



Investigación y Educación en Enfermería

ISSN: 0120-5307

revistaiee@gmail.com

Universidad de Antioquia

Colombia

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Investigación y Educación en Enfermería, vol. 34, núm. 1, 2016, pp. 84-93

Universidad de Antioquia

Medellín, Colombia

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# Body and Corporality in adolescents and young adults with spinal cord injury

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## Body and Corporality in adolescents and young adults with spinal cord injury

**Objective.** To describe the meaning given by adolescents and young adults to the changes in their bodies and corporality after a spinal cord injury.

**Methods.** Qualitative study based on symbolic interactionism in which 12 adolescents and young adults, who had suffered spinal cord injury 6 months or more before, participated. The information was recollected through a series of in-depth interviews and field journals. The guidelines proposed by Corbin and Strauss were followed for the process of codification and categorization of the data. **Results.** Four categories were identified that describe the meanings given by participants to the changes in their bodies and corporality: Transformation of self-image, living with contradictions in the relationships with others, withstanding the burden of a disability and adapting to the new conditions. **Conclusion.** The results allow for the comprehension of the meanings that are given by the people who have suffered a spinal cord lesion to their situation. This will in turn open the possibility of offering these people a better individual nursing care that focuses more on the particular needs, so that both

they and their families can be helped on their way to adaptation to the new situation.

**Key words:** rehabilitation nursing; spinal cord injuries; disabled persons; adolescent; young adult; adaptation; nursing theory.

## Cuerpo y corporalidad en adolescentes y adultos jóvenes con lesión traumática de la médula espinal

**Objetivo.** Describir los significados que otorgan los adolescentes y adultos jóvenes a los cambios en el cuerpo y la corporalidad luego de una lesión traumática de la médula espinal. **Métodos.** Estudio cualitativo basado en el interaccionismo simbólico, en el cual participaron 12 adolescentes y adultos jóvenes con trauma raquímedular con un tiempo mayor a seis meses desde el evento. La información se recolectó a través de entrevistas de profundidad y diarios de campo. En el proceso de codificación y categorización de los datos, se siguieron los lineamientos propuestos por Corbin

y Strauss. **Resultados.** Se identificaron cuatro

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**Article linked to research:** Body and Corporality in adolescents and young adults with spinal cord injury.

**Conflicts of interest:** none.

**Received on:** May 14, 2015.

**Approved on:** December 4, 2015

**How to cite this article:** Duarte DM, Torres YM, Moreno ME. Body and Corporality in adolescents and young adults with traumatic lesions of the spinal cord. Invest Educ Enferm. 2016; 34(1): 84-93.

**DOI:** 10.17533/udea.iee.v34n1a10

categorías que describen los significados que tienen para los participantes los cambios en el cuerpo y la corporalidad: Transformación de la imagen de sí mismo, vivir contradicciones en las relaciones con otros, soportar la carga de la discapacidad y adaptarse a la nueva condición. **Conclusión.** Los resultados permiten comprender los significados que otorgan las personas con lesión medular a su condición, para poder brindar un cuidado de enfermería individual enfocado en las necesidades particulares, para ayudarlos a ellos y a sus familias a adaptarse a la situación.

**Palabras clave:** Enfermería de rehabilitación; traumatismos de la médula espinal; personas con discapacidad; adolescente; adulto joven; adaptación; teoría de enfermería.

### Corpo e corporalidade em adolescentes e adultos jovens com lesão traumática da medula espinal

**Objetivo.** Descrever os significados que outorgam os adolescentes e adultos jovens às mudanças no corpo e a corporalidade após de uma lesão traumática da

medula espinal. **Métodos.** Estudo qualitativo baseado no interacionismo simbólico, no qual participaram 12 adolescentes e adultos jovens com trauma raquimedular com um tempo maior a seis meses desde o acontecimento. A informação se recolheu através de entrevistas de profundidade e diários de campo. No processo de codificação e categorização dos dados, se seguiram os alinhamentos propostos por Corbin e Strauss. **Resultados.** Se identificaram quatro categorias que descrevem os significados que têm para os participantes as mudanças no corpo e a corporalidade: Transformação da imagem de si mesmo, viver contradições nas relações com outros, suportar a carga da deficiência e adaptar-se à nova condição. **Conclusão.** Os resultados permitem compreender os significados que outorgam as pessoas com lesão medular a sua condição, para poder brindar um cuidado de enfermagem individual enfocado nas necessidades particulares, para ajuda-los a eles e a suas famílias a adaptar-se à situação.

**Palavras chave:** enfermagem em reabilitação; traumatismos da medula espinal; pessoas com deficiência; adolescente; adulto jovem; adaptação; teoria de enfermagem.

## Introduction

Spinal cord injury is known as the structural damage to the central nervous system that can happen in different degrees and to different extents. Spinal cord lesions can be linked to trauma, neoplasia, and congenital defects, among other causes and the effects can lead to physical disability.<sup>1</sup> Approximately 785 million people around the world (15.6%) above the age of 15 live with a disability and in Colombia traffic accidents are becoming one of the leading causes of trauma. In the year 2005 alone, more than 1 036 traumas to the region of the neck and pelvis were reported, and 37% of these accidents produced spinal cord lesions (SCL). Of these cases, 56% resulted in quadriplegia and the other 44% resulted in paraplegia.<sup>2</sup>

The disability that is associated to the aftereffects of this type of lesion can compromise the

correct functionality of the human being and thus it requires complex interventions that can help to overcome the resulting difficulties.<sup>3</sup> This experience is considered as “catastrophic” due to the implications caused by the limitations in the execution of daily-life activities,<sup>3</sup> the performance of the regular role and the psychosocial implications of the same.<sup>4</sup> The changes that come over the body of adolescents, associated with the disability caused by the spinal cord injury, can produce emotional issues, severe feelings of inferiority, mistrust, a sense of dependence, immaturity in the process of formation of the self-image and a delay in the correct process of social development.<sup>4</sup>

It is for this reason, and given the implications involved in the occurrence of a spinal cord injury during this period of life, that the purpose of this study was to describe the meanings given to the changes that take place in the body and

corporality of adolescents and young adults who have suffered this type of injury.<sup>5</sup> The study was based on symbolic interactionism because this perspective allows to describe how the meanings awarded by adolescents and young adults to the reality of the changes in their bodies and corporality influence their behavior and interaction with the environment.<sup>5</sup> Understanding these aspects is important to determine the strategies that may improve the nursing care offered to these people based on the meaning and relevance that the condition has for the participants.

## Methods

A descriptive-interpretative qualitative study was done based on the principles of symbolic interactionism. This study seeks to learn about the interpretation made by people about their situation. The participants of the study were identified through the snowball strategy in 2013 from a Rehabilitation Center located in the city of Bogotá (Colombia). 12 participants were included among which there were late-adolescents (15 to 19 years old) and young adults (20 to 24 years old) whose lesions had taken place at least six months previously. As for the socio-demographic characteristics of the participants: four were women and eight were men. Two were adolescents between the ages of 14 and 19 and 10 were young adults whose ages ranged between 20 and 24. Among the causes of the lesions, three happened due to firearms, four due to falls and five cases were due to traffic accidents. In relation with the injury level, nine were thoracic, two were cervical and one was lumbar. The data were collected by the researchers using semi structured in-depth interviews and field notes that were conducted in the place that the participants chose. The interviews were recorded and transcribed verbatim. Then the nominal and substantive codes were identified, and grouped into sub-categories and categories following the guidelines proposed by Corbin and Strauss.<sup>6</sup> The process of data collection finished when no new information was found in the interviews. Once the analysis was over, a process of contrasting of results began

with some of the participants, in order to establish the credibility of the interpretation.

**Ethical considerations.** Ethical approval was obtained from the School of Nursing and Rehabilitation at La Sabana University Research Committee, and from the Rehabilitation Institution review board where the participants were identified. Informed consent was obtained from all the participants in this study, and the researchers preserved the confidentiality of the information provided from them.

## Results

Four categories were identified that describe the meanings given to the changes that take place on the body and corporality of the adolescents and young adults that have suffered spinal cord injury: a) Transformation of the self-image, b) living with contradictions in the relationships with others, c) withstanding the burden of disability and d) adapting to a new condition. Each one of these categories is described next.

### Transformation of the self-image

*"Imagine yourself moving one day and then the next not being able to even move a finger. It was terrible! Yes, after some time... you begin to move your arms, or, all right, I have been able to move my arms, even though I was supposed not to be able to do so given the level of my lesion. They said I would not be able to move them, eh... not being able to write. Yes, in that moment, not being able to talk, totally falling. A person who used to weight around 100 kilos became one who weighted more or less 45 kilos. Yes, literally becoming a skeleton that is terrible, both regarding movement and psychologically. This can really become devastating for a person" (O08.1.3.1-5).* This note reflects the significance that the changes to self-image acquire for participants and the way this image changes from the one they had before the spinal cord injury. The subcategories that gave origin to this category were: a) "being fragile", because the adolescents

and young adults perceive a deterioration in their health and have a predisposition to suffer from complications; b) “losing control over their bodies”, due to the loss of voluntary movements below the level of the injury, the appearance of involuntary movements in their lower extremities, and the loss of control over the sphincters that result in urinary and fecal incontinence. This is why they have to learn how to perform their daily activities in a different way. These activities become very difficult and they need time and space to be performed which is why people perceive them as obstacles for them to live in society.

One of the consequences of this alteration is “*becoming dependent*” of equipment and supplies (like diapers, catheters, orthotic devices, and wheelchairs) as well as of other people to be able to maintain their vital functions and the integrity of their bodies, to eliminate and to mobilize. This experience is usually difficult to overcome and accept, it affects the mood, the people feel down and lose their interest in participating in different activities. In the same way, this situation generates conflicting feelings of pleasure at knowing that they have someone at their disposal who will give them the help they need, but also of discomfort, annoyance or dislike at having to constantly ask help, due to the loss of privacy, which causes difficulties to confront the condition.

Within this category the *Abandonment of Role* was also identified. This is described as the difficulty to study, work and realize sports activities due to the dependence from other people, from equipment and other supplies, as well as the presence of physical and architectonic barriers that limit and prevent mobilization. This awakens in the participants feelings of sadness and a difficulty to adapt to their condition of disability.

Another subcategory was “*Perceiving social rejection*” caused by the difficulty that people have of being accepted by society when they have a disability. They feel that people are at times indifferent to their particular needs, which is why the participants referred that they usually feel that they make others uncomfortable since they require

help and they take much longer to perform their activities. This lack of understanding and culture is perceived by these people as a selfish attitude and a lack of respect.

All these changes also cause a modification of the *corporal image*. The perception that disabled adolescents and young adults have of themselves is affected by the changes caused by the spinal cord injury and their condition and some of them become depersonalized and identify themselves by the level of their lesion. This situation turns into a difficult experience to handle because these people see and feel themselves as different from others. Likewise, disabled people perceive that their nuclear family has changed the perception they had from the one before becoming dependent from others, which generates suffering and discomfort, especially if the lesion was recent.

### **Living with contradictions when having relationships with others.**

*My friends have been a blessing... I have... three, four friends in particular who have been... a great help for me... My family, well, words are unnecessary. Before the accident, my family and I did not have a good relationship... we fought all the time... I was very isolated from my family. But then things changed from the moment I was in the hospital... in this situation... we have become really close... that's a good thing. With my friends likewise. Both those who were my friends before and the ones now... I have always been with the same and they have been there for me always, thank God (008.1.6.1-3).* This note reflects the significance that relationships with other people have for adolescents and young adults who have suffered a spinal cord injury. It becomes evident in it that *Support* is defined as the permanent and continuous accompaniment of the participants by others, especially the family, friends, partner, healthcare workers and others who are undergoing their same condition and also the spiritual accompaniment provided by the belief in a Superior Being. For this reason, the participants feel grateful. Because with the help from their family members: parents, siblings, significant other

and their friends they have been able to share and go through the whole rehabilitation process, which motivates them to continue moving forward with their condition. Also, they feel committed to giving help and support to other people with disabilities, making use of their own experiences throughout the rehabilitation process that contributed to their own improvement. However, they may also feel *Abandonment* on the part of their loved ones, their partners, their friends and those who used to be around them and that with time stopped sharing with them. Participants say that people in general have an erroneous concept of what a disability is and that they tag disabled people just because of their condition, without caring about their needs. This generates *feelings of fear and isolation* which makes the interaction and relation with those around them more difficult.

### Withstanding the burden of disability

*Every day it is the same routine. Wake up at 8, have breakfast, take a bath and do, and watch TV, read. It is 12, have lunch, have a snack, talk to the family, arrive at 7 in the evening, watch soap operas and then go to bed. Every day was exactly the same, so, it becomes really, really... dull* (008.1.4.2). In this note the significance that the burden caused by the condition of disability has for people who suffer it can be appreciated in what is denominated as *Rejection to hospitalization*. Adolescents and young adults with spinal cord injury reprove the monotony in the healthcare services and in the hospital routines that happen in all the activities of daily life. They feel there is a loss of privacy and of the autonomy that is caused by the dependence to healthcare workers and institutional rules. This situation generates discomfort because it forces people with disabilities to remain in unfamiliar places, where on occasion the food is not to their liking and the rejection to it causes further delays in the process of recovery and weight loss. Remaining in the hospital setting, and being surrounded by people who consider themselves “sick” causes a deterioration of the emotional state, which further delays the process of recovery.

Another meaning that acquires importance in this category is the *awareness of the severity of the lesion*. The presence of symptoms like intense pain in the affected zone, the loss of mobility, as well as the presence of sensibility on the upper extremities and/or lower extremities and the loss of response to external stimuli constitute a signal that indicates a severe compromise of the spinal cord. This situation is difficult to accept, it causes feelings of frustration and depression, especially when disabled people realize that they will not be able to achieve the objectives set for their rehabilitation. It is at that moment that feelings of hopelessness make their appearance, when the person realizes that his or her condition of disability is not going to improve, and they begin to lose interest in their rehabilitation process and they become demotivated to overcome the difficulties to be able to continue on with their lives.

The subcategory of withstanding a difficult experience is the meaning that the participants with a disability give to the change in their lifestyles due to the spinal cord lesion. For some of the participants it is a very difficult situation to go through because they experience a sense of guilt due to the condition they have. This change in lifestyle is very drastic and sudden since they feel now unable to perform what used to be their normal routines. Some of the participants manifested that as a consequence of their injury they had at times difficulties to control their emotions, they assumed attitudes of rebellion and negativity, to the point of stopping talking for a long time with their loved ones and that they began assuming negative behaviors with which they pretended to call the attention of those around them.

### Adapting to the new condition

*‘Continue doing your major, yes, well, I do not see, the limitation has to do with some mobility and so, but, in the end that does not affect, let’s say, doesn’t affect something... how can I say it... well... well that suddenly my career depended on my mobility. If I had been a soccer*



*player or something like that, well, maybe then (laughter), but no, no. I study Law and I do not see any problems to continue with my major (007.1.10.1).* In this note the significance of adapting to the new condition can be appreciated. Two subcategories were identified in this category, which were denominated as follows: *Regaining control over the body and Transformation of life when there is a spinal cord lesion.*

*Regaining control over the body.* In this subcategory some of the participants experiment new sensations, they recover the mobility and sensibility of their injured extremities partially or totally as well as they recover the control over their urinary and fecal elimination, important aspects that allow disabled people to recover their independence. Other participants do not have this possibility but they learn to perform their daily activities in a different way, which in turn allows them to recover the control over their body and prevent complications. The experiences lived as a consequence of the spinal cord lesion, and the changes in habits and daily routines, which had to take place after the event, force disabled people to care after their body and watch over it in a permanent and conscious way. This with the purpose of avoiding the appearance of complications like pressure ulcers, urinary infections, among others.

*Transformation of life after a spinal cord injury.* The changes that take place in the body and the changes in corporality due to the spinal cord lesion “*Transform the life*” of the people who suffer these lesions. They begin to constantly seek their physical and personal independence, which are important factors that help them to overcome their condition. Some of the participants recognize the value of being alive after such a catastrophic event like the one they have faced. This motivates them to continue and reflect on the way in which they were leading their lives before the lesion.

## Discussion

The adolescence is a stage in which people's bodies undergo physical changes and the self-

image and interests from childhood also change. During this time peer gatherings take precedence over other things and becoming independent from parents, maintaining social relationships, privacy and intimacy also become very important to reaffirm identity.<sup>7</sup> Both adolescents and young adults with spinal cord injuries experiment changes in their body and corporality that cause dependence from other people, equipment and other additions, which transforms their self-image due to the consequences of their lesions.

One of the adaptation modes described by Roy (2009)<sup>8</sup> in her conceptual Model is the mode of self-concept. It is defined as the group of beliefs and feelings that people have of themselves thanks to their self-perception and the one they acquire from the people around them. According to Roy, the self-concept has two components: the physical self, which includes the corporal sensations and body image, the personal self that is composed by the ethical, moral and spiritual self, the ideal self that is associated with the project of life and the self-consistency, meaning the organized ideas that surround the self. In adolescents and young adults the consequences of a spinal cord lesion alter the self-concept when these components are modified. There is a change in the perception and functionality of the body, which in turn alters the self-image people have and their social image. Society considers that young people must be strong and healthy and the people who have a condition of disability are considered sick.<sup>8</sup>

Due to the aftereffects of a spinal cord injury people lose the capacity to execute activities of daily living and they face an increase in the predisposition to have complications, such as pressure ulcers, urinary tract infections, spasticity, hyperesthesia, psychological stress and chronic pain.<sup>9</sup> For this reason both adolescents and young adults perceive themselves as weak and highly susceptible to suffering diseases that force them to remain hospitalized for prolonged periods of time and to be isolated from their family and friends. These results concur with the ones found in the literature where the high incidence of complications derived from the disabled condition

can be evidenced.<sup>1</sup> The studies done by Dewis<sup>10</sup> and Moreno *et al.*,<sup>11</sup> about the significance that living with such a condition has for people with a spinal cord lesion underline the impact of the body changes and the need these people have of constructing a new normality.

The results of this study describe the impact that physical changes have on the adaptation process to the condition. The participants express discomfort over the loss of their privacy due to the dependency from other people and also feelings of inferiority when they are stigmatized for their situation. This is why they show antisocial behavior like stealing; because they wish to call the attention of their peers.<sup>12</sup> These results concur with those made by Kim,<sup>13</sup> who affirms that adolescents with spinal cord injury face difficulties in adapting to their condition, that they display emotional distress, severe feelings of inferiority, mistrust, feelings of dependence, immaturity in the process of formation of the self-image, retardation in the social development and antisocial behavior.

One of the most influential aspects during the process of adaptation to the condition of disability in both adolescents and young adults is the support of the family, friends and partner, especially during the acute stage of the lesion. This matches with the findings made by Gonzalez,<sup>3</sup> who maintains that when disabled people find themselves forced to deal with the reality of the consequences produced by the lesion, the family support and the faith in God pushes them to change their attitude towards the process of rehabilitation.

In this study participants described the strategies that are used by their family members to help them, and among some of them it is important to underline the strategies of motivation and demand in the execution of daily activities only to the extent of their capabilities. It is also important to underline the commitment of caregivers to the process of rehabilitation and the fact that some of them abandoned the role they were previously performing to undertake the one of caregiver. This situation leads adolescents to re-discover

their family and it awakens in them feelings of gratefulness that motivate them to continue moving forward so that they can return in the future all the efforts done by their family. There is no perception of abandonment on the part of the parents.<sup>13</sup>

For adolescents and young adults the support of a partner also becomes important. These partners also have to adapt to the new condition, tolerate the emotional changes, provide care and company and this allows disabled people to keep moving forward. In some cases disabled people form strong attachments to their partners and they are able to reach the married state. However, these interrelationships can sometimes be contradictory because in time some family members, friends and even partners can distance themselves from the person due to exhaustion and in the case of friends, due to the impossibility for people to share in the same activities that they used to perform before the lesion. This situation becomes very hard to face, it awakens feelings of abandonment and even social isolation.<sup>14</sup>

The hardship of maintaining relationships with loved ones and friends leads disabled people to question the reason for their existence, but at the same time, they find a sense to their new lives. Adolescents and young adults must undertake the burden of confronting a new reality, of distancing themselves from their friends and from the activities they used to perform before the lesion. It is important to stress that in this situation the support from other people in a condition of disability, of the healthcare professionals, family members and the faith in God become fundamental to move forward. In those people who are facing their same condition, disabled people perceive the necessary strength and motivation to overcome all difficulties and achieve the results that at some point they considered impossible. These results became evident during the study performed by Moreno *et al.*,<sup>11</sup> in people who suffer from paraplegia caused by a spinal cord injury.

With time, both adolescents and young adults become adapted to their disabled condition. This



process is achieved when they learn to know their bodies and the new changes, they recognize the new sensations, they learn a new form of mobilizing themselves and learn to control their bodies and the process of elimination. This permits them to recover a sense of independence which was lost as a consequence of the lesion. Likewise, they become aware of the fact that they need to take care of their bodies to keep them in optimal conditions to prevent complications, which did not matter much before the injury. It is important to stress that the participants become able to surpass the difficulties and project themselves towards the future when they recognize the value of being alive, when they reflect upon their earlier lives and visualize the possibilities for improvement, when they become persistent in challenging their limitations, they maintain a sense of hope for their recovery and they construct a new life project taking their disability into account. These results concur with the ones found by Dornelles *et al.*,<sup>14</sup> who found that the changes that take place over the body and corporality of a disabled person acquire meaning when they allow a new life to start with the particular condition.

No information was found in the present study to back up the theory that young people lose their will to live and try to end their lives due to the loss of self-esteem and self-trust. On the contrary, the experience of having to live with a spinal cord injury changes their lives and with time they discover new opportunities, they solidify their lives' projects through study, sports activities and work life and they also strengthen their relationships with their nuclear family.

Lastly, the described results show the importance of the nursing care in the process of adaptation in adolescents who have a condition of disability. Some of the interventions that promote adaptation and that must be considered both during the hospitalization period and also after discharge are: the physical care, the development of anticipatory guides, educational programs and counseling both for patients and their families.<sup>8,15</sup> These interventions seek to help adolescents to recognize and acknowledge the changes that have

taken place in their bodies and to take advantage of the moments of care during the processes of personal hygiene, skin care, elimination, positional changes, movement, among others, so that they can really learn to use their residual capacities and so that they actively participate in the development of new abilities, which will allow them to obtain better results in the rehabilitation process.<sup>16,17</sup>

In the same way, with the development of guides based on evidence and the development of educational programs, it is the objective to have disabled people learn about the impact of the aftereffects of their lesion so that they can prevent some of the most frequent complications, like: pressure ulcers, urinary infections, constipation, contractures and deformities, among others.<sup>18,19</sup> The availability of counseling will also help these people to face their situation if they can count with the support of a professional that can lead them to clarify their doubts regarding their health state, the management of the equipment and other additions, among other things.<sup>20,21</sup> It is essential to design instruments that allow the identification of the meanings given by adolescents to a spinal cord injury during the different stages of hospitalization and discharge and also to develop studies to standardize the nursing interventions that aim at promoting the adaptation to this condition.<sup>22,23</sup>

As a conclusion to this study, the meanings that adolescents and young adults give to their spinal cord injuries represent the changes in the body and corporality from the participants' perspective and they constitute a valuable asset to improve the nursing care given to the patients with spinal cord lesions during the process of hospitalization and for the care at home. The latter constitutes an input that must be taken into account when assessing people and elaborating care plans. Likewise, it is advisable to develop nursing interventions that seek to promote the adaptation of the people with a disability. Some of the interventions that promote this adaptation process are: physical care, the design of anticipatory guidelines, programs of health education and

counseling programs that are directed towards both the adolescents and their caregivers, which have as a purpose to prevent the appearance of complications and help them to adapt to their condition as they understand the functioning of their body, which has changed and develop the necessary skills to take care of themselves. Therein lies the importance of involving the nursing professionals in the rehabilitation interdisciplinary team, not only during the phase of hospitalization, but also after the discharge, through the consult of nursing. It also becomes important to look further into this subject in the different areas of professional formation – teaching, since it is a little explored field that will allow to discover and plan new strategies of care for the people with disabilities.

The need for developing educational programs that support and provide learning for the caregivers of adolescents and young adults with spinal cord lesions becomes evident. With these, caregivers can really help people with disabilities to overcome the difficulties and they can also adapt to the presence of a person who has a disability. The application of nursing theories, in this case the theory of Callista Roy, allow the nursing practice to be supported and this is why it is important to perform research projects, that based on the application and generation of theories proper to the nursing field, allow to give an answer to the different care needs of the population. Nursing professionals must generate moments of opportunity, such as individual consults and small-group work that allow to identify the qualities and skills present in the people with spinal cord injuries with the aim of helping them overcome their condition. The intervention and company given by nurses in the rehabilitation units becomes essential because they can help to prevent the appearance of complications, which further delay the process of recovery and adaptation of people with disabilities.

**Acknowledgements.** To the Archangels Foundation in Bogotá – Colombia, for the support received during the development of this project.

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