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Daily life changes of family caregivers of subjects affected by Acquired Brain Injury in productive age

As transformações do cotidiano de familiares cuidadores de sujeitos acometido por Lesão Encefálica Adquirida em idade produtiva

Las transformaciones del cotidiano de familiares cuidadores de sujetos acometidos por Daño Cerebral Adquirido en edad productiva

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Abstract

Introduction: Acquired Brain Injury (ABI) causes major changes for the affected subject as well as for their relatives. **Objective:** The objective of this study was to reflect on the changes in daily life of family caregivers of ABI subjects in productive age, analyzing, especially, the impact of the absence from work of brain injured subjects on the perception of their relatives. **Method:** This is a descriptive study with qualitative approach. Data collection was carried out between June and December 2014, through active search in public rehabilitation services in Physical Therapy, Speech Therapy and Occupational Therapy of a medium-sized inland city in the state of Rio Grande do Sul. A total of 27 caregivers participated in this study, 26 of them were family caregivers and only one was a formal caregiver (excluded from the study since it did not contemplate our objective). **Results:** Data were analyzed using the Content Analysis method and are presented into two categories: 1) Family caregiver: a new role to play; 2) Perception of family caregiver on absence from work of ABI subject and its repercussion to family life.

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Conclusion: ABI brought to family caregivers feelings of fear and anguish in the act of caring, as well as physical exhaustion; it also brought financial difficulties and social isolation to family caregivers of subjects with ABI.

Keywords: Stroke; Sick Leave; Caregivers; Family Relations.

Resumo

Introdução: Lesões Encefálicas Adquiridas (LEA) provocam importantes mudanças no sujeito acometido e em seus familiares. **Objetivo:** Este estudo foi refletir sobre as transformações no cotidiano de familiares cuidadores de sujeitos com LEA em idade produtiva, analisando, especialmente, o impacto do afastamento do trabalho desses sujeitos lesionado encefálicos na percepção de seus familiares. **Método:** Trata-se de um estudo descritivo com abordagem qualitativa. A coleta de dados foi realizada entre junho e dezembro de 2014, por meio de busca ativa, em serviços públicos de reabilitação em Fisioterapia, Fonoaudiologia e Terapia Ocupacional de um município de médio porte do interior gaúcho. Participaram deste estudo 27 cuidadores, destes 26 eram cuidadores familiares e um cuidador formal (excluído do estudo por não contemplar o seu objetivo). **Resultados:** Os dados foram analisados pelo método de Análise de Conteúdo e estão apresentados em duas categorias: 1) Familiar cuidador: um novo papel a ser desempenhado; 2) Percepção do familiar cuidador sobre o afastamento laboral do sujeito com LEA e sua repercussão no cotidiano familiar. **Conclusão:** A LEA trouxe para os familiares cuidadores sentimentos de medo e angústia no ato de cuidar, assim como desgaste físico; também trouxe dificuldades financeiras e o isolamento social dos familiares cuidadores de sujeitos com LEA.

Palavras-chave: Acidente Vascular Cerebral; Licença Médica; Cuidadores; Relações Familiares.

Resumen

Introducción: Daños Cerebrales Adquiridos (DCA) provocan importantes cambios en el sujeto acometido y en sus familiares. **Objetivo:** Esta investigación buscó reflexionar sobre las transformaciones en el cotidiano de familiares cuidadores de sujetos con DCA en edad productiva, analizando, especialmente, el impacto del alejamiento laboral de esos sujetos que sufrieron daños cerebrales en la percepción de sus familiares. **Método:** Se trata de una investigación descriptiva con abordaje cualitativa. La recopilación de datos fue realizada entre junio y diciembre del 2014, por medio de busca activa, en servicios públicos de rehabilitación en Fisioterapia, Fonoaudiología y Terapia Ocupacional en una ciudad de mediano porte en el interior del Rio Grande del Sur. Participaron de esta investigación 27 cuidadores, donde 26 eran cuidadores familiares y un cuidador formal (en exclusión de la investigación por no contemplar su objetivo). **Resultados:** Los informaciones fueron analizadas por el método de Análisis de Contenido y están presentados en dos categorías: 1) Familiar cuidador: el desempeño de un nuevo rol; 2) Percepción del familiar cuidador sobre el alejamiento laboral del sujeto con DCA y la repercusión en el cotidiano familiar. **Conclusión:** El DCA trajo a los familiares cuidadores sentimiento de miedo y angustia en el acto de cuidar, así como desgaste físico; también desencadenó dificultades económicas y aislamiento social de los familiares cuidadores de personas con DCA.

Palabras clave: Accidente Cerebrovascular; Ausencia por Enfermedad; Cuidadores; Relaciones Familiares.

Introduction

Acquired Brain Injury (ABI), mainly when resulting from cardiovascular diseases (Stroke – ischemic and hemorrhagic CVAs)[1] and from Traumatic Brain Injuries (TBI)[2], cause functional incapacity and affect greatly subjects in productive age[1, 2] (women aged 16 to 60 and men aged 16 to 65[3]).

In 2011, the Basic Indicators and Data Brazil, last available data, evidenced that in the period between 2000 and 2010, the diseases of the circulatory system occupied the first place in the causes of death[4]. Data from DATASUS, in the same year, show that, in Brazil, 547.468 hospitalizations were performed due to varied external causes (falls and traffic accidents [cyclist, motorcyclist, pedestrian and car occupant], among others)[5].

The difficulties resulting from ABI might be transitional and/or permanent; they are characterized by sensory-motor and/or linguistic-cognitive limitations and impose barriers that affect directly the daily life of the injured subject[6]. A family's daily life also suffer changes after an ABI episode, because the sequels presented by the injured subjects may generate dependence to perform personal care activities, such as hygiene, feeding, getting dressed, mobility (walk and perform transferences), go to the bathroom, sphincter control (Daily Living Activities – DLA), Instrumental Activities of Daily Living, which are domestic management (preparation of meals, household hygiene and clothes), care of dependent family members, deal with money and go shopping, administer medications, use of transportation (own or public)[7], imposing, therefore, the necessity of a caregiver to assist them in their daily life[8].

The function of caregiver is usually taken up by a family member who, in most cases, becomes the responsible, the person of reference for any and all survival situations of an ABI subject. In other words, the family caregiver is the person (with some kinship bond) who takes up and/or manages the care activities of subjects with difficulty to perform with autonomy and independence their life and/or manage the care[8-9].

The family caregivers who assume the commitment of caring, generally, do not have a basic health training[9] and, this way, when carrying out the activities have to deal with feelings, such as fear, sadness, joy, gratitude, among others. Besides that, they experience the absence from social circles, associated with financial problems[10-9].

On this matter, the financial difficulties resulting from unemployment or precocious retirement are important factors to be researched and discussed. It is known that the profession has a fundamental role in the social life of human beings[11], however the absence from work may generate several problems at home; these could be reflected in the family daily life as some psycho emotional problems, arising from the difficulty of accepting the new family situation, from stress, from financial problems and from the physical and emotional overload, thus jeopardizing the quality of life of all people who are part of the family nucleus[6].

Based on the above considerations, this study aimed at reflecting on the changes in family caregivers' life of ABI subjects in productive age, analyzing, especially, the impact of the absence from work of brain injured subjects in the perception of their relatives.

Methods

This is a cross-sectional study, descriptive with qualitative approach, approved by the Ethics Committee on Research in Human Beings, of the University where the research was carried out, under the number 680.520.

Data collection was carried out between June and December 2014, through active search for family caregivers of ABI subjects in the different public services (municipal, philanthropic or private agreements to the public sector) in public rehabilitation services in Physical Therapy, Speech Therapy and Occupational Therapy of a medium-sized inland city in the state of Rio Grande do Sul.

The first contact with the family caregivers was through the therapist of the service responsible for the ABI subject. In that moment, we explained the study purpose and we invited them to participate; if they agreed, we would schedule a home visit, in which the study objectives, risks and benefits were detailed and then the consent was collected through the Free and Clarified Consent Term (FCCT). After that, in private, a half-structured interview was carried out, which was composed by the following questions: age, degree of kinship, changes in the family functioning and extended daily life, and also how the absence from work of the ABI subject affected the daily life of the family. The interviews were recorded in audio (recorder Sony Icd-Px240) for later orthographic transcription that subsidized the treatment and analysis of data.

A total of 26 family caregivers participated in this study; among them 20 were women and six were men, aged 23 to 80. Regarding the degree of kinship, 14 were wives, two husbands, three children, three parents and four siblings.

In order to analyze the data, the Content Analysis[12] was used; it includes a process of operations of dismembering the text into units, into categories, according to analog regroupings. Therefore, the following procedures were carried out: i) pre-analysis (reading of collected material, seeking to recognize the text and take the most superficial communication issues); ii) exploration/treatment of material (coding, classification of communications, establishing categories) and, iii) interpretation of data. In order to preserve the identity of family caregivers, they were identified as F/C1, F/C2, F/C3 etc.

Results

The data of family caregivers' speeches are organized in five registration units, which are: i) Acceptance of reality imposed by ABI; ii) Social Living –Relation with Family and Friends; iii) Requirements imposed on the family member who takes up the role of caregiver; iv) Perception of family caregiver on absence from work of ABI subject; and v) Absence from work of family caregiver and financial situation of family, according to Tables 1 to 5.

Table 1. Acceptance of reality imposed by ABI – reports of family caregivers.

Line	Registration Unit
1	*In the beginning ... I was very reluctant, because until that moment I didn't have a permanent job, you see. I was idealizing a way to build my life [...], that* [the ABI episode] *interrupted my plans [...]. I didn't accept that new reality, you see?* (**F/C1**; Son; on 28/07/2014).
2	*[...] on the first days, he couldn't eat properly with this hand, it spilled a lot of food and to take a shower he had a lot of difficulty, to take a shower, to get dressed was difficult he was very insecure and it seemed he was drunk, like he was dizzy, you know?!* (**F/C8**; Wife; on 04/08/2014).
3	*Yes, it was difficult, it was very difficult, [to accept], because it is something unexpected, right?* (**F/C10**; Wife; on 03/09/2014).
4	*It changed the whole life of everybody here at home, our children's life, my life, what can I say? Our life comes down to taking care of him.* (**F/C10**; Wife; on 03/09/2014).
5	*A lot, [...] everything stopped, and I don't like to be stuck, I can't be stuck because I get nervous and start shaking. I had to stop doing many things, after his injury, because if I leave him alone, he goes out and leaves the house open, he forgets to lock it, so I can't.* (**F/C12**; Wife; on 11/09/2014).
6	*We were obligated to accept... we didn't accept. I just cried, [...] he was the one who used to take care of me, it wasn't me who took care of him [...] and this way everything has changed [...]* (**F/C14**; Wife; on 24/09/2014).
7	*Yes, now we dedicate ourselves to her, right, my time is exclusive, sometimes I can't even take a nap, I can't [...].* (**F/C19**; Mother; on 08/10/2014).
8	*I couldn't accept his condition, because he was a man... he used to do everything for me [...]. For me as a wife and to my children it was very difficult. The youngest daughter is very attached to him and me; we were the ones who suffered the most. [...] and I couldn't see him like this, so, I didn't accept him in the condition he was [...], I was very sad.* (**F/C24**; Wife; on 27/10/2014).
9	*Oh, it wasn't very easy [to accept], no. But we overcome it.* (**F/C26**; Wife; on 27/10/2014).

Table 2. Social Living – Relation with Family and Friends

Line	Registration Unit
1	*The relationship between my father and my mother, the relationship between them in the marriage was no longer very well, and after the ischemia [...], it got worse.* (**F/C1**; Son; on 28/07/2014,).
2	*Social relations... the first one I can mention is that [...] the people who were our friends many of them turned away. There were always people at our house on weekends: hey, man let's make a barbecue in my home, let's have lunch there, [...] let's go fishing? After the stroke there was nothing else. And those people that I told you who used to be there in these moments as our friends, they suddenly vanished, disappeared [...]. [...] the main fact was the abandonment of people who said that they were our friends.* (**F/C1**; Son; on 28/07/2014).
3	*He has a daughter, the daughter has come once to see him, and after that never again, right!* (**F/C2**; Wife; on 29/07/2014).
4	*[...] his family turned away. His family was almost never there.* (**F/C3**; Wife; on 30/07/2014).
5	*[...] nobody turned away, the family got closer, mine, you know!* (**F/C3**; Wife; on 30/07/2014).
6	*Only unity, the girls, they are all always there. Many visitors, her relatives even, mine [...].* (**F/C4**; Husband; on 31/07/2014).
7	*[...] his brothers didn't help me [...], not even with the physical presence to talk, to see how he was doing, to check if he was experiencing any need. His son has been here only once too... because I asked him please to come, after that, neither him nor the daughter-in-law came anymore.* (**F/C8**; Wife; on 04/08/2014).
8	*The changes of parts... let's say like this... how can I say that? Intimate, private of the couple, after everything has changed, everything happened to be secondary and we started to dedicate ourselves more to our health, anyway.* (**F/C13**; Husband; on 16/09/2014).
9	*I believe that the greatest impact was on her friendships, because there* [at work] *she used to have many, but after they turned away, right!* (**F/C13**; Husband; on 16/09/2014).
10	*There were people who ... when he was fine, they wouldn't leave our house, you know! Every day, always at hour house, in the moment that we had to deal with the disease, the problem, I saw it had changed, you see. Certainly, they didn't accept and didn't help, you see [...] We were pleased to receive the person, in the moment he [...] got sick, they vanished, disappeared, everybody, you see! So, in relation to this, I see that we could understand who is who, you know?* (**F/C16**; Wife; on 30/09/2014).

Table 3. Requirements imposed on the family member who takes up the role of caregiver.

Line	Registration Unit
1	*I had to learn how to cook... I became the cook: make bread; clean the house, wash clothes ... I put them in the washing machine, and it washes, and I just hang the clothes... make the bed, organize things... chores like these, I had to learn, right!* (**F/C9**; Husband; on 27/08/2014).
2	*He used to solve everything, you know. I did the chores at home and went out to do knitting courses, these things, that I liked, but everything else was him; he said like this: you do this, you do that. So, then in everyday life... I had to take up everything, everything, everything, everything, it was very hard.* (**F/C10**; Wife; on 03/09/2014).
3	*I had to take up almost everything at home, since the bath... giving her a bath, even depilation, learning how to use the "modes" [sanitary pad], that until then I just knew it has to be done, but has never done it, right!* (**F/C13**; Husband; on 16/09/2014).
4	*Then... it changed ... before we went out, did everything together. After, it changed, because I had to learn everything out of nowhere... [...] bank stuff, supermarket, bills, he used to do that and then... suddenly, I had to take care of everything. It was quite a change, because I had to take control of everything.* (**F/C16**; Wife; on 30/09/2014).
5	*I didn't use to work at home, and then suddenly I saw myself taking care of the house, taking care of people so everything has changed for me. Even learn how to deal with [...] the housework, schedule, for food and to take, to do physiotherapy [...]* (**F/C18**; Sister; on 01/10/2014).
6	*[...] he took care of the bills, shopping, house, everything, right. And suddenly I saw myself alone, he couldn't do it anymore.* (**F/C24**; Wife; on 18/10/2014).
7	*Yes, my responsibilities increased more, like now I have to determine everything inside the house [...]. Because before he did everything, went to the supermarket to buy the groceries, now I have to do everything, so it has changed a lot. [...] it isn't so easy, but we keep going.* (**F/C26**; Wife; on 18/10/2014).

Table 4. Perception of family caregiver on absence from work of ABI subject.

Line	Registration Unit
1	*His self-esteem fell down, after he got sick, because until then he was a friend and he was valued by others, for being a good professional. You have value if you are a gear within the economic system, you have value, and people try to mask this, but you have value based on what you earn economically, not as a human being, [...] then in the moment he got sick he couldn't work anymore, so he became a disposable piece, then no one looked for him anymore, no one wanted to know about his situation [...].*(**F/C1**; Son; on 27/07/2014).
2	*My father suffered a lot because of this, because until then people used to flatter him, but if because of reason A or B, you got sick, something that let you absent from work, or if you can't do a task the way you used to, to the employer or to the coordinator you're no longer important, what was valuable was your economical side, even I understand that this has to be taken into account, you know??! Not like man you are sick, so I'll have to hire another employee*. (**F/C1**; Son; on 27/07/2014).
3	*He worked selling in the streets, right! And now he can't go, he couldn't stay standing there. No, he has been taking antidepressant drugs, because if he doesn't take it, he will freak out, and then he starts crying and shouting a lot*. (**F/C8**; Wife; on 04/08/2014).
4	*Well, I believe that for her it was difficult, because before she used to do all the housework and also helped with the farming, fed the pigs, the chickens, milked the cow. She helped me with the tasks, I think she misses it, not that today she doesn't help, she helps a little, but it's less than before, she does it the way her limitations allow her to*. (**F/C9**; Husband; on 27/08/2014).
5	*He misses it a lot, because he had a time to arrive in the carpentry shop, he arrived at 8 in the morning, but he didn't have time to leave. He loved to be there, while he was there creating, drawing, he was doing what he liked, so he misses it.* (**F/C10**; Wife; on 03/09/2014).
6	*It was really bad, because he stopped [working]. It was something he liked to do [...]! So much that he went into depression, he takes medicine to depression, because he stopped doing the things he liked.* (**F/C16**; Wife; on 30/09/2014).
7	*He was starting a new life cycle that he can't even enjoy. A new family, a new job, he was entering in a new rhythm, it was a flesh start that he couldn't enjoy because of the stroke, but I believe that he misses his job*. (**F/C18**; Sister; on 01/10/2014).
8	*He didn't have time to prepare for his retirement. But he misses it, there were even days he left and said he would take the bus to go to work, took the documents and left, once we reached him when he was almost at the bus stop, and he said he had to go to the [institution] to work, so I believe he misses it a lot*. (**F/C24**; Wife; on 18/10/2014).

Table 5. Absence from work of family caregiver and financial situation of family.

Line	Registration Unit
1	*I was idealizing a way to* build *my life, [...] and that interrupted my plans, and what was left for me specially as a son [...] I'll work, at the time my father had the stroke I was 23 or 24 years old, no, I'll work, work, work.* (**F/C1**; Children; on 27/07/2014).
2	*In my children's lives a lot has changed, the youngest son, while the [...] was fine he didn't work he just studied, he studied Architecture [...] and with the disease of [...] he had to pause the course [...], he had to start working, he works all day, because we didn't have money, because the financial situation got pretty bad, this has changed in our children's lives.* (**F/C10**; Wife; on 03/09/2014).
3	*Everything! Like, the financial situation and stuff, before he used to work, he went travelling he earned to travel, and if I wanted to go to work I would, if I wanted to go out I would and he would do his things and everything, you know. Now no, now we have to live with the retirement money and even I can't go to work, because how would I leave him alone.* (**F/C14**; Wife; on 24/09/2014).
4	*It has changed because he was used to work, you know! He worked in two places, he had two jobs, he used to leave home early, it changed a lot, a lot of difference in everything. And also, he made more money, so now it has changed, everything has changed.* (**F/C15**; Wife; on 24/09/2014).
5	*I'm a teacher, I've always worked in two schools, but I had to leave one of the schools, I had to reduce the workload.* (**F/C25**; Wife; on 18/10/2014).
6	*I used to work and now everything is me, only me and me [...]. Before I used to be a cleaning lady, I worked as a cleaning lady.* (**F/C26**; Wife; on 18/10/2014).
7	*I worked as a kitchen assistant in a restaurant. I left my job to take care of him, because it's only me, there is our girl, but she studies. So, I had to stop working to take care of him.* (**F/C27**; Wife; on 18/10/2014).

After the analysis of the registration units presented, two categories were created: 1) Family caregiver: a new role to play; 2) Perception of family caregiver on absence from work of ABI subject and its repercussion to family life.

Discussion of Categories

Category 1 – Family caregiver: a new role to play.

After the shock caused by the injury episode, the survival of a family member to a brain injury demands that the family nucleus adapt to a new daily reality. In this new phase, the family will come across the functional impairments caused by ABI which will interfere in the performance of daily activities of the injured subject, and facing this reality the family meets the act of caring.

The participants F/C1, F/C10 (line 3), F/C14, F/C24, F/C26 (Table 1) reported difficulties to accept the new health conditions of the family member affected by ABI and the new family life which was established after the injury. It is known that the emergence of disabling comorbidities is an especially critical moment of confrontation for the family, because it affects all the family members[13]. Studies carried out by Viana et al[14], Moleta et al[15] and Miolo et al[16] highlight that the family may have difficulties to accept the brain injured family member and his/her limitations.

These acceptance difficulties can be reflected in conjugal relations as explicit in the reports of family caregivers F/C1 (line 1) and F/C13 (line 8) (Table 2). When examining the report of F/C1 it is possible to notice that the current situation of the couple, exposed by the son, reflects the result of the conjugal coexistence previous to the injury, because when analyzing the report, it can be observed that the relationship might have been conflicting over the years, what made the act of caring a burden on the spouse.

Biolo and Portella[8] mention in their studies that couples that did not build a healthy relationship, when faced with the caring activity, imposed by the circumstances, the family caregiver tends to present negative reflexes facing this new reality. Besides this factor, the seclusion of the family caregivers to the home environment, the deprivation of activities that they used to practice, the absence from family and friends, the lack of time to take care of themselves and the changes in the family system may lead to a distance between the couple.

Regarding the report of F/C13 (line 8 – Table 2), the spouse reports that after the injury there was change in the sexual relations of the couple, the sexual relations started being secondary in the couple's life. Studies in investigating the correlation of the sexual problems of brain injured subjects point to sexual dysfunctions (impotence) as one of the main factors that lead the injured subjects to deprive themselves of the sexual act. Other factors mentioned in the study were: the fear of having a sexually active life after the injury and the physical limitation and/or emotional problems[17].

The everyday reality which involves a brain injured subject is lived by each family nucleus in a different way, as presented in some reports found in Table 2. This new reality can weaken the family life, leading to distance and/or negligence of some family members in relation to the ABI subject, as reported by F/C2, F/C3 (line 4 – Table 2), F/C8. But also, the new everyday situation and the act of caring can bring the family closer and strengthen the family ties, bringing the family increasingly closer, as exposed by F/C3 (line 5 – Table 2) and F/C4.

The reaction of the family nucleus regarding the injury episode varies according to the particularities of each family. Rodrigues et al[18] mentions in his study the distance of some family members after the injury episode. In most cases, the ABI subject needs a full-time caregiver, and this role is generally assumed by the wife. The new everyday reality and the caring demand, many times, continuous and complex, can generate in some family members feelings of fear, anguish and impotence, leading them to keep distance from the injured subject[19].

However, the fragility of relations does not occur only in the family, as reported by F/C1 (line 2 – Table 2), F/C13 (line 9 – Table 2) and F/C16. In their speech, they highlight the distance from friends, neighbors and coworkers after the injury. A study carried out by Brito and Rabinovich[13] indicates that friends are more present in the first moments after the injury. However, in the course of time, the family caregiver experiences the reduction of visits and the distance from friendship circles [10,13]. One of the factors that may contribute to the reduction of visits and, consequently, the distance from friends, are the language disorders (aphasia) presented by injured subjects[20]. The impact caused by aphasia in the life of family caregivers has been theme of studies on national level[15, 16, 20, 21] and on international level[22, 23]; they show changes in personal, social and economic life and highlight the difficulties found by them in order to live with the aphasia (difficulties of understanding and expression of the relative) and also with the behavior changes and mood swings.

Besides all these changes, the family caregivers face themselves with seclusion to the home environment, which makes them unable to participate in community, leisure and other activities that give them pleasure, thus generating a physical overload and emotional stress for them[10]. This seclusion leads the family caregivers to a social isolation, producing negative impacts on their quality of life, which could be reflected in the act of caring[13].

The return of the ABI family member to the home environment is a moment of happiness, because of the survival, but it is also a moment of much fear, anguish and uncertainty, it is a phase of adaptation both to the injured subject and to the family caregiver[13]. This can be observed in the reports of F/C8, F/C10 (line 4), F/C12 and F/C19 (Table 1).

An ABI episode monopolizes the family attention to the injured subject. The act of taking care of a dependent adult requires a great physical, emotional and socioeconomic availability from the caregiver, and this might be extremely exhausting. Therefore, the health care actions must be performed by a multi-professional team which will look for the individual demands of injured subjects, this way, guiding and preparing the family to the new reality that could arise. This team must guide the family caregivers, in groups or privately, about the exacerbations of chronic conditions, preventive actions, preparation of the family environment, educational actions and self-care actions[24].

The new functional condition demonstrated by the subject affected by brain injury may cause change in family, so, what before was responsibility of the ABI subject, after the injury, in most cases, goes to another member of the family (wife, husband, children, siblings)[13]. These changes appear in the reports of F/C9, F/C10, F/C13, F/C16, F/C18, F/C24 and F/C26 (Table 3).

In the speeches presented in Table 4, it can be observed that besides the act of caring, these family caregivers also took up the activity of management of the house. The change in the family structure is experienced as a disturbance in its system, according to Silveira, Caldas and Carneiro[25], when a family member triggers a process of dependence, this changes the entire family dynamic, resulting in changes of roles and in power relations, reinstituting a new family dynamic.

Taking up the caregiver role of an ABI subject is an act of courage and dedication. In some cases, the caregivers annul their private life in order to take care of the injured subject and take up household activities that before were responsibilities of ABI subjects.

Category 2 – Perception of family caregiver on absence from work of ABI subject and its repercussion to their work activities and to family financial life.

The impact of illness is greater than simply its effect on the subject. The disease consequences are related to the loss of professional identity, the resizing of everyday and economical life, the feeling of uselessness and disability, the social isolation, and insecurity[18]. The absence from work activities causes a great impact on the life of workers, because they have their professional status modified by ABI, moving from the status of worker to retired or beneficiary of Social Security. Family members are also affected by changes in work activities [13].

The feelings of uselessness and disability are perceived by family caregivers are explicit in the reports of F/C1 (lines 1 and 2 – Table 4). Through the reports of F/C1 it can be observed that the workers are truly valued while they remain productively active; when a problem occurs, that makes it impossible for these subjects to perform their work activities, they no longer are valued to the employer and coworkers.

Besides the professional depreciation mentioned by F/C1, it can be observed in the reports of F/C8, F/C9, F/C10, F/C16, F/C18, F/C24 (Table 4) the lack of work activity to ABI subjects and how this absence causes emotional impacts on their lives, because in the reports of F/C1 (line 1 – Table 4) he notices that the absence caused a low self-esteem on the injured family member, and F/C8 and /C16 (Table 4) report depression episodes and the use of psychotropic drugs to minimize symptoms.

According to Alencar and Ota[26] the illness impact goes beyond its effect on the subject. When people who have a profession are affected by ABI, they are taken away from their jobs, resulting in loss of professional identity and feelings of frustration, uselessness, low self-esteem, impotence, depression, anger, anxiety, mood swings, and professional depreciation, among others.

The absence from work of a brain injured subject and the demands of the act of caring involve a caregiver. In order to answer to this new dynamic, the family member, who takes up the caregiver role, frequently has to be absent from work (F/C26 and F/C27 – Table 5) or reduce the workload (F/C25 – Table 5), implying in financial difficulties as mentioned by F/C14 and F/C15 (Table 5). In an attempt to minimize the financial difficulties, it can be observed in the testimonials of F/C1 and F/C10 (Table 5) that the children became responsible for providing the household income.

The effects of the brain injury on the job of family caregivers represent loss and financial problems, even though they receive financial benefits. In order to dedicate themselves to the act of caring, family caregivers usually face problems in their jobs and they end up abandoning them or reducing the workload[10, 13].

Faced with this new financial reality, the children's contribution that before was optional/voluntary, now becomes necessary to support the family. With a low budget, the family establishes priorities, which usually tend to meet the needs of the ABI subject[13].

The family income is reduced due to the loss of financial contribution from the injured subject, and that associated to the increase in expenses resulting from the current demands on medication, transportation and accompaniment to rehabilitation, acquisition of assistive technologies (wheelchairs, orthoses, crutches, among others), widen the negative effects on the family budget. By taking up family financial responsibility, children tend to interrupt abruptly some life projects, as it can be observed in the reports of F/C1 and F/C10 (Table 5), because the new family dynamic determines some deprivation or renunciation of dreams and plans [25].

Conclusion

ABI compromises the family life due to the relation of dependence and protection that is established. The injury was perceived by the informants as a new chaos that made the previously existing structure collapse. The reaction to the new situation was experienced distinctly by each member of the family, suffering influences of personal matters and of the relationship that they used to have with the subject before the episode.

It was observed that the family nuclei tend to focus some activities on a single family member and the changes in roles demanded by the new health condition of the injured subject were sources of strangeness and stress to the family caregiver who took up these activities. Therefore, the act of caring and the need of taking up new competences and abilities were strongly signaled by the family caregivers.

The absence from work, both of the injured subject and of the family caregiver, has seriously affected the family financial situation. Faced with this new reality, families needed their children, who had not previously worked or were attending college, to stop their plans in order to work, and thus contribute to the family income.

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