



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

ORIGINAL ARTICLE

THE EXPERIENCE OF THE FAMILY CAREGIVER OF A TRAFFIC ACCIDENT VICTIM WITH FUNCTIONAL DISABILITY

A VIVÊNCIA DO FAMILIAR CUIDADOR DA VÍTIMA DE ACIDENTE DE TRÂNSITO COM INCAPACIDADE FUNCIONAL

LA VIVÊNCIA DEL FAMILIAR CUIDADOR DE LA VÍCTIMA DE ACCIDENTE DE TRÂNSITO CON INCAPACIDAD FUNCIONAL

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ABSTRACT

Objective: to understand the experience of family caregivers of traffic accident victims who have functional disability. **Method:** this is a descriptive study with a qualitative approach, carried out with nine family caregivers of traffic accident victims with disability. Data was produced through interviews and analyzed by content analysis technique in the form of thematic analysis. The research project was approved by the Research Ethics Committee of UFAL, CAAE 17118313.9.0000.5013. **Results:** four categories were constructed: "The experience of taking care of the victim with functional disability", "The process of change in routine", "Receiving care support" and "Adherence to religious values". **Conclusion:** the experience of the family caregiver of traffic accident victim with functional disability is permeated by physical and emotional aspects arising from misinformation and scientific technical lack of preparation by health team for patient and family care, compounded by economic and social difficulties. **Descriptors:** Family; Traffic Accidents; Accident Consequences; Activities of Daily Living.

RESUMO

Objetivo: compreender a vivência dos familiares cuidadores das vítimas de acidente de trânsito que apresentam incapacidade funcional. **Método:** estudo descritivo, com abordagem qualitativa, realizado com nove familiares cuidadores de vítimas de acidente de trânsito com incapacidade funcional. Os dados foram produzidos por meio de entrevistas e analisados pela técnica de Análise de Conteúdo na modalidade da Análise Temática. O projeto de pesquisa foi aprovado pelo Comitê de Ética e Pesquisa da UFAL, CAAE 17118313.9.0000.5013. **Resultados:** foram construídas quatro categorias: "A experiência de cuidar da vítima com incapacidade funcional", "O processo de mudança na rotina", "Recebendo apoio assistencial" e "Apego aos valores religiosos". **Conclusão:** a vivência do familiar cuidador da vítima de acidente de trânsito com incapacidade funcional é permeada por aspectos físicos e emocionais provenientes da desinformação e do despreparo técnico científico da equipe de saúde para a assistência ao paciente e família, agravados pelas dificuldades econômicas e sociais. **Descritores:** Família; Acidentes de Trânsito; Consequências de Acidentes; Atividades Cotidianas.

RESUMEN

Objetivo: comprender la vivencia de los familiares cuidadores de las víctimas de accidente de tránsito que presentan incapacidad funcional. **Método:** estudio descriptivo, con abordaje cualitativo, realizado con nueve familiares cuidadores de víctimas de accidente de tránsito con incapacidad funcional. Los datos fueron producidos por medio de entrevistas y analizados por la técnica de Análisis de Contenido en la modalidad del Análisis Temático. O proyecto de investigación fue aprobado por el Comité de Ética e Investigación de la UFAL, CAAE 17118313.9.0000.5013. **Resultados:** fueron construidas cuatro categorías: "La experiencia de cuidar de la víctima con incapacidad funcional", "El proceso de cambio en la rutina", "Recibiendo apoyo asistencial" y "Apego a los valores religiosos". **Conclusión:** la vivencia del familiar cuidador de la víctima de accidente de tránsito con incapacidad funcional es permeada por aspectos físicos y emocionales provenientes de la desinformación y por la falta de preparación del técnico científico del equipo de salud para la asistencia al paciente y familia, agravados por las dificultades económicas y sociales. **Descriptores:** Familia; Accidentes de Tránsito; Consecuencias de Accidentes; Actividades Cotidianas.

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INTRODUCTION

The choice of this theme was made by observing the current epidemiological profile of traffic accidents found while conducting a research entitled "Traffic accidents with adults and their consequences after hospital discharge." The findings of this research indicated the need for more studies, especially with regard to the concerns arising from disabilities caused by traffic accidents for the victims and their family.

Given this context, it was noted that the family is fully involved with the new condition of their family member, which is imposed to them, being noticeable in their expressions feelings and emotions arising from the new situation they experience. After hospital discharge and early home care, family members become the main caregivers, due to the need for assistance to the victim, who are often prioritized, interfering in family dynamics.

Traffic accidents are considered a serious public health problem. They currently represent the third leading cause of death in the age range of 30-44 years old, the second in the age range of 5-14 years old and the first in the age range of 15-29 years old, exhibiting indicative of an actual pandemic.¹ According to the data presented by the World Health Organization (WHO), only in 2009, there were around 1.3 million deaths from traffic accidents in 178 countries of the world.¹

In Brazil, in 2008, there were 39,000 deaths and 619,000 people were injured, more or less serious, resulting from traffic accidents.² In 2010, two thirds of the victims were pedestrians, bicyclists and/or motorcyclists. However, national trends of the last decade are marking an evolution with a significant difference in the decrease of pedestrian mortality and increased fatality of motorcyclists, becoming the focal point of the growth of mortality and disabilities on public roads.¹

In Alagoas, according to the latest traffic accident report, in 2010, accidents in Maceio and federal highways accounted only as fatalities people who died at the scene, totaling 6,408 accidents, 3,819 injured and 330 dead.³

In addition to the deaths, traffic accidents are responsible for generating physical and psychosocial consequences for those involved. Added to this, in recent years, the number of survivors has grown rapidly due to substantial improvements in care for trauma victims, which has aroused the interest of the scientific community to investigate the

consequences of accidents for the victims and their families.⁴

The growing interest in this situation has occurred because trauma has consequences in the medium and long terms, regarding the increase of the special needs and decreased quality of life of victims.⁵⁻⁶

One of the main implications generated by the traffic accident to the surviving victims is decreased functional capacity. Functional capacity can be defined as the ability to perform activities that equip individuals to take care of themselves and live independently.⁷ Thus, the person who has disability needs assistance to perform activities of daily living.

Given the above, the development of this study is justified by the need of the professional nurse to broaden understanding about the experience of care experienced by families of traffic accident victims with functional disability, stressing the importance of humanistic assistance to families and the possibility of subsidizing the daily practice of nursing service, contributing to the implementation of public policies and intervention strategies for holistic care of those involved. Based on these aspects, this study has the core question: How is the experience of family members who take care of traffic accident victims with functional disability?

OBJECTIVE

- To understand the experience of family caregivers of traffic accident victims who have functional disability.

METHOD

This study was drawn from the monograph entitled "The experience of the family of the traffic accident victim with functional disability", presented to the undergraduate course in Nursing, Health Sciences Center, Federal University of Alagoas (UFAL), Maceio (AL), Brazil, 2013.

This is a qualitative research, using as methodological theoretical support the content analysis proposed by Bardin, in theme-categorical mode.⁸

Participants were nine family caregivers of victims of traffic accidents, who were seen at the Emergency Unit Dr. Daniel Houly, in 2011, and who had a higher level of functional disability after discharge. These families were chosen based on previously collected data in the search "Traffic accidents with adults and their consequences after hospital discharge",

whose results evoked interest for carrying out this study.

Data collection occurred during the months from October to November 2013, through a semi-structured questionnaire, containing questions to characterize the family as well as a question that guided the interview performed with the family members: tell me, how is it being for you the experience of taking care of your family member with functional disability, after the traffic accident?

The interviews were recorded in MP3 player and had their contents fully transcribed and analyzed. To ensure anonymity, we used the letter "F" (family) for the identification of the study respondents, followed by Arabic numbers, considering the order in which the interviews were conducted (F1 to F9).

For the analysis of the content of statements obtained, the content analysis technique, proposed by Bardin, was used, consisting of unlocking the units of meaning that make up the testimony and whose presence or frequency of appearance may have some meaning to the analytical goal chosen. To go beyond the express wording in the message, the inference is used, reaching, then, a deeper interpretation. The inference, in this case, occurs through the categorical analysis, and consists of three distinct stages: pre-analysis, material exploration and treatment of results.⁸

Since it is a research involving human beings, and obeying the Resolution 466 of December 12, 2012, this study was submitted to evaluation and approval by the Ethics and Research Committee of UFAL by CAAE n. 17118313.9.0000.5013, receiving assent under Protocol 432,656. The family members had family ties, were over 18 years old and experienced the care.

RESULTS

Regarding the characterization of the family caregivers of traffic accident victims with functional disability, it was observed that eight were female, with this data already expected due to the cultural role of women as providers of care. As the age profile, it was observed that the age of the family member ranged between 29 and 73 years old with an average of 40 years old. With reference to marital status, six were married, two were single and only one family caregiver revealed another type of marital status. Among these, they presented themselves as spouses, mothers and siblings of victims.

As for the occupation, three informed to be housekeepers, two were responsible for the family income with retirement benefit and the others had other specific activities. From three to eight people lived in the same household. Regarding the distribution of family income, there was a variation of one to three minimum wages per family.

From the content analysis of the interviews, four main categories that characterize the experience of family caregivers of traffic accident victims with disability emerged:

♦ Category 1: The experience of taking care of the victim with functional disability

From the interviews, it was revealed that the family member responsible for the care of traffic accident victim with functional disability faces a challenge not previously experienced. However, they are dedicated to stick to it as best as possible in order to provide welfare for their family member:

The experience of taking care of him was something like, difficult and necessary. (F1)

Here we are four women. And it was rushed, we almost could not handle it, very, very, very difficult [...], a totally different reality. (F2)

During the process of adapting to changes arising from the new context, it is essential to prioritize assistance inherent to the dependence of the disabled family member, which may present a role reversal in the family:

I have switched phases, I have changed, I always say that now I am his mother instead of wife, because I feel like his mother, because I take care, and I have rushed a lot [...]. (F3)

Thus, the experience of taking care of the victim with functional disability is characterized by the emergence of a new family dynamics, which requires modifications to the family caregiver's routine, to meet the priority needs that their family member with disability needs for optimal care.

The interviews have shown that family members accompanied all phases experienced by the victim with disability, from the hospital treatment until recovery at home.

And it is in this last phase that the family members have the greatest impact, since when the victim receives hospital discharge, the family becomes responsible for care at home, starting a process of adaptation to the new situation imposed, being notoriously difficult to provide comprehensive care:

In Emergency Unit everyone helps, nurses and everything, when he was discharged to come home was when we came across the

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reality, because, there were a lot of people serving and everything, when he arrived home we felt a little lost. (F2)

In this process, the family member responsible for the care undergoes undesirable and uncomfortable situations, however, they ensure care maintenance:

The most embarrassing part was bathing, because man is usually a bit rough [...] and having to bathe him and making aseptic of all his body, changing diapers when he defecated, it was a tough task. (F1)

I was taking him to the bathroom, put him in a chair, and was pulling him, when we got to the bathroom he had already done the physiological needs, I felt nausea, but had to bathe him. (F1)

The adaptation of the family member is reported in the statements as painful and difficult to overcome, and may worsen when faced with the emotional reactions triggered in traffic accident victim due to disability:

He had already tried to suicide a couple of times, in our accounts, he went into the room and hid a knife and he came with all determination "give me that knife, give me" [...] another time was when he hid a knife in the alley, in a side, in the bedroom window [...], we never let him alone, when he is alone we always keep an eye. (F2)

After that, we came home; he spent three months without working, stayed home, he broke everything. (F3)

These reactions experienced by the victim with functional disability are predetermining factors for stress experienced by family caregivers:

At the beginning you have a greater patience, but over time you start wanting him to change, the hope he gets better is great, you start talking to him and thinking that he will change, will get better, only it did not happen [...] I started to become exhausted. (F3)

There are times when I cannot say anything because he is sick, but the person gets angry, that anger inside, that anguish. Then it happens! I get nervous. (F5)

My patience began to run out because it began to burden, besides the home expenses, child care, in addition to care for him, it even began to emerge a number of situations aside, I was even afraid of him, he began to have some problems outside home. (F3)

Reports reveal that family members consider essential psychological and emotional control during the care process with their family with functional disability, whereas the treatment of recovery is prolonged:

Thus, it was a very hard time because in addition to seeing my son suffering, we cannot do anything, just waiting, giving a time because we know that recovery is slow. (F9)

Although prolonged, treatment is maintained with the best assistance that the

family can provide, while focusing on recovery and rehabilitation.

Therefore, during the experience of taking care of the victim with functional disability, the family caregiver has changed their entire life context, having to adapt to a new situation, with mutual dependence, as experiencing changes in routine and daily habits, including work activities, studies and leisure. Moreover, as it will be presented next category, these changes are permeated by social vulnerability, which enhances the physical and emotional burden of those involved.

♦ Category 2: The process of change in routine

Family members revealed in their statements that before the traffic accident, their relative with disability was responsible for the leading role of financial manager, maintenance and organization of the family environment, becoming evident the absence of their collaboration after the accident:

It changed everything because he was the one who did the shopping, he did everything and suddenly [...] it was not done anymore. (F8)

The unfavorable socioeconomic conditions from the current situation are reported to be responsible for interference in the process of routine change and necessary family reorganization, since healthcare requires expenditures able to destabilize the pre-existing budget for basic human needs, focusing on the prioritization of these primarily for the treatment of health.

Family members report that the debts generated as a result of the traffic accident interfered in daily family life, causing conflicts and compromising the comfort, freedom and privacy of the entire family circle:

[...] the difficulties we are going through, because an unemployed family, four people in a house, it is difficult to deal with only a pension, to share out mainly to a patient that spends a lot, twice more in his case. (F4)

I had to take my youngest son out of school, I had to take the nanny that took care of them, I had to completely change life not to get into a bigger hole, I had to start taking my kids to my mother's house for us to stay there even to try to reduce spending here because we had to spend money to buy food, they had to support us. (F3)

It was in this struggle, 24 hours a day only at his side [...] He laid in bed and I laid beside him, because he could not stay alone, I stayed the whole day. (F1)

As seen in the statements, the inclusion of functional disability in a family member triggered an imbalance in the family that

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interfered markedly in the daily routine of all family members. Given the new context, family members become constant vigilant and prioritized the well-being of their family member with disability. To this end, they need support to overcome the difficulties that arise, especially concerning assistance to the individual and the emotional aspects that affect health recovery of the family member under rehabilitation, as well as of the family member that takes care themselves.

♦ Category 3: Receiving care support

In adapting to the new context established in their daily lives, family members reported in their statements that after hospital discharge they suffered abandonment by the team that had been offering assistance. The expected support by the Family Health Strategy was not obtained, although it has as one of its pillars the monitoring and assistance at home, mainly of individuals with functional disability and social vulnerability. This context makes users move to the Basic Health Unit (BHU), imposing overcoming the physical and financial barriers or compelling the family caregiver to perform the care of a lay way as they do not have the scientific knowledge to such task:

From the health center no one came here at home, no. (F2)

We started to treat her leg, make the dressing, do all the procedures of the day-to-day; we had to do. (F6)

We could not take him to the health center, it was far and expensive. (F8)

With the unveiling of this category, it is observed that some health problems developed after traffic accidents could be avoided with the guidance of health professionals and monitoring of the team of the enrolled area:

And he also had a neck injury, there was that pressure ulcers and we could not touch, I cut his nails, then he hurt it, it hurt so much, hurt so much that in the end it does not raise hair anymore. (F1)

The primary health care is responsible for the care and monitoring of these users at home, with effective actions and health services for disease prevention, promotion, recovery and rehabilitation. However, it is still deficient, requiring strategies for an effective service.

It could be observed in the testimonies of family members that lack of support and guidance of the health team unleashed feelings of insecurity and anxiety:

When she came home it was different, she felt pain, had to take oral medications, there was no serum that they gave in the hospital, the strong medications to relieve

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her pain sooner, put through veins, I did not know what to do. (F6)

I need a doctor to tell me what is his reality today, it is not to say to me that I need to get used to it, that I have to let him live the life he wants, I think this is not what I need today. I need information, how I should deal with him. (F3)

The right to health information becomes ineffective from the moment the health team does not account for those involved on diagnosis, prognosis, intervention and advice regarding the victim with functional disability:

At all times when you wanted some information, by doctors, it was like you were nothing, nobody [...] so the doctors, I do not know if it is the correct procedure because we are not from the area, we receive no information, they are very cold. (F3)

It was also showed that the multidisciplinary team is crucial in this process, as the deficiency and/or absence of guidelines and information on the health of the victim causes insecurity and uncertainty about the care and recovery. Thus, in this health-disease process an individualized and integrated assistance should be articulated considering the needs and culture of the individuals involved.

♦ Category 4: Adherence to religious values

Religion and hope are intertwined as a source of inspiration and spiritual help. Faith is one of the factors that help, also, in emotional control and determines the action, as the family finds strength in God to solve problems, highlighting mainly prayer as a means.

It was a phase that we remember, and is touched, because it was a struggle, struggle, it was quite hard and thank God, he got better. (F1)

God is so merciful that I filled the heart of blessings, both the Catholic Church and the evangelical, I made friends with everyone, and there was prayer, much prayer [...]. (F2)

As religiosity stands as emotional support, it is perceived as a way to relieve internal conflicts and foster acceptance of the situation experienced by the family caregiver.

A great joy because she was alive [...] and I was taking care of her and with faith in God that she would get better. (F7)

I think God gives this fortitude, which strengthens us, inside us, so we can handle this. (F6)

The family is supported by the faith, encompassing values that help in overcoming the crisis arising from affective interpersonal relationships, providing strength to accept and to overcome the difficulties in search of the victim's rehabilitation.

DISCUSSION

Traffic accidents stand out on the world stage as one of the major causes of morbidity and mortality. The consequences of these events affect not only the victim but also the family member who experiences new and conflicting situations in face of functional disability.

The consequences of traffic accidents go beyond injuries and can lead to physical, emotional, cognitive and social changes, which generate functional inability to perform activities of daily living and profound changes in professional and personal life.^{9,10} The time of the accident is permeated by moments of crisis, in which the family must accompany the injured victim in the hospital and, then, manage and promote the necessary care from the hospital discharge.¹¹

With the start of care at home, there is usually a change in family dynamics, with changing social roles and the decrease in income, leading to a process of reorganization of all family members. The experience of being a family caregiver has been reported as an exhaustive and stressful task, due to emotional involvement and the fact that there is a transformation from a previous relationship of reciprocity to a dependent relationship.¹²

It becomes visible, in the speeches of participants, the experience of the whole family in the post-accident phase, characterized by pain and suffering of those involved, generated by the dependence of functional mobility of surviving victim. In addition to the emotional alterations mentioned, it was revealed in the family members' speeches tasks overload, probably due to the long period of treatment and recovery of the injured victim and the fact that they have to take care without receiving adequate support from the health team.

Often the family caregiver feels responsible for the dependent person and assumes all tasks, even if they are not responsible by them, overburden themselves.¹³ However, in a study with caregivers of dependent elderly at home, overhead for lack of support was the aspect more present in the interviews.¹³ Accordingly, in addition to worrying about the health of the victim with functional disability, the lack of financial and/or emotional support potentiates the grievances and conflicts inherent in the environment of the traffic accident victim and their families.¹⁴

This process is experienced with depression, anxiety, sadness, fear, concern,

misinformation about the severity of the case, prognosis, rights and duties attached to the traffic accident, the legal, economic and social implications. It can be added to this problem, the imbalance in family relationships by the loss of a loved one, financial difficulties, role reversal and obscurity about future.¹⁴ Thus, it is observed that injuries and traumas caused by traffic accidents resemble a chronic injury, which leads the family to change their daily life and to reorganize in order to better adapt to the new reality experienced.

When performing activities related to the physical and psychosocial well-being of the injured person, the family caregiver starts to experience restrictions regarding their own life.¹² Studies show that, motivated by feeling of overload, events such as sadness, anger, fear and anxiety are common to the family caregiver. As a result of their commitment, the anguish sets in, which can result in illness and even death.^{14,15,16} Thus, it becomes easy to establish a vicious circle after the traffic accident: the presence of functional disability, lack of treatment for rehabilitation, worsening of the disease and, consequently, increased burden on the public health system and family.¹⁷

Due to the aforementioned aspects, it is clear that the traffic accident victim can no longer be seen in an isolated manner, since the family is vital to nursing care. However, after the accident, the victims and their families are faced with problems that apparently are hidden in the view of care of most health professionals.¹⁴

Therefore, the problems related to the lack of structure of health services and lack of human and technical preparation by professionals must be highlighted, and the inclusion of traffic accident victims and their families in the planning and execution care is challenge to the achievement of health actions.

The lack of information of family about the traffic accident victim's health and the absence of the narrowing in the relationship with health professionals are aspects emphasized in speeches. These findings end up establishing serious damage in care, exacerbating the hopelessness and fear about the prognosis.

The guidelines and information provided by health professionals are a social and emotional support, contributing to the physical and psychological health of those involved, to the extent that helps the person responsible for the care to find consistency in decision making and meaning to the role they

play.¹⁵ Therefore, it is imperative that nurses, during home visits, interfere in the health-disease process through dialogue and knowledge production, in order to offer better care to individuals and their families, promoting comprehensive care to community with respect to protection, rehabilitation and health maintenance.¹⁸

It is important to listen to the family and is also expected that nurses know when and how to answer their questions. For this, nurses must know families and remain close to them in a respectful attitude.¹⁹ The work with the family should strengthen their strengths, encouraging them to face the situation, developing new strategies for conflict resolution and ways to manage life.¹¹

It is emphasized the complexity involved in health, physical and mental well-being of a family caregiver of a victim with disabilities resulting from traffic accident. Their functionality requires a number of factors that passes by the care of the health system, involving the severity and type of injury, age, psychological aspects, socioeconomic conditions, and the social support received.¹⁶ On the other hand, in face of the crisis situation, the family has a chance to rethink values and ways of relating, providing affection situations and assistance to all members involved.²⁰

Considering the emotional dimension of social support, data suggest that religiosity is being useful for these caregivers as a pillar to mitigate the negative impacts caused by the traffic accident to the health of the victim. In this context, spirituality serves the purpose of developing new meanings for life, supporting the person in the difficult task of caring, in coping adversities and in health maintenance.¹⁵

CONCLUSION

This study highlighted the experience of the family caregiver of victim with functional disability after traffic accident, reaffirming the behavioral, social and emotional changes of those involved, generated by temporary or permanent disabilities. In addition, this study draws attention to the lack of preparation of health professionals to deal with the family caregiver of traffic accident victim. Thus, it is essential to rethink the practice carried out by those professionals and take into consideration the traffic accident victim and their family caregivers in the hospital context and at home.

It is considered that this study contributed to the characterization of the health status of

those involved, pointing to the psychosocial vulnerability they face and to the need for psychological support measures that promote rehabilitation and prevention of other diseases, given their negative impact for the individual and for society.

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Submission: 2013/12/13

Accepted: 2014/03/11

Publishing: 2015/01/15

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