



Revista da Escola de Enfermagem da USP

ISSN: 0080-6234

reeusp@usp.br

Universidade de São Paulo

Brasil

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pais/cuidadores

Revista da Escola de Enfermagem da USP, vol. 44, núm. 1, marzo, 2010, pp. 53-60

Universidade de São Paulo

São Paulo, Brasil

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# Functional (in)dependence in the dependent relationship of quadriplegic men with their (un)replaceable parents/caregivers

(IN)DEPENDÊNCIA FUNCIONAL NA DEPENDENTE RELAÇÃO DE HOMENS TETRAPLÉGICOS COM SEUS (IN)SUBSTITUÍVEIS PAIS/CUIDADORES

(IN)DEPENDENCIA FUNCIONAL EN LA RELACIÓN DEPENDIENTE DE HOMBRES CUADRIPLÉJICOS CON SUS (IN)SUSTITUIBLES PADRES/CUIDADORES

William César Alves Machado<sup>1</sup>, Ana Paula Scramin<sup>2</sup>

## ABSTRACT

The objective of this study was to identify elements of the international classification of functioning, disability and health, applicable to quadriplegic men's home care, to reduce the dependence on their parents' help for activities of daily living and self-care. Data were collected from June 2004 to March 2005. Semi-structured interviews were performed with eight adults with high spinal cord lesions who were being cared for at home. Content analysis was performed based on the categories of meaning extrapolated and the following themes were discovered: family support: safety for the corporal functions of the disabled; supporting technology: inventiveness to promote quality care; fears, uncertain future and parents' loss: thresholds and human fragilities; and functional gains: objective response of body functions. In conclusion, family support, and especially the presence of parents, is fundamental to facing limitations and to reacting in the search for balance with the deficiency, disability, disadvantage and health of that population, preparing them to achieve gradual functional gain and independence for daily activities and self-care.

## KEY WORDS

Quadriplegia.  
Caregivers.  
International Classification of Functioning, Disability and Health.  
Home nursing.  
Rehabilitation nursing.

## RESUMO

Objetivou-se identificar elementos da classificação internacional de funcionalidade, incapacidade e saúde, aplicáveis ao cuidado domiciliar de homens adultos tetraplégicos, com vistas à redução da dependência de ajuda de seus pais para as atividades da vida diária, e o autocuidado. Os dados foram coletados de junho de 2004 a março de 2005, a partir de entrevista semi-estruturada, realizada com 8 adultos acometidos de lesão medular alta, e com experiência de usuários do cuidado domiciliar. Optou-se pela análise de conteúdo, a partir das categorias de significados pautadas nos seguintes resultados: *suporte familiar*: segurança para as funções corporais do incapacitado; *tecnologia assistiva*: inventividades para promoção da qualidade do cuidado; *medos, futuro incerto e perda dos pais*: limiares e fragilidades humanas; e *ganhos funcionais*: respostas objetivas das funções corporais. Conclui-se que o apoio da família e, em especial, a presença dos pais, são fundamentais para enfrentar as limitações e reagir na busca de equilíbrio na deficiência, incapacidade, desvantagem e saúde dessa clientela, preparando-a para o alcance de gradativos ganhos funcionais e independência para atividades cotidianas e autocuidado.

## DESCRIPTORES

Quadriplegia.  
Cuidadores.  
Classificação Internacional de Funcionalidade, Incapacidade e Saúde.  
Assistência domiciliar.  
Enfermagem em reabilitação.

## RESUMEN

El estudio tuvo como objetivo identificar elementos de la clasificación internacional de funcionalidad, incapacidad y salud, aplicables al cuidado domiciliario de hombres adultos cuadripléjicos, con el fin de reducir la dependencia de la ayuda de sus padres en las actividades de la vida diaria y el autocuidado. Los datos fueron reunidos entre junio de 2004 y marzo de 2005, sobre la base de una entrevista semiestructurada efectuada a 8 adultos que sufrían de lesión medular alta y que recibían normalmente cuidado domiciliario. Se optó por el sistema de análisis de contenidos a partir de las categorías de significados pautados en los siguientes resultados: *apoyo familiar*: seguridad para las funciones corporales del discapacitado; *tecnología de apoyo*: soporte tecnológico para optimizar la calidad de los cuidados; *miedos; futuro incierto y pérdida de los padres*: los umbrales y las fragilidades humanas; y *ganancias funcionales*: respuestas objetivas de las funciones corporales. Se concluyó en que el apoyo familiar y, en particular, la presencia de los padres, son fundamentales para enfrentar las limitaciones y reaccionar en la búsqueda de equilibrios en la deficiencia, incapacidad, desventajas y salud de tales pacientes, preparándolos para alcanzar en forma gradual mejoras funcionales e independencia para realizar actividades diarias y ocuparse del autocuidado.

## DESCRIPTORES

Cuadriplejía.  
Cuidadores.  
Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud (CIF).  
Atención domiciliar de salud.  
Enfermería en rehabilitación.

\* Part of the thesis "Convivendo com a tetraplegia: da necessidade de cuidados à integralidade no cotidiano de homens com lesão medular cervical", Health Science Center, Universidade Estadual de Maringá, 2006. <sup>1</sup> RN. PhD in Nursing Sciences. Adjunct Professor at Universidade Federal do Estado do Rio de Janeiro. Founding Member of Brazilian Nursing History Research Group, Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro. Três Rios, RJ, Brazil. wilmachado@uol.com.br <sup>2</sup> MSc. in Health Sciences. Nurse Auditor at Maringá Municipal Health Secretary. anapaulascramin@uol.com.br

## INTRODUCTION

One of the greatest current challenges for nursing inevitably goes through the construction of knowledge to consolidate the care practice of disabled people, especially those with neurological spinal cord lesions in cervical level, due to the complexity of their segments and body functions, as well as the high level of dependence for the performance of basic self-care and daily living activities. It also involves the commitment to articulate new theoretical situations with the essential principles of the profession, in order to comprehend the possible applications/implications of the international classification of functioning, disability and health in the diagnosis and practices of nursing.

It is a fact that 10% of the people in Third World countries, in times of peace, present some sort of deficiency. In Brazil, The Brazilian Institute of Geography and Statistics (IBGE) estimated the existence of 24.5 million Brazilians in this condition in 2000<sup>(1)</sup>, and this social indicator suggests a reaction to make the nursing presence more visible as a group of effective agents of changes to act in this segment of society, focusing efforts on the discovery of new alternatives, in order to meet their care needs.

The World Health Organization (WHO) currently has two reference classifications for the description of health conditions: the ICD-10 (International Statistical Classification of Diseases and Related Health Problems) and the ICF. The use of the ICF has been highly expected by the organizations of people with disabilities and related institutions. The lack of a clear definition for deficiency or disability has been pointed out as an obstacle for promoting health to people with a deficiency<sup>(2)</sup>.

The ICF belongs to the family of international classifications developed by the WHO to be used in several aspects of health. This family of international classifications provides a code system for a broad amount of information on health (diagnosis, functioning and disability, reasons for contacting health services) and uses a common standard language that allows the communication about health and medical care all around the world among several disciplines and sciences<sup>(3)</sup>.

Autonomy is considered a way of personal freedom based on the right people have to express themselves through care, especially preserving themselves from the interference of third parties in situations that involve the violation/invasion of privacy and body intimacy, the risk of exposing internal smells, substances, thus, the need to share the most fragile side of the human condition. In order to be autonomous, the individual must be able to think rationally and self-manage himself, otherwise, his ability for making decisions will be compromised and another person will have to make the decisions for him<sup>(4)</sup>.

The presence of multiple functional limitations in people may represent the cause of different levels of dependence and greatly influence daily living activities and the self-care itself, as the care must be assumed by the home caregiver<sup>(5)</sup>. In this context, the functional ability has been considered an indicator of the process/program of rehabilitation for people with after-effects from a spinal cord lesion in cervical level, or for quadriplegic people. This indicator is essential for the planning, intervention and evaluation of this type of client, especially in terms of long term care in the dependent relation established between him and his caregiving parents<sup>(6)</sup>.

Studies evidence that family caregivers, for instance the parents of people with lesion in cervical level, receive poor information on health care by the professionals<sup>(5,7)</sup>, in spite of handling with the multiple aspects and complications of the people with incapacitating after-effects and life conditions that impose severe motor, sensation and sensory limitations, able to change their life dynamics, which often make them dependent on others to move around and act with greater or lesser independence in order to perform their self-care and daily living needs/activities<sup>(8)</sup>.

Although there are official policies for the rehabilitation care of those who develop a functional disability, there are few people who have benefited from or been assisted by them. Families and caregivers have been held responsible for the care to disabled with lesion in cervical level, potentially incapable, and this task often becomes rather hard due to the changes that necessarily take place in the family dynamics and to the lack of knowledge regarding how to manage care in face of the multiplicity of affected abilities.

It is known that the nurse, as a member of the transdisciplinary team of rehabilitation institutions and/or programs, may also contribute to the home care service, trying to interact to family members and caregivers, sharing knowledge and promoting favorable environments to the maintenance of the functional ability, in order to assume the co-responsibility of the care to the person with a high spinal cord lesion. Aimed at this fact, it is necessary to be aware of the daily living and necessary care activities that are being compromised at the point that the quadriplegic person faces the risk of being taken to the functional disability<sup>(6)</sup>.

Concerning the care to their children, it is a fact that the mother and/or the father experience, in their relation with their children, the intimate relation of the care that satisfies their needs for acceptance, trust and body contact, in the development of the self and social consciences<sup>(9)</sup>. This constitutes an allusion to the female archetype and its relation to the ways of human care, for instance the nursing, emphasizing what is evidenced through the exemplary care of mothers/fathers to their quadriplegic children, developed with unconditional dedication and love<sup>(5)</sup>.

Studies show that the ICF has a great relevance to the nursing care. As a general classification, it was not projected by nurses or specifically aimed at elements of the nursing care. This can explain some difficulties in the use of this classification which were identified in the nursing area, both in the teaching and research area and in the care scope. In order to solve this asymmetry and progress in the improvement and adjustment of the ICF to the nursing knowledge, nurses should invest in the comprehension of their essential elements, social dimension and practical implications in their contexts of teaching, researching and care, as well as become more visible and participative in future reviews of its constitutive process<sup>(9-10)</sup>.

The study question found is: in which way can nursing contribute to promote the functional independence of adult quadriplegic men in the routine of the care relations established with their parents/caregivers?

The study object constitutes the functional dependence of adult men with spinal cord lesion in cervical level, in the relation with their parents/caregivers.

## OBJECTIVE

The purpose of this study is to identify elements of the international classification of functioning, disability and health (ICF) which are applicable to the home care of adult quadriplegic men, aimed at the reduction of the dependence on the help of their parents for daily living and self-care activities.

## METHOD

This is an exploratory, descriptive, qualitative, field study. The qualitative study has been valued, since it works with the universe of meanings, representations, beliefs, values, attitudes, developing a non-perceptible side of the social relations and allowing the comprehension of the human reality socially experienced. The decision for the qualitative method is based on the fact that the qualitative approaches are capable of incorporating the meaning and the intentionality as inherent to the acts, relations and social structures, being the latter taken both in their advent and in their transformation, as significant human constructions<sup>(11)</sup>.

The meaning and the intentionality have central positions in the qualitative study, in which meaning is generally recovered by analyzing the speeches of the actors as study subjects and social subjects. These subjects provide, through the discursive mediation, the representations that compose the subjective part of the studies<sup>(11)</sup>.

A great part of the qualitative studies adopts the content analysis because by giving voice to the subjects, they make feasible one of the most appropriate ways to operate the recovery of the subjects' representations. Besides, the content analysis works the word, that is the practice of

the language performed by identifiable speakers, and tries to learn what is behind the words on which it stands<sup>(12)</sup>.

The subjects of this investigation were eight men between 22 and 45 years old, who lived in the South and Southeast regions of Brazil, had expressive experience in the condition of functional dependent and presented spinal cord after-effects of cervical level for a period between 4 to 18 years. Two deponents were victims of a firearm, two had after-effects resulting from diving in shallow waters, two suffered car accidents, one had after-effects due to judo strokes and another due to a motorcycle accident. In order to preserve the identity of the subjects, the extracts of their speeches were named after stars and planets, in an allusion to the magnitude of their lives.

Studies about this theme confirm that half of the spinal cord traumatizations result from accidents with vehicles, falls, work accidents, sport accidents (specially water sports), and others from injuries caused by firearms<sup>(13)</sup>.

The deponents were previously selected by their lesion level (C3 to C7) and by the functional dependence for the self-care and daily living activities. The study included people who:

- Had expressive experience in the condition of functional dependent;
- Presented cervical spinal cord lesion, acquired in a traumatic way;
- Had verbal communication ability;
- Were interested in participating in the study by signing a term of free clarified and informed consent.

The study took place in the houses of the study subjects, after a previous contact.

Data were collected through a guided interview with a semi-structured script. The interviews were performed according to the availability of the subjects, between June 2004 and March 2005 at the houses of the interviewees. They took 30 to 90 minutes and were recorded and completely transcribed afterwards. The researcher performed the interviews individually, following the guided interview model with the semi-structured script, focused on the collection of information on the way they perceived their experiences in the condition of functional dependents. The semi-structured interview is a way to collect information based on the interviewee's free speech. It is assumed that the informer is competent to express himself clearly concerning the questions of his own experience, to provide trustworthy information, and to manifest in his own acts the meaning they have in the context they take place, revealing both the singularity and the historicity of the actions, conceptions and ideas<sup>(11)</sup>.

It is worth highlighting that the oral speeches have been recognized little by little by the social sciences, as behaviors, values and emotions remain hidden in statistical data.

Provided with time and the progress of other disciplines, such as the linguistics, the semiotics and the anthropology, it was recognized that the discourse of the social actor has its own logic and is structured as a language, which may allow the comprehension of social phenomena that escape from the cold and distant observation of the researcher<sup>(11)</sup>.

The obtained data were analyzed according to the technique of content thematic analysis. It is a fact that the content analysis is a group of techniques of communication analysis that aims to obtain, through systematic and objective description procedures of the messages' content, indicators that allow the inference of knowledge related to the conditions of production/reception of these messages<sup>(12)</sup>.

In the content analysis context, the categorization is a classificatory operation for constructive elements of a set, through differentiation followed by regrouping based on analogies, from defined criteria<sup>(12)</sup>. In this context, the semantic criterion was observed in order to classify the data in the speeches of the deponents. Through this criterion it was possible to build a network of categories of interconnected meanings, which were named as: *family support*: safety for the body functions of the disabled; *supporting technology*: inventiveness to promote quality care; *fears, uncertain future and parents' loss*: human fragilities and thresholds; and *functional gains*: objective response of body functions.

The study was initiated after the approval of the Committee of Ethics Involving Human Beings of Universidade Estadual de Maringá, DOCUMENT CI 177/04. The participants were asked to sign the Term of Free Clarified and Informed Consent, according to the Resolution 196/96 of the CNS. Considering the functional limitations of the subjects regarding the motor damage of the upper limbs, which made it impossible for them to sign, it was their decision to either authorize someone else [witness] to sign the terms for them or to use a digital imprint.

## RESULTS AND DISCUSSION

### ***Family support: safety for the body functions of the disabled***

The ICF represents a change of paradigm in order to think and work the deficiency and the disability, constituting an important instrument for the evaluation of the life conditions and the promotion of social inclusion policies. The classification has been incorporated and used in several health areas, in multidisciplinary teams. However, it will be more appropriate as it is used by a greater number of professionals, in several places and with different people and realities<sup>(14-15)</sup>.

The dependence relation of quadriplegic people and the systematic presence and help of the family<sup>(7)</sup>, specially of their parents<sup>(5)</sup>, is considered bonded in substantially strong ties, which is confirmed in the following extracts:

The family has always been very participative. I received the best care, all the support, the family (SUN, 33 YEARS OLD).

In the first months that my mother and my grandparents were at home, and when my brother lived with us, I could do the exercises, because there were people to offer me what I needed (ORION, 22 YEARS OLD).

The family started to get sick, because my mother has a heart problem, diabetes, it is not easy to need people to take care of you. My father and my mother are getting old, my sisters have their own families, their children to take care of (VENUS, 45 YEARS OLD).

I have to think that I need them, otherwise they will not be able to take care of me. I cannot demand them to do everything I want all the time (SATURNO, 36 YEARS OLD).

Taking care of a disabled person at home constitutes a complex task, because, besides considering the characteristic elements of the disability of the person to take care, it often requires the use of materials and equipment to support the caregiver's work. Therefore, what defines the activities of the home caregiver of a disabled person – in this case, a quadriplegic man – will always be related to his level of disability/limitations for the self-care and/or daily activities, associated to the availability of material resources for the execution of these tasks. Each case is always singular in its particularities and requires cleverness and knowledge from the nurse for the detection of the client's needs for help and care.

If something happens, they know how to take care of me, what to do. I have a married sister and I identify myself with her. She knows everything I want, where to find, and what I want exactly (POLLUX, 33 YEARS OLD).

It is also necessary to consider the health and social inequalities among people with deficiencies, as well as the other social segments, substantially verified around Brazil<sup>(6)</sup>. In this study, it is possible to perceive, through the speeches of the deponents, more specifically, concerning the fact of people being able or not to afford treatments, periodic exams, access to rehabilitation programs, acquisition of equipment and material, besides expenses due to the fundamental presence of a caregiver<sup>(16)</sup>, either if he is a member of the family or a professional hired to develop this function.

Our relation was very distant, we did not talk, do you know? After the accident, my father, my mother, everything was united again. One month after the lesion I saw everybody turning their backs; my father did not have time anymore, my mother was already distant, then I started to perceive the difficulty I would have to face (JUPITER, 25 YEARS OLD).

It is not possible to imagine the way the life of a quadriplegic person would be without projecting the company of someone helping in the self-care and daily living activities<sup>(5)</sup>. In this idea, it is imperative for the nurse to be close to the



members of the family who are in charge of the care to the disabled person, in order to identify what it really represents for them<sup>(17)</sup>, as well as interacting through strategies that promote the self-care for his functional autonomy.

The term of the ICF model is the functioning, which comprehends the components of the body functions and structure, social participation and activity. The functioning is used in the positive aspect, and the negative aspect corresponds to the disability. According to this model, disability results from the interaction among the dysfunction presented by the individual (organic and/or regarding the body structure), the limitation of his activities and the restriction in the social participation, and the environmental factors, which may act as facilitators or barriers for the development of these activities and the participation<sup>(15)</sup>.

### **Supporting technology: inventiveness to promote quality care**

The National Ministry of Sciences and Technology (Ministério da Ciência e Tecnologia), which answers for the management of the national policies in science, technology and innovation – through its Department of Science and Technology for Social Inclusion (Secretaria de Ciência e Tecnologia para Inclusão Social – SECIS), has supported initiatives to promote the diffusion and the popularization of the scientific knowledge, the technological innovation, the inclusion of the elderly and people with deficiencies. The area of science aimed at the research, development and application of instruments to increase or restore the human function, which urgently needs to be strengthened in the country, is named Supporting Technology<sup>(18)</sup>, besides, it is a fertile space for nursing.

The ICF is clear in the definition of its components in the health context<sup>(3)</sup>. Body functions comprehend the physiological functions of the organic systems (including the psychological functions), whereas the body structures consist on its anatomical parts, such as the organs, members and their components. Deficiencies are problems in the functions or structures of the body, such as an important deviation or loss. At the ICF, an activity is understood as the execution of a task or action by the individual. Participation, on the other hand, is the involvement of an individual in a real life situation. Activity limitations are the difficulties found by an individual in the execution of activities. Participation restrictions are problems that an individual may face whenever he is involved in real life situations. Environmental factors consist on the behavioral, social and physical environment in which people live.

The fact that I also adapted the house helped a lot. I open and close the gate, I do everything with the control in the chair, I use the telephone, I use a Palm that is also a cellular telephone and an appointment book, I write what I need, send and receive e-mails, etc. In the house I turn the lights on and off, as well as the TV and the computer. Thus, these things give me autonomy, and I do not have that need to

have someone at home when I get there. I developed all these things so I would have this autonomy [URANUS, 40 YEARS OLD].

They gave me a transfer board, but I could not do it. I think I really need a motorized wheelchair [ORION, 22 YEARS OLD].

It is important not to leave behind the fact that quadriplegic people, with high cervical lesion, must be encouraged to participate effectively and actively in their own rehabilitation process, even though their objective gains may be slow. In this context, the activities and participation, according to the WHO<sup>(3)</sup>, must follow parameters designed on the scope of learning and application of the knowledge, tasks and general demands, communication, mobility, self-care, domestic life, interactions and relationships, great areas of life and community, social and civic life – all evaluated individually through the qualifiers of performance and ability, for the elaboration of the respective indicators of functioning and disability.

On the other hand, the supporting technology is not limited to mechanical devices of automation, but it is greatly valuable for nursing, as it comprehends the promotion of actions aimed at the simplification and independence in the daily life, improvement of the care in the services of rehabilitation and health, protection and personal care, with emphasis on the communicative processes aimed at the education in health<sup>(18)</sup>. This may be confirmed in the following extract:

It helped me a lot regarding the intestine, the urine. When I am lying down I touch my bladder, stimulate it, and the urine comes, I do not need the tube. But I need one catheterism a day, only when I go to bed. Now I am sitting here, but if I start to feel it, I lay down and the urine comes [SIRIUS, 26 YEARS OLD].

Autonomy includes the freedom of choice, action and self-control over life; so it is possible to consider that the autonomy is directly related to the ability of the individual to be dependent or independent in the execution of daily activities. Nevertheless, some people are capable of self-managing themselves only in some areas of their lives, needing the help of someone else for the other areas<sup>(4)</sup>.

It is worth highlighting that the functional ability is a broad concept that comprehends the ability to execute physical tasks, the preservation of mental activities and an appropriate situation of social integration<sup>(6)</sup>. Despite of the broad dimension of this concept, it is common to work with the conception of the binomial ability/disability in the rehabilitation practice of the quadriplegic client. In this context, the functional ability has been evaluated as the difficulty to perform certain daily living activities and, on the other hand, the ability for the performance of care activities to himself – the self-care, due to some deficiency caused by a neurological lesion. The study of the functional ability has helped both to comprehend the survival of those with movements' restriction and contributed to evaluate the

health condition of people with deficiencies – in this study, quadriplegic men.

### ***Fears, uncertain future and parents' loss: human fragilities and thresholds***

It is a fact that the nursing literature emphasizes the importance and the need for the participation and for encouraging the client to participate in his self-care; it is also notorious that the family must be instructed to cooperate in order to allow the client to try to do it on his own. The fears and anxieties of the disabled, and, mainly, the difficulty to express them openly make him adopt a passive attitude towards the care received from his family and/or home caregivers<sup>(8)</sup>.

I am afraid. Because today I have people by me side – my parents. And I am afraid of losing them. If I stay alone, who is going to be my placeholder? Who is going to take care of my things? That is not all. But also, staying alone, losing the love, the important care of my parents [VENUS, 45 YEARS OLD].

I fear that someone I depend on might die. I have this fear, but I am not afraid of death. I am afraid of being alone. But I think nobody does. It does not matter how bad the person is, she does not stay alone [JUPITER, 25 YEARS OLD].

The components classified in the ICF related to the category of activities and participation in the self-care – which is, thus, relevant for nursing – consist on washing himself, taking care of his body parts, the personal hygiene related to excretions, getting dressed, eating, drinking, taking care of his own health, besides other modalities of self-care, specified or not<sup>(3)</sup>. Evidently, it is necessary to consider that the present study focuses on the quadriplegic person, which implicated thinking in the functional limitations of these individuals, even in the terms of their ability/capability to execute elementary movements for getting objects such as the digital pinch.

This is a reason to justify the fear reported by the deponents in their speeches: the fear of being alone, not having someone to count on to meet their needs, which are elementary for people who do not share the same daily experience they face. The fear expressed by the deponents is based on the permanence of incapacitating after-effects<sup>(19)</sup>, which impose limitations of motor, sensation and sensory character as well as limitations in the comprehension and expression of thoughts. These after-effects may also change their life dynamics, not only restricting their daily activities, which often makes them dependent on others to move and act with more or less independence, but also compromising their abilities to manage their personal and family life<sup>(8)</sup>. Thus, the presence of a personal caregiver is fundamental, even though this person may represent a threat to the principles and privacy of the quadriplegic. Learning to manage the need to act prudently often means the most sensible option.

### ***Functional gains: objective response of body functions***

The disability may be conceived as a restriction resulting from a deficiency in the ability to perform an activity that is considered normal for the human being, in the case of this study, the person with spinal cord lesion after-effect. It is either caused as a direct consequence or it is the response of the individual to a psychological, physical, sensory, or other deficiency. It represents the objectivation of the deficiency and reflects the disorders of the person, in the essential behaviors and activities for the daily life<sup>(20)</sup>.

Being aware of the limitations and needs of people with spinal cord lesion in terms of functional independence allows the rehabilitation services to structure themselves in order to meet the demands of this population more efficiently<sup>(21)</sup>.

It is worth mentioning that the ICF performance qualifier<sup>(3)</sup> describes what the individual does in his usual life environment. As this environment includes a social context, the performance may also be understood as the involvement in a life situation, or their experience in the real context they live. This context includes the environmental factors – all the aspects of the behavioral, social and physical world that may be coded through the component of environmental factors.

The ability qualifier, on the other hand, describes the aptitude of the individual to execute a task or an action. This construct aims to indicate the probable maximum level of functioning that a person may achieve in a certain area at a certain moment. In order to evaluate the full ability of the individual, it is necessary to have a standardized environment to neutralize the variable impact of the different environments over the ability of the individual<sup>(3)</sup>.

Improving my arms, my hands, the functional question of my life in order to give me independence, so that I do not need to be afraid. I try not to be utopian in this situation, otherwise we get down [VENUS, 45 YEARS OLD].

I am aware that I need to have more independence, but for now I am only delaying this process until the limit, I do not know when, I know I am going to suffer a lot because I gave up on the main things in my life; but I will get through it [ORION, 22 YEARS OLD].

The difficulties, limitations or disabilities reported by the subjects of this study reinforce the meaning of achieving a greater functional autonomy for the self-care and daily living activities, and show the need to broaden the knowledge in order to help people and families. It is the nursing responsibility to search for means to fill the social gaps related to the health care of the people, either in institutional spaces or home environments. A greater comprehension of the ICF elements may be relevant.

The ICF means an advance towards the proposals to understand the needs and the specific conditions in which

people with some sort of deficiency in the body functions are inserted in the environment, in their social, technological and natural aspects. It constitutes a tool that allows to make a multidimensional evaluation of the functioning of patients with mental and/or physical deficiencies. Even though it is rather useful in the systematic classification of the patients' diagnosis, its application is difficult and its use is restricted to communities with a high level of institutional and political development<sup>(14,22)</sup>.

Applying the ICF to the functional gains mentioned by the deponents of this study, the deficiency may have bonds to the components of the anatomical, physiological and psychological functions, depending on the singular characteristics of each one of these people, their experiences, relationships with others, besides the environmental and behavioral influences. Similarly, it became evident that the disability of these people is reaffirmed by the dimension of the after-effects in cervical level, obstructive factor for coordinated active movements, which justifies such disadvantage to fit in the random standards of functional normality.

Concerning the contemporaneous theoretical models and their practical implications<sup>(20)</sup>, it is important to focus on the seminal differences between the medical and the social model of disability. Besides, the medical model emphasizes the dependence, considering the disabled person as a problem, and the social model attributes the collective and individual disadvantages of people with deficiencies, mainly to institutional discrimination. The solution suggested for the disability would be in restructuring the society. It is still necessary to think about what would be the meaning of the nursing models to meet the needs of people with deficiencies, disabilities and functional disadvantages.

In fact, it is evidenced that the nurses comprehend deficiency based on broad medical, functionalist and individual perspectives that do not consider its social implications<sup>(5)</sup>. One point to consider is that people with a deficiency may be more critical than they seem to be, many of them, including, conscious of this old-fashioned and prejudiced way of conceiving them in the area of society and attentive to what this represents as an impact in their health care. The ICF, with its recognition of the interaction among the people and the environments in health and deficiency, is a useful conceptual structure for the education, practice and research in nursing. It brings advantages as it broadens the comprehension of the nurses regarding the cultural, political and social dimensions of the deficiency<sup>(23)</sup>.

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Managing the emancipation implicates managing the care centered in the person as a subject of his health-disease process, developing care technologies that are capable of helping the construction of his own projects for improving and/or recovering the health, and focused on the value of the several values/knowledge of the nursing team as rich possibilities to care, interacting articulated and harmoniously to the not less complex system of values of the person under their care<sup>(24)</sup>.

## FINAL CONSIDERATIONS

This study evidenced the need to study, research and discuss the implications of the ICF with the care and diagnostic propositions of nursing, mainly, comprehending the challenge to participate effectively in international forums of discussion focused on the elaboration of policies for health and the inclusion of people with incapacitating cervical lesions.

The results of the present study confirmed that the presence of the parents has consensual relevance to the help in self-care and daily living activities; and in their absence, other family members are the most indicated people to play the home caregiver role, even in face of internal conflicts of the routine among people from the same family.

The application of the supporting technology was approved as an instrument for seminal contributions concerning the independence and functioning of people with spinal cord lesion in cervical level. Even though some options constitute a high cost and may be accessed by few people, other feasible and low cost options that also provide substantial gains have been demonstrated to their users.

Concerning the fear of losing the parents, the individuals clearly state doubts about what will come from the moment their parents are no longer present or healthy to take care of them and meet their daily needs. This concern is shared by all the deponents of this study.

Their hopes relate to the functional gain in order to obtain greater independence and live without depending so much on the help of others for their needs, regardless how elementary they may be. In this study, nursing may contribute significantly, by using the elements of the ICF for the performance of their procedures in the teaching, research and care scope, and sharing them with home caregivers of quadriplegic people, for instance.



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