



## RURAL COMMUNITY PARTICIPATION IN CAREGIVING FOR A YOUNG PERSON WITH CHRONIC ILLNESS AND HIS FAMILY

### PARTICIPAÇÃO DA COMUNIDADE RURAL NO CUIDADO DE JOVEM ADOECIDO CRÔNICO E SUA FAMÍLIA

### PARTICIPACIÓN DE LA COMUNIDAD RURAL EN EL CUIDADO AL JOVEN CON ENFERMEDAD CRÓNICA Y SU FAMILIA

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#### ABSTRACT

**Objective:** understanding the participation of the rural community in the experience of chronic illness of the young person and his family. **Method:** study of situation applying the life history, conducted by observation and in-depth interview. The analysis showed the units of meaning which were grouped in the analysis axis of this study. The research project was approved by the Research Ethics Committee, Protocol 671/CEP-HUJM/09. **Results:** the community mobilization potentialized the health care, because: a) its actions were guided by the perception/awareness of the needs of the young person and his family; b) did not limit that actions to the health needs; c) produced responses which sometimes exceeded the family expectations; and d) provided various subsidies that enabled the access to health care institutions and the judiciary. **Conclusion:** in the rural context persists the difficulty to access the quality health care. The rural community acted as a sustainer mediator in the chronic illness experience of the young person and his family. **Descriptors:** Social Support; Chronic Disease; Family Relations; Rural Population.

#### RESUMO

**Objetivo:** compreender a participação da comunidade rural na experiência do adoecimento crônico de jovem e família. **Método:** estudo de situação empregando a história de vida, conduzido por observação e entrevista em profundidade a jovem e família. A análise evidenciou as unidades de significado agrupadas no eixo de análise deste estudo. O projeto de pesquisa teve a aprovação do Comitê de Ética em Pesquisa, Protocolo 671/CEP-HUJM/09. **Resultados:** a mobilização da comunidade potencializou o cuidado em saúde, pois: a) suas ações foram pautadas na percepção/sensibilização quanto às necessidades do jovem e de sua família; b) não limitou sua atuação às necessidades de saúde; c) produziu respostas que, por vezes, superavam as expectativas da família; e d) forneceu subsídios diversificados que possibilitaram acesso às instituições de saúde e do judiciário. **Conclusão:** no contexto rural, onde persistem dificuldades de acesso e baixa qualidade na atenção em saúde, a comunidade rural atuou como mediadora sustentadora na experiência de adoecimento crônico de jovem e família. **Descritores:** Apoio Social; Doença Crônica; Relações Familiares; População Rural.

#### RESUMEN

**Objetivo:** comprender la participación de la comunidad rural en la experiencia de la enfermedad crónica del joven y su familia. **Método:** un estudio de situación utilizando la historia de vida, impulsada por la observación y la entrevista en profundidad con el joven y su familia. El análisis mostró el significado de unidades agrupadas en el eje de análisis de este estudio. El proyecto de investigación fue aprobado por el Comité de Ética en la Investigación, Protocolo 671/CEP-HUJM/09. **Resultados:** la movilización comunitaria potenció la atención de la salud debido a que: a) sus acciones fueron guiadas por la percepción/conciencia de las necesidades del joven y su familia; b) no limitó sus actividades a las necesidades de salud; c) ha producido las respuestas que a veces superan las expectativas de la familia; d) proporcionan diversos subsidios que permitieron el acceso a las instituciones de salud y el poder judicial. **Conclusión:** en el contexto rural, donde sigue habiendo dificultades de acceso y la mala calidad en la atención de salud, la comunidad rural actuó como mediadora en el sostenimiento de la experiencia enfermedad crónica del joven y su familia. **Descriptores:** El Apoyo Social; Enfermedad Crónica; Las Relaciones Familiares; Población Rural.

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## INTRODUCTION

Family is a community which represents "a place of welcome and safety among people who maintain kinship ties, love and respect".<sup>1:753</sup> Inside the family there are relationships and interactions where people share moments which can be conflicting or not. The experience of the health and disease is one of those moments.<sup>2</sup>

Regard to health care, family is taken as primary caregiver, being the basis of the community care. However, the community refers to a group of people who has family or is neighbor. Such group is made of respect, participation and solidarity.<sup>3</sup>

Considering the rural community, its conceptions of health and disease reflects the combination of its life context in what people observe the everyday elements and bodily changes, with their historical and social context. People experience daily challenges, financial hardship, body boundaries and still keep motivations, conscious or not, to live well.<sup>4</sup> It should be noted that this group of people is also permeable to biomedical knowledge, even if it have to change it or adapt to its reality.<sup>5</sup>

The experience of chronic illness implies several disorders to the ill person and his family every day; it demands changes in their lifestyle and has to have health management for an extended and unbounded period. In the case of this experience, studies about Therapeutic Itineraries<sup>6-10</sup> emphasize that people and their families undertake pathways for care in the different systems, not limited to health services; they also weave caregiving networks for health, which give some support and sustain them in the experience of becoming ill.

Such networks can be of support, set outside help and made up of people who worked in specific moments in the illness experience. Those are marked by more formal relationships and less affective density. And sustaining networks, which are linked to the ill person more constantly, with strong presence in the biography and in the production of family care, they are woven by closer and intimate relationship based on affection.<sup>11</sup>

In these networks it has been built social support in the daily concreteness - that is to say they are reached several features that the subjects need through social relations.<sup>12</sup> Thus, the analysis of such networks allows us to understand the printed directions on these woven, who attend them and the quality of their relationships. Besides, they permit us to

see other important elements used to understand the many "help" that emanate from them, especially those related to the care in the illness.

Currently, the solidarity networks, whether of kinship, friends or neighbors, have been included in social policies that defend the necessary approximation of institutional assistance to non-institutional. This is due to the consideration of families and community social networks as active subjects with potentialities to contribute with their own resources for the health production process, not mere recipients of health care.<sup>5</sup>

This study encompassed caregiving networks for health woven by the young person and his family who have experienced chronic situation because of kidney disease and cancer. This family was residing in the rural area of Mato Grosso state (MT) and the participation of the rural community in the provision of the care was highlighted.

The rural population in MT corresponded, in 2012, to 16,2% of the state's general population, approaching, therefore, from the Brazilian rural population, equivalent to 15,2%. In MT, even in the year 2012, the average income of its rural population was R\$ 587,69 and functional illiteracy rate was 36,29%.<sup>13</sup> Concerning the rural population health, it is recommended that special attention should be focused because, in addition to that vulnerable situation, they live outside of urban centers and, consequently, of public health services, so they must weave strategies to reach quality care, respecting their culture and their host needs.<sup>14</sup>

Among these strategies, with respect to the actions of social networks, authors<sup>15</sup> consider that the existence of several bonds, be they family, neighborhood and institutions such as church and community association, are perceived by the community as fundamental in assisting in disease situations and difficulty. Social networks can be responsible for the support, problems visibility and also the reception of certain social and health needs that exceed the State capacity of care.<sup>15</sup>

The need to arouse the attention of professionals, Government Authorities and health managers to the issue of the rural community participation and the tissue of social networks and their potential in the illness experience justifies this study. This is in order to achieve paradigmatic changes in the planning of health care, so that the provision of health services and informal assistance provided by the community reinforce in a reciprocal movement.

This study aimed to understanding the participation of the rural community in the care of a young chronic diseased person and his family. We assume that the understanding caregiving networks in chronic illness situation provides us with theoretical elements to unravel how this community mobilized facing its peculiarities, with a view to meeting the health needs of the ill person and how it potentialized the family care. The study also allows us to rethink the practices of care in health and nursing, from training to ongoing preparation of these professionals, offering support for the consideration of the person citizenship and his family in their life context in rural communities.

## METHOD

Study extracted from master's thesis << *Experiencing concomitant chronic diseases and caregiving in the life of a young person and his family* >>, carried out within the matrix research "The legal institution as mediator in the effectiveness of parental rights in health: analysis of therapeutic programmes of SUS/MT users and families (DITSUS)". Master's thesis presented to the Nursing Postgraduate Program, FAEN/UFMT, Cuiaba-MT, Brazil; 2012.

This is a study of a qualitative approach that was developed as a Situation Study<sup>16</sup>, whose universe is the ill person and his family's life, which allows the researcher to emphasize the sinuosities of several relations established during their lives.<sup>17</sup> Understanding the situation and the peculiar context - a rural community - of the ill person and his family's experience, we were able to draw some broadening deductions from the analysis of this micro-reality.<sup>18</sup>

As a methodological approach we employed the Life History, which allowed us "to understand the way people tell experiences in a recall effort of things experienced".<sup>19:56</sup> As a research tool, was used In Depth Interview (EP) shaped like a "conversation with intentionality, directed through the gradual chaining given to the story by the person who narrates and the choices of the researcher by certain narrative threads"<sup>19:56</sup> and oriented by the guiding question "Can you tell me about your disease experience and your search for health care?" To deepen the important meanings of illness experience, subsequent inquiries were conducted, anchored in the speeches of the people.

The research participants' selection was based on the following criteria: to have cancer established in adolescence; to be a SUS user; to have started legal proceedings and

elapsed more than one year since the start; and to reside in the State of Mato Grosso. The first criterion is as peculiarity of this study and others met the criteria of the matrix research. Found in a cancer treatment institution of the Unified Health System of Mato Grosso (MT-SUS) through medical record data, the subject of this study was a young person with chronic illness by cancer and kidney disease, whom we call Marco Antonio, and some members of his family: his father Olavo, his mother Rita, his sister Katia Adriana, his foster sister Helena and her aunt Lair. Other family members were present at one of the EP meetings: an uncle, an aunt and two neighbors, contributing to some extent. The family was approached in home in order to apprehend its context of life in the rural area.

We clarify to the participants about the research objectives, its operation and its ethical precepts. We obtained the acceptance of participation in this study using the Term of Consent. It is worth mentioning that the matrix research was approved under N° 671/CEP-HUJM/09.

Participants' anonymity was ensured by the use of fictitious names, as well as by replacing the names of the origin cities due to the possibility of identifying people, for being small social spaces. Cuiaba and Rondonopolis had not their names changed because they are very populous cities, what makes impracticable to identify the subjects.

The EP was conducted through eleven meetings from March to May 2011. The first two meetings happened at aunt Lair's residence in Cuiaba; in the first one, Marco was present and we got some contributions from his aunt; and in the second one, only his aunt attended the meeting. In the City A, where Marco and his family lived, we held eight meetings, at different times, with: Marco and his parents and relatives; Marco only; parents only; some people of the community. Some of these meetings occurred simultaneously, by dividing members of the work team: two Master's students and two undergraduate research fellows. There was a meeting with his sister Katia Adriana in the City B, where the subject lived with his three brothers at the time of the fieldwork.

The empirical material of this study was derived from the EP and field observation (OC) that emphasized the hear, seen and experienced elements in every interview encounter as well as the registration of ideas, strategies, reflections and insights of the researchers - two Master's students and two undergraduate students. In the text, the



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reference to the Field Observation Notes occurred by the acronym NOC, followed by the date of observation. This material, added to the everyday notes of the search for the subject and to the transcripts of recorded interviews, was gathered in the field diary totaling 224 pages, which formed the corpus of the research.

To transcript the EP, we seek to emphasize the language in order to provide certain affinity with the narrative of each study subject in its various rhythms, tones and intonations of speech and the various emotions that accompany each "storytelling".<sup>19</sup> We respect the complexity of the narrative modes, preserving the cultural speech of the study participants; therefore, we seek to reproduce their accents.

For the purpose of understanding the data, we conducted thorough and complete reading of the corpus of analysis over and after all the fieldwork, which showed the analysis axis of this study - "Potentialities of a rural community mediation and the legal intervention in the health care "- that has emerged from a complex process of grouping the meanings attributed by respondents to illness and care experience.

Concerning the process of organizing and analyzing the data, the corpus also allowed us to draw the "Sustainment network in the illness experience of Marco Antonio" (Figure 1), what enabled us to reveal the network participants, the quality of the relations with Marco and his family, the nature of the aid and its permanence in time, in view of the chronicity of the young person's illness. And yet, to draw the "Search trajectory to obtain a medicine by legal proceedings in the Marco's illness experience" (Figure 2), whose dimensions: a) spatial demarcated institutions accessed by him and his father and several returns to them in an attempt to obtain a single drug (specific for cancer treatment) by legal proceedings; b) temporal expressed the chronological order of events to obtain the drug, in order to contrast with the temporality of the illness experience by cancer and the urgency of drug treatment.

RESULTS AND DISCUSSION

We will discuss the moments in the experience of Marco Antonio where there was a higher volume of search mobilizations to the health care: childhood, due to kidney injury, and adolescence, a phase of life marked by the coexistence of kidney disease and cancer. At that time, Marco Antonio and his family lived in the rural area about 30 km from the City A, located 234 km from Cuiaba.

Marco lived in a place with his parents and

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four brothers, and also lived with some relatives, amongst them his uncles, grandparents and cousins who lived in the same place. We apprehend the local dynamics:

*[...] going up a small hill, lived the Marco's cousin and foster sister Helena, along with her children; above, lived her mother in law; and finally, the house of Marco Antonio's grandmother. That is, it is a land space in which live several family members [...] We were welcomed by his paternal uncle [...] we walk on a small trail to get to Marco's small farm. We saw by far too many people waiting for us [...] They greeted us, there were many people, cousins, uncles and friends [...] The backyard was huge with some trees, a feed depot, a sink with various dishes, a large wooden bench, a table, several plastic chairs. We saw a cocoa tree, several dogs, chicken, rooster, Helmeted Guineafowl, cows and oxen and, by far, we saw his pet, a trained bull, named "Foguinho". [...] Marco's house was made of clay, its roof was made of tablets covered with canvas [...] kitchen with refrigerator, wood stove and one shelf; two bedrooms, one where the parents slept and another where Marco Antonio and his brothers slept. The bathroom, outside the house, had only a hose for bathing. Besides the little house, there were one washing machine and a wooden bench. (NOC, 2011/05/21)*

In the vicinity of Marco's small farm existed other ranches, a grocery store and a Catholic church. 6 kilometers from the ranch of Marco's family was situated the Bom Jesus village, which also belongs to the City A. When we move to the village, we note that:

*The path, whose road is as bad as that one we came to Marco's house, is very beautiful because of diverse landscapes. At that time, a few cars passed by us and I was relieved because it would be possible to traffic there. Arriving at the village, I saw by far a stretch of asphalt and I thought it was strange. As we approached, we realized that it was covered by cobblestones in a stretch smaller than a hundred meters of the village main street. We stopped in front a house, right at the village entrance, where there were some people sitting in chairs placed on the street. (NOC 2011/05/21)*

In this tranquil village, there were some establishments that we visited, as the school where Marco and his brothers studied, a rural unit of the Family Health Strategy (URESF) and a grocery. We talked with the coordinator of the college who reported for us that the village has about 720 inhabitants, and he accompanied us to visit the village. This location was part of Marco's childhood and adolescence due to the proximity of where he lived, so there are many friends and acquaintances of his family there.

Other members of Marco's family resided in

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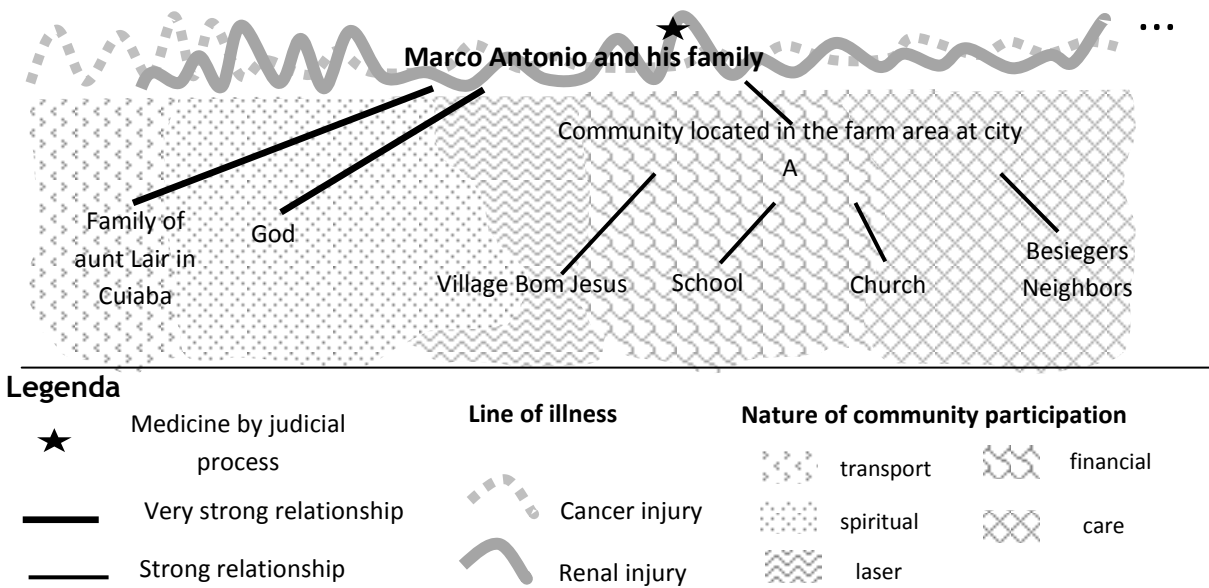
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the City B, 241 km from Cuiaba, where there were uncles, aunts and cousins. In Cuiaba also resided uncles and cousins of the young person, among them we highlight the family of his aunt Lair because of the importance it had in the Marco's illness experience, supporting him many times.

In the fieldwork we could realize, in some measure, the difficulties experienced by Marco and his family throughout the illness due the region's conditions, such as: long distance, precarious infrastructure of roads and lack of public transportation linking the community and the City A; URESF that attends the community only once a week; lack of public transport, as ambulances or vans, for driving sick people to health services in town A. Added to shortage of different types of the local population resources.

Despite the various difficulties experienced by the rural population, the health care required by Marco and his family were mobilized through intense tissue of caregiving networks for health, with emphasis on their "community". In this study we considered the Bom Jesus village, relatives residing in the place and the neighbors besiegers as his community.

A study showed that networks enable more help and support in the illness experience, in order to continuity of care.<sup>20</sup> In this article, the caregiving networks woven into Marco's experience of illness showed how the rural community was configured as sustainment network, represented in the diagram below (Figure 1).



Almeida KBB. Sustainment network in the illness experience of Marco Antonio, 2011.

Figure 1. Sustainment network in the illness experience of Marco Antonio.

Marco illness experience, located in a peculiar context of the rural life, demanded several family rearrangements helped by various actors (Figure 1). In the narratives, we could apprehend the meaning assigned by family members who lived with Marco to the community's activities in his illness experience:

*Then, is much friendship that people has for us [...] everyone who helped us gave a big support... so we know we have a very great friendship, and people... I think it's the best for us that people want, right?... because if health services were more or less equal the people is for us in the place that we live, health services would be so good! (Olavo)*

*And thank God everything went well, everyone helping, supporting, everyone*

*came to him, like you saw there, the way the ranch guys are... (Katia Adriana)*

We realize that Marco's family recognized itself and were recognized by the community as an important part of this. It leads us to think about the tie that emanates from the sense of belonging and that, being established within the networks, is configured in interactions between people, families, communities or organizations.<sup>21</sup> This tie is also manifested in received aid in the activities of rural daily life. This way of living in community seems to be a culturally constructed value that is reflected in the care dispensed to the neighbour, to meet their demands.<sup>22</sup>

The feeling of friendship and collaboration, perceived by the family of Marco Antonio, impelled us to refer to the community as a

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place of safety where the ties are coming from kinship, local proximity and especially the solidarity of neighborhoods, forming the basis of consistent relationships.<sup>23</sup> In this place of safety, things are shared and built in social interaction, such as the assignment of meaning to objects, words and other codes, knowledge and skills, all considered essence of socio-cultural life, in a reality in which people share and exchange experiences through interactions person/context/symbols/objects in a time period.<sup>24</sup>

Study, which aimed to discuss ties and social networks, pointed that the share "acts as reinforcer of ties, while it constitutes them, both spatially and temporally [...] Therefore, the term community is referred to a common sphere of conviviality".<sup>24:593</sup> In this sphere, social relations have a motion and the networks configuration can occur in many ways, been changing over time and space, giving them own conformations and dynamicity.<sup>25</sup>

There is a strong relationship between a person's health and the living conditions of his or her community; this one is "healthy" when provides "support, care and a sense of belonging of its members".<sup>26:72</sup> The rural community was conformed as a help network to Marco's illness experience because it offered "a condition of life that minimizes risks and accidents, an access to social and health service and a support network which are indispensable for the maintenance of this health".<sup>26:72</sup>

By the reports of Marco and his relatives, we saw the strong tie with the community where they lived and the intense movements of this to offer various subsidies to the family. The community ways of help to Marco's family enabled the arrangements and rearrangements for his care:

*[The phone] is in the neighbor up there [...] then, they called her and she came to bring the message... [Marco] was sick there [in Cuiaba] feeling ill, you know? They called her and she came to bring the message. I almost fainted seeing the boy [son of the neighbor] coming to bring the message... not good ... then I was feeling distress, you know? ... (Rita)*

*Back in his days we did not have a motorcycle here at home [...] the Doctor called, right? Then, we took a borrowed motorcycle for both of them [Marco and Olavo] go [to the city A] [...] and another time the neighbors carried them, right? And left them to sleep in City A to get the Municipal Health Office's car to go, at three*

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*am of the next day, to Cuiaba... it was so difficult ... (Rita)*

*They helped us with food too; they sent to us a lot of things. (Olavo)*

*And when he went over there with him [to treat cancer in Cuiaba] people here [in the community] met and prayed the rosary, you know? Nine days of prayer, they did a novena, nine days in the church, every day, for him to be healed... [...] asking God, right? (Rita)*

Marco's parents had no means of transportation, such as a motorcycle, to make the route from Marco's home to the City A - 30 km of unpaved road with numerous deformations and ripples; it's a slippery road when it rains. In town A, Marco and Olavo slept at friends' house, then in the next morning, they went in search of professional care in Rondonópolis, 210 km from Cuiaba, or in Cuiaba, in a car offered by the *Municipal Health Office* of that city.

The mobilization of the community members potentialized the care of Marco's family because it offered them news about the boy in his admissions, aid with food, spiritual support, and allowed their movements to search for care (Figure 1) in the City A, Cuiaba and Rondonópolis. Study<sup>22</sup>, which described the care practices to the person with cancer in the context of rural households, found that such practices by families were strongly reinforced by the social network, constituted of relatives, friends and neighbors.

The rural context showed us in this study the importance of weaving sustenance networks by the diseased person and his family, because when rural populations are compared to urban ones, we find that they "are disadvantaged in health care and in deficit with integral practices, since there is difficulties to access and poor quality of received care".<sup>14:203</sup>

At certain times, Olavo and Marco encountered limitations in the availability of the transportation offered by the Municipal Health Office of the City A, made at the time by ambulance and later by van. Then, Olavo had his scarce financial resources and bank loans to continue their movement in search of care. But each new moment in the Marco's illness experience, other health needs arose, as diagnostic exams, consultations, purchase of medicines, among other things. According to the family's progressive spending situation, people in the community mobilized to help it financially, each one in his or her way, alone or together:

*Our neighbor, right [...] I was in Cuiaba [...] I called my comrades because I needed*

*some money, so they raise money and sent it to me. (Olavo)*

*Then, at that time [...] he signed the check, only signed the check and said, "Look, I'm gonna tell you just one thing, if you rely on this you only call me, you can use the check"... he just signed the check, didn't put any word on it, just signed his name. So I got his check for thirty days huh. (Olavo)*

*At the beginning of my treatment, when people there encourages me a lot, it was my aunt and them all that told... that they would give me an aid, but then my father said, "Oh, but... if you people wanna do this, you people are who want to do! I'm not asking for anything!" They said they were going to do an auction... charity auction. So they did, it was in my community there in... in the church, because people there also encouraged us. (Marco)*

*Then, another auction was done, it was... was the community, that one nearby the ranch, Bom Jesus village. It was the school principal who... told me they wanted to do an auction for me too [...] so, there were two auctions that they did for me. But it was like this, it was they... they got together and said they would do... (Marco)*

*[The auctions helped] with the tickets, with many exams that I had to do by my own expense, right? Magnetic resonance I did a lot by my own expense... because it's always like this... [using the SUS]: "uh, just in four months" Then the Doctor said, "Look, we have this exam here [in the hospital], I need it now! It's urgent", then I did it by my own expense... (Marco)*

*This auction was a blessing, my child; we had available of it... (Lair)*

We realize that although many paths have been trodden and many care achieved by the family, there were resources and informations not obtained in these movements, which required the work of mediators. Participants of caregiving networks, such mediators provide greater connectivity of the person and his family to networks, linking them to new points and/or other networks through positive connections that provide them with better levels to that care happen. Thus, they act by enhancing family's care potential that can achieve better health care,<sup>20</sup> such as in this study.

The action of mediators enables to effective, to some extent, what the family has as a unmet need due the tensions generated by the scarcity of resources.<sup>20</sup> As we approach the notion of mediation we note that the rural community, part of its sustainment network for the care, mediated numerous cares and was able to affect in a very positive way the path of Marco. So, the community intervened

in the family needs situations of various natures, modifying them.

In the ways of offering support to Marco's family we could not detach someone in the community who could be called mediator. In the narratives we realized a synergy of efforts potentializers of the family care, which occurred as each person of the community was mobilized to act individually or collectively, as in the case of the auctions. These were performed with gifts and animals donated by the population. For example, animals such as chickens were auctioned off even if many people breed them in their lands.

Voluntary action is complex and full of possible logical, because in addition to refer to the reciprocity between people, it extends to the various interests that permeate the notions of participation, personal fulfillment and/or searching for results for certain social problems.<sup>27</sup> The actions of the study participants result of a mutual recognition as members of the community insofar as they value and accept themselves as well as they interact in their midst. This recognition, exemplified in the narrative abovementioned, is one of the bases to the confidence sedimentation, which, in turn, is the ground for social networks even in a greater or lesser extent and should be present in large amplitude.<sup>23</sup>

The notion of networks allows us to analyze this lively scene, whose characters interact constantly in motions of strengthening and loosening of ties, exchanges and articulation of new elements, insofar as the family takes care of the ill person, it is cared for and allows being cared.<sup>20</sup>

These moves reminds us of the gift, a reciprocity system in which exchanges tend to be uncertain, indeterminate and asymmetrical; it is open to diversity, to freedom of people undo alliances according to their own motivations and it is linked with solidarity and democracy.<sup>28</sup> Thus, we can say that the flow of the gift among members of a community occurs freely and, being gift, exchanges always occur in a different logic to the market logic, which is symmetrical and rigid. The actions of the members of Marco's community occurred spontaneously, offering something that would hardly be reciprocated in the same material value. But in the gift's logic, to some extent, there is always retribution because of the symbolic value attributed by the community to the act of helping their sick member.

By mobilizing relationships, resources and meanings the support network allows to

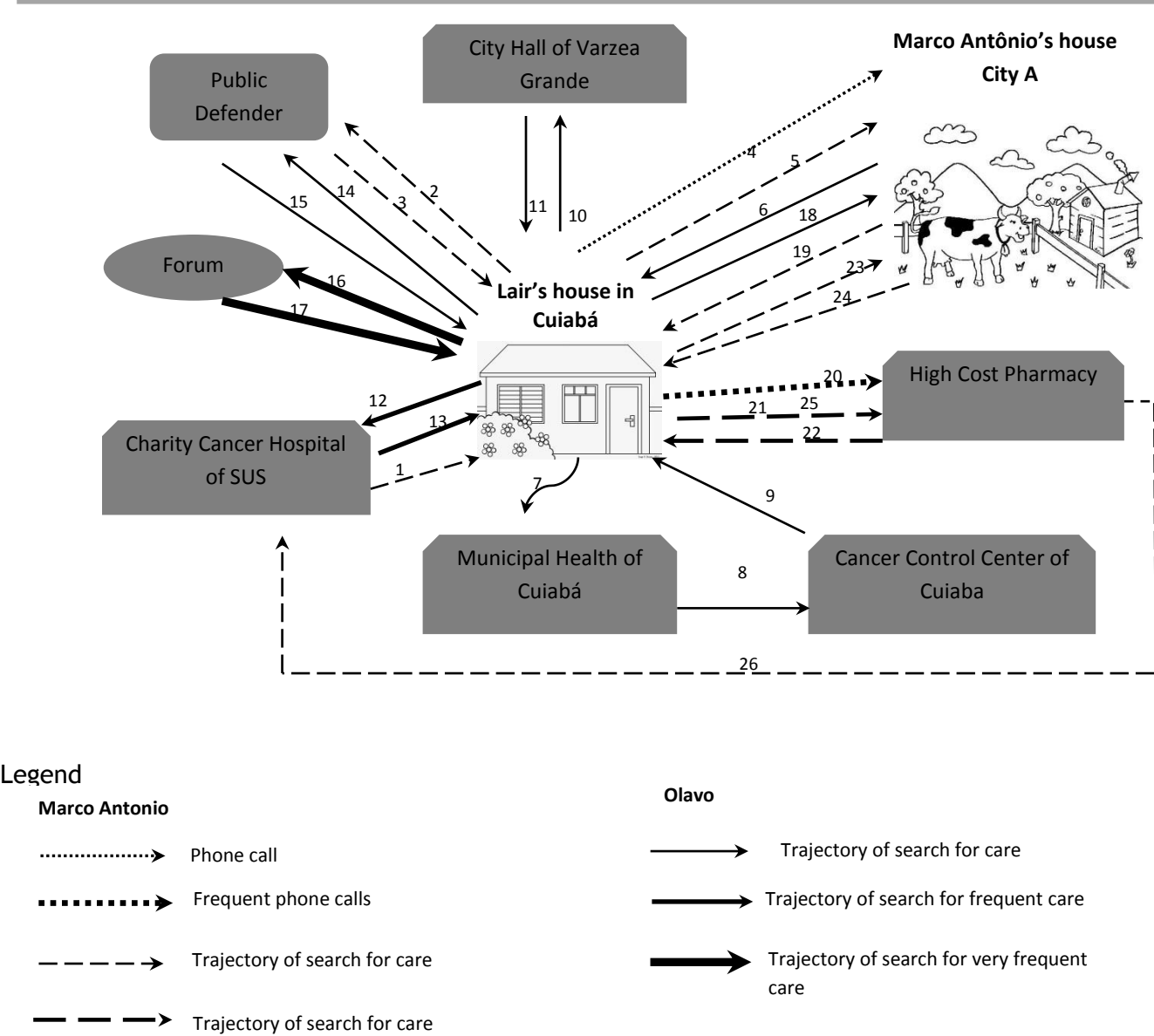
weave connections between different worlds and knowledge, transcending specific institutional domains and linking diverse arenas.<sup>21</sup> So we can also assign to the Marco Antonio’s community the potencialization of the search movements made by his family to obtain, by legal proceedings, the drug Rituximab wich is used in cancer treatment and was not provided by the SUS-MT at the time of its prescription.

[The pediatric oncology medical] said to me that I could get the drug, you know [...] but I had to fight to get it because it was difficult. (Olavo)

Olavo and Marco started the search trajectory for that drug, which resulted in several journeys undertaken by them, so they

could legally demand that right and be represented by a public defender of Cuiabá. This trajectory was represented in the drawing below (Figure 2) which summarized the numerous searches undertaken by Marco and his father Olavo starting from the prescription of Rituximab (arrow 1) due the loss of response to conventional lymphoma chemotherapy offered by the SUS-MT:

*I needed all the documents to take photocopy of the documents, then I took them to start the legal proceedings [...] they requested papers of everywhere. (Olavo)*



Almeida KBB. Search trajectory to obtain a medicine by legal proceedings in the Marco’s illness experience; 2011.

**Figure 2.** Search trajectory to obtain a medicine by legal proceedings in the Marco’s illness experience.

To gather the required documents for the legal proceedings by the public defender it was necessary the Marco’s (arrows 2-4) and Olavo’s (arrows 6-15) mobilization; at that time, Marco was 18 years old. After gathering

the documents and take them to the public defender (arrows 14 and 15), Olavo was guided in this institution to attend the forum to monitor the injunction processing that would anticipate the medication supply. So



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every working days for about a month, Olavo attended the forum (arrows 16 and 17), when it finally granted the injunction.

Despite the limited nature of the judicial response to health demands, this also allows some conditions for the care once not attainable.<sup>20</sup> The high cost of the medicine claimed by Marco in the legal proceedings, at that time costing more than thirty thousand Brazilian reais per application, was an unattainable value even through the community mobilization, according to the family narrative.

Study<sup>29</sup> showed that in addition to the high value of the drug and given the refusal of its access by SUS, the waiting time for the supply imposed by the health services often determines that the ill person plead it in court. This would allow, via injunction, getting the medicine on an emergency basis. However, in the case of Marco, granting the injunction was postponed for about a month and even after its grant, it took five months to Marco get it. Therefore, judicial intervention not effected immediately his right to health, understood in this study as the right of access to the needed medicine. Instead:

[...] It was when we fought a long time to get it, right?... but they sent, after forty-eight hours they sent the answer that they were not going to provide this remedy for him because in São Paulo there wasn't it anymore, it would have to come from abroad [...](Olavo)

Given the insidious nature of the tumor and the need for urgent cancer treatment, Marco continued to seek information about the drug provision, now contacting the high cost pharmacy (FAC) of Cuiaba (arrows 21 and 22), where, at the time, medicines granted by injunction were delivered to ill people.

[...] I always thought I should go [to the FAC], I went there and we talked, because by phone... nothing works... (Marco)

His father returned to his business in the small farm (arrow 18) and, after a certain period, Marco also returned to his home, but had to go to Cuiaba from time to time. Upon provision of the drug by the FAC (arrow 25), approximately five months after the beginning of the search, Marco was in Cuiaba and before getting the drug, it was necessary to seek a few documents:

Then they called, it had already be authorized [...] the remedy, then he went there, right? Took some docs that were lacking [...] to send to the FAC to provide the drug. (Olavo)

We realized an active and intense movement of Marco and his father to obtain the cancer drug, considered by them a right

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since the medical orientation of its need for health care. We know that the treatment with the drug did not mean the remission of Marco's tumor, requiring radiotherapy sessions later, performed by SUS, and also requiring chemotherapy. However, by the hope of healing/tumor remission, Marco's family made use of all its possible search resources for realization of the denied right. And, among these resources, we highlight the community mediation/susteinment.

FINAL NOTES

The community where Marco lived acted as a sustainer mediator in his illness experience due to certain characteristics: a) its actions were guided by the perception and awareness of its members about Marco and his family needs; b) acted potentializing the family caregiving in various areas of their experience, not limiting its performance to the health needs; c) when it was mobilized, always produced response that sometimes exceeded the family's expectations; d) it provided access, indirectly, to the formal institutions to meet the Marco's health needs, providing diverse subsidies for such access.

The judiciary, in turn, in its limited action, acted without taking into view the subject of needs but the zeal for enforcing legal provisions that deal with the right to medical treatment. The answer to this right was made with lengthy front of the urgency of the case; therefore, it seems not to mediate, since its act did not crave to modify, to some extent, the various needs situations of Marco Antonio's family.

By other hand, the community where Marco and his family lived made possible the meeting of needs of different natures and implemented actions that sustained them in the illness experience. Thus, the sustainment mediation, woven by the community within the cargining networks for health, extends the paradigm of mediation.

Therefore, understanding the sustainment mediation of the rural community, from the perspective of Marco Antonio illness experience, enabled us to broaden our thinking about health in order to tension the professional practices to be readjusted and to reflect on those that can be shared and reinforced each other by health professionals and community, basing actions befitting with the different realities, such as the rural one.

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