

THE FAMILY QUOTIDIAN: THE STAGE OF EXPERIENCE OF THE ILLNESSES OF A YOUNG ADULT O QUOTIDIANO FAMILIAR: PALCO DA EXPERIÊNCIA DO ADOECIMENTO DO ADULTO JOVEM EL COTIDIANO FAMILIAR: ESCENARIO DE LA EXPERIENCIA DE LA ENFERMEDAD DEL ADULTO JOVEN

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ABSTRACT

Introduction: The family a collective group formed by multiple arrangements in which chronic illness generates great changes. **Objective:** to understand the daily care expressed by a young adult in a condition of chronic illness and her family **Method:** Qualitative study based on Michel Maffesoli’s Comprehensive Sociology of Quotidian, operationalized through in Depth Interview conducted during 12 home visits to a person with chronic illness and her family. The analysis took place through the “sensible reason” being the cycles of repetitions and permanence that build in the daily quotidian guides of the systematic organization. **Results:** The study participant was Athena, a young woman with Lupus Erythematosus and Systemic Arterial Hypertension for 15 years, and Chronic Renal Failure in hemodialysis treatment for four years. The data were organized in order to demonstrate the characteristics of Athena’s family life, and later the two units of meanings are discussed. **Discussion:** It was understood that a family is a collective group that lives alterity, in a conflictive and harmonious balance which constitutes the basic sociality. It is because of the existence of sociality that forms of the quotidian can be used as a way of resisting the imposition of external powers by the sick person supported by family members. **Conclusion:** It is necessary to recognize the importance of family every day since it is the place where the choices and behaviors are built and shared in the face of the experience of illness.

Keywords: Family Relationships; Nursing; Activities of Daily Living; Humanization of Assistance.

RESUMO

Introdução: a família é grupo coletivo formado por múltiplos arranjos cujo adoecimento crônico gera grandes modificações. **Objetivo:** compreender o cotidiano de cuidado expresso por um adulto jovem em condição de adoecimento crônico e sua família. **Método:** estudo qualitativo fundamentado na Sociologia Compreensiva do Quotidiano de Michel Maffesoli, operacionalizada pela entrevista em profundidade realizada durante 12 visitas domiciliares a uma pessoa com doença crônica e sua família. A análise se deu por meio da “razão sensível”, sendo os ciclos de repetições e permanência que constroem no cotidiano guias da organização sistemática. **Resultados:** a participante do estudo foi Atena, mulher jovem, com lúpus eritematoso e hipertensão arterial sistêmica há 15 anos e insuficiência renal crônica em tratamento hemodialítico há quatro anos. Os dados foram organizados de modo a demonstrar as características da vida familiar de Atena e posteriormente discutiram-se as duas unidades de significados. **Discussão:** compreendeu-se que a família é um grupo coletivo que vive a alteridade, num equilíbrio conflitivo e harmonioso o qual constitui a socialidade de base. É devido à existência da socialidade que as formas do cotidiano podem ser usadas como maneira de resistir a imposições de poderes externos pela pessoa adoecida apoiada pelos familiares. **Conclusão:** é preciso reconhecer a importância do cotidiano familiar, pois é o lugar onde se constrói e compartilha as escolhas e comportamentos diante da experiência do adoecimento.

Palavras-chave: Relações Familiares; Enfermagem; Atividades Cotidianas; Doença Crônica; Humanização da Assistência.

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RESUMEN

Introducción: la familia es un grupo colectivo de múltiples disposiciones donde la enfermedad crónica genera grandes modificaciones. **Objetivo:** comprender la rutina de cuidados del adulto joven con enfermedad crónica y de su familia. **Método:** Estudio cualitativo fundamentado en la sociología comprensiva de lo cotidiano de Michel Maffesoli, con datos recogidos en entrevistas en profundidad llevadas a cabo durante 12 visitas domiciliarias a una persona con enfermedad crónica y a su familia. Los datos se analizaron según la razón sensible y los ciclos de repeticiones y permanencia que se construían en el día a día fueron las guías de la organización sistemática. **Resultados:** la participante del estudio era Atena, una joven con lupus eritematoso e hipertensión arterial sistémica desde hacía 15 años e insuficiencia renal crónica en tratamiento hemodialítico desde hacía cuatro. Los datos fueron organizados de modo a demostrar las características de la vida familiar de Atena; posteriormente se discutieron las dos unidades de significados. **Discusión:** se observó que la familia es un grupo colectivo que vive la alteridad, en un equilibrio conflictivo y armonioso que es la socialidad básica. Y por la existencia de la socialidad las formas del cotidiano pueden ser usadas como manera de resistir a las imposiciones de poderes externos por la persona enferma apoyada por los familiares. **Conclusión:** debe reconocerse la importancia del cotidiano familiar, pues es el lugar donde se construyen y comparten las elecciones y los comportamientos ante la experiencia de la enfermedad.

Palabras clave: Relaciones Familiares; Enfermería; Actividades Cotidianas; Humanización de la Atención.

INTRODUCTION

The family system is composed of interrelated elements, in constant interaction, that influence the behavior of all family members. It is a structure modified according to these interactions.^{1,2} The family cannot be understood as an abstract and universal entity, but as a collective group, formed by multiple arrangements whose chronic illness generates great modifications.^{3,4}

The daily life is directly implicated in the process of family sickness, once it is understood as a time-place where the lifestyle is realized and beliefs, values, meanings, behaviors, culture, and symbols are defined through relationships and interactions with each other throughout the life cycle.⁵⁻⁸

From day-to-day observation, it is possible to understand the family's reactions to the health and illness needs of its members, which can be both positive and negative, depending on how the relationship was established before the event.^{1,5}

It should be noted that observing how the experience of illness is expressed in family everyday life, it is indispensable to the acquisition of a fountain vision, which means a vision that sees, at the same time that feels, the soul of things. Sensitivity is necessary to make a science from within, that one who thinks the object without needing to be abstracted, since it understands that it is part of what one seeks to describe.^{7,9}

It is believed that, based on this sensitive observation about the reality of people in their health-disease cycles, it is possible to take care of valuing relationships and social-family relationships in all its completeness. The path of care and research carried out in this study favors this comprehensive view on illness, especially in chronic conditions, such as the complications of arterial hypertension, in which its course is fertile ground for knowing the complexity of everyday family relationships established from this event in the life of the family.

Based on a comprehensive perspective of daily life, this research emerged from questions about the care and relationships that are established in the family from the illness of a

young adult, since this unusual experience in youth can make the daily life of the family. Thus, the aim of the study responding to this research problem was understand the daily care expressed by a young adult in chronic condition and his family.

METHODOLOGY

This is a qualitative study, a case study based on the sociology of everyday life and sensible reason, by the sociologist Michel Maffesoli.^{8,9} It was decided to use this reference because it allows a more detailed approximation of the experiences of the people in their environments. It should be noted that to understand how daily care is expressed, the sick person occupied the central focus of the research and the family was the context of observation.

The search for the participants was in nine basic health units (UBS), suggested by the Health Department of a medium-sized municipality, in the interior of the state of Paraná. The possible subjects were indicated by the nurses of each Family Health Strategy (ESF) team, according to the following inclusion criteria: being an adult and having a family that experienced the chronic condition; reside with a relative; have been hospitalized at least once in the 12 months before the start of the survey; and be able to verbalize their experience during the interviews. The exclusion criteria were: pregnant and postpartum women.

The nurses indicated 30 possible families, and only eight fully met the inclusion criteria. However, only two accepted to participate in the research. During the collection process, one of the families declined, leaving only the Athena family. The fictitious name was chosen in analogy to Athena, the Greek goddess of war and wisdom, and aimed to express the strength and wisdom that the member of the study faced her 15 years of illness.

For data collection, the in-depth interview (IDI)¹⁰ was used, once this methodological strategy enables to understand the specificity of each experiment. In this sense, during the interviews, the researchers sought to highlight the "vital efferves-

cence^{9:30-1} of the experience of Athena and her family to visualize the main pillars that support their process of becoming ill. At the end, a total of 12 meetings were recorded during six months of collection, recorded after the consent of the participants. The transcripts of the empirical material were added to the field material, such as the observations, the construction of a genogram and informal contacts via a digital medium (WhatsApp) with Athena and her family, which became part of the research diary.¹¹ In this diary, in its composition, "as many parameters as possible, even those treated as superfluous or trivial"^{9:70}, which referred to daily life and family care with Athena.

In order to analyze the data, many readings of the research diary were carried out in order to construct - units of meaning that reflect the cycles of repetition and permanence of attitudes/choices that constitute the daily life of the participants, according to the - theoretical reference adopted.^{8,9} Thus, at the end of three months of reflection and analysis with the research group, the built units reflect the harmonious and conflictive family relations of Athena, as well as their transgressions to the treatment rules/guidelines offered by health professionals.

It should be noted that there was a sensitive reason at all moments of data collection and organization. In this sense, starting from the formative assumption proposed by Maffesoli, the discussion, always carried out in a collective way with a research group, was a process of thought characterized by being self-conscious, systematic, organized, instrumental and, above all, interactive between researchers, their experiences and the data.¹⁰

The study met the ethical requirements of the National Health Council (CNS) and had the previous approval of the Committee on Ethics in Research with Humans (Opinion Number 682.724/2014, CAAE: 31498914.3.0000.0104), of the State University of Maringá. All participants read and signed the Informed Consent Term (TCLE).

RESULTS

Supported by the analytical reference and a better visualization of the characteristics of the Athena family, the description of the course of illness and its family relationships was first carried out, and afterwards the two units of meaning were discussed: "*Harmony-conflict in the daily family life of Athena, the humus of organic sociality*" and "*Transgressions to treatment supported by the family, a shared Dionysian attitude.*"

DESCRIPTION OF ATHENA AND HER FAMILY: A FONTANA PERSPECTIVE ON FAMILY RELATIONSHIPS

Athena is a young woman, with remarkable eyes, 27 years old, married, without children and with complete high school.

She discovered systemic lupus erythematosus (SLE) and hypertension (AH) at 12 and since then, she started preventive therapy with corticosteroids and antihypertensives. She developed as chronic complications chronic renal insufficiency (CKD) and has been undergoing dialysis – hemodialysis (HD) since 2012. Athena has never followed the treatment correctly and maintained, during a long period of her life, habits harmful to her health. During the 15 years of searching for care, she was hospitalized eight times, all with an average duration of 15 to 20 days, two of them in the intensive care unit (ICU).

Her path was marked by death and loss (*petit mortis*).⁹ The hardest of them is an abortion due to eclampsia in the seventh month of gestation in 2012. Three years ago she was in the waiting line for kidney transplantation. She does HD three times a week. She is currently away from the job of a saleswoman at a shoe store near her home. The rest of the week she works as a manicure to boost the family's monthly income around four minimum wages. As a leisure activity, she visits her work friends, goes to church periodically and uses social networks to make new friendships. She also considers, as a leisure activity, to clean her house every day.

She has been married to Eros for three years, and she has a very intense relationship, full of love and concern. He is the primary and most important caregiver of Athena. He is a young man, 30 years old, and works in a graphic in the afternoon and evening, so he has time available to take Athena to the dialysis sessions in the morning. They live by dividing the land with Athena's brother, Abel, and her sister-in-law, Sparta. The parents of Athena live in the countryside and they are their support, mainly, financially. On the other hand, the parents-in-law, Hermes and Era, participate more actively in emotional and psychological support for the couple. Eros's brother, Atha's brother-in-law, Filotes, and his family, his wife Kera and their daughter Panacea, also maintain a relationship of support, trust, and friendship with the couple.

THE HARMONY-CONFLICT IN THE DAILY FAMILY OF ATHENA, THE HUMUS OF ORGANIC SOCIALITY

Throughout the years of illness, the health needs have been presented actively to Athena and her family. In the moments of re-emissivity and exacerbation of the disease, they re-organized and/or modified the family dynamics to accommodate, day-to-day, a series of rituals, norms, spaces, times and logics arising from illness. Simultaneously with this remodeling movement, knowledge and behaviors were defined, which directly influenced their choices to adhere or not to the treatments and guidelines offered by health professionals.

In the search to construct the image of the relationships that merge in the familiar daily life and care of Athena, it opted

for the genogram (Figure 1). It is emphasized that the intention is not to describe this tool, but rather to present the relationships of her family to later discuss the nuances of her family routine.

However, there were difficulties in giving visibility to the changes suffered by the Athena family throughout the process of 15 years of illness in the genogram, given their graphics limitation. Thus, it is emphasized that the use of this instrument allowed demonstrating only an "instant of the family moment."¹²

During her arduous path, Athena formed beautiful constellations and differentiated affective bonds, which in some way influenced her search for care. She considers her husband, her safe haven. The parents-in-laws are their main source of affection. Parents play an important role in financial support. Eros's brother, Filotes, and his wife, Kera, also made up their support and care network and Athena has a strong bond of friendship, as seen in her narratives:

Everyone gives me a lot of support, a lot of strength, so my parents-in-laws do not even say they are my in-laws, they are my second parents because they give me so much support and strength, they are always with me, supporting me and helping me. My brother-in-law also helps me a lot! My father and mother, I do not know what I would do without them [...] my brother too, but not so much (Athena, 2014/11/14).

My husband gives me the greatest strength, because of him that I began dialyzing. He is the foundation of everything (Athena, 2014/11/21).

At the same time that she lives in harmony with most of her family members, the triple dotted lines in the genogram design demonstrate Athena's highly conflicted relationship with her sister-in-law, Sparta. It was possible to capture in the narratives, the intensity and the involvement of the feeling of hatred between them. This conflict with her sister-in-law drove her brother, Abel, away from family life, which also generates a sense of sadness, sometimes limiting even her chance of IRC healing. Athena inferred that compatibility tests for kidney transplantation were positive for her brother, but Sparta interfered with her husband's choices by preventing Abel from donating her kidneys to her sister:

We did all the exams, he's the only one compatible. But then she [referring to Sparta] interferes with his choice. And that's how it is, he's not willing to donate, even though he knows he does. So, I will not be demanding of him, if he really wants, he donates it (Athena, 2015/01/14).

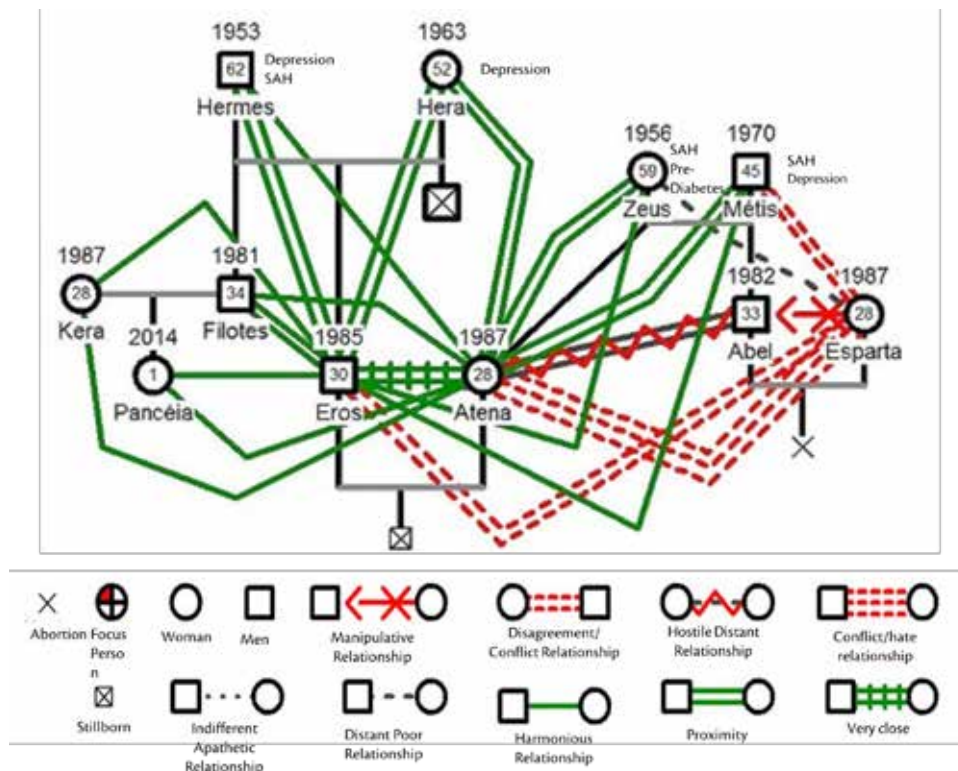


Figure 1 - Athena family's genogram.

It can be seen in Athena's words, as it was possible to observe during the entire course of data collection, that the fact that the brother does not offer to donate the kidney generates feelings of sadness and revulsion, both for Athena and for the whole family, according to the description in the research diary:

*It is possible to see clearly how much Athena and her close relatives feel **troubled** by this attitude of Abel. During an informal conversation via the internet, Athena describes that she feels the "chest burning" and when she thinks about it a lot, her hair falls more than normal. [Research Daily Note, 2015/01/18].*

However, despite the conflicts between the brothers, the atmosphere of family harmony is strengthened by the relationships that Athena maintains with the other relatives. Also, despite the difficulties in her relationship with her sister-in-law, Athena maintains brief dialogues with Abel, sharing her experiences at Sunday lunches at her mother's home, considered as a neutral ground for her.

FAMILY-SUPPORTED TRANSGRESSIONS OF TREATMENT, A SHARED DIONYSIAN ATTITUDE

When looking at the daily familiar micro-relationships, while considering the importance of the organization and construction of this social group, the researchers sought to understand why some care practices were adopted and/or maintained by Athena.

During the process of construction of the categories, the routine attitude of Athena was emphasized, which at all times transgressed the treatment impositions. She did not take and never correctly took the medications for lupus or AH, as well as maintaining inadequate nutrition for her health. Even family members aware that these attitudes are harmful, they support her in their choices, as can be seen in the narratives of Eros and Métis:

*[...] she pretended to take the medicines, she did **not** follow the diet at all. It was difficult, but not much has changed. She's still doing some nonsense [...] what she does, she chooses, she **knows** what's best for her, I do not talk anymore, I only listen (Métis, 2014/11/28).*

*There is a medicine that she pretends to take and she does not anything. The doctor does not even know that, if he finds out he kills her. But she is the one who must choose what she wants for her life, we talk, **but she chooses** (Eros, 2014/12/12).*

It was possible to observe that Athena's relationships with social groups shared a profound alterity with the one close to her. By highlighting and understanding the heterogeneous and plural world of their experience of illness, it is possible to affirm the importance of health services in adopting a systemic reflection to allow the interaction of the knowledge and, in this way, to offer an effective and humanized assistance, according to the health needs of the sick and their families.

DISCUSSION

It is necessary to use the sensitivity to understand the complexity that makes up the daily lives of people and their stories. To do so, it is necessary to build a close relationship and alterity with the sick people and their families, and to know the day to day, how the experience is shared and how the choices of care and cures are structured.¹⁵ This attitude towards the experience of getting sick on the other potentiates the understanding of the individuals' real health needs, allowing and strengthening the care provided.^{13,14}

By observing the life of Athena, starting from an approach and relationship of intense alterity, as well as adopting a science from within, according to Maffesoli's former assumption, it was possible to observe that her illness process is marked by comorbidities arising from chronic illness, considered potentially preventable.

To speak of the prevention of comorbidities of the chronic disease means to reflect on the acceptance or not of the sickness because the person's conscience about his health-disease process directly influences them in the choices of care or not care. Moreover, studies infer that acceptance is intimately influenced by everyday experience woven throughout life.^{13,15}

In the case of Athena, her illness began in pre-adolescence, a period of life characterized by generalizable aspects, such as aggression, rebellion, and depression. At that stage, she did not accept or even did not believe in the seriousness of her disease, constituting, then, like a period marked by transgressions to the treatment, attitude that accompanied her.

It should be emphasized that the behaviors, concepts, meanings, and choices of Athena and her family were formed throughout the process of chronic illness, according to the demands of care due to the exacerbation and reissue of her illness, as well as following the meanings already pre-established. This constant dynamic, present in the processes of chronic illness, triggers drastic changes in the form of family organization, as well as in the relationships and roles of this complex system.¹⁶ This movement of remodeling often produces great tension or anxiety in other family members, which react positively or negatively to changes.¹²

In this sense, when observing the family of Athena, it can be verified the positive relationships that support her, and, at

the same time, the negative relationships that make difficult her recovery. The way in which Athena's daily life was constructed refers to the allegory of a seesaw, for now, both positive and negative relationships are at the top, and thus routinely orchestrating a balance between harmony and conflict, between support and exclusion.

This ambivalent atmosphere, in which Athena's family is immersed, illustrates what Maffesoli reflects on family relationships, which are the privileged place of alterity and harmonious harmony.¹⁷ These relationships are shared cyclically every day, forming species of the fused ones in which each person revolves around himself, multiple in his individual experiences, at the same time as he constructs himself with the collective.¹⁸

This union of the subjects permeated by the relationships of alterity that happen within the collective groups, as well as the situations of ambiguity that structure them (harmony-conflict) is called, by Maffesoli,¹⁷ as organic or basic sociality. Organic because they are natural behaviors of man and based on affective social bonds and the basic ambiguity of symbolic structuring. In fact, it is the organic sociality that guarantees the cohesion of the group, the sentimental sharing of values, places, and ideas. This social behavior is much more pronounced in the domestic sphere because it is where the most intense relationships are formed, constituted with those who are close.^{8,9}

The domestic is a place that understands everything that leads to a feeling of belonging reinforced by emotional sharing. Often, this belonging can be classified as "forced", since there are conflicting relationships with whom Athena would not like to maintain. However, belonging, even if forced, enables to build the bond, making the humble space of the domestic place a place where it is shared with those who are close to it.⁹ Thus, it is the place where pure affection is granted, space for many conversations, in which the human being can show his limitations. That is to say, it is in the family, in the place of the domestic, in the daily (space-time) that the relationships of alterity are best lived in all its smallness and in all its tragic aspect.^{8,15,17}

It is because of the organic existence of sociality that the forms of everyday life, such as cunning and a double play, can be used to resist the impositions of external powers. Also, the disease situation exposes the person to the question of death and the awareness of his existence, considered the tragic side of life. This consciousness promotes freer living, turned to the here and now, and the future becomes less interesting. Exactly what one observes in the attitudes of Athena, which adopts a behavior called dionysiac attitude, that is, the pleasure of action, which values the inspiration and organic (natural) instinct of the human.^{8,9} This behavior *in natura* directs her choices to consider, first and foremost, daily pleasures. This implies, even, to go against what is imposed by the treatment of her diseases.^{17,19}

Maffesoli, in discussing social relationships in contemporary times and retaking the ideas of Lévi-Strauss and Aristotle, affirming that this Dionysian attitude symbolizes the nucleus of human identity and inscribed in his architecture.^{17,40} This inscription culminates in the ambivalent behavior of death and life (tragic), allowing the relativization of the imposition of factual powers, favoring the choice of what is considered important to satisfy the pleasure of habit, not what is imposed on them.^{17,44}

Concomitantly, the family, by collectively sharing the experience of becoming ill, seeks to accept the destiny and the tragic of experience together with its sick members.¹⁹ That is, by absorbing that the life of the sick person is permeated by a situation close to death and immersed in relationships of alterity, the choices, even if detrimental in the long term to the health of the subject, are respected by the other members of the group, as is the case with the Athena family over her choices of not taking the lupus medications and, for a long time, those of AH.

This fact shows the need to understand the family as a collective group that lives impetuously to otherness.^{2,3} In the case of the Athena family and many other families, it is a conflictive and harmonious balance at the same time. Since all sociality is conflictive, all harmony is founded on difference, and even in the more typical exchange, as the love relationship, its opposite acts.^{4,8}

It is this assumed ambivalence that explains the endurance of sociality. In this game of difference, exchange and complementarity become its structural elements. The sharing, whether space, time or affection, is conflictual because it goes beyond the logical aspects of reason, directly influenced by subjective values. It is done in the time and space of sharing, that is, in daily life.^{9,17}

Thus, it is observed that the professional aimed to promote the health and quality of life of families, need to assume the importance of them as a social group of support, care, inter-care and even non-care.¹⁹ As well as the need for the recognition of the daily theme in its depth and importance, bringing it to discussion, understanding that it is in this space that the routine is lived, - guided by short moments full of meanings.⁹

The small facts of everyday life are extremely relevant because they demonstrate that the banality of repetitive cycles that occur on a daily basis directly influences people's behaviors and choices.⁶ Thus, it is considered that to work with families and to promote their health with quality and effectiveness, it is necessary to consider their context, reflecting together – with them and having the support – of a multi-professional team, which dialogues inter-professional about the dimensions that compose human beings in their health-disease processes.^{4,6}

Also, the use of the genogram in this study proved to be a potential tool for analyzing the experience of the family in the process of becoming ill, making visible the way to organize family relationships for care²⁰ and later reflection on possible inter-

vention actions, being its use recommended by the researchers. Finally, it is possible to affirm that health professionals can act as empowering agents of care offered to families, supporting them in the search for solutions to problems and reorganization in the face of the needs arising from the process of illness.

CONCLUSION

This study – corroborated to the understanding that illness is collectively faced by the family, plunged into a conflictive harmony of their relationships. In this context, they make intense exchanges and influence the choices and behaviors of the sick people, inviting health professionals to rethink the way of offering care practices based on strictly instituted norms and protocols, based on hegemonic models of health care.

It was possible to demonstrate that, for the control of chronic diseases, it is necessary to consider other strategies and forms of intervention, less and less formal and closer to the reality of people and their families. To do so, the bond becomes a primordial part for access to the particularities of care in each family unit, and everyday life is the stage where the process of living and getting sick of people happens.

Thus, the main limitations of this study are its reduced possibilities of generalization of data, since the theoretical-methodological reference used was intended to describe the unitary character of the social data. Therefore, it was identified the need to carry out other research in different scenarios, since the behaviors of the people are also influenced by the culture of each region.

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