

## (HANDICAPPED) CAREGIVER: THE SOCIAL REPRESENTATIONS OF FAMILY MEMBERS ABOUT THE CAREGIVING PROCESS<sup>1</sup>

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*This study aimed to analyze what looking after physically disabled persons with spinal cord injury by trauma means to their caregivers and family members. The analysis of the testimony of eight caregivers, obtained in open interviews, which was methodologically based on the Social Representations Theory (SR), pointed out two main routes: coping with the suffering process in care practice and the troubled waters that permeate this suffering process. These two routes, characterized as SR Central Core and Peripheral System, respectively, consisted of themes like the way of looking at impairment, affectivity, religiosity, social-economical changes and (lack of) technical and institutional support. The results show a handicapped caregiver dedicated to look after someone who is physically disabled, considered incapacitated, and who leads his or her chores with distress and privations, based on guilt and religiosity, supported by ambiguous affection and affected by deteriorating social-economical changes and (lack of) technical and institutional support to practice an activity that implies so many peculiarities. The transformation alternatives of these caregivers' daily life principally lead to a symbiosis with the patient - to live for the physically disabled - or yet, for a few, a sketch to restart personal life projects - to live with the physically disabled.*

**DESCRIPTORS:** rehabilitation nursing; disabled persons; spinal cord injuries; social psychology

## CUIDA-DOR (D)EFICIENTE: LAS REPRESENTACIONES SOCIALES DE FAMILIARES ACERCA DEL PROCESO DE CUIDAR

*La finalidad de este estudio fue evaluar los significados del cuidar para cuidadores/familiares que comparten el cuidado domiciliario de minusválidos físicos por lesión medular traumática. Utilizando como referencial metodológico la teoría de las Representaciones Sociales (RS), el análisis de las entrevistas abiertas, realizadas a ocho cuidadores, apuntó dos ejes conductores de los significados: el proceso de sufrimiento vivido por las personas en la práctica del cuidar y el de las aguas turbulentas que atraviesan este sufrimiento. Estos ejes, caracterizados como Núcleo Central y Sistema Periférico de las RS, respectivamente, fueron compuestos de temas como la óptica que se tiene de la minusvalía, la afectividad, la religiosidad, los cambios socio-económicos y (la falta de) soporte técnico-institucional. Los resultados revelan un cuidador incapacitado volcado al cuidar de una persona también incapacitada, tenida como inválida, y este cuidar realizado con mucho sufrimiento y privaciones, fundamentado en la culpabilidad y en la religiosidad, sostenido por una ambigüedad afectiva y marcado por extenuantes cambios socio-económicos y falta de apoyo técnico-institucional, para una práctica que supone tantas especificidades. Las alternativas de transformación del cotidiano de esos cuidadores señalan, principalmente, para una simbiosis de invalidez con el otro - el vivir por el minusválido - o aún para unos pocos, un boceto de retomada de los proyectos personales de vida - el vivir con el minusválido.*

**DESCRIPTORES:** enfermería en rehabilitación; personas con discapacidad; traumatismos de la medula espinal; psicología social

## CUIDA-DOR (D)EFICIENTE: AS REPRESENTAÇÕES SOCIAIS DE FAMILIARES ACERCA DO PROCESSO DE CUIDAR

*Este estudo objetivou analisar os significados do cuidar para cuidadores/familiares que compartilham o cuidado domiciliário de pessoas com deficiências físicas, por lesão medular traumática. Tendo como referencial metodológico a teoria das Representações Sociais (RS), a análise dos discursos obtidos por meio de entrevistas abertas, realizadas junto a oito cuidadores, apontou dois eixos condutores dos significados: o processo de sofrimento vivido pelos sujeitos na prática do cuidar e as águas turbulentas que permeiam sofrimento. Esses eixos, caracterizados como Núcleo Central e Sistema Periférico das RS, respectivamente, compuseram-se de temas como a visão da deficiência, a afetividade, a religiosidade, as mudanças socioeconômicas e a (falta de) suporte técnico-institucional. Os resultados desvelam um cuida-dor (d)eficiente, voltado para o cuidar de uma pessoa também com deficiência, tida como inválida, e esse cuidar realizado com muito sofrimento e privações, alicerçado na culpa e na religiosidade, suportado por ambigüidade afetiva e marcado por desgastantes mudanças socioeconômicas e falta de suporte técnico-institucional, para uma prática que pressupõe tantas especificidades. As alternativas de transformações do cotidiano desses cuidadores sinalizam, principalmente, para uma simbiose de invalidez com o outro - o viver pela pessoa com deficiência - ou, ainda, para poucos, um esboço de retomada dos projetos pessoais de vida - o viver com a pessoa com deficiência.*

**DESCRIPTORES:** enfermagem em reabilitação; pessoas portadoras de deficiência; traumatismos da medula espinhal; psicología social

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## INTRODUCTION

During nursing visits at the Outpatient Clinic of the Sorocaba *Conjunto Hospitalar* (SCH), involving physically disabled persons with Spinal Cord Injury (SCI), mainly aimed at urinary-intestinal reeducation, maintenance of skin integrity, recovery of sexual activity and prevention of deformities, we mostly received these clients in the company of their home caregivers, who were frequently family members.

These care sessions happen weekly, always in a private room, in the presence of caregiver and patient, while the patient is taking part in the rehabilitation program at the above mentioned institution, that is, between 12 and 24 months. The relaxed climate, frequently established as a result of the familiarity that characterizes such an extensive professional relation, allows moments of technical advice to turn into real relief sessions, during which the pain and suffering that affect the attended families are exposed. This suffering mainly characterizes cases of SCI because of the violent and abrupt way it happens and invades patients' and families' lives, increasing potential losses and contributing to greater emotional intensity in reestablished relations.

Caregivers' most common reports refer to feelings of impotence towards such a distressing future and incompetence to perform specific and exhausting tasks, directed at a "new" relative who, each day, reveals him-/herself stranger in the home environment; both involved in a desolating crisis after the passage of the hurricane that disorganized everyone's life.

In view of people afflicted by so many disarrangements, although orientation and follow-up of patients since the early post-trauma stage are fundamental, which facilitate satisfactory adaptation to daily activities, knowledge about the relations established, developed and reorganized between caregiver and patient is also essential. In understanding the appointed inquiries, more beneficial results can be obtained in the rehabilitation program organized at the SCH.

Thus, this study aims to understand the social representations of care for these caregivers, which will certainly support a more adequate and effective nursing care, not only for patients but also for

caregivers, contributing to a successful rehabilitation and, consequently, improved quality of life for these clients.

## THEORETICAL FRAMEWORK

Spinal cord injury is defined as any aggression to the spinal cord that can lead to neurological damage, related to the motor, sensitive, visceral, sexual and trophic functions, and caused by trauma due to car accident, firearm injury, diving into shallow waters and falling from heights, or also by non-traumatic causes, such as tumors, infection processes, vascular changes, malformations, degenerative or compressive processes. In this universe, literature clearly indicates, in Brazil and abroad, the importance of traumas related to increased urban violence<sup>(1)</sup>.

Chronic physical manifestations of SCI include urinary and anal dysfunctions of neurological order, respiratory failure, erectile and ejaculatory dysfunction, orthostatic hypotension, autonomic dysreflexia, reflexive spinal cord hyperactivity, anhidrosis and/or hyperhidrosis, besides other motor and sensitive changes which, affect mobility and independence in daily activities. The acquired deficiencies are associated with a situation of living death, creating a mourning process about the losses, which exactly involve immobility, dependence, isolation, uncertainties and pain<sup>(2)</sup>.

The profile of possible physical complications deriving from SCI outlines another equivalent profile of problems, demonstrated by significant distancing and social isolation caused by constraint, rejection, self-degradation, damage to self-esteem and self-concept<sup>(3)</sup>.

However, this problem certainly does not only affect patients with SCI, but also their family, i.e. "other significant persons". Some authors<sup>(4-5)</sup> mention that the family also experiences a mental state of loss and death and, to allow them to receive the "actual" relative, they need to experience mourning over the "lost" one; and that this process can be experienced in simultaneous and coinciding phases or not. The visualization of a person with SCI, with all of the consequences mentioned here, raises reflections about concepts like physical disability\*.

\* Available at: <http://hygeia.fsp.usp.br/~cbcd/CIF/WebHelp/cif.htm>

## Complexity of caregiving - the care

After the hospitalization phase of SCI patients, during which the health team's care priorities are restricted to treating the consequences of the spinal injury, respiratory failure, changes in tactile sensitivity, muscle atony, tendon and cutaneous areflexia, paralytic vasodilatation, anhydrosis, urinary areflexia, autonomic dysreflexia, intestinal atony, erectile and ejaculatory dysfunction and amenorrhea - which characterize the spinal shock phase<sup>(4)</sup> - the family mainly invests in these patients' home care. The physical aspects of this caregiving at home involve specific and complex activities, such as adequate positioning and transferring, urinary-intestinal reeducation, care to maintain skin integrity, prevention and treatment of pressure ulcers, maintaining respiratory and ventilatory capacity in quadriplegic persons and sexual readaptation of clients and partners.

The need for this care comes about at a rather difficult time, generally marked by the memory of recent violence that dragged the individual into a new and unknown situation, which requires coping based on personal and social characteristics that are permeated by the symbols, perspectives, group references and past experiences in the individual's life story<sup>(6)</sup>. The author presents clients who survived trauma and experience a new reality, which involves a redimensioning of limitations and possibilities, corresponding to the complex experience of an adult who is faced with the obligatory relearning and new articulation of new ways of being/doing.

This same mandatory experience also refers to people in that patient's world of relationships, particularly with caregivers, imposing the challenge of a new order on both: social insertion<sup>(6)</sup>.

This order constitutes an extremely difficult and painful process, to the extent that both persons, i.e. the physically disabled patient and the caregiver, will be involved in a web of conflicting feelings, facing the performance of tasks that were unknown to their reality until then, and which require physical/mental/social/intellectual/financial resources they often do not have at their disposal.

In human history, care is related to survival, is reflected in health and, consequently, in quality of life<sup>(7)</sup>. Some experts<sup>(8)</sup> derive the word care from Latin - *cura*, whose ancient form - *coera* - was used in a context of love and friendship relations, expressing

attitudes of care, devotion, concern and unrest about the loved one or esteemed object. Other scholars consider it originates from the word *cogitare-cogitatus* and its wrong versions *coyedar*, *coidar*, *cuidar*, which mean the same as *cura*: cogitate, think, direct attention, show interest, disclose an attitude of devotion and concern. The association between both origins reveals the meaning of care as devotion, willingness, diligence, zeal, attention, good treatment, and arises to the extent of the care-needing subject's importance for the other - the caregiver. Therefore, due to its own nature, care includes two basic and closely connected meanings. The first, this attitude of devotion, willingness and attention to the other person, and the second, the concern and unrest, because the caregiver feels involved and affectively connected to the other. Thus, the etiology of the word already reveals a conflict.

Moreover, care is a way of being in the world, a way of existing and co-existing, of being present, of navigating through reality and relating to everything in the word<sup>(8)</sup>.

## The Caregiver

This reveals that all care implies the existence of a caregiver, that is, a person delivering care formal or informally. Formal caregivers are specifically trained for care delivery and are generally paid: nurses, nursing auxiliaries and technicians, health educators. Informal caregivers, on the other hand, are people who start to deliver care and learn, in practice - trial and error - the best way of helping people in need<sup>(9)</sup>.

Other care concepts refer to the characteristics of the delivered care. The primary caregiver directly assumes responsibility for the necessary basic care; secondary caregivers are identified as people who deliver occasional care or care that is considered less important for the individual's recovery<sup>(9)</sup>.

While the formal caregiver structure is well-defined through professional training and institutional affiliation, informal caregivers need to be "identified", which is not always easy. There are some rules inherent in family dynamics to define the main caregiver<sup>(9)</sup>. Gender, family relation, physical and affective proximity are important variables to determine who will assume the caregiving role. This analysis, de *per si*, presupposes that the caregiver is

a family member or, at the least, a kinsman. Actually, however, the criterion that is generally copied is the availability to carry out these tasks, giving rise to domestic arrangements, in function of professional, school and religious activities that best accommodate the situation.

Once the home/informal caregiver has been established, (s)he has to be defined as a social subject who absorbs both popular and scientific knowledge - transmitted by professionals' discourse - besides systems of socially shared values and beliefs which, together, constitute his/her imaginary thinking about family care. This thinking is loaded with cultural traits of the social group the caregiver lives in<sup>(9)</sup>.

Thus, social representations/meanings of care, in combination with the urgent need to take care of the family member and the lack or deficiency of a formal support network, start to determine the choice of the caregiver, whose tasks depend on the type of morbidity and dependence level of the care receiver. That person is also confronted with the fear of not taking care adequately, besides the need to redefine life projects and personal and social relations<sup>(9)</sup>.

In principle, we can deduce positive and negative meanings involved in caregiver-patient relations, due to the characteristics of physically disabled persons and the range of social marks imprinted in this care. However, in this study, we aim to unveil the meanings and representations of care for caregivers of physically disabled persons with SCI, with a view to contributing to the educative role of the multidisciplinary team, mainly nurses, in their activities that involve this binomial: caregiver-physically disabled person.

## METHODOLOGICAL PROCEDURES

In defining the study object, we determined that the qualitative method, in the framework of Social Representations (SR) would most adequately allow us to understand the meanings of care for physically disabled persons with SCI, from the caregiver's perspective.

In Classical Psychology, representing means an active process that implies reconstructing what is given by a context of values, reactions, rules and associations, in which the exterior existence is marked by individual and social psychism. Representation is the instance between perception and the concept and

its image character, the concrete mental contents of an act of thinking that symbolically restores something absent. It was *Moscovici* who proposed an interface between individual and collective phenomena, within a psychosocial approach using SR, as a way of thinking subjectivity in Social Sciences<sup>(10)</sup>.

With a view to getting to know some aspects of the contexts in which the study subjects live and considering the fact that poverty, work conditions, housing, customs and health factors intervene in the state of well-being<sup>(11)</sup>, we present some information that helps to unveil aspects in this scenario. These people - *caregivers of patients with traumatic spinal cord injury* who received care at the Rehabilitation Outpatient Clinic of the Sorocaba *Conjunto Hospitalar* - were the cases analyzed in this study, mainly in view of the observed exhaustive impact in the lives of families attended at the SCH, besides the relevance of trauma epidemiology in the Brazilian spinal cord injury scenario<sup>(1)</sup>.

The project was submitted to the Ethics Committee at the Medical Science Center of PUC/SP and approved together with the Free and Informed Consent Term (FICT).

Interviews took place in Sorocaba-SP, at the outpatient clinic, in the room where care was delivered, except for one caregiver, who requested to be interviewed at home because she could not remain absent for a long time. Before the interviews, caregivers received information about the research procedures and objectives. After they agreed and signed the FICT, the interviews started in a private environment, guaranteeing that subjects' identity would be kept anonymous.

The obtained discourse was tape-recorded and later transcribed, after the caregivers' approval. Recording is quite a significant instrument in studies using discourse for data collection, which permit researchers to relive the moments when statements were produced, with all of their peculiarities. Besides the central guiding question, "*What does it mean for you to take care of...?*", we also used some secondary inquiries during the caregivers' discourse, aimed at guiding them around the central theme.

The use of language as a way to obtain data is a fundamental option in the methodological framework, since it intermediates between the world and ourselves, to the extent that it allows for the elaboration of SR, as the personal meaning we attribute to socially elaborated meanings<sup>(12)</sup>.

Recorded and transcribed discourse was later submitted to content analysis through exhaustive reading and listening to the tapes, with a view to identifying recurring themes and contradictions that spontaneously emerged, the linguistic style with metaphors, affirmations through denials and omissions, the most used verbal forms and even the meaning of grammatical errors.

This initial and repeated analysis aimed to detect the Central Nucleus and elements of the peripheral SR system, as Jean Claude Abric proposed in 1976, in his Theory about the Central Nucleus of SR<sup>(13)</sup>. The Central Nucleus Theory of Social Representations is based on the assertion that representation is organized around a central nucleus, accompanied by a peripheral system<sup>(13)</sup>. According to the author, the Central Nucleus determines its meaning, stability and internal organization. It is a subset of the representation, consisting of one or more elements and whose absence would destroy the representation or grant it a totally different meaning. It is collected to the group's collective memory and history, defining its homogeneity and withstanding changes; it is the fruit of historical, symbolic and social determinisms; it constitutes its abstract part. The Peripheral System, on the other hand, is the concrete part and allows for the adaptation of the representation to different social contexts, in contact with daily contingencies. It permits the integration of subjects' individual experiences and histories, supporting group heterogeneity and contradictions.

## DIVING INTO HOME CARE: THE PROCESS OF SUFFERING IN TROUBLED WATERS

Eight caregivers participated, seven of whom were women, i.e. one sister and seven wives, while the only man was the patient's husband. Average age was 31 years, ranging from 21 to 46 years, and all participants were married. Education levels were low, with one illiterate caregiver, six who has not finished basic education and one who finished secondary education. Two participants worked, only one of whom was formally registered in the labor and social security system. All families lived on two minimum wages per person at most.

In the study, we found that the central nucleus of SR about care for caregivers of SCI patients was the *process of suffering* - which subjects

dive into when they are confronted with the sudden care process - involved in a peripheral system characterized by *troubled waters* - in which they struggle and start coping. The suffering process, constituted by the *caregiver's view of the physical disability*, by the role of *religiosity* in his/her life and by the influence of *affection* in his/her relations, is immersed in turbulent waters, which involve the *socioeconomic changes* imposed by the event of the disability and the *(lack of) technical-institutional support*, which interfere in the care process. *Table 1* presents the elements or constituent themes of the central nucleus and peripheral system of SR, as well as their sub-themes.

Table 1 - Themes and Sub-themes of the Central Nucleus and Peripheral System of S.R. for Caregivers of Physically Disabled Persons with S.C.I.

Themes		Sub-themes
Process of Suffering (Central Nucleus)	View of Physical Disability	Invalidity, dependence, incompetence, infantilization, duty, responsibility, revolt, change in social roles.
	Affection	Biased feelings (love/hate, joy/suffering, euphoria/depression, acceptance/ rejection), physical and emotional exhaustion, impotence, loss of identity, insecurity, fear.
	Religiosity	Guilt, atonement, divine punishment, dedication, bargain, faith.
Troubled Waters (Peripheral System)	Socioeconomic changes	Loss of purchasing power and goods, assuming financial burdens, conflicts and family arrangements, loss of privacy, decreased leisure, social status as caregiver.
	(Lack of) technical-institutional support	Trial and error tactics, level of dependence, nature and complexity of tasks.

The analysis of caregivers' discourse shows that the guiding line of narratives pointed towards a difficult daily reality, loaded with suffering and pain, permeated by biased feelings and determining many affective conflicts.

We will now look at the Central Nucleus, called process of suffering here, and dive into its deepest part.

### Diving into caregivers' process of suffering

The process of suffering is anchored in a view of disability guided by negative representations / actions, in a stigmatized perception, which can be observed at different times when the disabled person is associated with the stereotype of *invalidity, incompetence and dependence*.

The stigma, defined as a scar, as something that marks, clearly indicates the process of disqualifying the individual. This "look" places him/her in the world of the excluded, seen as "anybody who is rejected from our material or symbolic markets and from our values"<sup>(14)</sup>. The naturalization of the exclusion phenomenon and the role of stigma - as there are values and representations of the world that end up excluding people - serve to express the nature of the incidence of mechanisms that promote the reproductive cycle of exclusion, represented by acceptance at social level as well as by the excluded person<sup>(15)</sup>.

*...(then I told him like this): I'm never going to throw at you that I have an invalid husband, I won't do that... I want you to be happy, like you were before and now, but it's not because this happened to you, this accident to you, that I'm gonna say that you are an invalid man, an unhappy man, no...*

In their research, some authors<sup>(3,5)</sup> confirm the view of disabled people as useless, invalid and incapable of self-care. In the care relation, these meanings disclose an identification of disabled people with the feeling of helplessness characteristic of childhood. Hence, it is no longer about care for an adult, but for a child or, even more significant, for an adult turned into a child. A child outside his/her time and place, who lost, or almost, his/her autonomy. And who suffers.

Thus, disabled husbands turn into children, sons and siblings, while caregiving wives become mothers, older sisters and/or managers and businesswomen, in an evident *change of social roles*. The representations about the incapacity give a new meaning to the relations between caregiver and handicapped person, as they form/deform values, attitudes, affection and power relations, which support relationships.

*...he was a person like, for me he was ... you know? A man. Now I don't know if I'm taking care of my husband or a child.*

In the caregivers' perspective, the suffering that permeates the care process is influenced by the perception of the other person's suffering, for whom dependence - a strong mark of disability - by making him/her incapable of assuming his/her own life, creates feelings of aggressiveness and *revolt*.

*That's what I think, I think that I (if I were disabled), I would also want to do things I couldn't, I would think about the*

*way today and yesterday, I would wish today were like yesterday, I wouldn't want to remain seated, instead of running, so I think that, at that time, when people start to think like that, a lot of things go on in your head, that's when revolt comes, that's when nervousness comes, when anguish comes, I think that's where it starts...*

This new look - even if unwanted - of the other/disabled also reveals values anchored in historical, symbolic and cultural determination, such as the sense of *duty and responsibility*, according to which it is exactly how one should act towards people who need us, especially when they are inside our own home, our own family. Once again, the issue of women as responsible for the child comes up, as taking a maternal role deriving from *infantilization* and the conflicts and contradictions produced by this look.

*I think that, you have to, I lived well with him for ten years, I have to live with him till the end of my life, with him the way he is, you know? Or this way or worse. But I have to...*

In analyzing the process of suffering caregivers of disabled persons with SCI go through, we need to attempt to understand the affection involved in these relations. When assessing the family impact of disability, the *ambiguity of feelings* is pointed out<sup>(5)</sup>, comparing it with Hercules' fight against the hind Ceryneia\*, which had bronze clogs and gold horns. She was gigantic and extremely delicate in all of her gestures. The association between very strong extremes of feelings, such as love/hate, joy/suffering, euphoria/depression, acceptance/rejection is a constant in caregivers' discourse and evidences difficulties they overcame or maximized, at different times in care.

*I love him just the same... and... he was a person, like, for me he was... you know? A man... What can I do? Change him all the time, all the time at home, my husband, all the time, all the time, you know? Sometimes I don't want to... I don't wanna be close to him all the time, like that. To tell you the truth, it's fear, of one day arriving and abusing... of abusing... and not wanting anymore, wanting to get out. I don't even wanna think, but sometimes... For him to leave a little..., a little... for me to live... you know? When I leave home just for a while, I already miss him. And when I'm changing him all the time, I don't want to... I wanna leave a little... for him to leave. I don't, I stay at home, but I'm already afraid that one day, I will abuse, and I don't want that, I don't wanna do that (crying a lot). That's enough, that's enough...*

\* Mitos e lendas da Grécia Antiga. São Paulo, Melhoramentos-EDUSP, 1976

In the light of some studies and starting from the premise that any new, unknown situation entails bias, the author<sup>(5)</sup> affirms that failing to overcome it configures the passage from a critical situation to an actual crisis. This lack of success can be due both to the individual's impossibility to get organized in view of a new condition, and to the impossibility to modify or destructure an old situation that now bears new characteristics.

The ambivalence of the caregiver's feelings is a relevant piece of information<sup>(9)</sup>, frequently present and inherent to the care task, justified by the counterpoint of physical and emotional exhaustion - "being on the limit" - and satisfaction about doing one's duty.

*I get confused, then, for me, I hardly have any time at all, it's more than that, it's taking care of him, I get up at seven in the morning, I stay, I make breakfast, I give him breakfast in bed, that's what I do...*

*Ah, one day you feel nervous, you know, 'cause seeing a situation like that, it's hard, you know? The kids, everything. You feel nervous...*

Despite the presence of these contradictory feelings that ratify the crisis, one may say that care is supported by affection, emphasizing that, of course, the quality of the preexisting affective bond determines the elaboration of how this care is represented for caregivers and patients.

In combination with *physical and emotional exhaustion*, when control and power are desperately needed or wanted, the experience of *impotence* - which enhances the fact of "being on the limit" and revolt - has revealed to be one of the most destructive states of mind known in humanity<sup>(3)</sup>.

*Last Saturday, I cried so much because I don't have a gift to cure her pain... Then I get really revolted. Sometimes I'm gonna take care of her and I think about how life can be so...*

This destructive impotence contributes to the caregiver's *loss of identity*, in provoking transformations in daily life and social roles and to the extent that it marks the body-soul itself, represented by a notion of incapacity to permanently adapt. This loss is fundamental to recover or give up personal projects.

The annulment of personal desires, including one's own sexuality, can be identified in discourse, badly disguised as an acceptance of destiny, again characterizing the bias life itself has become.

*Sometimes it's... suffocating...it's not easy, no... sometimes you think like: How long is this gonna last? How long*

*do we have to bear it, mainly I, I'm a person, that I don't own... you know? I don't talk to many people, even you don't see me talking, this thing of friendship is not there, I don't have one friend I take home to talk.*

"Being on the limit" implies taking into account the fear that expressing one's own emotions can increase the disabled person's stress, making caregivers suppress their cathartic needs, afraid of being the trigger that delays the rehabilitation process.

Other relevant aspects are the *insecurity* about the violence the family has lived and the *fear* of new losses, or of not taking care adequately, which aggravate the suffering even more.

*What am I gonna do on my own? Then, my God, how am I going to do that (to take care)? Oh, my Jesus!*

Being the country with the largest catholic population in the world, Brazil has an infinite repertoire of religions readily offering themselves to adepts wanting immediate and simple answers to their constraints in life, and supernatural solutions to problems considered beyond the reach of interventions by professionals and institutions that deal with things in this world<sup>(16)</sup>.

When we talk about losses and *guilt*, in the religious context of western cultures, conflicts and bias also appear. The feeling of guilt related to the cause of the relative's disability is present in all reports.

*I think I was in default during the accident. I found myself sleeping, I woke up and I didn't stop. I feel guilty, not even God can take that feeling away...*

Thus, the caregivers' discourse contains a strong feeling of guilt about the disability which, in combination with the belief that one should not abandon a disabled person - the feeling of duty and responsibility - determines a care that can appear as settling accounts, a call for the *atonement* of guilt - understood as a sin - for ancient feelings that were rediscovered and reconstructed on the basis of memory<sup>(9)</sup>.

The idea constantly expressed as "bearing the cross that God gave you" leads to the question of *divine punishment*, as both, crime and punishment, represent the risk one incurs by not complying with God's requirements<sup>(17)</sup>.

*I have a daughter with an, with another girl, she's gonna be ten today... And we weren't meant to stay together... Sometimes, I even think, like that, about something stupid, you know? God is charging me for that. Because ... I made the girl pass through a very big humiliation, you know? God is charging me because I'm going to pass through great difficulty in life to*

*pay for my mistake here. That's another saying: what goes around, comes around.*

It should be observed that the motivations the caregivers present are based on a belief that legitimizes this symbolic universe: "it is in giving that we receive", as well as the practice of making promises, a religious characteristic of the Brazilian people: promises are paid for with prayers, pilgrimages, penitence, offerings, sacrifices, fruits of the land, animals, money, according to different religions. Thus, the requests God attends to confirm and concretize the *bargain* and nourish *faith* and hope. This faith often appears as support to face difficulties and suffering, offering strength to overcome them.

*...she had the accident, the severity of the injury, very high, and... I believe that He listened to me when I asked that He wouldn't take her away from me, that He would let me take care of her in any possible way. That He would allow her to stay in the world, even... the way I knew she would become, I would take care of her...*

As the goal of all representations is to turn something not familiar, or non-familiarity itself into, into something familiar, caregivers are now motivated by the mobilizing current of non-familiarity - represented by specific, sudden and unexpected care for a physically disabled relative - facing the need to find a way that guides them, and the safe margins to anchor them in this turbulent sea. At this moment, SR theory provides an understanding of one of the mechanisms to legitimize this care: *dedication* and effort to take good care, aimed at the bargain to cure the disability and/or achieve emotional sustainment for a daily reality that is so afflictive that, although disturbing, it imposes the obligation to reconstruct, in the attempt to regulate the harmony of mind itself. All statements indicate the guiding presence of God in man's destiny.

This anchorage is dynamic and mobile, which is characteristic of SR: as long as disabled persons are beings destitute of their own will and incapable, in the caregivers' view, and as long as the latter feel guilty about the situation that created the disability, care will be marked by effort and dedication, permeated by affection, sustained by faith and rewarded by God through the sustainment of suffering and through the slowly obtained processes in the rehabilitation process, thanks to the excellent care: hygiene, food, decubitus changes, wound dressing, medication, exercises and so many others; a care

that will provide for the atonement of guilt, as it involves so much suffering<sup>(3,5,9,14-19)</sup>. What certainly does not occur is an immediate process of transformation in the caregiver/care-dependent relative relations, but a progressive perception of oneself and the other in the way each of them presents him/herself "here and now"<sup>(9)</sup>. "This new other" is reaffirmed by the recognition of "this new other" by the other person, in a process of elaborating and giving a new meaning to care, guided by the transformation of something not familiar into familiar, which characterizes the dynamics itself of these representations.

Thus, the caregiver discerns the margins of these turbulent waters while struggling with the socioeconomic changes and the lack of technical-institutional support, which are elements of the Peripheral System of SR and are described below.

Walking along the margins of troubled waters

Being-in-the-caregiver world of a disabled relative implies living with other daily transformations, besides the ones we already discussed. By themselves, that is, without considering the disability and the suffering, these cause confusion and privations. These transformations, characterized as socioeconomic changes here, represent the concreteness of different losses involved in exclusive dedication to care, one of the roles of the Peripheral System of SR. Thus, the family is pressured to *assume financial burdens*, with different reactions, reflecting in new *family arrangements or conflicts*.

The caregivers' discourse reveals their dependence on relatives and friends, in a meaning that reproduces that of the disabled person.

*...And it has to be me, you know? Because his family rejected him, two months ago, when there was a problem with the boy (son of the caregiver and the disabled person), I told him to ask eighty reais for his (the disabled person's) father to help, his parents, they haven't come to our home until now, and they neither gave any response, the only thing they said was that they were building a house and that they couldn't come now, and then they said they would send a message, they didn't, so, that's something, it's only me and him...*

In this sense, the need for a caregiver's presence by the side of the disabled person results in a *loss of privacy* and of *leisure moments*, which contribute to mental disorganization and crisis over time.



*What I put into my head is that I want to take good care of him, I want to take good care of my daughter, I become like that, kind of nervous, because most of the time I spend with him, I want to spend some time with my daughter and I can't, you know? Today I don't have that time anymore, you know? So, I miss that a lot, because, it's hard, you know? Time goes by and I take care of him the whole day, stay by his side, do what I like to do when possible, and it's like that I lead my life.*

In line with the bias permeating these representations, the positive meaning of care in the caregivers' lives stands out since, at the same time as the performance of such hard tasks consumes them, dedication to care grants them visibility and *social status* towards friends, relatives and the professional team, which work as a feedback to the caregiver's interventions.

However, this status inside the family can give rise to new conflicts, repeating the so often mentioned bias.

*...Dr. Valdenisio thinks he has done better and, the other day, Dr. Valdenisio told him like this, he saw that we are getting better, but he told me, like that, not to me, to other people who were with him, that if it weren't for me, he (...) wouldn't be where he is today, he said like this: That's right, he has to be grateful for the wife he has, otherwise, he wouldn't be where he is today.*

Recent advances in the structuring of public health services, which may provide technical support for home care in the future, do not exist yet for most relatives who are confronted with the continuity of the rehabilitation process at home. Hence, what we detect in discourse is the lack of decoders for this specialty's reified universe, making them face the challenge through the *tactics of trial and error*<sup>(18-19)</sup>.

*...on Friday I took and arranged the chair for him, we tried to put him in the chair, I took him to the bathroom and everything, I washed him, it was so much better to wash him in the chair than in the bed, so I washed him and everything, I took him to bed, I changed his diaper, I put on the oil where his bottom was red and everything, then he even said that the chair, in the bathroom it's a kind of vase, you know, when he sits, so he managed to do his needs better, he even managed to urinate alone, like that, trying hard, you know? So, it's much easier to take care of him now than it was, it's much better...*

Although in many cases, disabled persons are physically capable of realizing different tasks, as the dependence level is related to the SCI characteristics, such as level and degree of injury, the caregiver often

ends up assuming an overload that jeopardizes both persons' independence process, in view of intervening mental, affective, cultural and social aspects, such as maternalism, disagreements, crises, etc. The *nature and complexity of tasks* to be performed are quite varied and not always related to the established prognosis, solely based on physiological changes<sup>(18-19)</sup>.

*Well, in the beginning, it was, well, practically everything, because he didn't sit, he couldn't move his hands, you had to feed him, you had to wash him entirely, one person alone couldn't wash him, he fainted, you had to take him, and it was everything, you had to do everything, like one of these four or five-month-old babies...*

The caregiver takes up his/her role by delivering care, there is no previous knowledge about how to proceed, whether by the lack of knowledge and support offered by society, or by the fact that caregiver/patient relations are loaded with shared histories<sup>(9)</sup>.

It should be highlighted here that the two proposed structures - Central Nucleus and Peripheral System - are mobile, which is characteristic of SR, intercepting one another at different times, mitigating/reinforcing the process of suffering, in such a repeated and characteristic ambiguity.

#### Sailing the seas of care

We should now try to understand the alternatives subjects in this study found to solve the equations proposed by the experience of such a difficult daily reality. The process of suffering presented possibilities to transform the subjects' daily life, who let themselves take over the steering wheel and sail sometimes turbulent, sometimes quiet waters.

The deepest investment marked their own body-soul, represented by a notion of incapacity for permanent adjustment, mobilizing feelings of impotence, clustering in caregivers their disabled side, of incapacity, finiteness and incompleteness. In this perspective, by attributing a meaning to their intervention, caregivers give a concrete nature to the symbolically shared disability.

Using the construction elaborated by some authors<sup>(20)</sup> and, in view of discourse analysis in this study, we see a (handicapped) caregiver, who lives in a changing symbiosis with the disabled person, concealing representations of him-/herself and mixing rejection and guilt with movements in reaction to the assimilation of this superposition, which submits both

persons to the same order of disability, in a move to "turn to one's inside", characteristic of *living with the disabled person*.

On the other hand, there is a smaller group which, with great difficulty, has attempted to elaborate the crisis situation we mention, whether by accepting failure or by denouncing difficulty, although still without any larger sketches of reorganization and relearning. This fragile perspective leads to the belief that the caregiver's focus of personal realizations is reduced to the figure of the disabled person, starting to *live with the disabled person* the entire plurality of meanings and representations this relation can outline. Figure 1 shows the representational scheme of care according to caregivers of physically disabled patients with SCI.

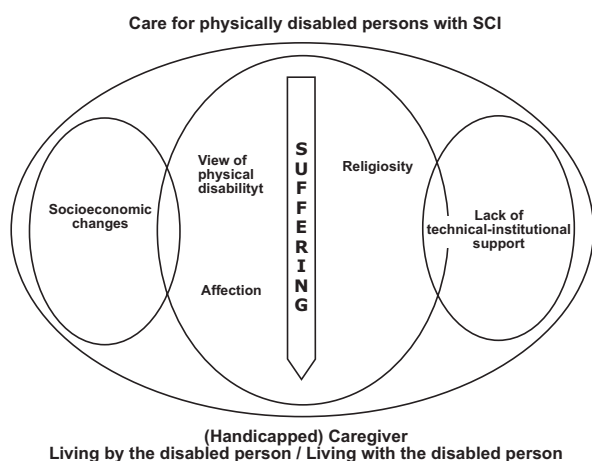


Figure 1 - Representation of care for caregivers of physically disabled persons with spinal cord injury

## FINAL CONSIDERATIONS

Reflections about the distinctive suffering process in specific care for patients with SCI and some perspectives to overcome it impose the priority need to prepare professionals and material resources, as a way of providing technical-institutional support, preferably linked up with public policies aimed at attending to such complex demands in the caregiver-physically disabled person binomial, considering all mental, cultural and social particularities presented here.

Although this study does not make any claim on covering the immense range of possible experiences in home care for physically disabled persons, their assessment in the light of Social Representations allowed the authors to mobilize feelings and emotions contained in a web of rational behaviors elaborated during their professional practice, considering that, often, in the continuity of the home rehabilitation process, nurses actually share the suffering of subjects: caregivers and physically disabled persons.

Thus, these results aim to contribute with a view to letting not only nurses, but all health professionals who deal with SCI patients and their caregivers, to face the challenge of receiving this suffering, expressing gestures of support, patience and dedication, in a complex and intense way of human social life. This is probably the hardest task, as it is not expected and requires the use of resources the academy does not provide. On the other hand, it can also be the most rewarding task, to the extent that it allows for the new elaboration of professional practice, leading to the conquest of a personalized care, as the road towards true care.

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