

Care needs of youth living in chronic situation resulting from concomitant disorders*

Necessidades de cuidado de jovem vivenciando situação crônica por agravos concomitantes

Necesidades de cuidado al joven viviendo una situación crónica por trastornos concomitantes

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ABSTRACT

Objective: To understand the care needs in the young experiencing concomitant chronic diseases. **Methods:** This was a situation study with a comprehensive approach employing Life History, interviews, and observations. The attentive reading of the material evidenced the health needs and care minutiae performed by the young and families arranged in a descriptive framework, allowing the election of sense axes. **Results:** Out of the many needs, efforts, and care, we intentionally elected two major mobilizing needs: "the need for the diagnosis for suffering caused by a kidney problem" and "the need for chemotherapy for cancer." The synthesizing fractal tree drawing enabled grasping different mobilized resources and the "myriad of care" conducted by the family toward each mobilizing need. **Conclusion:** The visibility of the entire care required in chronic situations allows guiding professionals involved in supporting families to alleviate suffering.

Keywords: Adolescents; Family; Family caregivers.

RESUMO

Objetivo: Compreender as necessidades de cuidado que emergem da vivência de jovem com agravos crônicos concomitantes desde a adolescência. **Métodos:** Estudo de situação com abordagem compreensiva empregando História de Vida com entrevista em profundidade e observação, compondo diário de pesquisa. Leitura atenta desse corpus de análise evidenciou necessidades de saúde e minúcias dos cuidados realizados pelo jovem e família dispostas em quadro descritivo, permitindo eleição de eixos de sentido. **Resultados:** Das inúmeras necessidades, esforços e cuidados evidenciados elegemos, intencionalmente, duas grandes necessidades mobilizadoras: "necessidade de diagnóstico para o sofrimento por problema renal" e "necessidade de tratamento quimioterápico para o câncer". Desenho sintetizador em forma de árvore fractal possibilitou apreender diferentes recursos mobilizados e a "miríade de cuidados" realizados pela família para cada necessidade mobilizadora. **Conclusão:** A visibilidade dos cuidados ampliados e prolongados exigidos na situação crônica permite orientar a prática profissional implicada no apoio a família, minorar-lhe o sofrimento.

Palavras-chave: Adolescente; Família; Cuidadores familiares.

RESUMEN

Objetivo: Comprender las necesidades de cuidado que emergen de la vivencia del joven con trastornos crónicos concomitantes desde la adolescencia. **Métodos:** Estudio de situación con enfoque comprensivo empleando Historia de Vida, con entrevistas en profundidad y observación. La lectura activa del material mostró necesidades de salud y minucias de los cuidados realizados por el joven y su familia dispuestos en cuadro descriptivo, permitiendo elección de ejes de sentido. **Resultados:** De las inúmeras necesidades, esfuerzos y cuidados, elegimos, intencionalmente, dos grandes necesidades mobilizadoras: "necesidad de diagnóstico para el sufrimiento por problema renal" y "necesidad de tratamiento quimioterápico para el cáncer". Diseño sintetizador en forma de árbol fractal permitió comprender diferentes recursos movilizados y la "miríada de cuidados" realizados por la familia para cada necesidad mobilizadora. **Conclusión:** La visibilidad de todos los cuidados exigidos en la situación crónica permite orientar los profesionales implicados en el apoyo a la familia, disminuyéndole el sufrimiento.

Palabras clave: Adolescente; Familia; Cuidadores familiares.

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INTRODUCTION

The prevalence of chronic diseases is currently considered a serious public health problem, in rich countries, as well as in those of middle and low income¹. Furthermore, children and adolescents constitute a considerable portion of the population with chronic diseases that result in complex situations with implications that reverberate throughout life², deserving, special attention from health policies.

In this study, a person is considered a child until the age of 12 years of age and an adolescent when aged between 12 and 18 years, which may be extended up to 21 years in exceptional cases, as reiterated by the Child and Adolescent Statute (ECA), Law 8.069, of 1990³.

The World Health Organization (WHO)⁴, in 2003, coined the term “chronic condition” to designate a range of health problems of various kinds, having in common persistence over time in diverse ways and the need for continuous care. However, although the concept of chronic disease has been expanded, this designation does not encompass the complexity of the experience with prolonged and/or permanent illnesses and the way they affect the lives of the sick people and their family members.

In this setting of illness and care, the name “Chronic Situation” appears more appropriate. With the study reference^{5:393}, we take the Chronicle Situation as “one that involves the illness and the many care actions required, as well as the emotions of becoming ill and seeking care in the life of the ill person and his/her family”. It also involves the meanings that the family and the ill people give the illness, how they wish to be cared for, the potentials and possibilities of these people to take care and to be cared for over time, highlighting “the ways of existence that sustain the care”^{5:395}. This is not, however, restricted to the disease process, but includes the routine of family life and care for its structure, engendering more effective responses to the needs of the ill person⁶.

Although childhood and adolescence are still regarded as stages in which the health, well-being and life are strongly engaged, not usually being associated with illness and hospitalization, important changes in the epidemiological profile of the child and adolescent population can be perceived, with a predominance of chronic injuries, following the same trend of the general population. Thus, the World Health Organization, in the document “The Adolescent with a Chronic Condition”⁷, revealed that, by 2020, these diseases will constitute the leading cause of death in the majority of developed and developing countries; and, among children and especially among adolescents, increased life expectancy due to improvements in nutrition, hygiene and infectious disease control are producing an epidemiological transition in which non-communicable diseases, such as chronic diseases, are emerging as serious public health problems.

This situation is even more worrying when the life of a young person is marked by the simultaneous occurrence of two or more chronic diseases in their adolescence.

We take here chronic diseases as constitutors of a way of becoming ill that, unlike the acute manifestations, involve a condition that endures over time, “producing potentially progressive, limiting and/or incapacitating situations”^{6:725}.

Regarding concomitant health problems, a situation experienced by the young participant of this study, this has been conceptualized as “comorbidity”, meaning the correlation originated from one or more diseases, which may simultaneously appear or precede the other; this correlation significantly interferes in the evolution of the diseases making their courses more aggravated and longer, with poor prognosis and response to treatment⁸.

However, in this study, we opted for the designation “chronic situation due to the simultaneous occurrence of chronic diseases”, taking into consideration the young man who, in adolescence, experienced kidney problems and lymphoma in the right jaw. This perspective allowed us to better portray the experience of this young man and his family, as well as the care needs which were greatly expanded and overlapping in their manifestation. We took here the concept of care as being a mutual relationship between two or more people that aims to achieve the relief of suffering or the realization of well-being, always mediated by knowledge specifically aimed at this purpose⁹.

We justify the importance of this study because we believe that: The perception of the care needs of the ill person and family may favor the recognition, by health professionals, of the adversities faced in daily life resulting from this condition, making it possible to mobilize resources to assist them in the necessary coping^{10:438}.

We highlight that previously developed studies^{6,11} have gradually expanded the approach of chronic illness due to concomitant diseases, with two of these performed from the experience of this young man and his family. These studies have allowed us to question what the care needs would be in this situation and how this care would be configured, produced, almost entirely, by the family itself.

The aim of this study was to comprehend the care needs in the chronic situation experienced by a young man with concomitant chronic diseases since adolescence.

METHODS

The approach was through “Situational study”, a term initially coined by the autor¹² and appropriated in studies^{13,14}, which refers to the comprehension of what is happening in the particular context of the life of the person and his/her family, especially the experience of illness and care, allowing the researcher to draw some broader inferences from that micro-reality. It was conducted from the review of the Matrix Research Database (BDP) to which this study is linked and which consists of a “qualitative set composed of collections of data and information about experiences of illness and care of people and family members - appropriately compiled in research diaries”^{15:55}.

The BDP is composed of a cohesive collection of data previously collected with families who have experienced

chronic illness in the context of the Brazilian National Health System (SUS), in the state of Mato Grosso. From this database, the collection of the Life History¹⁵ of a young man was chosen intentionally. The subject was fictitiously named Marco Antônio, and experienced chronic illness, due to concomitant renal injury and cancer, in adolescence, with the renal injury persisting from an early age.

This Life History was collected from March to May 2011 through eleven in depth interview meetings, both in Cuiaba-MT, home to some of the family members who participated in the illness experience of Marco Antônio, as well as in City A, where the young man lived with his family throughout his illness and B City, where he resided with two brothers and a cousin.

Open type interviews were conducted with each family member using guiding question regarding the illness experience and care of Marco Antônio and its development according to the recollection of the experience by the respondent, with gradual deepening of narrative threads¹⁵ that showed the most interest for the focus of the study. Thus, based on the reports of the people and the meanings that emanated, in every interview meeting new questions were asked in order to further deepen the recollection of the experience of the family¹⁵. These various meetings provided a better comprehension and deepening of the meanings of this experience from the perspective of the people interviewed.

The interviews were recorded using a voice recorder and transcribed in full in order to preserve, as closely as possible, the speech and modes of expression of each participant.

The interview was accompanied by field observations, as well as a film and photographic record, constituting a triangulation of elements in the data collection in qualitative research. This corpus, consisting of 212 typed pages, composed the material of analysis in this study.

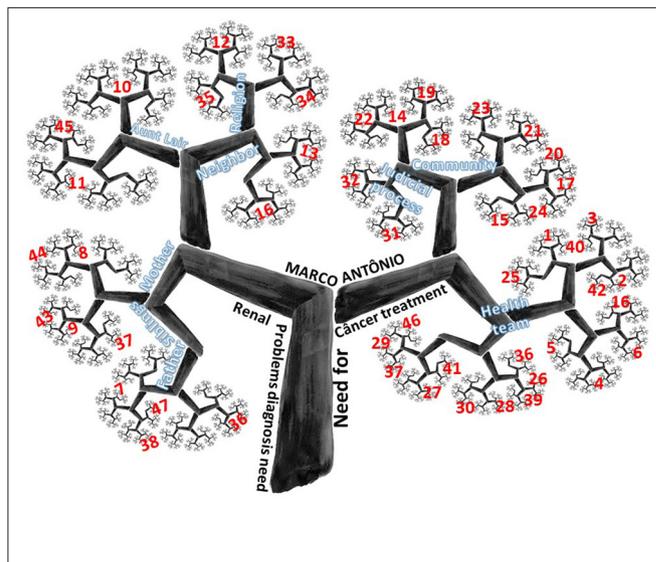
Thus, with the anchor point being the history of these people, at this time, the review of the BDP collection was directed by the goal now proposed. In it, a rereading sought to highlight the care needs in the illness of Marco Antônio. The care concept was considered broadly, not limited only to the context of the professional field of health.

With the readings of the corpus a descriptive framework was constructed, in "Microsoft Word" format, composed of the narratives of the young man and family members, who exhibited numerous needs, mobilizations, efforts and care actions produced for him throughout his illness. Within this framework, we intentionally chose two axes of mobilizing needs central in the experience of becoming ill and seeking, producing and managing the care, revealed by them, these being: "need for diagnosis for the suffering due to the renal problem" and "need for chemotherapy treatment for the cancer".

Based on these two axes of mobilizing needs, we constructed a synthesizer design, which took the form of a "Fractal Tree" (Figure 1), in "Power Point" format, in which the "resources mobilized" were listed, i.e., the people and institutions, of health and others, which could, in any way and measure, offer diversified care to the young man and his family. Thus, the fractal idea, as "irregular mathematical shapes with patterns that are repeated

in varying scales, i.e. the geometry of the smaller parts of the object is similar to that of the whole, but scaled-down"¹⁶, seemed quite appropriate for, imagetically represent this comprehension. The explanation of the design will be given below as part in the presentation and discussion of the results.

Figure 1. Myriad of care actions mobilized for the diagnosis of renal disease and chemotherapy for the cancer in 2015.



¹ Font: "Fractal Tree Nº. 1" by Robert Fathau. Available at: <https://aidobonsai.files.wordpress.com/2011/10/fractaltree.jpg>.

The matrix research to which this study is linked had approval from the Research Ethics Committee of the Júlio Muller University Hospital, authorization Nº. 671/CEP-HUJM/09, with the reviews of the Database being contemplated in it, and the interviewees consenting through the Terms of Consent. Fictitious names have been used, both for the people and the professionals and institutions cited by them, aiming to preserve their anonymity. Thus, this study complied with the ethical prerogatives of research with human subjects at the time of data collection, according to Resolution 196/CNS/1996, and also fulfills Resolution Nº. 466/12, now in force.

RESULTS AND DISCUSSION

To comprehend the resources mobilized, especially the efforts of the family to meet the care needs during the disease process of Marco Antônio, it became important for us to approach his way of life from birth. It was from this perspective that we could capture the potential of care driven by the family and the rearrangements set in motion to accommodate the care needs of the young man, as well as the people and institutions that, in some way, might contribute to the care that could be produced.

At the time of data collection Marco Antônio was 21 years old and the son of Rita and Olavo and brother of Fabio, Katia, Adriana and Keila. He experienced two chronic diseases: the first, from early childhood, due to sequelae of unilateral congenital

stenosis of the ureter that, being diagnosed late, resulted in unilateral hydronephrosis, with nephrolithiasis framework; and the second, emerging in adolescence, concomitant with the kidney problem, was non-Hodgkin lymphoma diagnosed in the right maxillary region. The young man was born in a city located 210 km from Cuiabá and, from his childhood, lived on a small farm near his hometown, along with his siblings and parents, later going to reside in another municipality of the state with cousins and two siblings.

One of his sisters, Helena, a girl raised by his parents and considered to be daughter, contributed significantly to the health care of the young man from his birth; she was older than Marco Antônio and lived next to the house where his parents lived. Another person very present in reports of the family is Lair, Olavo's sister, who lived in Cuiabá and who looked after the young man from birth. Because of her help in seeking the health services in Cuiabá, which became constant after the introduction of the diseases, and the emotional care for him, she was considered by him to be a second mother.

The family maintained a close relationship, especially with some uncles, cousins and grandparents on the father's side; and also, with the godparents of the young man, who participated in his care during the illness. The family mobilization for help was possible because they all lived in nearby houses, on the same farm.

The design that seeks to represent the intense mobilization of resources for many care needs presented by Marco Antônio constitutes the "fractal tree" (Figure 1), summarizing the view that, for each major axis of needs imposed in the chronic situation, a multitude of care was required.

In the drawing, the tree trunk is identified as the chronic situation that, although encompassing both concomitant diseases of Marco Antônio, is for him and his family experienced as part of a unique experience. The primary branches originating from the trunk represent the two major mobilizing axes of his needs, followed by the secondary branches identified as people and institutions that produced or participated in the care. Finally, each "resource mobilized" for each care action that could be produced was alluded to by the extensive branches that break away from each secondary branch, giving us a sense of the massive tree structure of care required by the young man.

These resources were, for didactic purposes, identified by the numbers 1 to 45, in red, which do not follow an order of magnitude or occurrence, but seek to show that different resources from different sources were mobilized throughout the illness experience sometimes sequentially, however, more often simultaneously, as needed by the young man, seen as being "care-measures" that contributed to the achievement of other "care-ends", as shown in Figure 1 below. Thus, a myriad of "small care actions" were necessary, but not always perceived or visualized as such, given their apparent insignificance or naturalization, mainly by health professionals, attentive to the "great act" of diagnosis and treatment for the renal problem and the chemotherapy treatment for the cancer.

We can understand that the care goes well beyond the measures and therapeutic procedures performed for the outcome of a treatment and arises from the mutual relationship between people who aim to offer relief from suffering and the promotion of well-being⁹. Care, in this sense, is seen as "a philosophical construct, a category with which you want to simultaneously assign a philosophical comprehension and a practical attitude when presented with the direction that the health actions acquire in different situations in which a therapeutic action is demanded"^{19:42}.

Marco Antônio started the first manifestations of illness due to kidney problems soon after birth, with episodes of edema in the face and limbs and pain in the lower back. At three years of age, his father took him to Cuiabá (Figure 1 - N^o. 38) for a medical consultation, however, the professional who attended said that the pain was a normal physiological process that would resolve itself spontaneously (Figure 1 - N^o. 2): *I think he was about three years old when I took him to Cuiabá, the doctor discovered, but then left it, you know. She said that he didn't need anything, that we could leave it, that he would grow and the problem would be solved, right (Olavo).*

As the stenosis of the left ureter was not detected early, at eight years of age, it evolved into unilateral hydronephrosis, with the child undergoing two kidney surgeries. At eight (Figure 1 - N^o. 39) and fourteen years of age (Figure 1 N^o. 40), all the procedures were carried out by public hospitals in Cuiabá (Fig 1 - N^o. 41.). We question, then, the delay in the diagnosis of the renal problem that Marco Antônio experienced, leading to two complex surgeries that caused him and his family much distress and suffering, mobilizing an extensive trajectory in the search for care.

The first (referring to the first kidney surgery) caused many problems. Then it was leaking a lot (referring to a drain) [...] I don't know, that thing hurt a lot [...] There was one time where I had almost forty degrees of fever... Then the doctor came here and nothing! He didn't find the problem, didn't know what was really going on. (Marco Antônio).

The paternal care became very present in the life of Marco Antônio as a great mobilizer in the search for care for the needs of the child due to the kidney problem.

When undergoing the surgical procedures, some doctors gave their own private phone numbers (Figure - N^o. 42) to the father of Marco Antônio so that they could be called if he needed care.

He [the son] was worried, so he came, he came to [names Philanthropic Hospital of Cuiabá]. He [referring to the doctor] gave me his phone number and the nurse did not want to call! I said: Oh, I will call the doctor. No, you can't, blah blah blah, call, doctor at this hour" [referring to the statements of the nurses]. I said: No, I have his phone number, he gave his cell phone to call him if there

was any problem. I'll call him!" [...] He even got angry with them because they had to call right away because he got worse! (Olavo)

We realize that, even though the young man was hospitalized, his father had to mobilize himself so that his son could be attended in his needs that were not valorized by the other health professionals. This comprehension corroborates the idea that the family is the great articulator of care, even that produced by the health professionals^{17,18}.

From all the narratives of the family, we understand that in this long period of frequent hospitalizations of Marco Antônio during which his father accompanied him, his siblings and his mother provided other types of care, in the form of organization (Figure 1 - Nº. 44) and maintenance of the lives of other family members in the home (Figure 1 - Nº. 43), in the work performed to support the home, as well as spiritual help through prayer. The aunt, Lair, was also very present in this period, helping Marco Antônio in the search for care in Cuiabá (Figure 1 - Nº. 45), and, when he suffered from kidney pain, she took him by public transport to a hospital emergency room in Cuiabá (Fig 1 - Nº. 46): *It was like a kidney problem. We took him to the emergency room. We got there and they gave saline, gave him an injection and he got better [...]* (Aunt Lair).

Sometimes it was necessary for the father and the aunt of the young man to carry out the care in relays (Figure 1 - Nº. 47) during the hospitalizations: *When it wasn't me it was his father [...] his father stayed for two, three days. Then he got tired so I went so he could rest. Then I stayed* (Aunt Lair).

The manual of the Ministry of Health¹⁹ conceives the caregiver as an individual with special qualities, expressed by strong traits of solidarity and giving to others, aiming to ensure the well-being, health, recreation, among others things, of the sick person¹⁹. Over the time of the care, especially during hospitalization, the caregiver is faced with personal, emotional and physical stress; and, to avoid this, it is important that there is joint participation with others in the process.

However, while this relay is a strategy organized by the family, as in the case of Marco Antônio through the care provided either by the father or the aunt, it does not cease to produce suffering and distress in the caregivers. In the case of the father, he was forced to be away from work on his farm, which caused financial difficulties to support the family; for Aunt Lair it represented a departure from the domestic chores of caring for her own family. In this situation, other arrangements in everyday life, in the form of care-measures, needed to be organized by the other family members to support the more direct care to Marco Antônio.

Amid the renal situation, Marco Antônio, entering adolescence, was again affected by a serious event: the initiation of cancer, synergizing with the kidney disease. To better comprehend this experience, it is essential to report here how his diagnosis was given.

At thirteen, the young man began to report pain in the ear and after going (Figure 1 - Nº. 36), along with his father, to some

consultations (Figure 1 - Nº. 1) and examinations (Figure 1 - Nº. 2) was diagnosed with lymphoma in the right maxillary region. However, to start the chemotherapy, the physician of the hospital specialized in cancer treatment (Figure 1 - Nº. 3) reported that there would be a need to treat the kidney problem that still persisted. With some tests for the investigation of kidney function (Figure 1 - Nº. 2) requested by the medical oncologist who attended, organ dysfunctions were identified, with him undergoing a second surgery (Figure 1 - Nº. 4) for the correction of the left ureter, remaining hospitalized for seven days (Figure 1 - Nº. 5). In his reports, we observe the abruptness of the initiation of the cancer in tandem with the need to perform kidney surgery and begin the chemotherapy (Figure 1 - Nº. 6) on the day following the hospital discharge for the renal surgery: *It was like this, he came out of one hospital at night and went straight into the cancer hospital... He left straight for the cancer hospital [...] He didn't even take out the stitches. I left and I went there to the cancer hospital. Without removing the stitches* (Olavo).

When experiencing chronic illness that requires prolonged, complex treatment, with constant care in relation to therapy and all the situations that could aggravate the health of the young person, the family is essential, it is their responsibility to search for, produce and manage the many care actions required²⁰. The illness of Marco Antônio with cancer, as well as causing much suffering and fear in the family, forced the development of intense peregrination in search of care for his needs, requiring, again, the family members to find other ways to live when presented with the limitations and new situations generated, even leaving the business on the farm, the place from which they received a living.

Oh it was difficult, you know, but I had to go [...] He was always taking care of the things [referring to the eldest son]. Me and her [referring to the mother of Marco] would go there, right, and stay there. There were times that I came back once a week, other times it took months (Olavo).
[...] I stayed there with him for three months (Rita).

We noted, in this narrative, that the chronic condition requires continuous and long-term care, this being produced and managed by the family in a particular way. In the case of Marco Antônio, the family, including the father, mother and siblings reorganized their daily lives (Figure 1 - Nº. 7) and the affairs of the farm (Figure 1 - Nº. 8) in order to provide better care (Figure 1 - Nº. 9) for the health needs of the young man.

It should be noted that we understand "health needs" as all that is experienced by the individuals and family members, as a "lack" or "shortage", whether conditions, means or instruments, so that they can take care of their own health or that of someone under their responsibility. Therefore, we take this lack or shortage in the meaning indicated by them, that is, from their own logic²¹. This concept is extended in relation to the narrow limits given by the professional field which limits what can be translated as "health problems". In the situation experienced by Marco Antônio and his family members we see is a huge range of

“care-measures” to reorganize the daily family life, providing the best conditions possible for a family member to be with the ill person, supporting him in what was needed. These “small care actions” are rarely placed on the list of intelligibilities and visibilities of what the health team takes as “health care”.

Aunt Lair and her children were also present in this period of illness as a strong support in the search for care for Marco Antônio, welcoming him in their house (Figure 1 - Nº. 10) for stays in Cuiabá during the treatment, occasionally contributing to the search for care at the health institutions (Figure 1 - Nº. 11), as well as helping through their prayers (Figure 1 - Nº. 12). Also the neighbor, who lived next to the house of aunt Lair, became important at times when the family needed help to take Marco Antônio to the hospital by car (Figure 1 - Nº. 13), as well as providing help at specific moments of worsening of the illness.

Contributing further to the multiple care actions in his illness, Marco Antônio had the support of friends (Figure 1 - Nº. 14), the rural community which his family was part of (Figure 1 - Nº. 18, 19, 20, 21, 22, 23), some health professionals (Figure 1 - Nº. 15) and also support groups (Figure 1 - Nº. 16) and associations (Figure 1 - Nº. 17) that were touched emotionally with the situation of him experiencing the concurrence of the diseases: *Look, we were struggling, because before he got rid of one problem, came another even more serious right. It was hard, both for us here, as well as for the people there of the farm, his friends...* (Lair).

Throughout the search for care, Marco Antônio and his family faced a shortage of financial resources and lack of appropriate care by the health services. Mobilized by the severity of the disease and aware of costs of the treatment, the friends of the community provided care (Figure 1 - Nº. 14) of great value to the young man and his family. In his statements, Marco Antônio emphasized that the community, including the church (Figure 1 - Nº. 18), friends (Figure 1 - Nº. 19), the school (Figure 1 - Nº. 20) its director (Figure 1 - Nº. 21) and the teachers (Figure 1 - Nº. 22), as well as the neighbors (Figure 1 - Nº. 23) organized two auctions (Figure 1 - Nº. 24) in order to raise funds to help in the cost of his treatment. All the efforts and cooperation of the people for the auction led to a profit of approximately, ten thousand reais, passed on to the family of the young man.

[...] It brought together the community right, the farmers. The family with the community, everyone. After, they decided to do an auction as well. The teachers, students. The teachers, right, they got together and did an auction as well, it made around... all the money was nearly eleven thousand. It was ten thousand eight hundred and a bit at that time. It was a very big help (Rita).

I had help, a very big help you know [...] They did the auction in the church up there. Everyone got together. At that time we got, just from the church, about eight thousand, right Marco? (Olavo).

This support received by Marco Antônio helped significantly to meet his needs regarding the treatment, because sometimes he

and his family had to pay costs of exams and expensive procedures that would take a long time to get in the Brazilian National Health System (SUS).

As mentioned, Marco Antônio, after feeling pain in the ear, sought medical care at the hospital in Rondonópolis (Figure 1 - Nº. 25). Not having faith in the medical procedures, his father, Olavo, took him to the university hospital in Cuiabá (Figure 1 - # 26) aiming to resolve his pain. Marco Antônio, in turn, was referred to a specialist otolaryngologist who detected a lymphoma (Figure 1 - Nº. 27) and sent him to a specialized pediatric oncology hospital (Figure 1 - Nº. 28). In this hospital, Marco Antônio underwent eight chemotherapy drug cycles (Figure 1 - Nº. 29). However, a year and eight months after the end of treatment protocol the lymphoma recurred, requiring further treatment, this time using a drug not provided by the SUS. There was a social worker in the health institution that helped (Figure 1 - Nº. 30) them start a judicial process (Figure 1 - Nº. 31) to get the drugs. Although the judicial ruling took a month to be granted, the provision of the drug by the SUS (Figure 1 - Nº. 32) took six months: *Then I started a court process. It still took a long time for the medicine to come... We went to one place, went to another, they send you to another place, right* (Olavo).

In this search, Marco Antônio and his family, faced with the intense peregrination due to the bureaucracy of the judicial process, still found it difficult to move around Cuiabá, due to a lack of financial resources to pay the bus fare, having to resort to going on foot.

We used to go by bus, at this time it was more difficult, it was only by bus [...] He spent the day there, he left here in the morning, they would eat lunch and dinner at night, chasing after the things. Sent them to one place..it wasn't there, it wasn't at that place; they sent them somewhere else and it wasn't there. Then he went until he found the right place for him to leave the things all organized [...] All by bus, on foot, there were times that he left here and go all the way on foot, can you believe it! Because sometime he didn't have any money... (Lair).

The trajectories of the search for resources for the care undertaken by individuals and families are motivated by needs of various natures²¹. Marco Antônio and his family had to undertake intensive search trajectories to have their needs even partially resolved. Care is sought where people can find resolution, not restricting such searches to a given institutional place or going through a flow previously established, but rather following their own logic and possibilities²¹.

Also contributing to the coping and care for his health in his experience of chronic illness by concomitant diseases, Marco Antônio reported “*I always believed in God, right*” and “*I never put in my head that it was a problem for me*”, demonstrating that he always had faith (Figure 1 - Nº. 33) and the strong connection with God (Figure 1 - Nº. 34) to ease his suffering, using positive thoughts in relation to the illness.

As well as Marco Antônio, the family and the community also gathered to provide spiritual help through prayer (Figure 1 - Nº.

35). *We did the prayer group here at home a lot, right. We would pray in the house of other people, we had a campaign of prayer in which we carrier around our Lady Immaculate Heart of Mary, every Wednesday she's would be taken to a house and we would pray there* (Lair). To cope with the illness and the treatment imposed, families, friends and the very ill person turn to spirituality, faith and beliefs to find strength in order to withstand situations considered difficult²², such as the treatment of the cancer and kidney problem that was permeated with stressful events.

At 20 years of age, Marco Antônio was sent to a Clinic Specializing in Oncology (Figure 1 - N^o. 36) to be monitored by an adult oncologist. The lymphoma had improved very little with the use of medication and the young man began to perform radiotherapy (Figure 1 - N^o. 37), with which a good reduction in the tumor mass was obtained. For the young man, to experience the treatment for cancer, both chemotherapy and radiotherapy, was marked by suffering and difficulties arising from adverse reactions, such as alopecia and damage to the epithelial surfaces of the oral mucosa that prevented him from eating. This coping, according to the reports, was made possible by strong support from family members, friends and faith in God.

We believe that the family is the sustaining pillar of the care for the life and health of their loved ones, mediated by affective relationships woven the in daily life; such care becomes more intense with the establishment of chronic illness⁵. This illness generates many situations of stress due to the impossibility of its remission and its extension over time⁶. Thus, the resilience of the young man and family, supported by the family relationships for the care, as well as by faith, significantly contributed to the establishment of other normalities for life in each situation imposed by the illness.

In the period of field research, the young man moved to City B, was dating and reported the prospect of starting a family and studying in the future. Regular monitoring continued with the specialist oncology physician and in the Public General Hospital in Cuiabá for the renal illness, using the drug potassium citrate for the kidney stones that affected him. This shows the indefinite continuity of the search for health care, conforming in a myriad of care actions for the chronic condition experienced, requiring from the young man and family the constant ability to rearrange, renew and reconstruct their ways of life.

Therefore, the need is evident for permanent professional assistance over time, which is known as “longitudinality²³, constituting a personal relationship of long duration between the health professionals and the ill person and his/her family, in order to guarantee them the necessary care in chronic illness. We remember, too, the author^{6:63} stating that “The care amalgamates different knowledge. It is knowledge that does not create products, does not generate systematic and transferable procedures, does not create universals, since it only fits in the same moment in which its judgments are made necessary”.

FINAL CONSIDERATIONS

This study sought to comprehend the health needs that emerge in the chronic situation arising from concomitant diseases in a young man, in order to give visibility to the myriad of care actions that emerge from them. We believe that the synthesizer design of the tree representing this myriad of care actions allows us to capture that, for each need, the different “resources mobilized”, largely by the family, included many “small care actions”, as well as action-measures so that other care-ends could also be produced for each mobilizing need.

In its systematizing and synthesizing capacity, the design presents important elements of the illness history of the young man, as well as allowing the capture of the intense efforts that the family undertook over time to provide care actions of different natures and purposes necessary in the chronic situation. This expanded comprehension of health needs and the mobilization of resource to provide the many care actions makes us reflect on the insufficiency of the linear idea coined by the professional field that is “health demand”, with little resemblance to what the ill person and his/her family experience as the “need”.

We consider that other studies should be conducted enabling a broadening of the comprehension and visibility of the family as a key in the provision of care in everyday life, notably in chronic situation of illness in children and adolescents.

Also the understanding that the chronic situation due to concomitant diseases is configured as an experience in itself, not merely the sum of diseases, which implies thinking about the need for extended, continuous and long-term care, produced dynamically, especially by the family. Therefore, it is essential that health professionals have a practice involved with the family care over time, supporting the family with the substrate necessary for this care network to be engendered.

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