

FAMILY CAREGIVING IN CHRONIC ILLNESS: A YOUNG PERSON'S EXPERIENCE*

CUIDADO FAMILIAR NA EXPERIÊNCIA DO ADOECIMENTO CRÔNICO DE UM JOVEM

CUIDADOS FAMILIARES EN LA EXPERIENCIA DE ENFERMEDAD CRÓNICA DE UN JOVEN

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ABSTRACT

This study aimed at understanding family caregiving for a young person with chronic illness since childhood. He had a kidney disease and cancer. The researchers used a comprehensive approach as situational analysis from his life history. During fieldwork, researchers carried out in-depth interviews and direct observation aiming at apprehending elements they had heard, seen and experienced. These elements were then registered in a field diary. After vertical and horizontal reading, the corpus of analysis was identified and different aspects that permeated the narrative were highlighted. A genogram of the individual and his family was built. The individual's chronic condition changed family life: they were compelled to look after him in a synergy of actions and constant motion that provided some support. New routines were created and other ways of overcoming the new obstacles were developed.

Keywords: Family Relations; Life Change Events; Chronic Disease; Caregivers.

RESUMO

Objetivou-se compreender como se moldou o cuidado familiar na experiência de adoecimento crônico que perpassou a infância e a adolescência de jovem acometido por doença renal e câncer. Estudo de abordagem compreensiva, moldado como análise situacional a partir da história de vida. No trabalho de campo, empregou-se a entrevista em profundidade e observação para apreensão dos elementos ouvidos, vistos e experienciados, registrados em diário de campo. A partir deste último, moldou-se o corpus de análise que, após leituras vertical e horizontal, evidenciou aspectos que permeiam as diferentes narrativas. Do corpus, desenhou-se o genograma do jovem e família. Conforme os afetamentos do adoecimento crônico do jovem repercutiam na vida dos familiares, estes eram compelidos a cuidar dele, numa sinergia de atuações e constante movimento, oferecendo-lhe certa sustentação. Desenvolveram-se outras normalidades na vivência do adoecimento pelo jovem e família e a cada nova condição imposta, novos meios de superação foram por eles desenvolvidos.

Palavras-chave: Relações Familiares; Acontecimentos que mudam a vida; Doença Crônica; Cuidadores.

RESUMEN

El presente estudio tuvo como objetivo entender cómo se forma el cuidado familiar en la experiencia de enfermedad crónica de un joven con cáncer y problemas renales desde la niñez y en la adolescencia. Se trata de una investigación comprensiva proyectada como análisis de la situación desde la historia de vida. Durante el trabajo de campo se utilizaron la entrevista en profundidad y la observación para obtener elementos oídos, vistos y vividos, registrados en el diario de campo. Luego, se fue formando el corpus de análisis que, después de su lectura vertical y horizontal, mostró diferentes aspectos que impregnaban la narración. Se elaboró el genograma del joven y de su familia. A medida que los daños de la enfermedad crónica del joven repercutían en la vida de los familiares, éstos eran obligados a cuidarlo, en una sinergia de acciones y constante movimiento, brindándole una especie de apoyo. Hubo otras situaciones en la experiencia de enfermedad del joven y su familia y ante cada nueva condición impuesta, ellos fueron buscando nuevos medios de superación.

Palabras clave: Relaciones Familiares; Acontecimientos que cambian la vida; Enfermedad Crónica; Cuidadores.

INTRODUCTION

The family is an agent of socialization; it nurtures the formation of values through the establishment of bonds and a feeling of closeness that are shared daily between its members; "it shapes individuals' selves and personality and it forms the core of people's lives."¹ As an organization, the family is a group of mutual support and, consequently, fundamental to members with a disease. Suffering caused by a disease affects not only the person who is sick but also those who are directly involved in the caring process.

A chronic disease is a long-term condition with progressive, limiting and/or disabling symptoms, unlike acute diseases whose symptoms are relatively all of a sudden.

People and families experiencing a chronic disease are usually affected in their routine, demanding changes in their lifestyle and health management for unlimited period of time. Furthermore, the situation can be unsustainable unless the family, which is the primary caregiver, is given support.^{2,3}

The present study deals with the experience of a young man suffering from chronic illness who lived with his family. He had a chronic kidney disease since childhood and had developed cancer when in his teens. The study examined the impact of the disease on their lives, as well as the organization required to meet the patient's care needs. Researchers believe that understanding how such family cared for the individual may provide elements to rethink nursing practices, from training to higher education, for them to be guided by people's health needs.⁴

Family caregiving, equated with household duties, is socially undervalued and invisible: it is an unqualified and unpaid task whose importance is only appreciated when it is missing.⁵ The present study aims at calling health professionals' attention to the importance of family caregivers in order to implement health practices that take into consideration such people's living and care conditions and have a positive impact on their experience.

The objective is to understand how family caregiving was organized in the context of a young person affected by concomitant diseases - kidney disease and cancer.

METHODOLOGY

This study used a comprehensive approach of a situation analysis.⁶ Such approach enables the understanding of relationships and processes in family caregiving, in view of the conflicts arising from complications of the disease and the implementation of new standards. It also shows the network of care woven by the family, given the consequences of the condition and the need to seek treatment.

The study subject was searched from December 2010 to February 2011. Researchers located the patient in a hospital specializing in oncology that maintains an agreement with the Uni-

fied Health System of Mato Grosso (MT-SUS). The contact between researcher, patient and family was made by the institution. The research was carried out at the patient's place, which allowed researchers to learn first-hand their family life context.

Inclusion criteria were:

- a. to be a SUS user;
- b. to have cancer;
- c. to have been diagnosed in adolescence;
- d. to have started legal proceedings;
- e. to have elapsed more than one year since the start of the mediation of legal proceedings;
- f. to reside in the state of Mato Grosso. Apart from "to have been diagnosed in adolescence" all other criteria are related to the matrix research.

People's stories are valuable in the analysis of life experiences because they reflect collective experiences of social groups. Moreover, they allow health professionals to improve care and human relations.⁷ Using life history as a methodological strategy enabled researchers to fully approach the experience of disease and family caregiving. In-depth open-ended interviews⁸ were carried out as informal conversations when the following guiding question was raised: "Can you tell me about your disease experience and your search for health care?"

Subsequent questions were asked in order to explore the disease experience and care, based on the person's report.

Eleven meetings were held in different places between March and May 2011, namely Cuiabá, city A and city B – all of them within the context of the participants' lives.

Direct observation of elements heard, seen and experienced by the research team followed the interviews; methodological notes of recorded ideas, strategies, reflections and insights. The field diary comprised the observations carried out by research team members – two master's candidates and two scholarship students –, notes on the search for the research subject, as well as transcriptions of recorded interviews, which formed the *corpus* of the research. The observation notes are identified in the text by the abbreviation NO followed by their registration date.

During interview transcription due attention was paid to the little nuances in the discourses in order to grasp implicit emotions in pauses, silence, laughter and tears.⁶ Such task was carried out as faithfully as possible, respecting the modes of speech that characterize the cultural background of the participants, in order to make the written record as complex as the oral narrative. Interview transcription was performed by the main researcher to preserve cohesiveness of record.

A thorough reading of the *corpus* was carried out to identify issues to be approached in subsequent meetings, mainly emerging units of meaning highlighted in different colours according to their meanings. When fieldwork was finished, the researchers

did a vertical reading of the entire *corpus* to create a "prior categorization" with clusters of units of meaning and codes related to their senses. Horizontal readings⁹ of the *corpus* highlighted common aspects of the different narratives of the subject and his family. The search for the "individual" character of each narrative is considered essential as a reflection on the personal dimension¹⁰ of the disease experience, self-care or caring for others.

After categorization, new readings were made, in a "process of bringing together similar fragments, trying to apprehend the connections between [...] units of meaning",⁹ so as to highlight different experiences and verify the correspondence between previous categories. Thus, specific aspects were highlighted for each unit of meaning part of a previous category. The meanings and clusters of meaning of these preliminary categories were fully investigated. Researchers chose to address in this article the central meaning "family care in the experience of chronic illness caused by concomitant diseases".

The *corpus* also enabled researchers to build the family genogram, a graphical representation and data organizer. They sought to represent and analyse how the family was composed, their relationships and the groups they organized for Marco Antonio's care¹¹ and to identify adjustments made for the delivery and management of such care.

The study complied with the ethical guidelines for research with human beings. The matrix project was approved under No. 671/CEP-HUJM/09. The study subject and his family, as well as their hometown were identified by fictitious names. The names of the state capital of Mato Grosso – Cuiabá - and Rondonópolis were kept because they are large cities. The Statement of Informed Consent was read to the participants, and research procedures, its objectives, its modus operandi and its ethical guidelines were explained. The statement was signed by participant and researchers, and each part kept one copy.

RESULTS AND DISCUSSION

FAMILY ADJUSTMENTS FOR MARCO ANTONIO'S CARE

Marco Antonio was a 21 year old individual who lived with his family in a city 234 km from Cuiabá, referred here as city A, when he was diagnosed. He had experienced kidney disease since early childhood, congenital stenosis of the left ureter caused him severe pain and progressed to hydronephrosis diagnosed shortly before he was 10 years of age. During this period, he had undergone surgery to correct stenosis; the affected kidney was not removed.

When he was 14 years old he sought various health institutions due to pain in his right ear and was later diagnosed with non-Hodgkin lymphoma of the right maxillary sinus. During

the exams to start cancer treatment, alterations in the affected kidney were detected: a new urethral stenosis surgery was needed. At the time of this study, the subject was being monitored for nephrolithiasis and cancer.

Kidney diseases are a significant and relevant research matter. Experiencing chronic and concomitant diseases strained the relationship between Marco and his family. The illness did not overlay his life prospects and he experienced the process in his own terms. However, the disease required both his and his family's constant adaptations, allowing researchers to apprehend aspects of family life and dynamics of care.

Marco Antonio's family genogram highlights the care groups formed.

Members of Marco's extended family lived in three different places:

- a. in a small farm 6 km from the Bom Jesus district, in city A where Marco lived;
- b. in city B, 241 km from Cuiabá; and
- c. in Cuiabá. His house in a small farm called the researchers' attention for its simplicity and dynamism:

Marco took us to his home; we went on foot because we couldn't get there by car. We walked about 200 meters and arrived at a very simple place with many animals, horses, dogs, chickens, cattle ... [...] Marco showed us a trained bull. When we arrived, there were many people talking. I was impressed by the simplicity of their house made of clay, wood and canvas roofed (NO, 2011/05/21).

Marco Antonio lived with his family of seven people, amongst them his father, Olavo, his mother, Rita, and his foster sister, Helena; they made up the care group in the small farm (Figure 1). Ties with his aunt Lair's family from Cuiabá were strengthened since this was the primary treatment site and it made up the care group from the capital (Figure 1). At the time when search for care was most intensive, Lair was married to Almir, who passed away when Marco was an adolescent. Their house was simple, in the urban area of Cuiabá:

The house is in an unpaved road; it has a green gate [...]. It was 7:30 a.m. and it was all closed. There were plants in the front, a balcony with a dog and a car (the neighbour's). [...] We entered a side corridor that led to the end of a terrace at the back; there was a washing machine and a dog was barking (NO, 2011/03/14).

Marco's three biological brothers and their Cuiabá relatives, including uncles, grandparents and some cousins, also helped on an ad hoc basis, assisting with the maintenance of both care groups. Members of Marco Antonio's family living

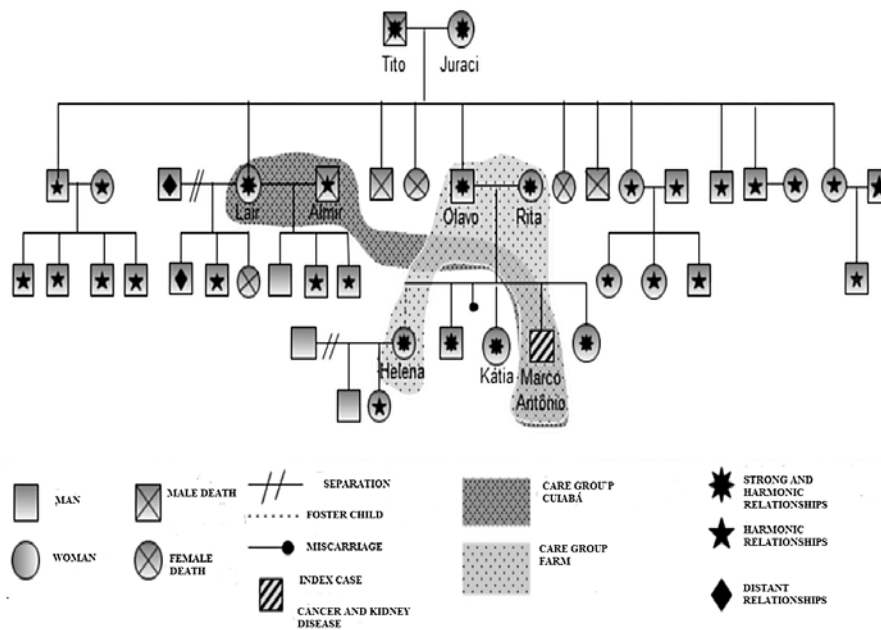


Figure 1 - Marco Antonio's family genogram representing the care groups.

Source: adapted from Souza ÍP. Therapeutic itinerary: experience of young person and family who experience chronic illness caused by concomitant diseases; report of scientific initiation GPESC/FAEN/UFMT 2010-2011. Cuiabá: PIBIC/UFMT/FAPEMAT; August 2011.

in city B were not part of any care group and were only mentioned sporadically. Marco's sister, Katia, was the only family member who participated in the study and, although she had lived in the farm with her brother, at the time of the interviews she was living in city B.

The family organization of the two care groups - one in the state capital and one in the hinterland - allowed researchers to understand the dynamics of care considering the different contexts and the relationship between the two groups in order to meet Marco's care needs. These items are discussed below.

Several people participated in Marco's care (Figure 1). They strived to overcome his life circumstances, each in his own way. Kidney disease and cancer, the family limited economic resources, distance between Marco's home and treatment sites, difficult access to services and inadequate responses from managers and health services were some of the problems.

Marco's father, Olavo, was one of the caregivers:

When he [Marco] came to live here he was very little, he was about nine and his father was always up and down with him (Lair).

It's always been my father [referring to whom had watched over him since childhood] (Marco).

Unlike a study on care practices of rural families for a person with cancer¹² which demonstrated that women held

knowledge on care by learning it with other women and transmitting it mainly to daughters and granddaughters, Marco's family recognized his father as primary caregiver.

Care provided by Olavo was shaped and renewed according to his son's needs. Therefore, several family readjustments were necessary:

Ah, it was difficult, but I had to go (Olavo).

There was the older boy, you know? (Rita).

It was always him who took care of everything (Olavo).

The eldest son and Marco's mother, Rita, were put in charge of the farm when Olavo went out to seek health services in city A, Rondonópolis and Cuiabá. During Marco's childhood and adolescence, Rita also went with him, sometimes together with Olavo. In Marco's hospitalizations for ureter stenosis surgery, at 10 and 14 years old, and at times during his cancer treatment, his mother stayed in hospital: "Then I went and stayed with him..." (Rita).

Family routine, once revolving around the coexistence of healthy people, is affected by rearrangements needed, such as:

Variations in people's daily life, looking for new living arrangements to face the disease process, for the well-being of the sick person and their living together as a family.¹³

Rearrangements enable care and are produced insofar as the sick person's needs are put in evidence, perceived and then recognized by the family in a synergistic and non-uniform motion of consequences.

Family life goes through several changes due to rearrangement of relationships, the establishment of new standards, breaking up the notion of disease as a morbid, biological and physical entity, understanding it as part of life.¹⁰ It is important to note that caring for a person with a chronic disease is shaped by daily needs, by constant and complex synergy of efforts among those willing to provide care.

In search for professional care, Olavo had to leave his duties at the farm, where he earned his livelihood, and develop other skills, "All by bus ... by bus, on foot ... there were times when he left here and went to [Department of] health walking, can you believe that?! (Lair)".

Learning to get around in large, unfamiliar cities was a challenge for Olavo and a big effort appreciated by the family:

It was his choice [talking about Olavo] (Helena).

Marco said: "– no, I don't want my mother to come; she doesn't know how to move around Cuiabá!" (Olavo).

Willingness, dexterity and accumulated knowledge were some of the qualities that, according to Marco Antonio and his family, made Olavo more suited to seek medical help. Constant and ceaseless activity also showed how he cared for his child. The experience enabled him to expand his knowledge about the health care system allowing the weaving of invisible movements that escape from the formal flows of the SUS.³

Always under limiting conditions, searching for healthcare overcame several obstacles:

It was difficult, wasn't it? I was tired, sometimes ...we didn't have a car to go [a car from the Municipal Health Office]. [...] then I had to pay to go there and to come back. [...] I managed to get some money in the bank [...] for the treatment. [...] when I was told about his condition, I said: "– I will sell what little I have to take care of him, because we are what we have, right?" (Olavo).

Lack of proper health care services and the family's limited financial resources were factors that hindered Olavo's search for health care; the stress and fatigue were exacerbated by the extra expenditure. Given the lack of responses from the professional care subsystem, the family took other paths to solve the problems. Notably, the notion of problem solving in health care is constantly recreated depending on the apprehension of the needs of sick people and their families in the health system.³

In view of the family readjustments, Rita developed other care potentials: "Marco went home to pack up, his mother organized his documents, and he went to city A on a motorcycle" (Helena).

Marco Antonio's mother played an important role at home, providing conditions for her son's care and for Olavo for she used to replace him when he needed to rest or to look for financial support: "Olavo got very tired, and then we changed roles and I stayed with Marco [...] while he was having chemo [...] and then he came back here, to get money" (Rita).

Such rearrangement relativizes the notion of primary caregiver - usually Olavo - because without Rita and other relatives' support, his caring potential would have been reduced. Considered in isolation, the researchers realized that the person's health care needs exceeded each family member's caring potential: Olavo and Rita needed a support network to carry on caregiving.

Accepting help, whether formal or informal, is the subject of a study¹⁴ on the processes that sustain family resilience. The study demonstrated that to accept help has a positive impact on care provided by a caregiver, who feels supported, as well as on a care receiver, who feels safe in the face of complex life situations. Another study dealing with the experience of the father of a child with cancer¹⁵ revealed that help, whether financial, material or spiritual, gives strength and courage to keep on caring for the family.

Rita and Olavo were also helped by Helena, their foster daughter: "At that time I still lived [...] with them. I was little [...] and helped to take care of Marco. Then they'd say: "– you have to take a look at the boys there [...] scold them, reprove them" (Helena).

The family feeling of belonging made Helena get involved in many significant events in Marco and his family's lives; she knew many things of his illness experience.

In this case, care was provided within the family, which is here understood as a group whose members perceive themselves and each other as such and whose relationships are built, not imposed, by its members. Love is the unifying element in their coexistence.¹⁶ It is a space of relationships permeated with norms that define affiliation, contribution and members' reward, where each person's identity is shaped. Family is where love that sustains it and each of its members circulates.¹⁷

In Cuiabá, Marco Antonio's parents were helped by Lair and Almir, who provided favourable conditions for care, as mentioned below:

I told him [Almir]: "– I know you don't have much money [...]. My brother has a nice house, but I'd rather be here, because here I feel fine. I can eat my rice and beans, like only at home" (Rita).

He [Marco] used to sleep with my boys in a single bed. [...] Then after my husband passed away, [Marco used to

say:] “– Aunt, I'm going to sleep with you” - and he slept with me! [...] I didn't give anything [she is talking about the auctions carried out in the district of Bom Jesus to raise funds for Marco's treatment], but he said: “– Jesus, aunt you are already helping me by giving me a place to stay, coming to hospital with me, you are already helping me a lot”. I only helped [...] to care for him here, you know? Washing his clothes, because when he was feeling sick, he didn't, I washed his clothes, cared for him (Lair).

Lair's house became Marco's and his parents' second home because the readjustments within Lair's family to meet their needs made them feel welcomed. Lair's home gave them a sense of belonging: a place “where people want to be, where things are organized or reorganized whenever new events happen, such as disease.”¹⁰ Lair's family members reorganized their routine within their capabilities to take care of Marco and to strengthen his parents' care. Her house became an extension of theirs; distant geographically, but united by a “family network” woven to provide him with the best care.

In this context, family is a network of relationships whose participants share different experiences (e.i. illness). Such network has stored knowledge by their living in society – understood as biography¹⁸ - which builds other types of knowledge, values and beliefs. The concurrence of those elements makes it possible to cope with health care needs. It configures a network that supports illness demands of its members.¹⁹

According to Marco's experience, knowledge, values and beliefs are present in many ways in this support network:

I used to think: “– I wish I were there! But God is there in my place” [in hospital];

[...] then one evening, Almir, Lair and I said: “– let's pray for Marco, shall we?” (Rita).

I could go there [...] care for him, but I don't because I can't stand it. [...] I am praying God for him (Helena).

During hospitalization, even if not physically present at Marco's side, the family broke geographical boundaries and took care of him through praying. Faith pervaded the potential of each caregiver, prayers and promises made them feel closer to Marco.

Marco's family sought and offered encouragement through faith sharing, which proved to be a strong pillar of support for coping with the chronic condition, allowing them to take care of him wherever he was:

We always asked God not to let him [Marco] feel discouraged, to stay firm, have faith in Him and follow the

treatment, right? Then one day he came back home and said to me: “– Oh, I'm tired of all this stuff! I go [to hospital] and come back the same way”; I replied “My son, you can't get discouraged! Cheer up; you have to carry on with the treatment. You can't stop, and God willing, you will go back and get better, you'll see!” (Helena).

According to other studies,^{12,15,20} the ways to confront disease are closely related to the family and sick person's spirituality. The belief in spiritual forces comforts and encourages them in the face of an imposed condition and the uncertainties of scientific knowledge.

Confronting his child's suffering enabled Olavo to expand his knowledge and potential caring for him:

His father wanted to ask the doctor what he was talking about. [...] Father read the results... he hasn't studied, but knows what to look for! Amazing! He read ... [mimics expression of one who reads and tries to understand something] his eyes would be filled with tears ... We asked: “-? Are the results ok?” [Olavo replied:] “– I don't think so” (Lair).

[Account previous to the diagnosis of kidney disease] I arrived at hospital and said, “– Doctor, you have to find something out! He has been feeling like that for a long time! He is admitted here, you find out nothing; he goes to Cuiabá, nothing” [The doctor said:] “– No, no problem, it will get better” I said, “– it will not!” (Olavo)

[Account previous to cancer diagnosis] I said [to the otolaryngologist]: “– Wait I'll see.” She said: “– No, you must undergo surgery next week!” I said “– No! I'm going to Cuiabá first!” [...], Then I spoke with the doctor there, he looked at the tomography and said: “– No, this is not the case for an otolaryngologist!” (Olavo)

Marco's father knowledge was based on his life and his caregiving experiences, as well as on shared experiences; he confronted those experiences with medical knowledge to make the choices he deemed most appropriate. This agrees with a study²¹ that affirms that such knowledge is not replaced by exogenous information. Olavo's life experience provided evidence, consolidated truths and modified concepts, practices and behaviours. Therefore, knowledge can only be understood by considering the context from which its logic and rationality derive, being something invariably dynamic and continually emergent.²²

Olavo was able to translate for himself to understand several aspects of his son's illness, medical terms and treatments. He moved in the opposite direction to the limitations imposed

by his low educational level seeking in his practical knowledge the support to move in other contexts, sometimes unknown, taking ownership of them. Dialogue between different knowledge is possible and desirable, because if "all knowledge is, somehow, an attempt to make sense of the strange, this means that all knowledge is able to find the strangeness of the unknown and mediate the differences it finds".²² Olavo's approach to knowledge of a science previously strange illustrates the movement he made to understand the care receiver's chronic condition in order to provide better care.

Olavo's reactions to the impositions of his child's disease can be transcribed thus:

Then, we talked to him [Olavo] and he gave us more strength than we gave him [...] because my father... he is very strong (Katia).

He [Olavo] used to cry ... but never in front of his son ... And when Marco did something wrong, he corrected him right away"- Marco, you can't go out in the sun!" [...] he didn't cry in front of his son, no he didn't ... (Lair).

His daughter's words, confirmed by family members, draw a picture of Olavo as someone who offers support to face suffering brought about by the chronic condition.

Olavo's attitudes have to do with resilience which, according to a study¹⁴, is the ability of "some human beings to mitigate or avoid the negative effects that certain situations considered potentially hazardous may have on the health and development of people, families or communities". The same study demonstrated the skills a father had developed to support the emotional and physical needs of his children, even allowing the creation of a relational space that enabled them to boost their potential.

On the other hand, some of Marco's relatives were more fragile when faced with the situation:

His mother was always crying. [...] He was old enough to understand it; he was in a bad condition but he didn't want his mother to cry ... And then he sent for his father [to Cuiaba] (Lair).

Then [Almir] was really worried about Marco; he sometimes cried [because of] a result we didn't expect much from ... (Lair).

Resilience can be as well recognised when the family members, even when expressing their weaknesses, sought to understand the meaning given by the boy to manifestations of grief and sorrow caused by his illness:

I have not tried to find out details about his problem because of him, you know? [...] Because he wanted it that way! So, okay, we made things the way he wanted ... (Katia).

She [meaning Rita] only talked to me (Helena).

Marco felt even sicker in the face of his family's fragility. He did not want them to cry neither him to be asked about his health. This was his coping strategy. Therefore, his relatives tried to respect his wishes, opinions and attitudes, which is an important aspect of care. Such care results from resilience based on the ability to develop ways of constantly overcoming long term complications of the chronic disease and new norms required to cope with the condition.

FINAL CONSIDERATIONS

When the effects of Marco Antonio's chronic illness started to have an impact on the lives of his family members, they felt compelled to take care of him. The synergy of actions and the constant motion gave him some support to deal with the chronic condition associated with concomitant diseases. Family care was organized in care groups, shaped according to the way each member dealt with the situation. Such "approach" is variable – it depends on the status and interaction of family members with each other. It also considers the demands arising over time, which demonstrated the caring potential of every member to perform the task. The family potential for caregiving arises from the synergy of the individual potential of each caregiver and not the mere result of their sum.

Marco's father caring was the result of the caring potential of the other relatives. This leads to turning the primary caregiver figure into something relative and to think about a diversity of potentials which, together, make up the potential for family caring at different stages of the illness. By the way, Olavo was more mentioned in the speeches than the other caregivers.

The synergy of potentials that made up Marco's family caring can be characterized as follows:

- a. search for professional health care;
- b. development of practical knowledge, such as how to move in big cities and mobilise in unknown situations;
- c. setting up a new home in Cuiabá able to support and minimize the impact of being away from his own;
- d. back up support at the farm to take care of the place and of the other children;
- e. ability to overcome obstacles, such as little financial resources and physical exhaustion;
- f. relay of caregivers;
- g. appropriation of different knowledge from one's own;

- h. mutual protection pact among family members, such as spiritual, emotional, financial, and others;
- i. understanding of the meanings the sick person gave to his illness experience, identifying coping strategies and mutual respect.

Amid the discussions of this study, the groups that cared for Marco Antonio were linked by a family woven net in order to better care for him. Even if they were geographically distant, the members of both care groups underwent rearrangement in a synergy of efforts and development of caring potential. This web of relationships allowed Marco to recognize his own place for family care.

The advent of a chronic disease causes stress given the impossibility of its remission and its long-term duration. Family resilience, sustained by religious faith, contributed to the development of new routines, so that new means of overcoming new obstacles were developed.

The present study, although limited in its generalizability, aims at encouraging nursing professional needs to learn about the specificities of caregivers' daily life. It could provide health professionals with an insight into caring routine of a rural family and the rearrangements the disease demands.

It is of great importance for health professionals, especially for nurses, to learn about each family's peculiarities and caring potential for them to increase their chances of working in the area. Practices should be based on knowledge sharing between professionals and relatives, generating more effective responses to the needs of the sick individual and his family.

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