisis preliminar, ordenamiento, vinculaciones clave, codificación y categorización.

**Resultados:** se hicieron evidentes las siguientes categoría y subcategorías: Puntos favorables en la adhesión a la rehabilitación - recibir con brazos abiertos y caminar lado a lado; rehabilitación: un retorno a la vida; la convivencia que acerca a la familia, al igual que como practicar la fe. Límites en la adhesión a la rehabilitación - la (d)eficiencia de los profesionales de la salud en la atención.

**Conclusión:** la rehabilitación se presentó como una posibilidad de retornar a la vida, que hace posible la convivencia entre semejantes, estimula el autocuidado y la adaptación. La familia rescata la voluntad de vivir, y la fe es un mecanismo de esperanza y optimismo. Se destaca que el déficit de recepción en la Atención Primaria de la Salud y la escasez de cuidados de rehabilitación en el ámbito hospitalario determinan la aparición de complicaciones evitables, además de la falta de orientación y/o derivaciones, lo que caracteriza una falla en el Sistema de Derivaciones y Contraderivaciones.

**DESCRIPTORES:** Traumatismos de la médula espinal. Actividades cotidianas. Rehabilitación. Familias. Enfermería en rehabilitación.

## INTRODUCTION

Living with Spinal Cord Injury (SCI), in the daily lives of people with this acquired condition and their families, requires changes, struggles and mobilization to create paths and actions that strengthen coping in daily life, seeking to redefine daily activities and their strengths to move on with life together in this new condition. The “experience of chronic illness is marked by conflicts, relapses, limitations, and deprivations resulting from (re)signifying, inter-subjective negotiations, and in-depth looks at the role of sick people and their families in the daily management process”.<sup>1</sup>

Success in the physical and psychological readjustment of the person with SCI depends on a gradual process of rehabilitation, which consists in the creation of conceptual and operational resources that favor the better functioning of the organism and the best functional capacity, improving the quality of life of patients and families, as it aims at autonomy and re-socialization.<sup>2</sup>

SCI is among the disabling syndromes with the greatest impact on the lives of people and their families. It affects physical, psychological and social integrity, determining different levels of dependence in everyday activities, which is now experienced in a complex and challenging way.<sup>3</sup>

Families feel unhappy, inefficient and insecure most of the time for assuming roles/care that they do not feel confident to perform. Thus, considering that the families will continue the process of rehabilitation of people with SCI in their homes, it is essential that nurses and service networks integrate and promote family involvement in care, preparing them for daily life at home, considering that home care can generate stress due to overload of activities when there is no guideline to follow.<sup>4</sup> The factors that “negatively influence the caregivers’ quality of life are the following: presence of chronic disease; longer care time, age and number of children; and lower schooling level”.<sup>5</sup>

A study<sup>6</sup> carried out in Portugal that investigated the experiences of people who had their lives marked by a spinal cord injury and were undergoing rehabilitation highlights the cultural and socio-political questioning of the person with this disability. The obstacles are present in social inclusion due to the weak politicization of the issue of disability in Portugal and to the failure to present alternative and positive models. This has been an important constraint in the process of identity reconstruction of people with SCI for not having a political intervention activity for inclusion.

There is an urgent need for transition in the care of people with SCI “that is focused on the prevention of preventable sequelae, on follow-up in the process of rehabilitation and psychosocial care, and on greater investments in basic training and qualification of the health professionals in this field”.<sup>7</sup>

From this perspective, it appears that a successful rehabilitation contributes to physical and emotional recovery, avoids or minimizes possible complications and, consequently, reduces the number of readmissions. It is also understood that adherence to rehabilitation involves integration between people affected by SCI, their families and health professionals, especially nurses, due to their holistic ability to care, although it is poorly developed in the practice, due to lack of professional qualification in the field in Brazil.

Considering SCI as a serious problem that affects human beings in their physical, psychological and social condition, and, with the understanding, based on Comprehensive and Everyday Life Sociology,<sup>8</sup> that strength is the power that comes from within each person, being of the liberation and cooperation order; and that the limits are notions of determination or commitment, being a survival mechanism in the face of everyday situations, that is, what protects us from certain events inherent to the human condition, the following question arises: What are the strengths and limits in the daily life of the adherence to rehabilitation of people with spinal cord injury and their families?

This study aimed to understand the powers and limits in the daily life of the adherence to rehabilitation of people with spinal cord injury and their families.

## METHOD

This is an interpretive study with a qualitative approach. The research was carried out in a Specialized Rehabilitation Center, a Public Institution linked to the State Health Secretariat, a reference center in southern Brazil in the care of people with physical and intellectual disabilities. A total of 12 individuals with SCI and 9 family members, chosen by the people with SCI as their primary caregivers, participated in the study, and the other 3 family members invited did not accept to participate in the research. The selection of the subjects was carried out based on the indication of the institution. The criteria considered for the inclusion of the participants were as follows: individuals with traumatic or non-traumatic SCI, with more than one year of injury, of both genders, who were participating in or already concluded a Rehabilitation Program, aged between 18 and 50 years old, and family member characterized as primary caregiver, chosen by the person with SCI. The invitation to participate in the study was made by the main researcher to the individuals with SCI at the end of the activities of the Rehabilitation Program or reassessment.

Data collection took place between January and March 2014, by means of 21 interviews guided by two semi-structured scripts, prepared by the authors, one for the person with SCI and the other for the family member of the person with SCI, based on two guiding questions: For the person with SCI: 1) What are the practicalities and difficulties you encounter in living and dealing with SCI in the rehabilitation process? 2) What facilitates and what interferes with the adherence to rehabilitation in your daily life? For the family member: 1) What are the practicalities and difficulties you find in caring for the family member with SCI in the rehabilitation process? 2) What facilitates and what interferes with the adherence to rehabilitation of your family member with SCI in daily life? Data was collected by the main author. The interruption in the inclusion of new participants occurred when the data collected were repetitive, thus determining that the primary data were sufficient to achieve the proposed objectives and understand the object under study.

The interviews were audio-recorded, lasting approximately 90 minutes, took place in the location preferred by the participants, and were later transcribed in full, and pre-analysis was carried out. For data validation, 2 workshops were held two weeks after the end of the interviews: "Workshop 1: Living SCI", in which the 12 individuals with SCI participated, and "Workshop 2: Taking care of the family member with SCI", in which the 9 family members participated. Each workshop lasted approximately 120 minutes.

The workshops were held after the pre-analysis of the interviews, consisting of three moments:<sup>9</sup> Relaxation and Welcoming - A moment when the environment was prepared, making it more welcoming, followed by a relaxation technique; in this case, a breathing exercise and relief maneuver in a wheelchair, for people with spinal cord injury; and stretching exercises for the family members; Central Activity - A moment when the data collected in the interviews was presented individually to the participants in order to validate and further investigate the data from the interviews. This further investigation enabled clarity and understanding of the experiences regarding the theme under study and was part of data analysis and delivery of the results; Integrative Relaxation - A moment for everyone to express their feelings about the workshop.

The Atlas.ti software was used for data collation and organization. As the method of analysis, the model suggested by Schatzman and Strauss<sup>10</sup> was used, as it is considered an "interactive process between the researcher, his experience and the data", reinforcing that any valid idea (in the workshops) that deserves a few minutes of attention can become a central theme or sub-theme, or simply act as a catalyst for another idea, integrating with the logic of Comprehensive and Everyday Life Sociology,<sup>11</sup> by considering that everything that is human deserves to be the object of analysis.

The analysis process suggested by Schatzman and Strauss<sup>10</sup> comprises the following: the transcription of the interviews and the previous reading with delimitation of the key points, resulting in a codification, which is made from the discovery of classes and their connections. In this stage, the information contained in the material was coded in order to reach the core meaning of the text (codes). Text clippings (quotations) were performed, generating a pre-established registration unit in the pre-analysis. Finally, the aforementioned clippings were classified in the thematic categories (families), guided by the perspective of Comprehensive and Everyday Life Sociology.<sup>11</sup> It is noteworthy that the analysis included triangulation of the interview data and of the workshops.

The research was developed after approval by the Ethics and Research Committee and followed the ethical precepts regarding research and care with human beings. To guarantee the participants' anonymity, they were identified in the study by the letters "E" ("*Entrevista*" in Portuguese) for the interviews with the person with SCI and "F" for interviews with the family, followed by the Arabic number in the order in which the interviews took place.

## RESULTS

The sample consisted of 21 participants, of whom 12 were people with SCI and nine were family members. The sample characterization variables, both of the participants with SCI and of the family members, are reflected in Table 1.

**Table 1** – Characteristics of the sample. Florianópolis, Brazil, 2015. (n=21).

Characterization variables		Participants with SCI	Family members of the person with SCI
Gender	Female	3	8
	Male	9	1
Age	16-30 years old	8	-
	31-39	-	4
	≥40 years old	4	5
Schooling	Higher Education	1	1
	Incomplete Higher Education	6	-
	High School	2	4
	Elementary School	2	4
Marital Status	Incomplete Elementary School	1	-
	Stable union/Married	6	7
	Boyfriend	2	-
	Separated	3	2
Number of children	Single	1	-
	1 to 4	10	-
	Without children	2	-
Degree of kinship	Mother	-	3
	Wife	-	4
	Husband	-	1
	Sister	-	1

**Table 1 – Cont.**

Characterization variables		Participants with SCI	Family members of the person with SCI
Occupation	Retired	9	-
	Receiving benefits	2	-
	Works (administrator)	1	-
Sequelae	Paraplegia	9	-
	Quadriplegia	3	-
	Motorcycle accident	4	-
Nature of the trauma	Traffic accident	3	-
	Firearm	1	-
	Fall	1	-
	Spine surgery-related sequelae	2	-
	Arteriovenous malformation	1	-
Religious belief	Yes	-	9
	No	-	-
Time dedicated	Full	-	3
	Partial	-	6
Work activity	Technical level	-	8
	Pedagogist	-	1
	6 months-1 year	-	3
	≥ 1 year	-	2
Labor reinsertion	Changed schedule	-	1
	Retired	-	1
	Did not resume	-	2
Total by groups		12	9

The familiarization with the daily life of people with SCI and their family enabled the researchers to understand the strengths and limits in the adherence to rehabilitation. The results present two categories and their subcategories: (1) Strengths in the adherence to rehabilitation – welcoming and walking side by side; rehabilitation: a return to life; coexistence that brings the family together, as well as practicing faith; (2) Limits on the adherence to rehabilitation: (d)efficiency of the health professionals in health care.

## **Strengths in the adherence to rehabilitation**

### ***Welcoming and walking side by side***

The strengths appear in welcoming and walking side by side. Welcoming was characterized as a strength in the everyday life of the adherence to rehabilitation of people with SCI. It is an advantage in the rehabilitation process, characterized by dedication to care, attention, affection, respect, good conversations that encourage walking, establishing a relationship of trust and correspondence.

*[...] The service here is different, I'm treated well, [...] with affection, dedication, friendship, respect, there's love in the air, in the tone of the voice, in the care (E6).*

*[...] The contact with people, the conversation with the professionals stimulates the desire to go further, and this helps a lot in the rehabilitation process. Knowing how to listen is fundamental (E2).*

Nurses skilled in the art of caring promote better quality of life in the midst of the disease, motivate people and families, and recognize and involve them in the self-care process. They make the journey together, showing the directions, considering the singularities, qualifying the work by the affectivity and effectiveness of their actions:

*[...] We become friends with the professionals, friends with chatting, supporting, playing, [...] this is encouraging. This “joy” in the midst of illness and rehabilitation made my husband grow and I grew too (F2).*

*[...] Rehabilitation stimulates, it is happy, she gets better, makes her feel good (F5).*

Therefore, it is up to the health professional to identify the stage in which the person is and know how to act considering their individual characteristics, and that they may regress at a given moment. Thus, it is necessary to have consistency and common sense to identify the moments to move forward (“hit hard”) and to back off (“loosen up”) in the care of people in the rehabilitation process, as stated by the research participants:

*[...] There are times when you have to hit hard and then back off [...] there’s the time to give affection and the time to scold [...] you’re calling on me to be responsible, I can’t back off (E7).*

*[...] The professionals need to be strict, but they have to know how to balance. They can’t be too good, too sweet; they have to tell patients to do it and control them closely (F2).*

Another aspect considered as a strength is the home visit as an extension of care, allowing for an expanded diagnosis, *in loco*, of the care needs in the different aspects of human life.

*[...] The professionals guide the rehabilitation, but they must follow-up this process at home, which is experienced with great difficulty (F2).*

*[...] Receiving the home visit of health professionals is very important, because they guide [...], they identify things that are not said in the institution (E2).*

Another strength which emerges in the adherence to rehabilitation of people with SCI and their families is the follow-up by a reference professional, who articulates the information and is responsible for conducting the rehabilitation process.

*[...] We wish we had a reference professional, a person that supports us and articulates the information and is our reference, because we are lost with so much information (E4).*

## **Rehabilitation: a return to life**

Rehabilitation is a possibility of returning to life through the edifying way of teaching the “first steps”, after SCI, through the reuse of the body, continuous movement, challenge, and independence in the activities of daily living.

*[...] Rehabilitating a wheelchair user is the same as teaching a child to take the first steps, learning all over again (E2).*

*[...] For a wheelchair user, rehabilitation is everything, you learn everything again, you learn to use your body (E10).*

*[...] He likes to come here, every time he comes, we start to feel hope again (F6).*

The contact with other people in similar situations, or in more complex situations, makes them more resilient in the face of adversity, there are new hopes of recovering their role and status in the family and social contexts.

*[...] When I go to rehab, I’m happy; it’s an opportunity to see people [...] it’s fun, I’m going out of the house! (E6).*

*[...] I noticed a great progress in my life; I go out of my house, I see people, I talk to them (E8).*

*[...] My son is very ashamed to walk in a wheelchair, to talk to people; rehabilitation worked on communication with him, here he's talkative (F6).*

After SCI, people isolate themselves due to embarrassment of their self-image, as well as to the attitudinal and architectural barriers that make it difficult to live in society, but there is a desire and curiosity to know how their peers and their families live with the disability, what they do on a daily basis, that is, how the re-socialization process takes place, as shown below:

*[...] I'm curious to know how the daily life of wheelchair users is, how they live, whether they feel their feet, how they deal with problems [...] I wanted to talk to them, ask what they do all day, but I'm embarrassed (E2).*

It is necessary to provide coexistence spaces, given their therapeutic contribution to people and families who are in the Rehabilitation Program. Thus, during the workshops, the Support Group for People with Spinal Cord Injury (*Grupo de Apoio às Pessoas com Lesão Medular*, GALEME) was created. It was observed that the participants, involved in making progress in their rehabilitation, changed their routine, aiming to improve their quality of life. The practical result of the group was that the participants themselves assumed their own management, creating a page on a social network, expanding their possibilities of communication, raising reflections about habits and attitudes that promote health, as well as the development of awareness for self-care.

Contact among people in the same situation teaches that it is necessary to establish rehabilitation goals. The functional gains are gradual and almost imperceptible, generating frustrations along the way. However, over time, people recognize that short-term goals are more effective and offer possibilities for reaching medium- and long-term goals.

*[...] Working was my first goal, but recovery is slow and you have to be patient; we ended up being frustrated with goals considered short-term and that took us time to achieve them. [...] I started to notice that at home there are things I need to do first, like getting out of bed, from the bed to the wheelchair (E11).*

*[...] There's no point in rushing, I can't even think about working, [...] I need to overcome one stage at the time, as the nurse said (E4).*

The success of rehabilitation can be strongly influenced by the way these people are managed, especially by the communication established between practitioners, individuals, and families in the rehabilitation process. Rehabilitation is a possibility of returning to life, a process to be overcome one stage at the time. However, self-will and determination are necessary in order to achieve the desired goals.

*[...] What opens the door to the life of a wheelchair user is the acceptance of living, with the chair as our legs. [...], I'm tired of trying to walk again, now I'm putting more emphasis on my health, learning to stand up, taking care of myself (E9).*

*[...] Rehabilitation is difficult, the professionals do their part, (but) it's hard for the person who suffered a spinal cord injury, it depends on the will of each one (E7).*

In the adaptation phase of SCI, patients and families recognize that rehabilitation is the way and, although the professionals are the mediators, it is the person's own will what consolidates the rehabilitation process.

*[...] It's no use saying that people have to go out of the house, go to the movies, go out... [...], people have to want it (by themselves) (E9).*

*[...] Rehabilitation offers the tools, and the family is there, but they only move forward if they want to (F8).*

*[...] Rehabilitation depends on the person's effort and involvement (F10).*

Thus, it is reinforced that the emphasis on rehabilitation should be drawn up with the individuals themselves, which favors their engagement in the activities. However, this will depend on the interest, motivation, and time that each person has to confront and seek to minimize their functional difficulties.

*[...] Rehabilitation depends a lot on us, both physically and psychologically (E10).*

*[...] My physical conditions are very limiting, but my psychological conditions allow me to do more things (E8).*

### ***It is coexistence that brings the family closer.***

The family occupies a larger and more important space in people's lives after an SCI. The moments of crisis can distance or bring people closer to their families, considering the type of affective bond existing prior to the disease. In this study, closeness to the family is referred to as a strength by the participants, because the experience of getting closer and seeing oneself in the other is strengthened and rebuilt daily with the ability to overcome, making them more partners, stimulating them to walk side by side:

*[...] On a daily basis, we neglect our family, we live in the same house, [...] we don't communicate. It's interesting that now, as we stay so much together, the relationship with my children and my wife has improved, we are more present, [...], closer (E7).*

*[...] My wife says that my way of coping with what happened ends up giving her strength to endure. Actually, her certainty and strength keep me going (E11).*

### ***Practicing faith***

Practicing faith becomes a form of hope nurtured and supported by a religious creed that helps to overcome hopelessness. For the participants, practicing faith keeps them "on their feet", helps them in the process of acceptance, escape in difficult times, and encouragement at the time of falls; in short, it cheers them up, strengthening coping.

*[...] I don't practice religion, I practice faith. If I'm standing today, it's because Our Lord supported me and is giving me another opportunity in life (E10).*

*[...] It helps a lot in the process of acceptance and overcoming the limits. [...] since I ended up in the chair, I imagine it is to improve something in me [...] and stop whining (E9).*

### **Limits on the adherence to rehabilitation: (d)efficiency of the health professionals in health care**

The limits are manifested in the (d)efficiency of the health professionals in dealing with people with SCI and their families, resulting in avoidable complications due to lack of specific guidance.

The limits on the adherence to rehabilitation in the daily lives of people with SCI start when they are faced with the diagnosis of an acquired disability that can be amplified by the carelessness of health professionals. This is because it generates situations as incapacitating as the acquired disability:

*[...] We weren't informed about what we should do. [...] it's all new! (F8).*

*[...] At the health center, we have access to medical appointments, but the protocol for people with spinal cord injuries is deficient, they don't know how to instruct about what to do when things get worse (F6).*

The lack of guidance is not limited to the professionals in Primary Health Care (PHC) units; it is also seen in the services offered by independent professionals. Thus, the Specialized Rehabilitation Centers (SRCs) become the reference of care for people with spinal cord injury.

*[...] With regard to spinal cord injury, rehabilitation is the reference, [...] the private physician didn't have much knowledge on how to guide a person with spinal cord injury (F4).*

*[...] All guidance on how to live after the injury was at the rehabilitation center [...] I had no guidance at the clinic. Not trusting the professional who takes care of you is absurd! It's sad; it's your reference near home (E1).*

Evidenced in the participants' statements, the Referral and Counter-Referral System is precarious and there is no guarantee of continuity of care, due to the lack of guidance and/or referral to the reference units, leading to an increased risk of complications due to the time of arrival at the SRC.

*[...] There was no information about the rehabilitation center [...] things are so close, but people send you to another place and you get lost, we are left with no answers, not knowing what to do (F4).*

*[...] I left the hospital and nobody told me to look for rehabilitation, later I found out from my uncle who works at the INSS (E1).*

With regard to the health care policies for people with disabilities, it is observed in the reports below that people and their families are very little oriented about what the law determines as a right and its implementation in the practice.

*[...] We don't know anything about policies for disabled people and we didn't look for information (F7).*

*[...] I don't see the policies being executed. The politicians see what matters to them [...] health is an expense when it should be an investment. The public policies need to reach the health services, so that people are more informed about their rights (E3).*

In the SRCs, care for people with SCI and their families involves co-responsibility and availability of the health professionals, creating a bond as they approach each other's experiences and daily lives, facilitating adherence to rehabilitation. However, in a way, a "dependence" bond is also created, expressed by the feeling of abandonment after discharge.

*[...] When I was discharged from rehab, I felt like I was forgotten [...] nobody called to check on me [...] We have a great identification with you since you are our reference, we can't lose contact. [...] we need this "push", we'll always face obstacles on the way (E1).*

## DISCUSSION

The predominance in this study of young male individuals with traumatic SCI is corroborated by a research study conducted in a large teaching hospital in the city of Belo Horizonte, state of Minas Gerais, Brazil, showing that all patients were male, with a mean age of 39 years old, which is consistent with the world and national incidence pattern of spinal cord trauma; the main etiology associated with the accident was trauma caused by firearms, which evidences the tendency of increased violence and criminality in large urban centers.<sup>12</sup> Another study showed that the trauma caused by firearm projectiles was responsible for 9.2% of the spinal cord injuries, with a mean of 14.8 new cases per year; 86.5% of them were male patients and 73.1% were under 30 years old.<sup>13</sup>

Considering the strengths revealed in the process of adherence to rehabilitation of people with SCI and their families, welcoming is characterized by dedication in moments of care. According to Ordinance No. 793/2012 on the guidelines for the operation of the Care Network for People with Disabilities, welcoming is an essential element of care for the reorganization of the health services and expresses the relationships established between patients and professionals.<sup>14</sup> In addition, the home visit is seen as a strength, being an extension of care, which allowed for an expanded *in loco* diagnosis of the care needs, in the different aspects of people's life. The facilitating factors for achieving the care strategies observed for the health of people with disabilities are the following: rehabilitation actions, home visits, and matrix support, bearing in mind that these factors are essential for comprehensive care and adherence to rehabilitation.<sup>15</sup>

Home visits allow for the familiarization with daily life, starting from the recognition of the “way of life of human beings that is shown in daily life, expressed by their interactions, beliefs, values, symbols, meanings, images and imagery, which outline their process of living, in a movement of being healthy and getting sick, punctuating their life cycle. This journey through the life cycle has a certain cadence that characterizes our way of living, influenced both by the duty to be and by the needs and desires of everyday life, which are called the pace of life and living”.<sup>16</sup>

The support of a reference professional, who articulates the information and is responsible for conducting the rehabilitation process, also emerges as a strength. The health team, especially nurses, for being closer and for spending more time with the person with SCI and their family members during hospitalization, should provide means of teaching and learning self-care after discharge, in order to prevent avoidable sequelae and to favor the rehabilitation process.<sup>17</sup>

The creation of the GALEME group, developed during this study, served as a stimulus for social interaction and reflections about the process of living with SCI, as well as it favored awareness for self-care; it was considered a group that strengthens the therapeutic contribution in the rehabilitation process. Reinforcing the thought of sensitive reason,<sup>18</sup> the meaning of “tribe” comes to light. Thus, it is possible to think about the tribe of people with spinal cord injury and their families, expressing a factor of communion, an identification, to constitute the identity of each person, a feeling of sharing, which transits through the ethics of aesthetics, a ‘feeling together’.

Coexistence among peers is a strategy to privilege the subjective and inter-subjective elements in the care process for the chronically ill, considering their needs as the guiding thread of interdisciplinary actions in a counter-hegemonic division.<sup>1</sup>

Practicing faith is also pointed out as a strength and reinforces the emphasis on rehabilitation, which should be drawn by the individuals themselves, providing engagement in the activities; however, it will depend on the interest, motivation, and time of each person. When evaluating the influence of spirituality, religiosity and beliefs on the quality of life of people with SCI, in the constructs, a higher quality of life was observed which is related to hope, optimism, spiritual strength, and also faith.<sup>7</sup>

The family support for the person with SCI rescues the desire to live, which stimulates and offers security, bringing certain normality to life, promoting the necessary adjustments so that the person adapts to the new pace of living, configuring a strength in the adherence to rehabilitation. The family, as well as the health professionals, has a fundamental role in the rehabilitation process, being able to provide support and encouragement in coping with the acceptance of the new condition, in order to live in harmony with the injury and the limitations it causes.<sup>19</sup>

The process of *acceptance of life*, as a more astute way of looking at life,<sup>18</sup> in no way means settling. The phase of acceptance and adaptation to the new pace of living happens when the individuals realize the need to restructure life, turning to what is essential, taking advantage of their own power. There are several factors that influence the person’s adaptation, namely: the neurological level of the injury, the support of the family, institutional/governmental support, support from society, the engagement with the health professionals and, mainly, the person’s own will to get rehabilitated.

The focus of the rehabilitation process is in line with Michel Maffesoli’s postmodern thinking. Rehabilitation focuses on the transfiguration of daily life and works with what there is “today” of preserved ability, for the greatest possible independence within the functional potential of each individual, aiming at a better adaptation to their new condition. Postmodern thinking<sup>18</sup> aligns with today, with the here and now, and concerns what people have been looking for: life in its eternal restart. A cycle ends, forcing the recognition that the saturation of a world with disabilities is not the end of the world but the end of a world to be reborn in another, expressed by the resumption of strength and vigor, adapting to another pace of living, bringing the importance of life, the cult of the body (self-care), the feeling of tribal belonging ((re)socialization), the return to the desire to live, today and now, rehabilitation.

With regard to the limits on the adherence to rehabilitation of people with SCI and their families, (lack of) care during rehabilitation in the hospital environment and the gaps in the Referral and Counter-Referral System are limiting factors that will reflect negatively on individual and family care in life-long confrontations. After discharge, in addition to the family, there should be a sufficient and complete social support network to respond to the needs required by the high complexity of a person with SCI.<sup>20</sup>

Care and rehabilitation actions in PHC are still scarce, the professional practices still lack qualification for the comprehensive care of people with disabilities, and the lack of physical and attitudinal accessibility in PHC units perpetuates a cycle of historically constructed inequalities.<sup>21</sup> In this context, Nursing is an integral part of the rehabilitation team, present in the different levels of health care of the person with SCI and their family, standing out for the systematized action, evidenced by the Nursing Process that aims at a comprehensive, contextualized and humanizing care, in order to ensure improvements in the quality of care and support for self-care.

The disarticulation of the assistance networks, identified in this study, render unfeasible the actions of health promotion, prevention of risk factors, assistance to harms, and the early rehabilitation of the person with SCI. People with disabilities have worse health prospects, low schooling levels, lower economic participation, and higher poverty rates. This is partly due to the fact that these people face barriers to access services such as health, education, employment, transportation, and information.<sup>15</sup> In this context, people and their families are given little guidance on what the law determines as a right. In the case of the Person with a Disability, within the scope of the SUS, the Health Care Network was established by Ordinance No. 793 of April 24<sup>th</sup>, 2012, establishing guidelines for the care of people with temporary or permanent, progressive, regressive or steady, intermittent or continuous disability.<sup>22</sup>

Thus, “it is necessary to develop public health policies and to elaborate more comprehensive intervention strategies that include not only the person with SCI, but also the caregiver”.<sup>5:123</sup> “Remedying, thus, an inequality of opportunities that has long been neglected by the Democratic State of Law”.<sup>15:233</sup> From the perspective of Comprehensive and Everyday Life Sociology,<sup>18</sup> “expanded care” is of the order of the person, of organic solidarity, which is based on affective social ties, on the basic ambiguity of symbolic structuring, guaranteeing the “cohesion” of the group, of the exchange, of the sharing of values, of places, of ideas, in contrast with mechanical solidarity, which is of the order of the institution.

Weighing the family caregivers of adults with spinal cord injuries, a study identified that “those of quadriplegic individuals have worse quality of life, mainly in the physical health component, in relation to those of paraplegics. Caregivers of paraplegic people have worse quality of life in the domains of pain, vitality, and physical appearance.”<sup>5:132</sup> In this sense, understanding the daily lives of people and families, as a scene (lived) and scenery (context), requires *libertarian thinking*,<sup>11</sup> based on the notion of “typicality”, of which we are an integrated (and interested) part of what we want to talk about (care); the researcher (professional/person/family member) is also an actor and participant. In fact, it is what makes the critical perspective give place to the statement that, in different ways and through different modulations, we are elements of this reality. Libertarian thinking, which is part of subjective and inter-subjective understanding, involves generosity of spirit, closeness, correspondence – an exercise of putting oneself in someone else’s place, empathy.

Understanding the daily life of the person with SCI and their families allows the health professional, especially nurses, an analysis from a look at what in fact “is”, profoundly apprehending the singularity with these people, being a substrate for the actions on the determinants and conditions of this condition in the health-disease process with a view to Health Promotion and the establishment of a care plan that approaches the unique experiences of people with SCI and their families and that may provide the opportunity to rescue citizenship and facilitate adherence to rehabilitation.

As a limitation of this study, its intentional sampling is to be noted, due to the selection of people with SCI linked to a scenario that was predetermined but, based on the results found, intentional sampling can be considered representative in similar populations and conditions. There were no limitations regarding the difficulties in the development of the research, as well as in obtaining the results. The participants showed interest and the scheduling of the interviews and workshops was established according to their availability and location of interest.

The indication is evidenced of future research studies that portray the continuity of the rehabilitation process at home and its implications for the re-socialization of people with SCI and their families.

## CONCLUSION

By understanding the strengths and limits in the adherence to rehabilitation of people with spinal cord injuries and their families, it was possible to show that rehabilitation is a possibility of returning to life, as it allows for coexistence among equals; setting goals; the awareness that it is necessary to have a will of one's own to rehabilitate; accepting and adapting to the new pace of life. The family occupies a larger space in people's lives because of closeness, through care, for the support it rescues and for the convenience of dialog, being strengthened by faith.

However, the rehabilitation process still has some gaps in the different health care services: a welcoming deficit in PHC, shortage of rehabilitation care services in the hospital (resulting in avoidable complications), in addition to the lack of guidance and/or referral to Specialized Rehabilitation Centers, characterizing a gap in the Referral and Counter-Referral System.

Nurses are important in all segments of this journey, from hospitalization to home, consolidating their practice by means of the Nursing Process in the different dimensions of care, contributing, evaluating, and improving the care and self-care plan. This indicates the need for specific training to enable care in rehabilitation, so that the professionals working in the Health Institutions can be prepared and motivated to integrate themselves into the daily experiences of people with SCI and their families.

As a contribution, this study shows the strengths and limits that impact on the adherence to rehabilitation of the person with SCI and their family, which can corroborate with more inclusive and effective health strategies.

It is important to note that the data collection strategies used (individual interviews and workshops to validate and deepen the data), enabled an approximation to the experience of these people and families. The workshops went beyond the academic objectives and proved to be an important social product of the study with the creation of the GALEME group, constituted from the workshops of this study and which has been maintained through monthly meetings, with activities and specific themes based on the needs of the participants, to the present date. The GALEME group enables coexistence among equals, characterizing a strength in the adherence to rehabilitation of people with SCI and their families. It allows for the encounter of different people, concepts, values and cultures, in which people identify with each other in a dynamics that makes it possible to speak and listen, reflect and learn about their own lives, involving aspects related to recognition, acceptance and active adaptation to the new pace of life, identification of risk factors, cultivation of habits and attitudes that promote quality of life, especially awareness for self-care, aiming at the peak of rehabilitation: the re-socialization of people with SCI and their families.

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## NOTES

### ORIGIN OF THE ARTICLE

Extracted from the dissertation -The daily life and pace of living of people with spinal cord injury and their families: strengths and limits in the adherence to rehabilitation for Health Promotion, presented at the Graduate Program in Nursing of the *Universidade Federal de Santa Catarina*, in 2015.

### CONTRIBUTION OF AUTHORITY

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Discussion of the results: Tholl AD, Nitschke RG, Veigas SMF.

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There is no conflict of interest.

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