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## Dimensão espaço-tempo e os atos-attitudes de cuidado na experiência familiar

Space-time dimension and acts-attitudes of care in the family experience

Dimensión de espacio-tiempo y actos-actitudes de atención en la experiencia de la familia

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### ABSTRACT

**Objective:** to understand the space-time dimension and acts, attitudes of care in family experience of chronic illness situation. **Method:** comprehensive Approach, conducted as “the study of the situation”, with the empirical material of three family experiences of care and illness. The analysis allowed us to intuit some “notions about the care” of them and extract the space-time dimension and acts-attitudes of care as their substance. **Results:** we demonstrated different ways of caring and being/living with others in care, such as the modeling produced by the family in their daily lives, taking this as a privileged space-time provision of care and virtuous acts-care attitudes of family members and of health professionals throughout the experience of illness, that provided that care happen. **Conclusion:** health professionals need to want to shape the care provided for people aiming to become support and referral care for families, adding to its potential care in building a “careful with.”

**Descriptors:** family; family relationships; caregivers; professional-family relationships.

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## RESUMO

**Objetivo:** compreender a dimensão espaço-tempo e os atos-attitudes de cuidado na experiência familiar da situação crônica de adoecimento.

**Método:** abordagem compreensiva, conduzida como “estudo de situação”, sendo o material empírico três experiências familiares de cuidado e adoecimento. A análise permitiu-nos intuir algumas “noções sobre o cuidado” e delas extraímos a dimensão espaço-tempo e atos-attitudes de cuidado como sua substância. **Resultados:** evidenciamos diferentes modos de cuidar e de ser/estar com o outro no cuidado, tal como a modelagem produzida pela família em seu cotidiano, tendo este como espaço-tempo privilegiado de provisão do cuidado e atos-attitudes virtuosos de cuidado dos familiares e de profissionais de saúde ao longo da experiência do adoecimento, que propiciaram que o cuidado acontecesse. **Conclusão:** os profissionais de saúde precisam querer moldar o cuidado oferecido para as pessoas objetivando tornarem-se apoio e referência de cuidado para as famílias, somando-se aos seus potenciais cuidativos na construção de um “cuidado-com”.

**Descritores:** família; relações familiares; cuidadores; relações profissional-família.

## RESUMEN

**Objetivo:** comprender la dimensión espacio-tiempo y actos, actitudes de atención de la experiencia familiar en la situación de enfermedades crónicas. **Método:** enfoque Integral, llevado a cabo como “el estudio de la situación”, con el material empírico de tres experiencias de la familia de la atención y de la enfermedad. El análisis nos permitió intuir algunas “nociones sobre el cuidado” de ellos y extraemos la dimensión espacio-tiempo y los hechos-actitudes de atención como su sustancia.

**Resultados:** demostramos diferentes formas de cuidar y ser/vivir con otros en el cuidado, tales como el modelaje producido por la familia en su vida cotidiana, tomando esto como una disposición del espacio-tiempo privilegiado de la atención y las actitudes de cuidado actos virtuosos de miembros de la familia y de profesionales de la salud en toda la experiencia de la enfermedad, que siempre que el cuidado suceda. **Conclusión:** los profesionales de salud deben querer dar forma a la atención recibida por la gente con el objetivo de convertirse en el apoyo y la atención de referencia para las familias, añadiendo a sus potenciales cuidativos en la construcción de un “cuidado con”.

**Descriptor:** familia; relaciones familiares; cuidadores; relaciones profesional-familia.

## INTRODUCTION

Studies of families addressing care produced by its different entities have raised our interest in understanding certain elements that make up this production,<sup>1-7</sup> based on family experiences of care and illness from chronic situations. These situations refer to the experience of the disease by the people and the events which they faced producing overlapping and intertwining with each other, affecting the different dimensions of life, shaping their ways of living and their rearrangements for the maintenance of everyday life with sickness.<sup>8</sup>

The care in a fundamental understanding has its origin linked to the family, as it seeks to safeguard the lives of its

members through the fulfillment of basic survival needs.<sup>9</sup> Thus, family care occurs to “feed and to strengthen growth, development, health and well-being, both to members and the group”,<sup>10</sup> therefore, produced in and for many aspects of life, not restricted to the disease condition.

However, with the presence of illness, the family is mobilized in greater efforts to find, produce and manage the daily care to meet the needs brought about by their loved ones.<sup>1</sup> The illness can be understood as an event close to their living, and that is why it is experienced by each person in a personal way. In turn, care produced by the family takes an artisanal way, configured as a “very personal care”.<sup>11</sup> This is because, in this care unit, such provision is made in the continuous modeling process, according to their potential and possibilities, in which the family can build care “with” and not just “to” the family entity, seeking to meet their care needs. In this context, we consider that each family takes care differently, not only for relationships between its entities, that is the existing ties but also by the different requirements of care required in each situation.

Seeking to respond to these demands, the family uses numerous features, such as cultural knowledge, values, beliefs, and practices that guide their actions in providing care.<sup>2</sup> However, given the permanence in time of chronic illness situation, understood as the own way of experiencing the disease by the people, and the events which they faced produce overlapping and intertwining with each other, affecting the various dimensions of personal and family life, shaping their ways of living and, their rearrangements for everyday reordering in presence of the illness.<sup>8</sup> The family care potential may not be sufficient to meet the broad and diverse needs of care required in the situation, and in those moments that other possible care supply levels are triggered.<sup>12</sup>

The professional care can sum up to the educational potential of the family, and their effective participation in family care can help reduce the wear and suffering of those who care, as well as the ill person.<sup>13</sup> Therefore, healthcare providers need to discern new possibilities for action, especially with the family, where they can offer an articulate practice with their life and their needs.<sup>10</sup>

Therefore, we understand the need for shaping professional practices offered to sick people according to dynamic situations in which they operate, to enhance the daily care engendered by the family. This necessity requires that health professionals envisage new possibilities of action with families, which should be able to articulate the needs of this care unit and the context of their experiences.<sup>10</sup>

Thus, to sense how professional care can be involved with family care, **we aim** to understand the space-time dimension and caring activities-attitudes in the family experience of a chronic illness situation.

## METHODS

Comprehensive approach research<sup>14</sup> that focuses the senses and meanings created by families in the daily life

of a chronic illness situation. It was conducted due to the “situation study”, which aims to understand the everyday life context and the peculiar situation of illness and care of the person and his family. This perspective allows the researcher to draw some broader inferences from micro-reality studied and highlight the windings of the relationships of various orders established over the people’s life.<sup>8</sup>

The empirical material was obtained from the database in Qualitative Research (QRDB) of a research group that contains the data and information on family experiences of care and illness in chronic situation.<sup>15</sup> At the time of the study, the database had thirteen family experiences, from which we selected intentionally, the experiences of families Soneto, Esperança and Resiliência. This choice was motivated by evident terms of own care needs of loved sickened for which families undertook great effort of provision. Also, such families resented intensely in their lives, the effects produced by health professional practices.

In Soneto family, the illness by sickle cell anemia affects three of its members: Assis, the father and the two sons Olavo and Cecília, and her mother, Clarice had some traces of the disease. Before these children, the couple had Cora, who died when she was one and a half-year-old due to complications of the late diagnosed disease. Esperança family with Baltasar, Maria, and their children Mirra and Belchior experienced the illness adrenoleukodystrophy (ADL) of Belchior. This disease was degenerative and progressive, diagnosed in the child at seven years old. Finally, Resiliência family had the disease of mental suffering, also progressive. The family has the mother, Dona Ana, 72 years old, and her four children, participating in the study are children Ivete and José.

These family experiences were obtained using a methodological approach to the history of life, operationalized by interview strategies and observation, and the resulting material in this collection organized in daily research<sup>15</sup> with the life story of each family. Also, to these strategies, the footage in gathering information on Esperança family was used, which allowed a more detailed of some scenes and care scenarios to Belchior.

The *corpus* of analysis of this study is, therefore, the footage, totaling 138 minutes and 55 seconds of recording, and the information contained in the three research diaries, resulting in 400 pages typed in Microsoft Word Document file (.docx), in Times New Roman source, size 12 and 1.5 line spacing.

In the interpretation of this corpus, we did repeated readings, drawing the narratives that we consider the care requirements in chronic illness situation. Such requirements were ordered to its context and particular situation, being possible to infer, then, a set of “care scenes.” On the scenes of each family experience, our effort was to grasp some “notions of care”, representing them, and then through a “descriptive-analytic diagram”.

The diagram is a visual reflection that embodies a thought through graphics, that is, lines, shapes, words,

symbols, arrows or plans.<sup>16</sup> We use this resource to build a palpable speech that facilitates us to organize ideas; thus, we constructed a diagram on each family experience and subsequently a general understanding of them.

Therefore, we perform a thorough reading of all the diagrams seeking to understand some constituents and supporters of the multiple dimensions of the family experience of care, considered as “care substances.” In this study, we address about the dimension of space-time and caring activities-attitudes as some of their substances. Such substances were observed within the family, in the ways of caring and being/living with others in care, represented by the empirical categories: “every day family life as space-time of care ” and “virtuous activities- attitudes of care.”

The study meets the ethical aspects of research with human beings, with the authorization of the participants by signing the Consent and Informed Form, which includes database creation and the possibility of their use for future studies. Access to the library of every experience was through formal authorization from the Coordinator of each matrix research, and fictitious names were used to preserve the anonymity of the participants and institutions mentioned in the interviews.

## RESULTS

In the experiences of the families Soneto, Esperança and Resiliência, the ways of taking care of/with other, showed the family routine as a privileged space-time care modeling, therefore, their provision. The ways of being/living with another showed some acts, attitudes, both by family members as professionals, denoting the ways of care in a chronic illness situation.

### Family every day as care of space-time

The three experiences discussed in this study show that chronic illness produces a multitude of affectations of different magnitudes to be set up in people’s lives and their families. Such affectations are understood as the effect of the clash of many modifiers events of everyday life, adduced by a chronic illness situation. Therefore, they do not constitute the sum of events, but rather effects of what is added, amplifying and synergizing each other. Thus, it is the purpose of illness situations that reverberate or leveraged on each other, capable of promoting substantial changes in various dimensions of family life, not restricted to health care.

This understanding leads us to conceive the every day as a privileged space-time live; stage care for expressions and life, since it is the family the main provider of care, arranging and rearranging to better live.

In this sense, we agree that the every day is:

*[...] a privileged space-time experienced of people, referred to by them as the place where things take next*



*and own senses experienced, exacerbating and taming a circularity, entered into routine rhythm that takes organic conformations closer to the habit than the stopwatch.*<sup>11</sup>

With this perspective, we understand that it is in this space-time that changes are unfolding in the ways and rhythms of life to meet the care needs with a chronic illness, which occurs from the reverberations produced by it. Clarice tells how was being ill by sickle cell anemia with two children with a small difference in age, showing the changes experienced by the family: *“It seems that your life is turned upside down. Then you just, like it or not, depend on the family! You need someone to help. Moreover, everything had changed [emphasis].”* (Clarice, Soneto family)

The changes produced by the illness caused the family to move, rearranging their routine to “consider” the new mode and pace of life, now mainly driven by care needs to the children. The family’s efforts are recognized by the authors as resulting from the profound changes the illness in their way of living, forcing her to produce rearrangements for everyday reordering.<sup>8</sup>

The need for everyday rearrangements are from aspects apparently simple family day-to-day, as concern about the ambience of the home by Esperança family because of the need for mobility of their son, Belchior, in a wheelchair due the advanced stage of the ADL: *“[...] the furniture were lined up against the wall, as if we have to keep the center free”* (Note about Esperança family). It is also present in some visible minutiae and completing the daily life of people, but that cause profound changes in living. In Resiliência family experience, it stands out, for example, loss of the reference to “home-place” for Dona Ana because of the way the children organized the provision of care to her, turns from time to time, his house by different houses of the families of children:

*There we go enduring more, but we have to go to another sister. Then you go there, stays there a while... you get stressed. [...] There is the time you have to go to another house. To another sister! [...] So it is ... It is complicated! Moreover, there is, when you have this peak stress, we see that one gives more, you know, usually, I’ll take her one week yes and one not when I’m here. I take her on weekends, right. Then I’ll take her home, then I get Friday, Saturday, Sunday; on Monday morning, I take her to her sister. (José, Resiliência family)*

Rearrangements in the every day allow families to print on a model for the care they also consider the routine chores (Esperança family), as well as its care by rotating basis among the children (Resiliência family). Thus, there are “variations that people can take in their everyday existence in the search for new living arrangements for coping with the sick person”, seeking, where possible, to provide welfare to the ill person and other entities the person lives with.<sup>6</sup>

Rearrangements engendered by family reaffirm daily life as “space” in which it produces the essential care for life, and in illness situation, such provision intensifies, causing substantial changes in the dynamics of the own life. It follows that the illness of a family one, care times overlap the times of the other dimensions of life.<sup>17</sup> Therefore, the chronic illness raises disruptions of the rhythms of life every day. This understanding led us to realize certain rhythms in the everyday household of Soneto, Esperança, and Resiliência families, printed by such a situation because of the care needs.

In the situation of Soneto family, the early years of children’s lives have been marked by the appearance of the very intense way, the symptoms of sickle cell anemia, which required being organized to take care of two children. During this period, their routines were marked by frequent exacerbations of the disease with recurrent hospitalizations and consultations with specialized professionals. With the passage of time, the symptoms began to appear less intense, allowing them some stability in everyday life, even at the risk of a new crisis:

*Time has changed, they shouted. There, or throat inflamed, and then the throat crisis triggered the flu, there was pneumonia, bronchitis. So, we passed one, a very long season with them hospitalized [...] we have been through a very difficult time with them. Now it is all quiet; they were growing up, you know, have been gaining more strength, enhancing immunity in the body. (Clarice, Soneto family)*

In the experience of the Esperança family, Belchior’s illness began abruptly and, since then, it has been rapidly progressive, and in a short time, the child now requires constant and uninterrupted care. The routine of the family has become due to the frenetic pace on the child care needs, as we can draw from observation:

*This experience tells me of a couple who are “stuck” [emphasis that was already included in the collection] at home by the need for continued attention to the child. A couple who had a restricted social life, as well as their circulation space. They just go to work and cannot work at the same time from each other, because some of them always have to be at home. Mirra, another daughter, was on a farm that day. The mother, Maria told us she has no way to say no to the girl because she had to leave her out a little of that “stress [highlight that already appeared in the collection].” (Observation notes on Esperança family)*

The rigidity in setting the pace of realization of care that is, long-term without breaks, affects the level of social family interactions.<sup>17</sup> Thus, Esperança family’s routine

was changed, since there are no pause intervals in care; and parents now have their lives dedicated to child care, arising certain isolation, although they do not express in their narratives such perception.

In Resiliência family, the illness situation is similar about progressive disease; however, it differs in care needs, because they are not so intense. However, in this family, the care of the deceased mother produces emotional overload that affects especially Ivete, perhaps because of her conflicting relationship with her mother, but concerning to the own illness characteristics - psychological distress - which has particularities in the ways of manifestation for each person and may exacerbate the conflicts between family members. In this case, for the care of the mother be possible even in this reality of conflicting family relationships, it is shared among the daughters. Therefore, each child is responsible for performing it; the only son with whom the mother maintains a different relationship, perhaps by more narrowed ties, acts as this care manager:

*It is a nuisance all night! So, it stressed who lives with her, stresses nephews, stresses the husband, my ex, my brothers-in-laws... There are times when everyone gets nervous! Everyone gets stressed. There is, this time, you have to go to another house. To another sister! Then my sisters often called already crying that they "can handle it" [highlight of the collection] because she is speaking in her ear because she is complaining, it is sometimes aggressive. (José Resiliência family)*

We realized that the family, through its various bodies, creates numerous ways and means to care, which sets its ways of taking care of/to each other. Such care search follows the rhythms printed by the situation experienced by the family. Thus, care modeling to do in the face of everyday situations, ranging from ways to initiate the grievance in their lives to the ways this manifests also permeated the affections present in family relationships, allowing the family to find alternatives and solutions to better care.

The repercussions run the establishment of a chronic problem in family life affects all the loved ones, mobilizing them to shape their ways of life and everyday household to meet the varied and intense care needs emanating from the illness.<sup>7</sup>

The three experiments in which we look back, we highlight some care in ways that tune with the illness printed rhythms in everyday life and which are in response to ill entity needs family care through surveillance, performing duty in caring and/or rotation care of their bodies.

The experience of Soneto family highlights the constant vigilance of parents with health and welfare of children as a substantial feature in the care modeling in a chronic illness situation for sickle cell anemia. In the reports of Assis, we infer the surveillance as routine care and how they anticipate the painful crises of Olavo:

*When we see Olavo, who goes early to sleep, um, soon we are worried about him. Because whenever he sleeps, he goes around seven hours or so, at eleven o'clock he wakes up and then he does not sleep more. (Assis, Soneto family)*

*The little eye will look yellowing! That is when hours. It is so fast that it is a matter of hours. Early in the morning, they wake up with an eye like this so we put liquid and at lunchtime they are so much better. (Clarice, Soneto family)*

Parental supervision allows them to be ready to act at any time, to small threat signals. The unpredictability of the sickening situation seems to be motivating this care modeling, as parents organize to be wary of what might happen to their children, regardless of whether the grievance shown stable or not. Another aspect that motivates this care is in the difference of the demonstrations and the care needs of the children because although Olavo and Cecília have the same problem; every child manifests differently the signs and symptoms of sickle cell anemia requiring constant vigilance to do differentiated care needs.

Having more than one sick person in the family by a chronic illness intensifies the pace of required care, since each has different complications of the disease, requiring families to be aware and awake to perform the needs of each family.<sup>7</sup>

Recognizing the uniqueness of each child falling ill was instrumental in shaping the provision of care for this family, because, from this recognition, they have organized to offer what each child needed. Clarice shows that while narrating about the differences in the growth and development of children:

*In such case, the two may suffer. However, she is within the normal range. But not him! He is a bit late. Everything about him is pretty childish. He is very child [...] I have two children at home with the same health problem, but it manifests in a totally different way from each other. (Clarice, Soneto family)*

The mother's perception of the stunted growth of Olavo, about Cecília, lead the family to seek professional help to solve the child's problem. Also, parental supervision provides opportunities they act avoiding worsening crises and need for hospitalization when there are acute exacerbations of the disease, which for them is critical, once leaving the everyday household expenditures and generates many afflictions for everyone.

The care of the parents was crucial at different times of illness experience, including a critical event of Cecília illness, when it had a cerebrovascular accident (CVA):

*Then she looked at me and smiled, then when she looked; she smiled at me, then I realized [narrating the moment*

*she realized that her daughter was having, she says, a stroke]. I said - 'My God! It is happening in my house', right?! We knew it could happen. It happened! Then I grabbed my cell phone, I walked around here on the side of the house and called him [refers to Assis]. I said - 'Dear! You need to come; I believe Cecília is having a stroke.' (Clarice, Soneto family)*

The mother's care helps to identify, early on, that the problem was going on, allowing her daughter be taken away, quickly, to a specialized service to receive the care she needed. Therefore, surveillance caring mode allows care to happen according to the needs of each child and also ensures that it be done with all potential care that the family provides, resulting in the possibility of better coping with a chronic illness situation.

*The duty stands out as the modeling way to watch Esperança family situation. They intensely experience chronic illness due to the instability of Belchior's condition, including the possibility of the end of his life at any time. The unpredictability is present in family life, given the progression and severity of the disease, which requires parents to provide uninterrupted care to children through an on-call system among parents, which guarantees the child to be care all day long: "Full-time caring for him. Thankfully, my husband also takes good care of him, thank God" (Maria, Esperança family). "That is how she cares during the day, and I care during the night. Only here, it is the same as, for example, being at the hospital, one day she sleeps with him the other day I sleep" (Baltasar, Esperança family).*

The intense demand for care by the ADL, already at an advanced stage, was motivating the duty to care for this family, enabling parents to meet the child's needs, ensuring him to live in the best possible way. For this modeling to be plausible, Maria had to reduce the hours of work performed in a health service as a maid, and Baltasar, to take care during the absence of the wife also needed arrangements in their work period:

*I got a decrease. I worked like this: I work one day, two off, twelve of sixty. With this law, I decreased three hours, there was that time because we also had to get someone to take care of him, right. Then when I'm leaving, my husband comes, then take care of him. (Maria, Esperança family)*

*He left early to the service; I took a document showing there because I needed. Because sometimes they may think I'm lying! Then I took it, I leave four hours, I come here, and she goes to the service. (Baltasar, Esperança family)*

The work in the family life needed larger arrangements so that care could happen daily; in this case, the mother takes care of the child throughout the day and in her absence, while working, the father takes care. The way that work is organized by the family is vital to allow care to happen.<sup>7</sup>

In Resiliência family, the rotation system was the way of modeling found by the children to her mother's caring. Conflicts and tensions among the daughters and the mother generated a burden on the one who was in charge of taking care of the mother, which led the girls to make a rotation for the direct provision of care, leading their mother to live with each of them for a period. José tells how the family manages this rotation:

*Here when one gets tired, she has to go to another sister. She goes there; she is there until... she is stressed. [...] There is, this time, you have to go to another house. To another sister! [...] So it is ... It is complicated! Moreover, there is, when you have this peaks of stress, we see that one gives more, you know, usually, I'll take her one week yes and one not when I'm here. I take her on weekends, right. Then I'll take her home, and then I get Friday, Saturday, Sunday; on Monday morning, I take her to another sister. [...] But, yeah, yeah, that is it think, it will not be like us to escape, we will always do this (José makes the right index finger circles on the table) [note on collection]. This rotation, such rotation there, to relieve attention indoors. Right, and we keep moving forward. (José, Resiliência family)*

Such modeling has been used among other things, by the weakness in family relationships, in addition to the progressive needs of the psychic illness, already in an advanced stage that generates burden on caregivers. The study shows that this overload may be evidenced by stress, withdrawal from social life and work reported by caregivers of elderly patients with psychological distress.<sup>18</sup> The rotation organized by Resiliência family was their way to facilitate the care, diluting the burden between different caregivers.

The bonds that permeate the relationships among family members were essential in shaping the care through a rotation system, showing that not only the illness needs mobilize the care modeling but also the ways in which family relationships conform influence the choice of how this can happen.

From what was mentioned above, we understand that there are multiple elements that mobilize the modeling of care by the family, and although certain care models are more striking in a given experiences, the three modeling encompassed in this study are present in three families, enabling them to provide the proper care for the sick person needs. In Soneto family, surveillance demand cares in the form of duty and also the rotation between parents for the care of two children.



From this perspective, surveillance with the singularities of the illness, the shift in the provision of care and shared rotation among the family are expressed at various times as modes of care, showing that the needs are renewed and prolonged. Therefore, such models of care show the dynamics of a chronic illness situation, requiring the family to move continuously to offer care shaped to the needs of each one, and their situation. Thus, the term “in situation” aims to point out that each ill family member, every moment form the life of these people/families and every event that happens in the daily life of these families raise a range of diverse care needs that require personalized answers in the form of care.

Understanding the space-time dimension of care can bring health professionals closer to the singularities of the everyday people and their families, making it possible to provide them with professional care sensitive to their needs in a way that exceeds the disease perspective. Considering such perspective becomes important, since “each sick person in their way and time.”<sup>7</sup>

### Virtuous activities- attitudes of care

The care experiences and illness of families Soneto, Esperança and Resiliência, show us that certain “attitude” is needed between people that provide care and those who need it so that this interaction may result in a caring way of being/living with each other. Such an attitude calls for letting people know how to have the relationship with each other so that care improves.

In this sense, we understand the “sensitivity” to perceive the minutiae of other care needs as a virtuous attitude, represented in Baltasar’s experience that can maintain communication with the child, even the impossibility of his speech due to the advanced stage of his disease (ADL) as he says: “I say: ‘- if you want such a thing, you blink your eye.’ Then, after that, we know more or less what he is wanting” (Baltasar, Esperança family).

The sensitive eye of Baltasar permeates the communication between him and his son, allowing to recognize, with dexterity, what he needs, even if the child is no longer able to express himself; thus, Baltasar is ready to take care of him. To develop this sensitivity, he shows their involvement and interest in the child’s care, since, to develop it is necessary that he should endeavor to great effort to interact with the child, which could then be presented with the greatest potential for care.

The sensitivity was noted in a study that proposed a concept of care as an important element for the identification of care need to others.<sup>19</sup> Baltasar’s capacity to establish a dialogue with his son is the potential sensitivity as due to an attitude produced by the family that goes beyond merely identifying the needs of the sick one since it is in their care. Such dialogue is here set in motion as possible expressions to be perceived in a face with eyes and face, extrapolating verbal communication.<sup>20</sup> However, professional practice distant

from this because, while the actions and attitudes of health professionals are mechanized, showing little sensitivity to each other; it should be noted, too, the little appreciation of nonverbal communication in their relationship with the people.<sup>21</sup>

“Availability” is also an attitude towards other’s care, as demonstrated by José in his “way of being” with his mother, stricken with psychological distress in an advanced stage:

*I talk to her about ten [emphasis] minutes on the phone and say - ‘Oh mother, I’ll call you in fifteen minutes.’ Then I turn away about fifteen minutes. Yeah, and then talk to her some more: - ‘Oh! I’ll call you in half an hour.’ So, if I tell her I’ll call you later, these fifteen minutes she waits for my call, she gets quiet. If it passes, she starts to become more agitated. Then, I’ll go and call to her again. (José, Resiliência family)*

By being available for the mother, José demonstrates that he is ready to give care when necessary. His narrative pronounces the availability as a “being there at any time” to each other, whenever necessary, offering his time to caring.

The provision in the care relationship shows plasticity and has a catalytic ability to puts care in motion, and enhances the experience, since everyday situations allow people to act and are willing to take care.<sup>2</sup>

The “presence” is also set up as an essential attitude towards each other so that care occurs. Being present confers a membership perspective to the relationship, that is, refers to a “being with”, it is not necessary to order those who care, because they are near and ready to care as long as it takes. As in the following scene that exposes Belchior’s mother’s attitude to look after him, “We have noticed that every time Dona Maria was addressing Belchior, she maintained dialogue, always stating that she was present, it was okay, that he did not need to cry” (observation note on Esperança family).

Dona Maria, mother of Belchior, shows him her “presence” in care, even when considered routine. Despite they are repeated, she cleans and accommodates her son not mechanically, but establishing with him a tune, allowing her to reaffirm her presence and deep connection to the maternal relationship. The mother’s voice becomes the way of strengthening ties with the child while performing everyday care. Thus, she does not plan to get his response, but rather to demonstrate her presence in the care that is waived him.

An author names a “very light technology of care” actions that are based on “pure gesture”, the contact between the subjects, this technology breakthrough in acting<sup>23,p548</sup>, in everyday experience. Thus, we can say that the voice of Maria is as a care technology engendered by her in the child’s illness experience.

The “readiness” is also present as a caring attitude, as we show in the notice that expounds on the many times that



parents devote to childcare in the short time duration of the interview:

*During our interview, Belchior had to be constantly attended by parents that time was setting up their stance on wire chair, time adjusted diet and wiped the saliva of Belchior he could not swallow. The attention of parents to the child remains throughout our meeting. There was a time when Baltasar took Belchior on the lap and placed him beside him on the couch, giving him support when moving the arm on the child's back. (Observation note on Esperança family)*

This readiness has become fundamental in the care provision under Esperança family because with the child affected progressing to finitude, care is needed even more intensely. The urgency in the provision of care for Belchior is configured as a virtue essential to a caring attitude that assumes about the other, because it produces the ability to react to the need for care, enabling his provision.

In the experiences of families Soneto and Resiliência, such readiness is also present with the same urgency, since the diseases are also characterized by unpredictability, requiring constant attention from relatives. These denoted experiences, convincingly, that this readiness to care is the care of demand or its unpredictability and is present especially through mobilization of affection that permeates the bonds within the family.

Studies on professional care perspective define readiness as sitting by the ill person, making their way, knowing them, to recognize their care needs and create with it a life space.<sup>24</sup>

Sensitivity, availability, presence, and readiness are attributes of offering personalized and proactive attitude that assumed with the needs of others, conform "being with others" in care.

In the following statements, we highlight some of those attributes in the attitude taken by professionals. The first narrative is the Soneto family experience, specifically on an examination conducted by a medical professional to diagnose possible sequelae of stroke in Cecília and prevention even in Olavo. The second section is about the Resiliência family at the time of the first diagnosis to Dona Ana.

*[...] We made this assessment with her [refers to the medical neurologist] thank God, because it was not sent to be evaluated by her, but as she did the Doppler she was talking all. Then at the end she sat down, she talked to me, she showed me, then, it was a note that she gave me [emphasis], but it was not an appointment. You got it? However, as soon as she spoke, she finished the examination of the children, she sat up, she gave me a special attention, she talked to me, she said, I guided me a lot, and so I reassured [emphasis]. (Clarice, Soneto family)*

*Then we take her [refers to the mother Ana] in doctor Angelica, there Dr. Angelica did tests on her, it was almost two hours talking to her. With her, then with my brothers, then with each one. [On the care of psychiatrist]. (Ivete, Resiliência family)*

In the narrative, the verb "talk, sit, show, explain and guide" are highlighted and, also, there is the expression "special attention," which allows us to identify attentive listening, dialogue, being to another, the concern and zeal, reaffirming the virtues discussed above. Thus, for these families, these professionals demonstrated a caring attitude on these meetings. We can affirm it as such, considering that the care in one of its meanings, refers to caring, to care, to genuine attention that is deposited to a person.<sup>25-26</sup>

The importance of this attitude in being with another in care, especially among professionals and sick people, it is shown in Clarice's narrative to expound on the elements considered important to be willing to care for others as a nursing technician, starting from that, in her experience of taking care of children, aims professional attention:

*Then, there are certain postures that with the experience I had in my house [emphasis]; I end up also bringing to the professional field. [About her current experience as a nursing technician]. So, it helps me a lot, because I try to do my job with love, I give myself what I do, that is the right word! I do the best I can. [About her role as a nursing technician]. (Clarice, Soneto family)*

We can see that the care and family illness experience gave Clarice a desire to have sensitivity, availability, accountability in care, striving to give her best in the relationship established with people. Thus, to take and get involved allows us to say that Clarice offers professional care practices insofar as they are based on attitudes of care.

Also, when Clarice says that her family experience reflected in her professional practice, we can reveal that it is important to "be in someone else's shoes" to take care. What enables us to reflect that to be with each other in the care one must take hold of the attitudes that we would like to receive. So, we put in with all the commitment and potential to care.

Without care actions, attitudes, the interaction with the other will become "not a caring relationship." An author states that the relationships that are characterized by not caring behaviors become the most remarkable experiences of people, sometimes the lack of care becomes traumatic.<sup>25</sup> Therefore, ways of being/living with each other allow the manifestation of care; and when it comes to professional performance, one should pay attention to the positive or negative effects of professional practices in people's lives, especially for the chronicity of the situations in which they operate, where the lack of professional care can have

devastating effects on them in extent that exhausts their potential care.

Thus, it appears that health professionals reflect on the “ways of being/living with each other” in their practices. This is because the value of human relationships is an indispensable tool for care.<sup>21</sup> An author points out that the sensitivity with the other is a competence of the nurse professional to be designated as a care nursing profession,<sup>27</sup> highlighting the importance of the discussion presented here, as it allows to reflect on how we have behaved in with others in care, since our attitudes determine the ability to bring practical, truthfull care.

The example of care of Maria, mother of Belchior, can be taken by health professionals as an important lesson for modeling care, since such practices have offered little open dialogue with people who say they care, preventing necessary virtuous attitudes to the fact of care exists. We hope that the ways of being/living of the family, presented in this study can be an inspiration for health professionals also becoming care of professionals to the sick people and their families.

## CONCLUSION

Based on family experiences of care in a chronic illness situation, we infer that the professional care should be guided in line with the specific needs of sick people and their families and can then answer them. To this end, healthcare professionals must be willing to settle their practices in a plasticity to provide them with a caring modeling that is in tune with the dynamics of lived situations, such as family can engender.

Producing such modeling will enable health professionals to offer personalized care to consider the singularities of illness of each person. Additionally, it may become support and care of reference for the family, adding to their potential care, building care “with” it.

This construction urges that the professional be “willing” to offer personalized and active attitude to the care, based on a sensitive eye for the needs of others, willingness to work, presence with the sickened person /family and readiness to mobilize all know and can do, establishing care relationships with people.

To encourage that relationships, materialize in health professional practices, we believe other studies are necessary which point out how health professionals can achieve the necessary harmony with the other care. Thus, we need to deepen the reflection on more friendly professional practices for the attention of space-time in the family’s daily life, as this is strongly affected every day by the occurrence of a chronic illness situation, needing to be rearranged to allow for good living. It also takes as discussion; the activities and attitudes conducive readiness to take care to be undertaken by professionals, embodied in sensitivity, availability and welcoming the presence of new ways of care need to people and families experiencing such a situation.

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