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MEANINGS OF ACQUIRED DISABILITY IN ADULTHOOD: IMPLICATIONS OF SEVERE SPINAL CORD INJURY

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ABSTRACT. A traumatic spinal cord injury can result in significant losses of various functions of the organism, thus characterizing an acquired disability. The objective of this research was to understand the experiences of hospitalized patients newly diagnosed with spinal cord trauma, revealing the meanings attributed to this affection and the consequent acquired disability. It is a qualitative research, exploratory, descriptive, with an emphasis on the singularities of the cases. Participated in the study two male patients, aged 35 and 40, admitted to a public hospital, reference in traumas located in the northern region of Brazil. The results revealed significant losses, such as loss of autonomy and fears related to discrimination and abandonment. It was identified that the acquired disability in adult phase explains the challenge of re-signifying different aspects of being and of living. This signals the importance of developing research on comprehensive care for these patients from the moment of diagnosis, favoring the experience of suffered losses and adaptation to the new life condition.

Keywords: Spinal cord injury; emotional adjustment; hospitalization.

SIGNIFICADOS DA DEFICIÊNCIA ADQUIRIDA NA VIDA ADULTA: IMPLICAÇÕES DO TRAUMA RAQUIMEDULAR

RESUMO. Uma lesão medular traumática pode resultar em perdas importantes de diversas funções do organismo, caracterizando assim uma deficiência adquirida. Nesta pesquisa, buscou-se compreender as vivências de pacientes hospitalizados, recém-diagnosticados com um trauma raquimedular, desvelando os significados atribuídos a este acometimento e a consequente deficiência adquirida. Trata-se de uma investigação qualitativa, de caráter exploratório, descritivo, com ênfase nas singularidades dos casos. Participaram dois pacientes do sexo masculino, com idade de 35 e 40 anos, internados em um hospital público, referência em traumas, localizado na região norte do Brasil. Os resultados revelaram perdas significativas como a perda da autonomia e temores relacionados à discriminação e o abandono. Identificou-se que a deficiência adquirida na fase adulta explicita o desafio de ressignificar diferentes aspectos do ser e do viver, o que sinaliza a importância do desenvolvimento de pesquisas acerca da assistência integral a estes pacientes desde o momento do diagnóstico, favorecendo a vivência das perdas sofridas e adaptação à nova condição de vida.

Palavras-chave: Lesão medular; ajustamento emocional; hospitalização.

SIGNIFICADOS DE LA DEFICIENCIA ADQUIRIDA EN LA EDAD ADULTA: IMPLICACIONES DEL TRAUMA RAQUIMEDULAR

RESUMEN. Una lesión medular traumática puede desencadenar pérdidas importantes en diversas funciones del organismo, caracterizando así una deficiencia adquirida. En esta recerca se busca comprender las vivencias de los pacientes hospitalizados, recién diagnosticados con trauma raquimedular, desvelando sus significados en este suceso y a la consecuente deficiencia adquirida. Se trata de una investigación cualitativa de carácter exploratorio, descriptivo, con énfasis en las singularidades de los casos. Participaron dos pacientes del sexo masculino, con edades de 35 a 40 años, ingresados en un hospital público, referente en traumas, localizado en la región norte de Brasil. Los resultados revelan pérdidas significativas como la pérdida de la autonomía y miedos relacionados con la discriminación y el abandono. Se identificó que la deficiencia adquirida en la fase adulta explicita el desafío de resignificar los diferentes

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aspectos del ser y del vivir, lo que señaliza la importancia del desarrollo de investigaciones acerca de la asistencia integral a estos pacientes desde el momento del diagnóstico, favoreciendo la vivencia de las pérdidas sufridas y la adaptación a la nueva condición de vida.

Palabras-clave: Traumatismos de la medula espinal; adaptación emocional; hospitalización.

Introduction

Spinal cord injury is one of the most serious complications that can affect the human being, being able to cause physical, psychological and social impacts, among others (Brazil, 2015). Injuries of this nature can be of two types: non-traumatic and traumatic. The former are those originated from congenital malformations or diseases; while traumatic injuries, which will be emphasized in this study, occur from external causes such as car accidents, situations derived from violence, falls and shallow water dives (Lianza, Casalis, & Greve, 2011; Cerezetti, Nunes, Cordeiro, & Tedesco, 2012).

Traumatic spinal cord injury (tSCI) includes injuries that affect one or more components of the spine, including bone structure and spinal cord. Therefore, here the term “tSCI” will refer to injuries that affected the spinal canal, being used as a term analogous to traumatic spinal cord injury (Frison, Teixeira, Oliveira, Resende, & Netto, 2013).

Because it is considered the bridge that connects the brain to the other parts of the body, spinal cord exerts an important function of regulation and conduction of nerve, sensory and motor impulses. An injury to this structure causes interruption of flow of information below the level reached, which, in turn, compromises the functioning of various systems of the human body (Brunozi, Silva, Gonçalves, & Veronezi, 2011; Cerezetti et al., 2012).

A tSCI has as its main sequelae paraplegia and tetraplegia. Paraplegia can compromise the functioning of the trunk and lower limbs, whereas tetraplegia affects upper limbs, trunk, and lower limbs. In addition to the locomotor system, important changes can occur, such as partial or total loss of bladder, bowel, vascular, autonomic and sexual functions, as well as significant psychosocial changes (Ministério da Saúde, 2015; Lianza et al., 2011; Cerezetti et al., 2012).

Because it is not a notifiable condition, there is no precise data on the incidence of spinal cord injuries in Brazil. However, it is estimated that about 6 and to 8 thousand new cases emerge each year, of which 80% are caused by trauma (Ministério da Saúde, 2015).

According to Araujo Junior et al. (2011), gunshot wounds are the second leading cause of tSCI, behind only of injuries caused by car accidents. These data are corroborated by Castro, Leobas, Araujo, Coutinho and Figueiredo (2015) and Cerezetti et al. (2012) when they say that car accidents, gunshot wounds and falls from height are among the main causes of traumatic spinal cord injury, affecting mainly previously healthy young men, in full productive capacity who, when affected by a sudden event that can generate sequelae, are faced with limitations that can cause a great impact on their lives.

Although the prevalence is relatively low, when compared to other types of trauma, the cost for the treatment of spinal cord injury victims is high due to the severity and sequelae, making this impairment not only a personal misfortune, but an important public health problem (Ministério da Saúde, 2015; Frison et al., 2013; Pereira, Gomes, & Rodrigues, 2015; França, Coura, Sousa, Almeida, & Pagliuca, 2013). For the survivors, the abruptly acquired disability due to a spinal cord trauma reveals the need to cope with different losses imbued of meanings.

In these cases, more is lost than the movements of the body. Life habits, social roles, responsibilities, future perspectives, among other aspects that will be experienced by each individual in a very particular way, also change, according to their personal characteristics and lifestyle (Dal Berto & Barreto, 2011; Venturini, Decésaro, & Marcon, 2007).

Given this scenario and considering the complexity of a tSCI, this study aims to understand the experiences of hospitalized patients, newly diagnosed with spinal cord trauma, unveiling the meanings attributed to this impairment and the consequent acquired disability.

Method

This is a qualitative study of exploratory and descriptive type, with emphasis on the singularities of the cases, choosing the meanings attributed to this experience as the main focus of analysis (González Rey, 2011; Minayo, 2014). The research was carried out in a public hospital of intermediate and high complexity, a reference in severe traumas and burns, located in the northern region of Brazil.

Participants

Two patients diagnosed with tSCI with sequelae of total or partial paralysis type of two or more members, participated in the study. They were hospitalized in the Neurological Clinic of the hospital in question and were called in this study by Fernando and José, in order to preserve their identities. Patients with verbal communication difficulties and those who were already receiving psychological counseling were excluded from the study. Initially the sample was estimated in four patients, two men and two women, however, there were no hospitalizations of women who were victims of tSCI in the period stipulated for data collection, a change that did not interfere with the results obtained.

Instruments

The data were collected by the first author, who also provided psychological care to these patients, having as a trigger question: “How do you feel?”. The open question focused on favoring a space for listening in which the patient could deal with what he considered significant for himself (González Rey, 2011). In addition, the field diary and the medical records were used as resources.

In the psychological sciences, the field of action of the researcher is in all the scenarios in which the practice of the psychologist can be conducted, being psychodiagnosis, psychotherapy or any other professional practice, important and permanent sources for the scientific research. From this perspective, research and professional practice are intrinsically interrelated (González Rey, 2011).

Procedures

The research followed the guidelines and ethical standards set forth in resolution 466/12 of the National Health Council – Ministry of Health being previously approved by the Committee on Ethics of the State University of Pará (under opinion number: 696,731).

Participants were selected according to the order of admission to the hospital when data collection began, through the identification in the medical record of the diagnosis of tSCI and the contact made with the multiprofessional team.

Psychological consultations happened daily, from Monday to Friday, during the entire period of hospitalization of the patient/participant, with an average duration of forty minutes each; after which, they were transcribed.

The data collected were subjected to a descriptive-interpretive analysis, with emphasis on psychological analysis, following the proposal of González Rey (2011), which highlights that the construction of information in qualitative research does not occur only during data collection, this is done through a process of construction and interpretation that follows all the moments of the research.

Results and discussion

The participants and their histories

Fernando is a 35-year-old, athletic-looking, smiling and receptive young man, since the first moment, showing willingness and interest in sharing his life history. Single, currently he lives alone in the metropolitan area of the capital of the State of Pará and says that he has a complicated emotional life involving his ex-wife and his current girlfriend.

His family of origin comes from a city of few inhabitants, located in the countryside of the state, where he likes to spend moments of rest and leisure. Riding motorcycles, traveling, hunting and fishing are activities that bring him great satisfaction and pleasure. He is an active person, who likes to practice activities related to nature, exercising his autonomy and freedom to come and go.

About his profession and income, he informs that he is a motorcycle taxi driver and rents studio apartments to complement the family budget. He points out that during the years he worked in the streets he was robbed a few times, but never something serious happened to him, such as what happened now.

Fernando says that from the moment he was injured onwards he only felt his entire body becomes numb and that he waited for help for long minutes until the ambulance arrived. In his words: *"... I remember that he threw me and I fell forward on the motorcycle, and I thought 'oh my God' and I only felt my body falling asleep ... it was a long wait until the ambulance arrived ..."* (Fernando).

He was admitted to the hospital as a victim of a gunshot wound motivated by an attempted robbery, being diagnosed with thoracic spinal cord injury, resulting in loss of leg and trunk movements, and loss of sphincter control. The injury suffered was of the conservative type, that is, the treatment did not require surgical intervention; but it was still necessary to remain hospitalized and take medication for a few days and a follow-up with rehabilitation treatment after the hospital discharge.

During the days of hospitalization, the patient presented collaborative to the treatment. However, he was confused and fearful about the diagnosis. He says: *"... it seems that no one wants to tell me the truth, if I am going to stay like this forever... will I be like this forever?*" (Fernando). Although confused, he perfectly describe the path made by the projectile in his body, claiming to know about the unpredictability of the definitive sequelae, at this early moment, shortly after the trauma. While at other times, he showed the sensation of being deceived as to his prognosis, transiting between facts, desires and fears related to the situation experienced.

Jose, the second participant, is a 40-year-old man who emphasized enjoying his joviality as much as his strength and constant availability to work. In a first contact, he was suspicious, but still requested to be listened to and makes use of this space whenever offered, transforming his initial fears into a relationship of trust and partnership with the researcher therapist in the meetings that followed, sharing aspects of his life previous to the trauma, in the present moment, and plans and fears about the future.

He was born in a medium-sized town in the countryside of the state, where he lives with his wife and children, working as a trader. Work activity is referred to as the center of his life, regarded as both the livelihood of the family and a leisure activity. He emphasizes that his family is of fundamental importance for his wellbeing and being in the company of his family is a reason for great satisfaction. He claims to be moved by his faith and that belief in God is his religion.

He reports that he was shot while leaving his workplace. At that moment, he was in the company of his son, who says he was brave and attributes to him the responsibility for saving his life (sic). He describes the path to the hospital of the capital with words permeated by the fear of death. He says:

> *My son was with me when I was shot, it was he who took me to the hospital driving the car. If it was not for him... until the rescue came I had not resisted... I said to them 'I want to at least come home alive from there ... at least in a wheelchair to stay on your side' this for me it is very important* (José).

He was admitted to the hospital as a victim of gunshot wounds, resulting in thoracic spinal cord trauma and consequent loss of leg and trunk movements and loss of sphincter control. It was necessary to perform surgery for spinal decompression and removal of the projectile. The treatment also required José to remain hospitalized for a few days in the hospital for post-surgical follow-up and, after discharge, follow-up with rehabilitation treatment.

Although the feelings and thoughts related to the trauma suffered are intense and painful, they pass with certain frequency by feelings of hope that border the certainty of the cure, based on his faith and the divine plans for his life.

In the two cases studied, numerous losses as a result of spinal cord trauma are identified, being attributed to them different dimensions and significances, since surviving an injury of this magnitude, an event that is potentially lethal and generates irreversible sequelae, requires a process of change and consequent adaptations to a limiting and often disabling condition. Next, the data regarding the meanings that the participants attach to the experience of the abruptly acquired disability.

Loss of autonomy: is not being able to walk and not provide

Becoming a person with physical disability from a tSCI is an unexpected event that brings with it the need to adapt to a new condition that involves facing several changes in the way of living (Alvarez, Teixeira, Branco, & Machado, 2013).

When acquiring physical sequelae, the individual starts to face life from a new perspective, now from the perspective of a person with a disability, an underprivileged situation that brings with it the need to reorganize, rethink concepts, roles and functions, implying a process of understanding and acceptance of a new condition, which was unknown until then (Chagas, 2010).

According to the International Classification of Functioning, Disabilities and Health - ICF, disability can be understood as problems in body functions or structures such as a significant disorder or a loss. Functions are the physiological functions of organic systems, as well as psychological functions, whereas the structures refer to the anatomical parts such as organs, limbs and their components (OMS, 2004).

In the case of the traumatic spinal cord injury of both Fernando and José, the most evident loss is the loss of movements of the legs and part of the trunk, typical of paraplegia. No longer being able to walk with their own legs is a loss of great impact for them, since it brings with it a series of consequences, the main one being the loss of autonomy. On this issue, Fernando states:

> *See how I look now... I was always a person, who solved my things, I worked... I was always very independent. One thing is a person to depend on himself, now having to depend on others is very bad... It is terrible to depend on another person to go to the bathroom, not being able to get up at night to throw some water on my body. You know, sometimes I feel like running away from here, screaming, but then I remember that I cannot run.* (Fernando).

It is possible to perceive in his words that Fernando feels bothered to have to depend on third parties to supply his basic needs. He complains at various times on the embarrassment of having to need the help of other people to perform tasks that hitherto were done without difficulty and independently.

The feeling reported by Fernando, of "*being a burden*" to family members and having to rely on "*favors*" was also observed by Santos (2000), when dealing with the dependence experienced by patients victims of traumatic spinal cord injuries in the rehabilitation phase. The author also affirms that such sensation prevents the subject from feeling full as a person, always making comparisons about his autonomy and freedom before and after the injury (Santos, 2000).

The autonomy here can be understood in two aspects: being able to independently perform activities of daily living (ADL) such as dressing, making personal hygiene, eating, moving between the wheelchair and the bed, for instance; as well as having the freedom of choice and action, exerting control over his own life (Borges, Brignol, Schoeller, & Bonetti, 2012; Ferreira, Maciel, Costa, Silva, & Moreira, 2012).

It is noteworthy that some people may be able to govern themselves, but they do not have independence to perform some daily activities. Others may find it easier to carry out such activities, but have difficulty to govern themselves, such as people with dementia. Therefore, it is important to understand that independence and self-governance are not interdependent concepts, but they are part of a broad concept of autonomy (Ferreira et al., 2012).

What is perceived is that in the moments that follow the tSCI, even though there are aspects of self-governance preserved, the loss of independence linked to significant functions, such as moving with his own legs, becomes the main focus at that moment. For Borges *et al.* (2012), the spinal cord injured feels powerless in certain situations, this makes him feel unable to govern himself, a feeling that is linked to the losses experienced as a result of the injury.

Acquired disability causes the spinal cord injured to experience ambivalent feelings because he sees himself physically different from what he was before and, at the same time, he sees himself just as he was before because he preserves his cognitive abilities and life history. However, feeling incapacitated does not make him passive. On the contrary, he remains active in his process of self-constitution and, as such, he feels the need to re-signify several aspects of his own identity (Santos, 2000). Having to reconstruct his identity from a limitation also implies the need to review social and family roles.

For José, the loss of autonomy is experienced as the loss of his productive capacity and the role of provider of the home. Not being able to walk is to be bound to depend on others to meet apart from his basic needs, his financial needs, making him feel threatened to lose his place in the family and in his social circles. He says: *"... I lost all my movements from the waist down ... That's it [silence] ...I'm going to be an invalid man who cannot work... but I will not fall, No! I won't.*" (José).

José presents a certain difficulty to be exposed to the suffering generated by the losses resulting from the injury. However, his concerns about the labor issue are pertinent, after all, if he is not the working man and family provider, as he has always been, what will he be? This question pervades the words of José with some frequency. For him, labor activity is not only his source of income, but also a pleasurable activity that takes up much of his day and his life, now becoming a source of intense concerns.

The aspects related to finances and work are also present in the discourse of Fernando. While referring to them as possible issues to be handled, he shows concerns. He says, "*I know my income is enough for my family, but life is bound to change, that's for sure*". It is possible to perceive that fears about the future appear in his words, especially when it comes to the role of family provider. He reports: "*Here on a bed, I will not be useful in anything... what woman will want to be by my side? How will I sustain a house? I know I will not go back to being like I was before...*"

For both José and Fernando, the sequelae of the injury suffered result in the loss of the role of provider, which is experienced with great concern, having in mind the current condition of dependence imposed on them by the trauma. At this time, both bring concerns about the uncertain future in the face of so many changes.

Venturini et al. (2007) and Cerezetti et al. (2012) show that among the main difficulties experienced in the daily life of individuals with spinal cord injuries are economic issues and dependence on the other. The authors also point out that these two difficulties are interrelated to the extent that the need for care often ends up depriving the caregiver of also contributing economically to family maintenance.

In this first moment, still in the period of hospitalization, having an acquired disability is an information of difficult understanding. It is possible to perceive in the discourse of Fernando and José moments of sadness, doubts, fears, as well as the hope in a possible cure capable of reversing the still imprecise sequelae. The literature indicates that the spinal cord injury generates several feelings. The shock, sadness and frustration at the possibility of permanent disability, the anger and revolt at the gloomy prognosis, the uncertainty about the labor market, among many others feelings that will follow the whole process of rehabilitation and adaptation to the new condition of life marked by acquired disability (Alvarez et al., 2013; Borges et al., 2012).

Fears and perception of disability

The losses experienced as a result of the tSCI favor the emergence of several feelings, among them, fear of prejudice, discrimination and abandonment. These are unveiled through recurrent questionings regarding the permanence of certain people at his side after the occurrence of the injury. This can be seen in the discourse of José:

> *... many disappear, they say that they are friends but in those times... I will try to see who is really friend, right? See how they will react when they see me in a wheelchair because I know that many there ... Who knows…right? What do you do with a wheelchair user... (José).*

In another moment, moved, José reveals:

> *[tearful] I close my eyes and I only imagine foolishness ... (what type of foolishness?) Being abandoned, right? But, I know that my family will not abandon me, my children, but... I will be a disabled man without being able to work... b but I will not fall, No! I won't... (José).*

For José, the belief that being disabed and unable to perform his duties as before the injury generates fears about being abandoned, no longer being loved and well-liked in society, given the changes that have occurred in his body and his life as a whole. These fears are experienced by Fernando tied to affective-relational issues, as he suggests in his report concerns about the possibility of not being attractive to the feminine look. He says:

> *...I have no doubt that I will be very pampered by my family, especially because of my condition, right? [He looks at his legs]. But, I also know that people will disappear over time... One thing I am sure of, that I can count on my family, they certainly will not abandon me. But wife, I do not know, right?... When the guy is well, working, everything is fine, but the way I am now, it is difficult to have someone who endures the situation for a long time... I know people will soon disappear and I am afraid of this happening. (Fernando).*

When they perceive themselves physically disabled, they fear abandonment and rejection on the part of society, a real and palpable fear. As Dal Berto and Barreto (2011) affirm, the acquisition of a physical disability is permeated with stigmas and prejudices, not infrequently occurring the exclusion of social environments and the marginalization of the individual.

The reports by Fernando and José confirm that spinal cord injury is an event with great disorganization power, as stated by Kovács (2003) when referring to experiences of losses throughout human development, and it is perceived that unexpected losses also keep this characteristic. Breaking the spinal cord is also breaking with much of what he has been known about himself and the world.

The self-image before the trauma was a healthy person who learned through life to walk with his own legs, make choices and have the capability of self-managing his life, having the freedom to exercise his activities independently. This was how he recognized himself as a person and related to other people within society (Santos, 2000).

Therefore, having to learn to live with an acquired disability already in adulthood presupposes the challenge to face great changes, to suffer innumerable losses and to re-signify different aspects of being and of living, demanding of the affected individual the search for new resources to adapt to a new reality permeated by limitations, difficulties and possibilities.

Final considerations

The word “abrupt” is perhaps the most adequate word to describe the transition between before and after being injured in the spinal cord by a trauma. In a matter of seconds, life changes completely, forcing the individual to face different losses that will require confrontation and adaptation to a new way of living.

Although the literature on the experience of losses due to tSCI is scarce, it was possible through this study to reveal the suffering experienced due to the impact generated by losses resulting from the traumatic spinal cord injury and the unexpected physical disability.

Acquired disability in adulthood explains the challenge of facing great changes and re-signifying different aspects of being and living. Having to deal with changes in lifestyle, in family and social roles exercised up to then, facing the need to rethink plans in the face of the uncertainties of an unfavorable present moment, are issues that arouse great suffering, meant by each person in a very particular way.

In the reports of Fernando and José, corroborated by the literature, it was possible to understand that, when they perceived themselves as physically dependent, they expressed fears about the loss of autonomy. It was also possible to identify in their reports, fears related to the risk of rejection and abandonment, both from a personal perspective regarding the difficulties in perceiving themselves as physical disabled, and from the social environment that certainly presents real obstacles in the adaptation of a person with a disability.

Unlike studies found in the literature that work with victims of tSCI in rehabilitation, generally after years of injury, the present study focused on people newly diagnosed with a traumatic spinal cord injury. Therefore, it is important to consider that the uncertainties and fears, among many other feelings reported by the participants, are limited to a specific moment of life: facing the newly acquired disability in adult life.

The importance of psychological counseling as part of multidisciplinary care since the first moments of the treatment of a spinal cord injury is highlighted, considering that victims of this type of trauma lose body functions and movements, however, their cognitive and emotional functions are found preserved in most cases, making this experience permeated by several feelings of difficult understanding and coping.

The results obtained indicate the importance of the development of researches in this area, especially with regard to integral care, in order to favor the emotional rehabilitation, from the diagnosis of a spinal cord injury, thus contributing to a commitment in future rehabilitation treatments and healthy adaptation to his new condition of life.

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