MEDIATION IN CARE NETWORKING FOR PATIENTS AND FAMILIES EXPERIENCING COLORECTAL CANCER[1]

Leandro Felipe Mufato[2], Laura Filomena Santos de Araújo[3], Roseney Bellato[4], Marly Akemi Shiroma Nepomuceno[5]

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[2] M.Sc. in Nursing. CNPq grantee. Faculty, Universitary Center of Várzea Grande. Mato Grosso, Brazil. E-mail: leandro.mufato@yahoo.com.br

[3] Ph.D. in Nursing. Faculty at FAEN/UFMT. Mato Grosso, Brazil. E-mail: laurafil1@yahoo.com.br

[4] Ph.D. in Nursing. Faculty at FAEN/UFMT. Mato Grosso, Brasil. E-mail: roseney_bellato@yahoo.com.br

[5] M.Sc. in Nursing. Nurse, Mato Grosso State Health Secretary. Mato Grosso, Brazil. E-mail: marlynepo1@yahoo.com.br

ABSTRACT: The objective was to analyze how mediation affects the experience of seeking care in case of illness due to the chronic condition caused by colorectal cancer. A comprehensive research approach was used through the Focal Life History, put in practice through an in-depth interview. The study subjects were a person and his family, who experienced illness due to this chronic condition, as well people from their healthcare network, considered as mediators, totaling six interviewed subjects. The mediators acted by facilitating the ill person's access to health assets and resources. The logic these mediators imprinted in the search for care differs from the logic of public health services, but they influence each other through the bonds of friendship that permeate mediators and public servants. Mediation was observed as something positive in the user's perspective, due to the dynamics it guarantees for care search networks.

DESCRIPTORS: Social networking. Family. Social support. Family relations. Health care.

MEDIAÇÃO NAS REDES PARA O CUIDADO DE PESSOA E FAMÍLIA QUE VIVENCIA O CÂNCER COLORRETAL

RESUMO: Objetivou-se compreender como a mediação afeta a experiência de busca por cuidado no adoecimento pela condição crônica decorrente do câncer colorretal. Utilizou-se a abordagem compreensiva em pesquisa por meio da História de Vida Focal, operacionalizada pela entrevista em profundidade. Os sujeitos do estudo foram uma pessoa e sua família que vivenciavam o adoecimento por essa condição crônica, bem como pessoas de sua rede para o cuidado à saúde, tidas por nós como mediadores, totalizando seis sujeitos entrevistados. Os mediadores atuaram facilitando o acesso da pessoa adoecida a bens e recursos em saúde. A lógica que esses mediadores imprimiram na busca por cuidado difere da lógica dos serviços públicos de saúde, mas elas se influenciam mutuamente por meio dos laços de amizade que permeiam mediadores e servidores públicos. Observamos a mediação como algo positivo na perspectiva do usuário, pela dinamicidade que ela garante às redes de busca por cuidado.

DESCRITORES: Rede social. Família. Apoio social. Relações familiares. Atenção à saúde.

MEDIACIÓN EN REDES PARA EL CUIDADO DE PERSONA Y FAMILIA QUE EXPERIENCIA EL CANCER

RESUMEN: El objetivo era examinar cómo la mediación afecta la experiencia del búsqueda de atención en condiciones de enfermedad crónica causada por cáncer colorrectal. Se utilizó un enfoque integral de la investigación a través de la Historia de Vida Focal operada por Entrevista en Profundidad. Los sujetos del estudio eran una persona y su familia experimentaron esta enfermedad crónica, así como las personas en su rede para el cuidado a la salud, tomadas por nosotros como mediadores, seis entrevistados. Mediadores actuaron facilitando el acceso a los bienes y recurson en salud para la persona enferma. La lógica que estos mediadores se diferencia de la lógica de la salud pública, sino que se influyen mutuamente a través de los lazos de amistad que impregnan los mediadores y los funcionarios públicos. Vemos la mediación como algo positivo en la perspectiva del por asegurar una mayor dinámica de las redes de búsqueda de atención.

DESCRIPTORES: Red social. Familia. Apoyo social. Relaciones familiares. Atencion a la salud.

INTRODUCTION

Healthcare networks consist of individuals and families who experience illness and are a source of different care forms, which are as important, if not more so, in view of the social vulnerabilities these families are in. Social relationship networks, marked by mutual recognition and help, based on family and neighborhood bonds, considered as relations in which goods and services are exchanged on a non-market base, have been an important source of wellbeing.[1-3]

We believe that these social relationship networks can be capable of supporting and sustaining health care in the disease experience. They are woven in illness experiences, with emphasis on chronic conditions, in which the families start to constitute trajectories of care search, production and management; and it is through the methodological approach of the Therapeutic Itinerary (TI) that these trajectories can be understood and analyzed, revealing "how the illness process and the search for care took place, how the patient and family interpreted the experience, the meaning of the event in their lives, as the event experience fits into the framework of the sociocultural contexts they share in their socialization process, as well as the life prospects they outline".[4:188]

In families' care and disease experiences, the relation between their health needs and the professional care they are offered can be evidenced. Particularly in the disease experience due to chronic conditions, the difficulties people face to get access to and solve their needs in public health services are evidenced.

Also, people participate more or less effectively in their trajectories in search of care, mitigating their difficulties. Present in the health care networks, they have mediated situations in which access to care is hampered by difficulties to organize the services offered in the Unified Health System (SUS) and by professional practices that lack effectiveness and problem-solving ability. This mediation positively affects the care search trajectories, granting patients and their families better benchmarks for care practice, enhancing its effectiveness.[5]

In these care search trajectories, mediation permits more organic attendance to patients and families' health needs, establishing connections with other people and institutions that can be of help in the search for care. This connectivity granted by mediation, by linking patients and families' existing network with new points and/or other networks, allows them to follow new courses in the search for care, which had not been considered earlier and are sometimes more effective for care purposes.[5]

In this approach of the mediation phenomenon, the dynamics of daily life and the small creative acts experienced there have been taken into account. Efforts are made not to think of "social life as it should be, or as one would like it to be",[6:114] but as it is. Therefore, without attempting to say "what mediation is", but considering its movements, with different possibilities of expression in people's networks, as well as their consequences in the disease experiences.

The dynamic movement it promotes in health care networks illustrates the importance of studying the theme. As a theoretical construct, it is a notion capable of broadening the concept of participation and social movement, which remains very formalized.[7] What is more, studying medication permits theoretical discussions about the lattice movements that take place in families' daily search for care, in view of the impasses in the implementation of public health policies, including insufficient funding, slow and low-quality growth of primary care, regionalization and integration between cities and almost virtual services, and practices with lower-than-expected effectiveness and efficiency levels.[8]

The notion of mediation enriches our understanding about the disease experience by addressing the movements in support and sustentation networks for care in which, one might say, social support is constructed in the concreteness of daily life, that is, different resources are achieved which the subjects receive through social relations, "ranging from the most intimate relationships with friends and close relatives to relationship of greater social density, with groups and social networks".[9:5] The aim in this study was to understand mediation in the health care networks woven in the disease experience due to a chronic condition deriving from colorectal cancer, involving a patient and his family in the context of the SUS in a Brazilian state.

METHOD

The qualitative research approach, which "applies to the study of history, of relations, of representations, of beliefs, of perceptions and opinions, products of humans' interpretations about how they live, build their artifacts and themselves, how they feel and think",[10:57] showed to be a powerful strategy to investigate the prob-

lem addressed. The methodological approach of the Focal Life History (FLH) revealed the logic of the patient in search of care, as they possess the "history of their disease process and of the search for care from health services".[11:852] This approach permitting showing the routes and the production of meaning along the trajectories of ill people and their families, as well as addressing the logic that directed their trajectories.

In the search to understand these people's experience, we used the In-Depth Interview (IDI) as an instrument. This modality consists of an open conversation in which the person is "invited to freely talk about a theme and the researcher's questions, when asked, are aimed at elaborating the reflections in further depth".[10:262] It can also be characterized as an open but intentional conversation. Thus, people can be valued in their disease experience, which presupposes the need to understand their logic in this experience and the way they seek care, that is, it privileges their narratives, which the researcher should try and understand.[11-12]

The experiences narrated were audio-recorded and later transcribed in a field diary. The same diary also included the researchers' observations during the meetings when the IDI were held,[12] and expressions of perceptions, anguish and inquiries. The richer the notes, the more this instrument helped to describe and understand the research problem.[13] Therefore, it was systematically used since the first entry into the field until the end of the research.

The selection of the study subjects followed the same criteria as the matrix research project: being an SUS user; going through the disease experience caused by a chronic condition; having accessed a legal entity between April 31st 2008 and May 1st 2009; and living in the State of Mato Grosso. An active search at the specialized health service identified the patient André,* who was suffering from colorectal cancer, and his relatives. In addition, one person participated in the study, who served as a mediator in his health care networks, totaling six interviewees.

Seven interview meetings took place with the study subjects, which took about two hours each: three meetings with André and his sister Clara, at a health institution in Cuiabá, where he received chemotherapy; two meetings with André and relatives at his home, in the interior of the State, including his sister Clara, his brother Emanuel, his wife Gabi and his children Tobias and Narcisa; and an exclusive meeting with André's wife Gabi. A final meeting was held with Alexandre, a mediator in André's search for care, at his place of work.

The fieldwork, including the meetings, took place between April and June 2010. Data analysis started together with the fieldwork and, thus, pertinent elaborations were gradually constructed between the different interview meetings. On the same occasion, the themes for discussion were selected.

The rereading of the narratives revealed the units of meaning that emerged,[10] expressed by narratives. Through this reading, two main axes of meaning were observed: the first about mediation in healthcare networks woven in a disease experience; and a second about the repercussion of mediation in the family experience of a chronic condition due to cancer. On these two thematic axes, the units of meaning were highlighted and grouped in two categories, which were: (a) I do not think that, because there is a public hospital here, you need to get care here – in which mediation acts in a characteristic movement, dialoging and diverging from the logic established by public health services; and (b) I got there and she was ready. I don't occupy paper, I don't occupy any signature, I don't occupy anything – in which the consequences of the mediation on the care search trajectory of André and his family were observed, characterized by the facilities the mediations produced. Through the reading of each category, the meanings that emerged from the data could be presented and discussed.

In this study, the methodological and ethical criteria established and approved by the Ethics Committee at Hospital Universitário Júlio Müller (CEP/HUJM) were followed, under protocol 671/CEP-HUJM/09, in compliance with National Health Council/Ministry of Health Resolution 196/69.

RESULTS AND ANALYSIS

A summarized outline of André's history is presented, which is important to understand the implications the chronic condition entailed for him and his family, and how people in his social relationship network affected his care search tra-

* Fictitious names were used to guarantee the anonymity of the participants and institutions.

jectory. Next, we specifically discuss the actions of Humberto, Alexandre, Saulo and Emanuel, people considered as mediators in his care search trajectory, which demand a more detailed analysis in order to reach the study objective.

Getting to know André and his search for care

André, a 49-year-old man, went through the experience of a chronic condition caused by colorectal cancer. His disease started in 2004, when his intestinal function changed as he started to perceive blood in his feces. First, he treated the problem as a hemorrhoid, went to the pharmacist's and bought medicines. As the changes did not get better, he visited the public health service and the physician told him his problems were caused by worms. André, a bricklayer and municipal servant in an interior city in Mato Grosso, talks about the problem to this friend Humberto, a physician and mayor of the city, who offers him a consult to investigate his problem. Then, André discovers that the changes that recently appeared in his body, and which he considered as a hemorrhoid, could actually be due to cancer; a suspicion raised by Humberto. In view of this suspicion and with the help of Alexandre, André is rapidly forwarded to a specialized cancer hospital in the State of São Paulo. Alexandre, an influential person in the city, holds annual actions for the hospital and mentions that he guarantees financial resources of about 170,000 reais. Therefore, when he forwards people to that institution, he is able to get care more rapidly. André's wife, Gabi, wanted him to start his treatment in Cuiabá, given the closer location, but André's family disagreed. The ticket to get treatment in São Paulo was guaranteed by his friend the mayor, while Alexandre guaranteed the diagnostic consultation at the specialized hospital. André returned a second time, when the diagnosis was confirmed and the colorectal resection surgery and installation of the colostomy bag were suggested. Upon his third trip, the surgery took place. On that occasion, he was accompanied by his brother Emanuel. Gabi had to request a leave of absence from her job to accompany her husband when Emanuel could no longer accompany him. André returned to the specialized hospital a fourth time for radiotherapy and chemotherapy, where he stayed for about 75 days, accompanied by his son Tobias, who was 18 years old at that time. For more than three years, he returned every 21 days for chemotherapy, travelling alone as his relatives were working. André started to experience difficulties to pay for the tickets and applied for them in the municipal court once, but Humberto, who intervened in the situation, once again guaranteed the tickets through the municipal Health Secretary. He took distance from the case, however, when his mandate as mayor ended; in addition, André and his family faced difficulties to travel to São Paulo. Therefore, André asked to be transferred to Cuiabá, three years after his first trip to São Paulo. For another three years, he continued his treatment at a public referral service for cancer in Cuiabá and, as the trip was shorter, his sister Clara accompanied him. During this period, he had to go to court to get the chemotherapy drug, prescribed by the responsible physician, who oriented him in that sense. André's brother Emanual was responsible for this search, first through the ombudsman of the Unified Health System in Cuiabá, and later through the municipal forum, as the ombudsman himself informed him that he would only get the medication through the court. In court, Emanuel affirms that he was able to speed up the trial because he "had contacts". Thus, after getting this medication through the judicial system, André received six months of treatment; as he did not improve as expected, however, his physician prescribed a new drug, which he received from the institution where he received treatment. André got his retirement thanks to Saulo, who used to be the municipal lawyer when Humberto was the mayor; he guaranteed the retirement André had been applying for during one year.

I do not think that, because there is a public hospital here, you need to get care here

Alexandre's mediation granted André access and agile care at a specialized cancer treatment service in another state, following a logic that differs from the public power's established referral and counter-referral flows in the SUS. Thus, through a different logic, the mediator diverges from the logic of health service access, not only inside the State, but also from the possibility to regulate service access between States. This mediated course conflicts with the regulated trajectory and, by understanding these different logics, the mediator avoids turning to the local public power to get help for the people who come for help. André, one of these people, ends up being unable to get access to treatment within a logic that differs from that established through the mediation. Alexandre tells that [...] *some people are able to travel on their own resources. Others are not able and sometimes ask us if*

we can help. I don't ask the public power, no, because [...]. *I don't think that, because there is a public hospital here, you need to get care here. People make the choice to go there, then it's a matter of public policy, not mine. So I don't ask the mayor.*

In his statement, Alexandre shows the meanings of public services, including access, difficulties to get support to forward people rapidly for treatment at the specialized hospital, as this forwarding does not follow the logic established in the health services in his city, also indicating that he already knows the managers and mayor's answer to this request, and disagreeing from the opinion that, if there is a public hospital in the city, then everyone should be attended there. Alexandre always looks for resources in his own social relationship networks, showing that, for mediation to take place, articulation among countless people is needed. This evidences the mediator's power in his ability to mobilize people and resources in networks, in accordance with other authors.[5,7,14]

The support the mediator receives from his social relationship network is important to enable him to influence the care search trajectories of the people who contact him, making him a participant in the healthcare networks of each ill person. This shows that the mediator does not act alone, but first needs the recognition of the ill person, the institution he serves as a mediator for, as well as the support of the people who share the idea that being mediated to the specialized hospital is better than following the regulatory trajectory of the local SUS. Thus, although the figure of the mediator stands out by constructing the recognition, mediation only takes place through the mediator's ability for articulation. Mediation always takes place collectively, in a network, guaranteeing its power. [...] *some people help to gain benefits, so they're no good for us. It's no good for us. It's no good for our midst* [...]. *If the person is poor and really in need, he comes here, we forward him and see what he needs, I call and get it, in half an hour I get the go-and-return ticket and there's housing there and the person does not spend anything. A lot easier than administering a third party's money, because there's evil everywhere, right?* (Alexandre).

Assets circulate based on the acknowledgement of the same value among the stakeholders, which in this case is related to a notion of solidarity.[15] Alexandre articulates with people who associate with this life values and who share his notion of solidary with the ill, and is selective as to the people who help him in this mediation, by saying that *if they help because they expect benefits for themselves it's no good*. Thus, Alexandre rejects the utilitarian interest present in the social context, which impedes the circulation of assets, and values exchanges based on social bonds of friendship and family.

It would be mistaken to believe that the gift can only circulate in primary social relations, of friendship and family, even at the heart of public services, in social relations that are considered secondary; gift exchanges act vigorously.[15] The mediators who act on André's trajectory seem to mobilize, for their own benefit and that of the people who contact them, the primary networks based on the law of gifts.[15] This would mean saying that the mediator is able to construct flows to get access to cancer treatment through relationships of friendship, acknowledging the services that deliver this care, in this case the specialized hospital in the interior of São Paulo State. In that sense, this service seems to act within a management logic based on solidarity, like the mediator's actions, as this would create mutual recognition among the mediator, André and the institution.

Alexandre's role as a mediator in his city for ten years reveals that his actions seem to gain different forms with regard to and influenced by the political context. André's case shows that articulation takes place between the mediator and the local public power, and that his mediation is affected by who is in charge. The narratives show that André got to Alexandre through the former mayor. Alexandre talks about him: *he's a private friend! You see? Our friendship goes back a long time. He was the one who diagnosed my wife's cancer. It's… when I need forwarding, which is an SUS document, who signs it is Humberto. I simply call him, ask, send him the documents and he does the forwarding. Because you need the paperwork* [...] *until today. A wonderful person. He's got a giant heart.*

Mediation shows a movement influenced by the local political context, taking form and being involved in the bonds of friendship woven among the stakeholders, as the mediator Alexandre shows, affirming that he does not ask help from the local public power, but that he received a lot of support when his friend Humberto was the mayor. This reveals an explicit game between the friendship bonds, interfering in a social context where impersonality would predominate, showing that bonds constituted in primary social relations are stronger, independently of the social position of the people involved.[15]

Similarly, while Humberto is in public office, he uses the social contact possibilities and the power it grants him to put his help to André and Alexandre in practice, according to André: *when I didn't meet the mayor it wasn't easy. When I met him, I talked, it was immediately, right? When I didn't... there was once really... the last times I tried to talk to him, I couldn't find him. I went there, talked to his secretary, she told me he was in a meeting* [...] *when I got to the secretariat his car was chirping. He said: 'hey brother! How are you doing?'. Well! I'm here, fighting* [...]. *'No, calm down. You can leave. You can come and pick up your ticket here'. So, thanks God, he was like a father, right*.

The mediator's ability to get resources and access to health, based on friendship bonds, shows his ability to move beyond the bureaucratic and slow logic that permeates public health and social services. In André's history, his mediators acted to facilitate his access to different resources and health services, including access to the specialized hospital, retirement and travels to get treatment, acting through different social bonds and combining efforts to enhance the power of care delivery for ill people and their families.

The mediators can be considered "key persons", as they launch new flows of exchanges in the networks woven by the families who experience illness, granting them access to health services; and these mediators could be relatives, community members or even health professionals themselves.[7]

André's family experienced the mediators' action modes as agile to guarantee this access, sometimes too fast for them to consider other treatment possibilities more cautiously, such as the treatment local public health services offer on a regular base. Next, the discussion will be focused on the difficulties the mediation mitigates.

I got there and she was ready. I don't occupy paper, I don't occupy any signature, I don't occupy anything

To get answers to his different health needs, André can count on the mediators' rapid intervention, avoiding too long waiting times to get care, such as medication treatment against cancer, retirement, tickets, transportation and agile access to institutions, including court, as means to sustain his care. These are some elements through which the mediators gain André's acknowledgement, while queues symbolize the delay in public care, considered as the main obstacles to get access to the services offered there.[16]

Due to countless conflicts with the social security service and delays to obtain a disability retirement, André turned to Saulo for help, the municipal lawyer, and who comes forward as his friend, saying that he could turn to him whenever he needed, finally getting his retirement: *it took a year and a bit. They started to twist me for a while* [...]. *That's when I talked to Doctor Saulo* [...]. *He said: 'no André, your problem is retirement, you don't... you can't work any more'. Then they started to twist me, twist me, twist me to get retired, right? And when I went there one day, I talked to the chairman* [...]. *I said: but, so, I want my retirement. Then, I stepped by Doctor Saulo. Doctor Saulo said: 'no. You're not going to work anymore, you're going to retire'. Then, he pulled that chair 'cause he's a really strong man, you know? Afraid that he was going to break the whole thing and he got the phone and: 'what's going on with André's retirement? I told you a year ago that he was about to retire and he still hasn't!'. 'Ah! no Doctor Saulo, you can be sure that we'll solve it!'. Then, the next day they already… called for me to go there, I got there and it was ready. I don't occupy paper, I don't occupy any signature, I don't occupy anything* (André).

The care search trajectories are marked by the arduous pilgrimage of who seeks public health services, partially caused by the low problem-solving ability and integrality of the professional practices offered.[4,17] André's experience reveals a service that, according to him, went "twisting, twisting, twisting…", which, in his words, transmits the feeling of delay, of something whose solution takes a long time, or even that never gets solved. In this case, the mediator took a stand in between the patient and the service, so as to gain a solution to the problem from the second. According to André, the mediator acted as a "friend", granting him a distinguished treatment among the many people who turned to him; towards the institution, the mediator acted as a "lawyer", solving André's problem, by questioning the service about the delay.

This mediation demonstrates that health and in this care social service institutions could give a distinguished and more effective treatment. The success of the case depended on a mediator's action though, acknowledged as such by the institution, as that is what grants him the power to move around in this social context. What matters for now is to reveal the benefit of this intervention for André, who had been trying to get his retirement for a year.

These findings seem to support the notion that social relationship networks of mutual recognition and help, based on family and neighborhood bonds, considered as relations in which assets and services are exchanged on a non-market based, have been considered as a compensation for the absence of the State's production of social well-being,[1,3] in which people, feeling the need to find a solution, turn to the instruments of "informal" relationships.[15] The case of André's retirement seems to be emblematic of this compensation. That is, the mediators' actions, who seek agile help for ill persons in view of the public power's delay to solve their problems, can be an expression of a new type of social awareness, stimulated by the solidarity that takes form through concrete daily acts, considered as "new autonomies".[18-19]

André and his family experienced several difficulties, at other times along his trajectory, like getting access to chemotherapy for example. In this case, demanding the judicial route, Emanuel acted as a mediator: *complete negligence by others: 'ah, I don't know', 'haven't seen it', 'can't find it', 'it's not here'. You provide the protocol numbers, provide the data, everything, all of that... right? 'Ah no. It's not!'. Then, two or three days go by, a week, you call again: 'no, it's here, but it hasn't been taken yet* [...] *it has to go through the patient's district court', that stuff. So, I went back, got there, took it, came, got the attorney's protocol, talked to the judge, until, let's say, the staff from the register office there… at the courthouse, they're our friends, everyone helps to get things formalized more quickly, right? That contributed. But, not by itself, there's not that evolution according to the disease itself, right? The case* (Emanuel).

It is highlighted that Emanuel presents the numerous difficulties faced to get, in this case, a chemotherapeutic drug for André, through the judicial system; these difficulties, according to him, would be even bigger if André had to experience them himself, without his intervention as a mediator. As evidenced, in this case, the mediator took the forefront in the search for care resources and felt the difficulties due to the negligent attendance, loaded with empty positions. This also illustrates the mediator's articulation with a network of people who helped, guaranteeing some agility in getting an answer. After forwarding the chemotherapeutic drug request to the municipal court, this demand went forward quicker, thanks to the mediator's friends at that place. Also, regarding Emanuel's articulation to solve André's needs: *it's always a lot of friendship, right? He knows a lot of people. From there, he talks to them here, arranges for the car. I know that it was ready the next day and we went* (Clara).

Emanuel manages to arrange for transportation to receive the chemotherapy. According to Clara, he has many friends, which enhanced the dynamics of the healthcare networks, so as to speed up care for André. In the narratives of André and his family, the facilities resulting from the mediators' actions are presented as intrinsically related with the mediators' agility and speed, showing that they are acknowledged as people who can mitigate the suffering in the disease experience, not only because they get the resources needed to solve the patients' needs, but also because of how they get them, very agile and rapidly when compared to the health services' institutional procedures. [...] *it was like, a drive I got real fast, he didn't even have time to think* [...]. *It was fast, like, the drive, 'cause as soon as I suspect it, I send it* (Clara); *I went to work,* [...] *he didn't let me work anymore, he said: 'no, you're gonna leave and arrange your stuff because you're going to Barretos tomorrow or the day after tomorrow'* [...]. *He called there and I went with everything arranged for my problem* [...]. *It took like three, four, two days, it was fast* (André); *When I went there the first time, the doctor said… the mayor told me: 'André, I've already arranged for this, that, your tickets are ready… there's the go and return ticket. The return ticket is open, if more than thirty days go by, more than thirty days, you pass by the bus station and ask them to change it for you'* (André).

Because of the help achieved so quickly, André gets support from the mediators in his arduous search for care in health services with low problem-solving abilities,[4] compensating for the public power's actions filled with bottlenecks and delays.[3] The action of social relationship networks in contexts of public fragility to protect people is observed as compensatory.

In the health care networks people and their families construct to get sustention and support in the illness experience, to a certain extent, the mediators' actions show one of the ways how the "crisis of the provider State, provoked by the globalization process, dramatically affects the relation between popular classes and health services in Brazil".[19:53] This crisis demonstrates the harmful effects of individual interests on collective care, demanding further and more in-depth research on social support, considered as the support provided in health care networks.

FINAL CONSIDERATIONS

The empirical findings in this study evidenced that, to a certain extent, the mediators facilitated a patient and his family's search for care in the experience of care. The mediation they produced occurred more intensely at times of more intense needs, and also due to the impossibilities resulting from the illness – such as working; and the difficulties to get access to health care.

The mediators intervened in the care search trajectory to direct the trajectories followed, indicating those course that are less difficult to follow and/or better solve André's problem. Through these actions, the mediators were moved by something that cannot be readily measured, in the affective sphere, like the feeling of comfort and solidarity because of being able to somehow help someone. This help is achieved through each mediator's articulation with his networks of friends, which contributes to be able to help the people who turn to him, turning mediation into a social and collective production, seen and acknowledged by the people and institutions involved in the mediation. Visibility and acknowledgement without which the mediation would be unable to continue over time.

Unable to follow their guiding principles, the public health services ended up not granting effective answers to André's needs, making it impossible to practice the right to health at certain times. The ways the healthcare networks are constituted expressed the rearrangements needed for André and his family to obtain more comprehensive and problem-solving care.

The mediators, who allow the patients/families in situations of illness to get access to care in this fragmented professional health care system, somehow and to a certain extent showed how more flexible action, that is, less guided by strict care protocols, can advance professional practices to put the right to health in practice. Despite the study limitations, as it addressed the experiences of a sole patient, some mediation effects were outlined and the need for further research was revealed.

This study also shows the great movement needed for people to be able to achieve more effective answers from public health services, evidencing that an ill person's entry through a service door hides an articulation in networks that are sustained by the movements of many other people. Further research on mediators is needed, as a way to better observe the dynamics of the healthcare networks and get to know the effects of health services' disintegrated actions with low problem-solving ability. Thus, professional actions can be reconsidered in search of more ethical care delivery.

Through this study, the experience of illness and its consequences could be understood, as well as the way healthcare networks are woven and how mediators act in them, showing that these networks are more necessary in view of people's vulnerabilities and the limited effectiveness of practices in the professional care system. Nurses need to understand the power of these networks, and the mediation inside them, also participating to contribute to the constitution of care networks, in which the bonds can put the right to health in practice.

REFERENCES

1. Portugal S. O que faz mover as redes sociais? Uma análise das normas e dos laços. Rev Crí Ciên Soc. 2007. Dez; (79):35-56.
2. Portugal S. "Quem tem amigos tem saúde": o papel das redes sociais no acesso aos cuidados de saúde. In: Simpósio Família, Redes Sociais e Saúde, Hamburgo, Instituto de Sociologia da Universidade de Hamburgo, 2005 Abr 7-8; Hamburgo, Portugal; 2005.
3. Santos BS. Sociedade-providência ou autoritarismo social? Rev Crít Ciênc Soc. 1995. Mai; 42. i-vii.
4. Bellato R, Araújo LFS, Faria APS, Costa ALRC, Maruyama SAT. Itinerário terapêutico de famílias e redes para o cuidado na condição crônica: alguns pressupostos. In: Pinheiro R, Martins PH. Avaliação em saúde na perspectiva do usuário: uma abordagem multicêntrica. Rio de Janeiro (RJ): CEPES/IMS/UERJ, UFPE, ABRASCO; 2009. p.187-94.
5. Bellato R, Araújo LFS, Mufato LF, Musquim CA. Mediação e mediadores nos itinerários terapêuticos de pessoas e famílias em Mato Grosso. In: Pinheiro R, Martins PH, organizadores. Usuários, redes sociais, mediações e integralidade em saúde. Rio de Janeiro: UERJ/IMS/LAPPIS; 2011. p.177-84.
6. Mafessoli M. Elogio da razão sensível. Petrópolis (RJ): Vozes; 1998.
7. Araújo LFS, Bellato R, Hiller M. Itinerários terapêuticos de famílias e redes para o cuidado na condição crônica: algumas experiências. In: Pinheiro R, Martins PH, organizadores. Avaliação em saúde na perspectiva do usuário: uma abordagem multicêntrica. Rio de Janeiro (RJ): CEPES/IMS/UERJ, UFPE, ABRASCO; 2009. p. 203-14.
8. Campos GWS. Reforma política e sanitária: a sustentabilidade do SUS em questão? Cien. Saude Colet. 2007; 12(2):301-6.

9. Lacerda A. Apoio social e a concepção do sujeito na sua integração entre corpo-mente: uma articulação de conceitos no campo da saúde pública [dissertação]. Rio de Janeiro (RJ): Escola Nacional de Saúde Pública. Fundação Oswaldo Cruz; 2002.

10. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 11ª ed. São Paulo: Hucitec; 2008.

11. Bellato R, Araújo LFS, Faria APS, Santos EJF, Castro P, Souza SPS, et al. A história de vida focal e suas potencialidades na pesquisa em saúde e em enfermagem. Rev Eletr Enf. 2008 [acesso 2009 Out 13]; 10(3):849-56. Disponível em: http://www.fen.ufg.br/revista/v10/n3/v10n3a32.htm

12. Costa ALRC, Figueiredo DLB, Medeiros LHL, Mattos M, Maruyama SAT. O percurso na construção dos itinerários terapêuticos de famílias e redes para o cuidado. In: Pinheiro R, Martins PH, organizadores. Avaliação em saúde na perspectiva do usuário: uma abordagem multicêntrica. Rio de Janeiro (RJ): CEPES/IMS/UERJ, UFPE, ABRASCO; 2009. p. 195-202.

13. Neto OC. O trabalho de campo como descoberta e criação. In: Minayo MC, organizadora, Deslandes SF, Neto OC, Gomes R. Pesquisa social: teoria, método e criatividade. Petrópolis (RJ): Vozes; 1994.

14. Martins PH. Usuários, redes de mediadores e associações híbridas na saúde. In: Pinheiro R, Mattos RA, organizadores. Cuidar do cuidado: responsabilidade com a integralidade das ações de saúde. Rio de Janeiro (RJ): CEPESC: IMS/UERJ: ABRASCO; 2008. p.115-42.

15. Caillé A. Antropologia do dom: o terceiro paradigma. Petrópolis (RJ): Vozes; 2002.

16. Pinheiro R. As práticas do cotidiano na relação oferta e demanda dos serviços de saúde: um campo de estudo e construção da integralidade. In: Pinheiro R, Mattos RA, organizadores. Os Sentidos da Integralidade na atenção e no cuidado à saúde. 6ª ed. Rio de Janeiro (RJ): IMS/UERJ – ABRASCO; 2006. p. 65-112.

17. Thaines GHLS, Bellato R, Faria AP, Araújo LFS. A busca por cuidado empreendida por usuário com *Diabetes Mellitus* - um convite à reflexão sobre integralidade em saúde. Texto Contexto Enferm. 2009 Jan-Mar; 18(1): 57-66.

18. Genro T. Globalitarismo e crise da política. Folha de São Paulo. 25 Mar. 1997; Cad.1, p.3.

19. Valla VV. Redes sociais, poder e saúde à luz das classes populares numa conjuntura de crise. Interface - Comunic, Saúde, Educ. 2000. Ago; 4(7):37-56.

Correspondence: Leandro Felipe Mufato
Rua 24, 85, ap. 103A. Residencial Esperança
78068-620 – Boa Esperança, Cuiabá, MT, Brasil
E-mail: leandro.mufato@yahoo.com.br

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