

Spinal cord injury in the contexto of families: structural assessment with genogram and ecomap

Lesão medular no contexto da família: avaliação estrutural com genograma e ecomapa

Lesión medular en el contexto familiar: valoración estructural com genograma y ecomap

RESUMO

Objetivo: Avaliar a representação estrutural de famílias com entes que possuem lesão medular com base no genograma e no ecomapa. Método: Estudo qualitativo, realizado com duas famílias que possuem entes com efeitos do traumatismo da medula espinhal que foram atendidos no PROAMDE. Utilizou-se o genograma e ecomapa como estratégias de coleta de dados na Avaliação Estrutural, componente do Modelo Calgary de Avaliação da Família. Resultados: O genograma das famílias apontou reestruturação com formação de novos arranjos familiares por meio da recomposição de seus membros na estrutura interna familiar com vista à melhoria da mobilidade e acessibilidade. O ecomapa elucidou os vínculos das famílias extensas e dos sistemas mais amplos para ajustes e possibilidades de intervenção da enfermagem no âmbito da atenção básica. Conclusão: As famílias ajustaram-se diante das situações estressoras e de mudanças com o intuito de efetivar o cuidado no cotidiano familiar.

DESCRIPTORIOS: Assistência domiciliar; Cuidadores; Enfermagem; Família; Traumatismos da medula espinhal.

ABSTRACT

Objective: To evaluate the structural representation of families with spinal cord injury based on the genogram and ecomap. Method: Qualitative study, carried out with two families that have members with spinal cord injuries who were treated at PROMADE. The genogram and ecomap were used as data collection strategies in the Structural Assessment, a component of the Calgary Family Assessment Model. Results: The family genogram pointed to restructuring with the formation of new family arrangements through the recomposition of its members in the internal family structure with a view to improving mobility and accessibility. The ecomap elucidated the links between extended families and broader systems with clues for adjustments and possibilities for nursing intervention in the scope of primary care. Conclusion: The families adjusted themselves in the face of stressful situation and changes in order to effect care in the family routine.

DESCRIPTORS: Home Nursing; Caregivers; Nursing; Family; Spinal Cord Injuries.

RESUMEN

Objetivo: Evaluar representación estructural de familias con lesión medular a partir del genograma y ecomap. Método: Estudio Cualitativo, realizado con dos familias que tienen miembros con traumatismos de la Médula Espinal que fueron atendidos en PROMADE. El genograma y ecomap se utilizaron como estrategias de recopilación de datos en Evaluación Estructural, un componente del Modelo de Evaluación de la Familia de Calgary. Resultados: El genograma familiar apuntó a la reestructuración conformación de nuevos arreglos familiares a través de la recomposición de sus miembros en estructura familiar interna con miras a mejorar la movilidad y accesibilidad. El ecomap esclareció los vínculos entre las familias extensas y los sistemas más amplos con pistas para ajustes y posibilidades de intervención de enfermería en el ámbito de la atención primaria. Conclusión: Las Familias se adaptan ante situaciones estresantes y cambios para efectuar el cuidado en la rutina familiar.

DESCRIPTORIOS: Atención Domiciliar de Salud; Caregivers; Enfermería; Familia; Traumatismos de la Médula Espinal.

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INTRODUCTION

Spinal cord trauma affects spinal canal structures, causing motor, sensory, autonomic or psychoactive changes. Such changes are characterized by spinal cord injury, which can be paralysis or paresis of limbs, changes in muscle tone, changes in superficial and deep reflexes, change or loss of sensation, loss of sphincter control, changes in body temperature, sexual dysfunction and autonomic changes.¹

The family becomes the support to which all the problems and needs of its member with Spinal Cord Injury (SCI) flow, and this transforms the routine plans of activities of daily living for both. Thus, life after spinal cord trauma requires constant processes of change, learning and adaptation on both sides, since the injured individual becomes dependent on a family member. The latter, when faced with the new (the situation is unusual for both), needs to signify what is happening, as they have to get out of their comfort zone and play a role that they never thought of, that of “caregiver”. For this, he needs strategies to create a new normality and support actions that can equip him to take care of the person with SCI.²

In this way, the family, when considered a system, needs adjustments, restructuring and reconfigurations to support, care for and adapt the family member to the home environment, whatever the changes: physical, motor or sensory.³ It is a complex role, which requires responsibility and performance in home care, which can cause overload for the whole family or for some of its members.⁴

In line with such a way of assimilating the experience of this new reality, this study adopts the perspective that the family is the primary care unit that adjusts and reorganizes itself in order to under-

take efforts to care for the loved one with changes in physical mobility.⁵

A way to understand the efforts, adjustments and confrontations of the care management performed by the family in the post-traumatic readaptation process is the use of the genogram and the ecomap. These are tools that explain and analyze family experiences, which make visible the changes, adaptations, rearrangements and even the bonds established based on the social support network with health services and professionals and other social organizations.⁶⁻⁷

From this perspective, the study generates subsidies for understanding the family as a care unit and achieving a broader view of the health-disease process. Given this context, this study aimed to evaluate the structural representation of families with entities that have spinal cord injury based on the genogram and ecomap.

METHODS

This is a retrospective study, with a time frame from June to September 2018, a qualitative study that used the genogram and the ecomap to assess the affective bonds of family members as well as the methodological reference used the Structural Assessment, component of the Calgary Model of Family Assessment (CMFA).⁸ A semi-structured script was used in three blocks of themes: elements that can be evaluated in their subcategories: Internal (family composition, gender, sexual orientation, birth order, subsystems and limits), External (extended family and wider systems) and Context (ethnicity, race, social class, religion and environment).⁸

Data collection was performed with patients treated in the Motor Activities Program for the Disabled (PROAMDE) was the starting point to have contact

with the families. This program provides interdisciplinary and equitable care under the supervision of a multidisciplinary team (Nursing, Physical Education, Social Work, Psychology, Physiotherapy) within the scope of the Federal University of Amazonas (UFAM), in addition to being one of the fields of action of the Multiprofessional Residency in Health in the Comprehensive Care Program for Functional Health in Neurological Diseases at UFAM. The choice of this program is justified because it offers a rehabilitation service for people disabled by spinal cord injury. Inclusion criteria were families monitored by the PROAMDE of UFAM, in the city of Manaus, with a time equal to or greater than six months post-trauma. Family members under 18 years of age were excluded.

Two families who had family members with spinal cord injuries participated in the research, one with quadriplegia and one with paraplegia. The second stage was at the participants' homes. Data collection was carried out from June to September 2018, through semi-structured interviews, recorded with the proper authorizations, using a script of questions proposed by the Calgary Family Assessment Model.⁸

It was carried out in 3 phases: in the first, there was the initial contact with the families, explaining what the study was about, what the objective was. In view of the positive response for participation in the study, we requested the signing of the Free and Informed Consent Form.

In the second phase, which took place after the interviews, families were presented with a manually drawn drawing of the genogram obtained based on information on the composition of family members and their internal and external family relationships. The sketches were validated with the family and the family members were able to complete or chan-

ge the drawings.

In the third phase, the external subcategories and the context were worked on. After the interviews with the generated data, genogram and ecomap diagrams were created, with the help of Genopro software 2.5.3.9, version 2016, and exported to Microsoft Office Powerpoint 2007 software, for adjustments and finalizations.

The analysis of the speeches made it possible to develop a system of records capable of identifying each stage of the structural assessment of families, according to the CMFA.

As this is a scientific research involving human beings, the ethical and legal principles set out in the National Health Council Resolution No. 466/12 were assured. All participants signed the Free and Informed Consent Term (FICT). The present study is approved by the Research Ethics Committee of the School of Nursing of the Federal University of Amazonas, CAAE nº 82725418.1.0000.5020 and opinion number 2,598,945 of April 14, 2018. In this study, fictitious names were used to preserve the identification of all participants involved and cited.

RESULTS

Lucca's family and its internal structure

The first family had Lucca as an index person, who, at the age of 14, suffered spinal cord trauma when falling from a slab, when flying a kite at her grandmother's home. He was rescued by family members and taken by the family's own transport to an emergency service in the city of Manaus. At the time of the research, Lucca was 18 years old, single, had no children, had not yet completed elementary school, had a clinical picture of incomplete quadriplegia with motor and sensory deficits, with deformities and atrophies in the hands, wrists, ankles and knees. His internal family consisted of her maternal grandmother (Fernanda, 73 years old), her mother (Carol, 44 years old),

ars old), aunt (Thaísa, 40 years old) and her cousins (Júlia, 19 years old; Rômulo, 14 years old and July, 11 years old.) as shown by the family genogram (Figure 1).

It should be noted that Lucca's family was recomposed to meet Lucca's health and life needs, being predominantly presented by female caregivers. In this way, young adult women were directly linked to Lucca's care for carrying out their activities of daily living (ADL).

Lucca explained that, before the spinal cord injury, he performed his ADLs normally. After the accident, there was a rupture in the fulfillment of her roles, tasks and daily activities, as she began to depend on the help of the women in the family, especially her mother, Carol.

He took care of himself, in terms of eating, bathing. He knew how to do all this alone... now, I am responsible for everything: scheduling an appointment, physical therapy, bathing, hydrating his skin, turning him over, tidying up, the food... He even ate alone, but , due to him taking botox, it was so strong that it rose to his arms, and now he has no strength to eat.

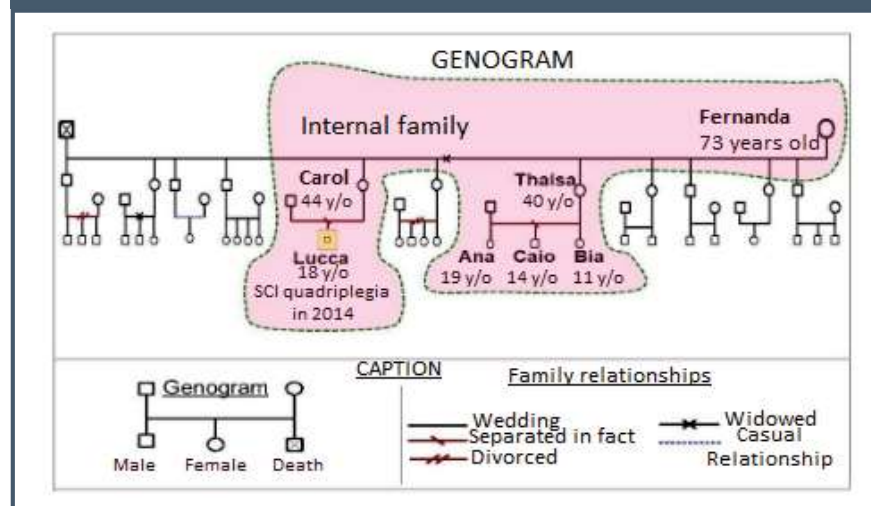
I put the food in his mouth to eat. As soon as the effect [of botox] wears off, I believe he can go back to doing some things on his own, such as brushing his teeth [...](Carol, mother of Lucca)

The family members pointed out that Lucca's daily care tasks, such as the daily bath, changes in position, intimate hygiene after bladder and bowel eliminations, among others, were under Carol's responsibility, since she was the one who dedicated most of the day to performing these cares.

It was observed that Carol takes care of home care, in addition to accompanying him in his rehabilitation and in the performance of other domestic tasks, which points to the possibility of overload. As for the preparation of meals, cleaning of Lucca's home and room, they were also under the care of Carol and her aunt, Thaísa (40 years old). Fernanda (Lucca's grandmother) was responsible for cleaning and organizing the other rooms. When Carol and Thaísa could not take care of Lucca directly, it was Fernanda who took care of that.

Lucca's family's social support

Figure 1 - Lucca's family genogram. Manaus, Amazonas, Brazil, 2019



Source: Prepared by the authors, 2019.

network

The ecomap outlined the arrangements of the care centers. Internal and external social support networks were (re)adjusting, (re)formulating and (re) adapting to support Lucca and her entire family. Internally, there was a greater flow of mutual energy between Carol, Thaísa, Fernanda and Lucca.

When Lucca was in the rehabilitation service or in consultations with Carol at the specialized outpatient service, household chores were divided between Thaísa and Fernanda, as represented in the ecomap (Figure 2), which also illustrates other important ties for the family.

Lucca received the Continuous Cash Benefit (BPC - Benefício de Prestação Continuada), important for supplementing Carol's income, given that, due to Lucca's health condition, she had to leave the job market, just like Thaísa.

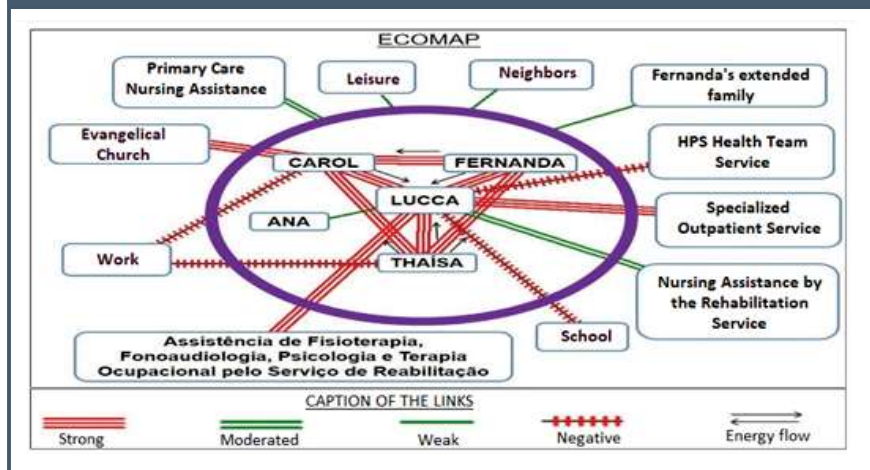
The relationships and ties of Lucca's family with Fernanda's extended family and with neighbors were weak, but when they exist, they enable expressive exchanges of support for the entire family. The support and support of evangelical church members helped Carol significantly. The church assisted them in acquiring emotional and spiritual support for Carol.

Other external systems exerted influence and had strong and significant links for Lucca, such as, for example, the health services of the specialized outpatient clinic and the health care offered by the multidisciplinary team that worked in the rehabilitation service.

Home care and nursing care offered to Lucca and her family by the rehabilitation service, within the scope of primary care, were considered moderate. However, the care provided by the nursing teams and other health professionals, during their hospitalization period at the Hospital and Emergency Room, were considered negative. Later, care was shared and reported to Carol, as she describes:

During hospitalization, he had es-

Figure 2- Ecomap of the family of Lucca. Manaus, Amazonas, Brazil, 2019.



Source: Prepared by the authors, 2019.

char on his head. They didn't say I was supposed to switch sides. Then a nurse came and taught me how to do it, explaining the importance of it. In the outpatient service, several professionals said good things to take care of him: the nurse said to take care of his skin, food and change sides so as not to give him bed sores [...]. (Carol, Lucca's mother).

It is also worth mentioning that Lucca reported having a negative bond with the school, since, since her accident, she stopped attending and had to stop studying in the ninth year of elementary school. Lucca and her family performed few leisure activities, as they did not have private transportation and their economic situation was unfavorable, since the income was primarily for their rehabilitation, for travel to medical appointments and to meet other needs.

Allison's family and its internal structure

The second index person is Allison. In the year 2017, she suffered spinal cord injury due to a gunshot wound. At the time of data collection, she was 27 years old, had a clinical picture of paraplegia with

motor and sensory deficits (tactile and thermal).

Her internal family consisted of Martha, 24 years old, with whom he had a stable relationship, and their three small children (Silvia, 3 years old; Cris, 2 years old; Fábio, 1 year old), as shown in the genogram in (Figure 3).

Allison has not yet completed elementary school. Before the incident, Allison was the one who made the main financial decisions for the family, as can be seen in the testimony:

Before the accident, he worked, left early in the morning and returned in the evening. He is the one who supported the house. I am a housewife, I take care of the house and the children [...]. (Martha, wife of Allison).

Upon returning to her new home shortly after the incident, Allison was placed under the direct care of Martha and her sister Alexis (30 years old). Allison and Martha claimed to have received help from Alexis (Allison's sister) and Maria (50 years old and Allison's mother) to start daily care, given that, in the first six months after the trauma, Allison was bedridden at home and partially dependent on the care of her family members

to perform ADLs, needing help to feed, dress and bathe.

Martha claimed to be the main caregiver who performs home care for Allison. She was the one who accompanied him to medical appointments and/or examinations. She also took care of household chores and was also responsible for her three small children. However, she sometimes needed to rely on Maria (Allison's mother) for help. There is evidence of task overload for Martha to perform on a daily basis:

[...] I take care of him, prepare the food, do the housework, schedule medical appointments and accompany him, do the shopping and pay the bills. I put him in the bathroom so he can shower. His mother helps, taking care of the children, when we have to go to the Rehabilitation Service, for consultations and for tests [...](Martha, Allison's wife).

It can be seen that Allison's family sought to restructure itself, defining new rules, norms and roles in their home.

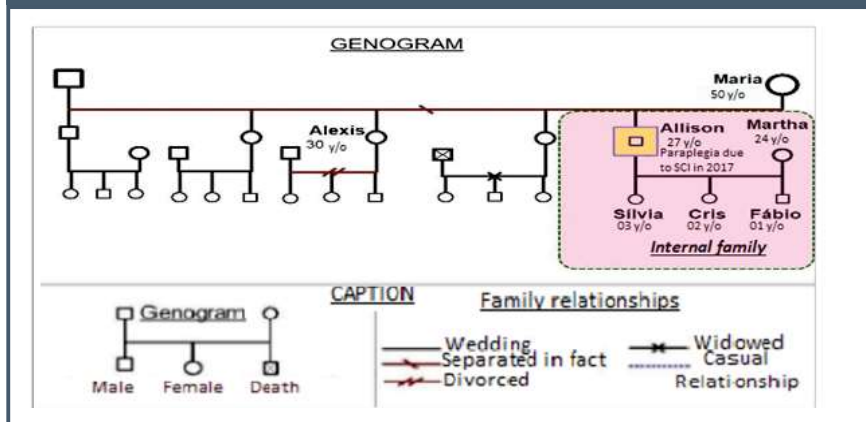
Allison's family support social network

Regarding the ecomap of Allison's family, it was possible to understand that this family needed great support from the external social network, given that Martha was the one who directly took care of the entire family. It was evident that the greatest influence of contact and social support that Allison and her family received came from Maria's extended family (Allison's mother), as represented in the ecomap (Figure 4).

It is also noteworthy that, during Allison's stay at the Urgent and Emergency Hospital, some bonds were established with health professionals, with positive and other negative impacts on the family.

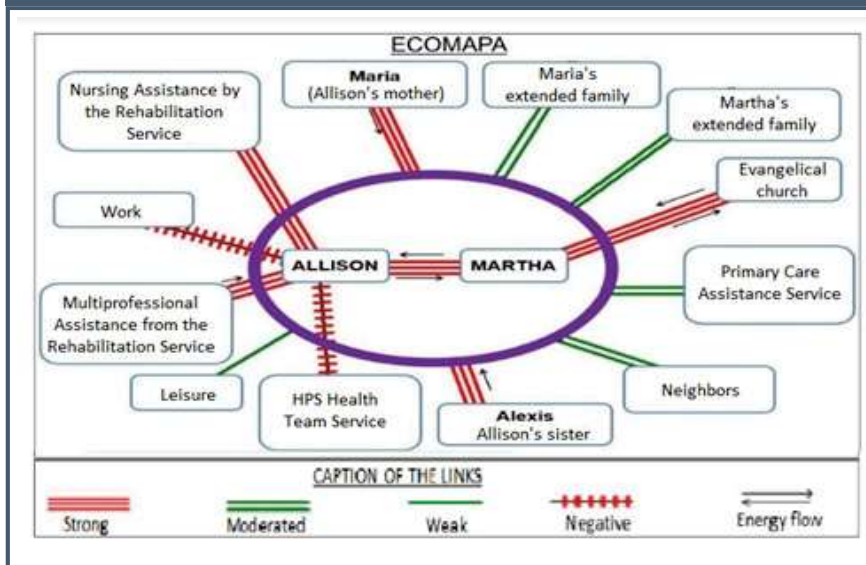
Other important links were highlighted by the family, such as, for example, the support offered by the health service of the Basic Family Health Unit (UBSF), which offered services such as

Figure 3 - Genogram of Allison's family. Manaus, Amazonas, Brazil, 2019.



Source: Prepared by the authors, 2019.

Figure 4 - Allison's family ecomap. Manaus, Amazonas, Brazil, 2019.



Source: Prepared by the authors, 2019.

consultations, appointments for exams, among others; and by the Church, which provided emotional support for Martha and, in some situations, financial support for Allison's family. Regarding moderate bonds, the neighbors and owners of the house where Allison and her family lived allowed changes to the physical structure for Allison's accessibility.

DISCUSSION

The use of the genogram as a data collection instrument, in qualitative studies, with the families, makes it possible to represent the family's data, being able to reveal information that defines its life history, as well as the composition of the internal structure.⁹ The ecomap represents the family's relationships in its context and its social support network.¹⁰

The literature describes that traumatic