



Men's position in family care on situations of chronic illness*

Lugares do homem no cuidado familiar no adoecimento crônico

Lugares del hombre en el cuidado familiar en el proceso de enfermedad crónica

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ABSTRACT

Objective: To understand the care by men in situations of chronic illness of one or more of his children, based on the dimensions of care. **Method:** It was based on a comprehensive approach and on the (re)view of the database of the matrix research to which the study is linked, with emphasis on three experiences of illness, in which the men effectively participated in the family care: two children with sickle cell anemia; son with adrenoleukodystrophy and son with concomitant diseases (cancer and kidney disease). **Results:** The analysis diagram of each family demonstrated different ways of caring, explaining the relationship between the dimensions of care by men: social; affective/relational and physical/circulation, as well as the reverberations between these dimensions in the care. **Conclusion:** This understanding is important for health professionals to consider and respect the personalities, dignity and particularities of each family. It also gave visibility to care that has been significantly provided by man, thus supporting him in this process.

DESCRIPTORS

Child; Chronic Disease; Caregivers; Parent-Child Relations; Family Relations.

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INTRODUCTION

This study explored the experience of care performed by men from families with one or more children with chronic illness. Care within the family has been highly valued, since the family reorganizes itself to provide the 'best in health' for each of its members in the various situations of life⁽¹⁾. Family is defined as a system with affective, social and economic ties, which has its own dynamics in the daily relations between its members.

The family environment is an important space to provide daily care, and the family is considered a primary care unit, which is organized to search for, to provide and to manage care for each family member 'in' and 'for' life⁽¹⁾. And, of course, when illness strikes, it affects the family and intensifies the need for care, and, to meet these demands, rearrangements become necessary.

And if, on the one hand, responsibility to care is historically attributed to women, on the other, several studies point out that men have been increasingly available and proactive and, in many cases, their participation in family care stands out⁽²⁻⁴⁾.

The discussion about the care provided by men in situations of chronic disease is necessary and relevant, especially in times of policies that focus on Men's Health with the objective of improving their health status⁽⁵⁾. A brief analysis of this policy showed that it emphasizes the men's perception of his own health care and of his family's health, focusing mainly on self-care. It considers health care only in relation to some prevalent conditions and does not consider men as an actor that also provides care in the family environment. Thus, it is pertinent to cogitate a care that goes beyond the scope of illness and positions itself as a care for life, considering that in the family environment the man also cares for other people.

Care, whether if provided by a man or a woman, is shaped by the relationship between the caregiver and the care recipient, and parenting relationships have an important role in this process, although not a decisive one. The study points out that the mother-child care relationship has been more commonly studied, mainly in relation to child development⁽⁶⁾. However, we understand that care by men is becoming more and more present, particularly in the relation of fatherhood and, especially, in situations of chronic illness.

Therefore, it is necessary to look at this care and understand its characteristics and its dimensions. In this study, the concept of "Dimension of Care" designates its different contexts, from the social, affective-emotional, physical, and circulation perspective. The objective was to understand the care by men in situations of chronic illness of one or more of his children, considering the dimensions of its production.

Most research on family care has the woman as main source of information. Therefore, this type of care has been regarded especially from the feminine perspective – which may reinforce historical and social trends of considering

women as the main responsible for health care in the family environment⁽⁷⁾. The preference for women as interlocutors, which has not been really questioned, reinforces the exclusion of men, who have only few opportunities to manifest.

METHOD

In order to understand the family's daily life and the context of life in which care is provided by man, this study was guided by the comprehensive approach – a research method that allows the sensitive apprehension of the fluid and dynamic reality of the human experience (and in it) the family experience of care⁽⁸⁾. To do so, it is essential that the researcher remains open, sensitive and attentive so that he can embrace the dimension of the experience and, in it, the senses and meanings of the family experience of care.

Our *corpus* for analysis came from the Matrix Research Database⁽⁹⁾ and consisted of information from family experiences of illness and care in the context of SUS in Mato Grosso. We intentionally selected three families in which men, as fathers, were very present. The families were fictitiously named: a) Assis' family, with two children with sickle cell anemia; b) Baltasar's family, with one child with adrenoleukodystrophy and c) Olavo's family, with one child suffering from concomitant diseases (cancer and kidney disease).

The open posture adopted to apprehend these families' experiences and the meanings given to disease and care was consonant with the Life History research, since it gives priority to people's experiences according to their own perspectives and expectations⁽⁹⁾. Thus, this was the primary strategy to collect information from each family. The data collection was performed through In-depth Interviews (EP, Brazilian Portuguese acronym), conducted as intentional conversations guided by the question: "Tell me how has been your experience with illness and search for health care". Thus, the rest of the interview was directed by the person interviewed and the researcher, gradually deepening the narrative threads of interest for the research. Several meetings were necessary for this study⁽⁹⁾. The interview was complemented by observation, and both were transcribed and organized in the research diary. In summary, the corpus of this study consisted of the diaries of the three family histories, which totaled 558 pages typed in Microsoft Word, font Times New Roman, size 12 and 1.5 line spacing.

In the analysis procedure, we conducted a first reading of each experience, highlighting elements that referred to the positions occupied by men in family care. From these, we create a first descriptive-organizing table, with excerpts from narratives, context, description and insights related to these various dimensions in each family. This exercise broadened the view, and required a second analysis-synthesis table about care by men, considering it

according to the social, affective, relational and physical/circulation “dimension”.

From this last table, we created a diagram for each family in order to elucidate the relationship established between the different dimensions of care by men in the very act of producing it or in its repercussion, showing that these “dimensions/contexts” are not fixed and are associated with each other. The set of diagrams of the three experiences of care by men directed us to the following analysis categories: social dimension; affective/relational; physical place/circulation and reverberations between the various dimension of care by men. Of the 20 care scenes identified in each care situation performed by men, we selected six for this display.

This study followed the ethical principles for research with human beings, it was approved by the Research Ethics Committee protocol No. 671/CEP-HUJM, containing the composition of a Research Database the possibility of review, included in the Informed Consent Form signed by the subjects of the study.

RESULTS

To understand the care provided by men in situations of chronic illness, it was relevant to understand his life context within his family, which supported us in the description of the details of the events. Thus, we were able to clarify the care provided by them, considering the implications of illness in the everyday life of men, articulated with the other members of the family.

The first family to be presented is the family of Olavo, a 48-year old semi-literate small rural farmer who lives on a ranch in a city located 240 kilometers from the capital of the state of Mato Grosso. Olavo is married to Rita, who does the housework at the family ranch. Olavo and Rita have four children, two men and two women. Marco Antonio, one of their children, aged 21, suffers from concomitant diseases: kidney disease, which began in childhood, and cancer (non-Hodgkin's lymphoma), which was diagnosed in early adolescence.

The second family is the family of Baltasar, 49, a high school graduate who works as a plumber in a construction company. He is married to Maria, 50, a public servant in the general services sector of a health institution in the city of Cuiabá - MT, where the family lives. The couple has two children, Mirra, a 13-year-old teenager, and Belchior, a 10-year-old child with adrenoleukodystrophy (ADL) since age 7.

The third family is the family of Assis, a 40-year old man with complete higher education who works in a large company in Cuiabá - MT, where the family lives. Assis is married to Clarice, 34, who works as a Nursing Technician at a public institution. The couple has two teenage children, Olavo and Cecilia, who are 14 and 13 years old, respectively. In this family, three members have the same health problem - sickle-cell anemia - namely, the father and the

two children. The mother has only traces of the disease, without symptoms.

In the three experiences, there was significant participation of the men in the care for the sick children. As primary analysis revealed some common elements to the experiences: a) type of the disease - the experience of taking care of a child/children with a chronic disease requires continuous and prolonged care, as well commitment from the man, his wife and other family members; b) child's age - the illness occurs soon after birth or during childhood, and persists through adolescence; c) father's age - all three are adults, aged between 40 and 50 years; d) search for institutions devoted to children's and adolescent's rights - the three men persistently sought legal institutions to ensure their children's right to health.

We also point out some different elements in these three experiments. Regarding the family arrangement for care, in the experience of Baltasar, despite his large family, only he and his wife share the care. This is because his son is severely compromised by adrenoleukodystrophy, which makes this care very specific and demands an accurate perception, dependent on daily proximity to the child.

In the family of Assis, care began in the first months of the children's lives, due to the intense signs and symptoms of the disease. Professional attention was given both in the outpatient unit and in the emergency service, and the care was performed mainly by the couple.

In Olavo's family, who lived in a rural area, care was organized in a way that, on most occasions, he would only go with his son to search for treatment in the city, because he was the person who could move more easily.

As for the level of education, Assis has a higher education degree, which facilitated access to knowledge about the disease. Also, as a member of the association of people with sickle cell anemia in the state, he was able to attend seminars that addressed the subject. Baltasar has a high school diploma, and has shown that he is able to provide proper care, even if it is a technical one, as he has learned during the experience of illness. Olavo, who has not completed elementary education, was attentive to the medical guidelines, which represented a good part of his learning, and could remember details of the professional recommendations and recognize situations of aggravation of the disease.

These situations of life and illness - so diverse and at the same time so common - show the particularities of families when dealing with illness and the different conditions of the care required by their sick children, in a prolonged and/or permanent control and treatment routine⁽¹⁰⁾.

Next, we present the care provided by each man, through the “Representative Diagram of the ‘positions’ he occupies”. Each image presents small scenes of care, through small narrative excerpts. These scenes are located in columns called “Social Dimension”, “Affective Dimension”, “Relational Dimension” and “Physical and Circulation Dimension”, each one with the respective colors: blue, orange, green and red. From the place where each narrative starts, there are lines and stars that go to other places

where the actions and attitudes of care by men reverberate, giving the idea of the plurality of dimension of care related to the same scene.

Then we explain the conception of each “dimension of care” by men, while we dialogue with the corresponding diagram, then stop in the scenes of care that it contains.

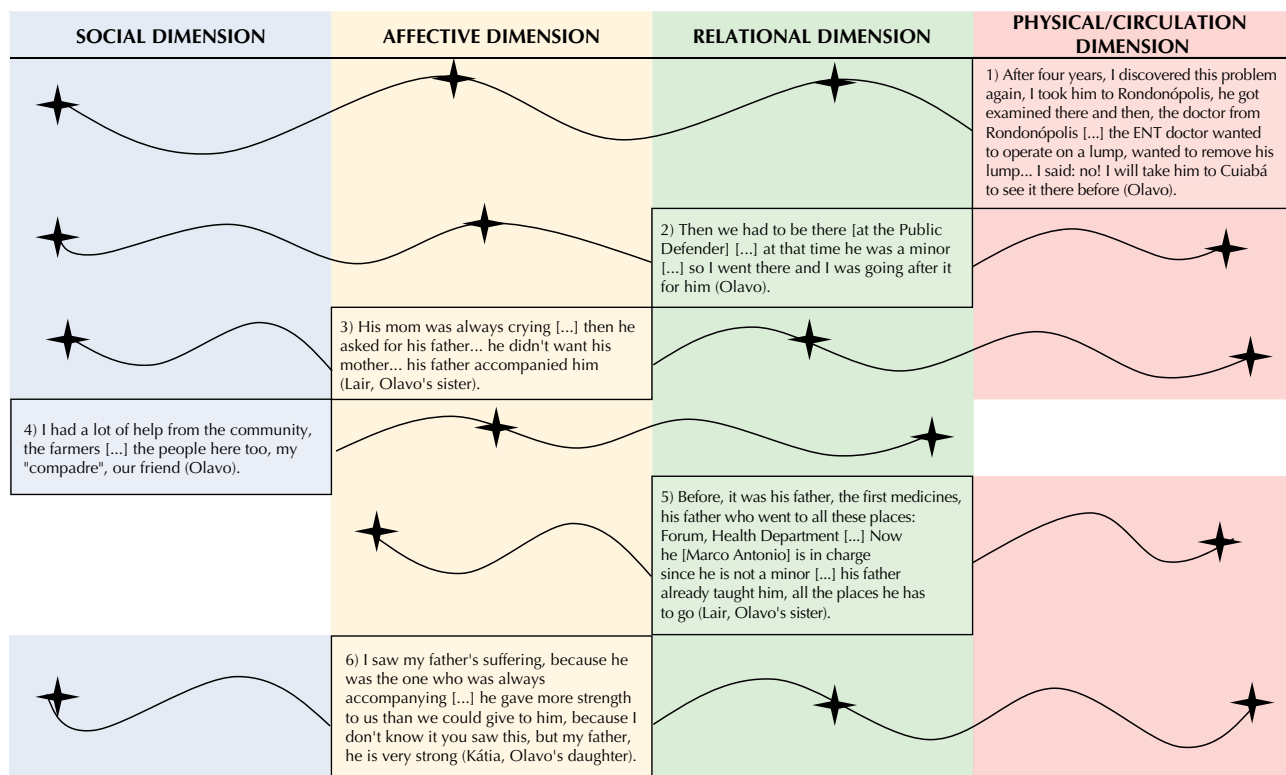


Figure 1 – Representative diagram of the “positions” occupied by Olavo.

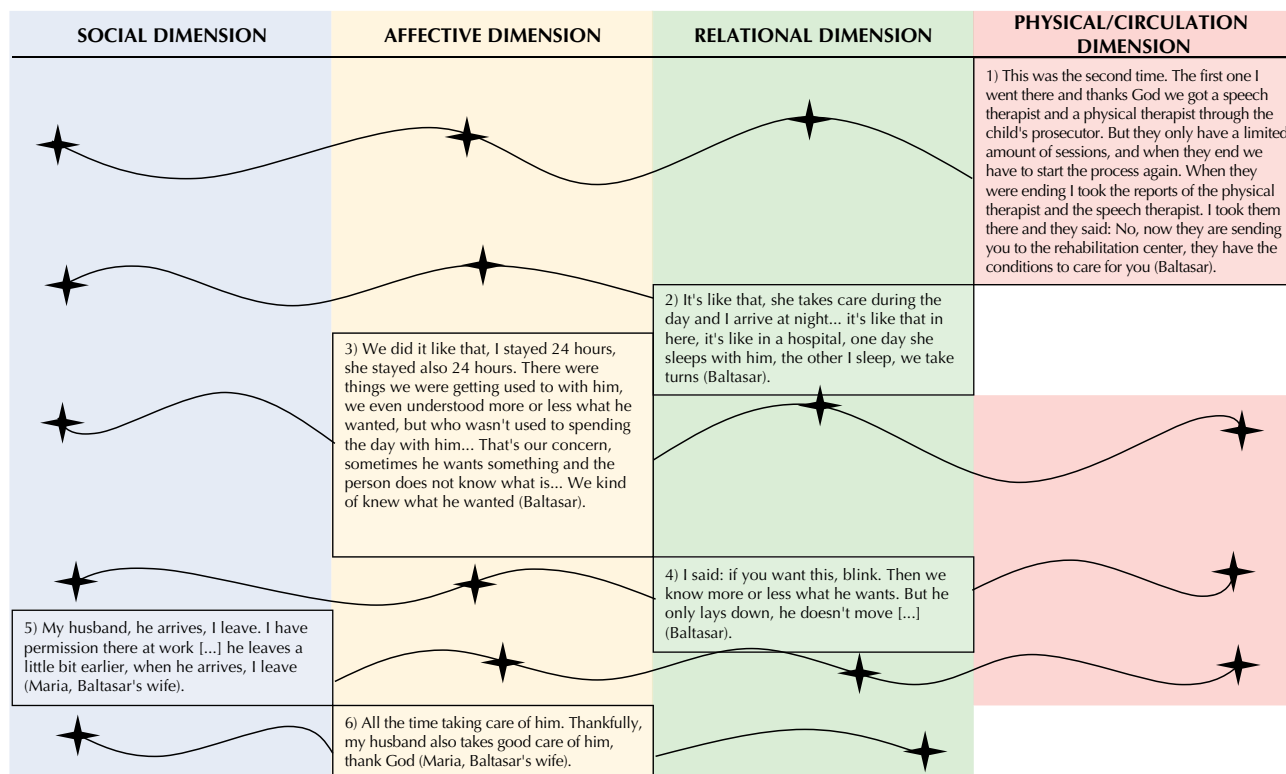


Figure 2 – Representative diagram of the “positions” occupied by Baltasar.

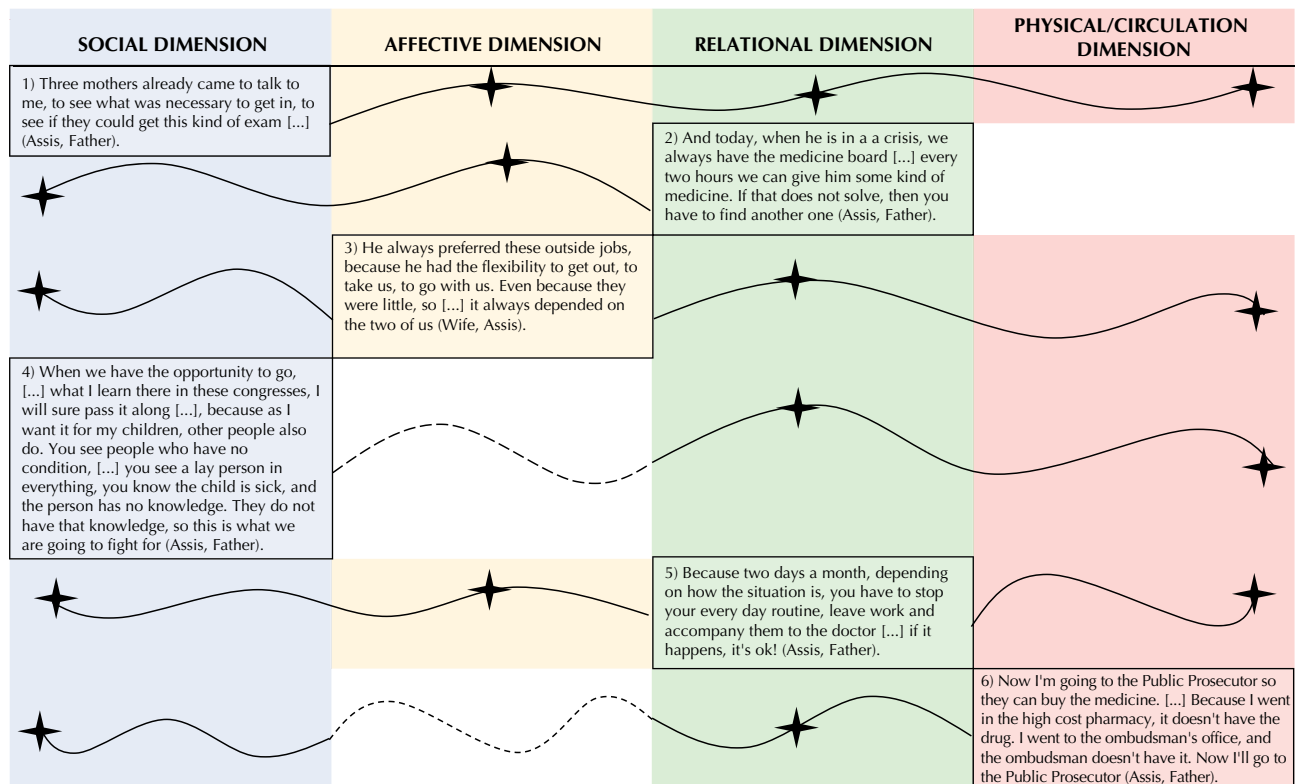


Figure 3 – Representative diagram of the “positions” occupied by Assis.

DISCUSSION

SOCIAL DIMENSION OF CARE

The social dimension of the care provided by men is directly related to the history of mankind and the complexity of the transformations that have occurred in society over time⁽¹¹⁾, dependent on the evolution of relations, the development of societies, technological advances, among other factors. In the families of this study, we observed that men placed themselves at the front line of care, sharing it with the other family members. The position of caregiver assumed by them was intense, gaining importance in family history and in other environments.

The social dimension of care for Assis (Figure 3, Scene 4) materialized through his desire to seek knowledge to improve the health of his children in congresses or through his participation in the association of people with sickle cell anemia. Still, he considered important to share his knowledge about care, acquired over the years, with other parents. Baltasar recognizes his importance in the care of his son Belchior when he negotiates the reduction of his working hours (Figure 2, Scene 5). This arrangement allowed him to stay with his sick son when his wife left for work.

The experience of having a diagnosis of a chronic disease causes changes in the family dynamics, and the person and his or her family must find new ways of living among themselves and in society. The illness is considered not only as a variation of the health dimension, but as a “new dimension of life”⁽¹²⁾, which, if it lasts for a long period of time,

generates its own normalities in daily life. This normality means “being able to deal with challenges by overcoming adverse conditions, in the attempt not to restrict the way of leading one’s life to the limitations of chronic conditions”, but being awake, open and always on the move to create new ways to be happy⁽¹³⁾.

As it is affected by the repercussion of illness, the family will rearrange its way of life to provide the necessary care to the family member and begin to carry out activities that were not part of their daily life⁽¹⁴⁾. These rearrangements sometimes take the form of support networks that help them to effectively meet the varied and dynamic health needs of their children.

In the situation lived by Olavo, the community was very important (Figure 1, Scene 4), since the family, who lived in a rural area, had financial difficulties and obstacles to access health services. The community recognized the importance of the treatment of Olavo’s son, which occurred in other cities, particularly in the capital of the state, and supported the family with resources of different dimensions – social, emotional, financial, among others – and this assistance was vital to the family.

This assistance came from both the wealthiest, the farmers, and from humble people, the ‘compadres’, including the principal of the school where his son studied. Thus, the lack of resources of various types in rural areas is overcome by the solidarity of the members of the community, who provide mutual assistance within their means.

According to a study⁽¹⁵⁾, a particular trait of these communities is their focus on access to resources related to

health care, since they rearrange themselves according to the problem presented and the answer it requires. The bonds between the members of these networks, and between these members and the person helped, are also activated in different ways, depending on the situation. When discussing the social dimension of care, the understanding of these ties is related to the social and affective relation between men and a support network that can help him and his family in situations of need.

AFFECTIVE AND RELATIONAL DIMENSION OF CARE

The relationship of the men/fathers with their children was filled with affection, demonstrated in the fathers' concern for their children's health and in their vigorous search to meet the many needs of the disease. To that end, they shared care with other family members and accompanied their children to health services most of the time.

Olavo built such a close and trusting relationship with his son that, when he was being treated in the capital he asked for his father, even more than for his mother (Figure 1, Scene 3). This happened because the father could control his strong emotions in the critical moments of the disease, showing greater confidence to the son.

It is also possible to perceive the affective involvement of fathers in the rearrangements they made in their lives to take care of their children, even in socially valued areas such as work, where this kind of change is usually restricted. Thus, recognizing the demand for care, Assis opted for an employment bond that would give him flexible hours, so that he could accompany his children to routine consultations, examinations and hospitalizations, whenever there was an aggravation of the disease (Figure 3, Scene 3).

Baltasar, on the other hand, discusses the difficulties he and his wife faced to provide 24-hour care to their child, which was required by a disease that leads to total dependence and death (Figure 2, Scene 3). In this situation, parents are afraid to leave the child with other people, because the care is very specific and meticulous, with the addition of the child's difficulty to communicate and expression through gestures and inarticulate sounds, understood only by parents in the proximity and continuity of daily care.

In this sense, we understand that Baltasar's care for his child is intimately based on an affective relationship, demonstrated through feelings and within an artisanal dimension, referred to as "care modeling", alluding to the idea of an artisan that, in his work, gives form to the clay in a singular and personal way⁽¹⁶⁾. This modeling results from the fullness and flexibility that life requires. Modeling care as a work of art implies, therefore, being intimate with it, feeling it, accepting it, respecting it, giving it some peace and quiet. Caring is being connected with things. To listen to the rhythm and being in tune with it⁽¹⁷⁾.

As an author affirms⁽¹⁸⁾, care assembles different knowledge, it is wisdom that does not create products, does not generate systematic and transmissible procedures, does not create universal truths, since it only fits in the very moment it is necessary. Anyhow, family care is constructed based on how the person and the family experience the disease, their

affective relationships and the conditions and possibilities they have to provide this care⁽⁸⁾.

In the three life situations included in this study, each family experiences countless small care acts that are quite effective and whose provision by the father/man is mediated by bonds of affection and dedication.

PHYSICAL AND CIRCULATION DIMENSION OF THE CARE

The fathers/men in this study circulated in different spaces – health services, legal and social institutions – that provided access to the best there was in terms of therapy for the needs of their children.

Assis knew in detail the procedures and paths to be followed to ensure the rights of his children by legal means (Figure 2, Scene 6). However, to follow this path to guarantee his rights, he needed to go to several health and legal institutions, in a difficult and exhausting journey for him and for his family.

With the onset of his child's kidney problem still in childhood (Figure 1, Scene 1), Olavo, who lived in a rural environment, rearranged his daily work as a farmer so he could search for care in cities that offered more support in terms of specialized care. And, despite being a person with little education and simple habits of rural life, he was resourceful and showed initiative in formal spaces that were unfamiliar to him, such as legal institutions with its many rituals⁽¹⁹⁾. His active posture and his circulation in unfamiliar spaces made Olavo be recognized by his family as the most prepared person to accompany his son to the health services and other places.

REVERBERATIONS BETWEEN THE VARIOUS DIMENSIONS OF CARE BY MEN

It was possible to perceive that each disease and care situation presents particular characteristics. However, the care provided by the man/father in each dimension reverberates in the others, as perceived in some scenes in which the focus of discussion was precisely the dynamics between the different dimensions of care.

Assis knew the legal paths to be followed to ensure the rights of his children to some extent. As an active member of the sickle-cell anemia association, he became a reference for other parents, who sought his guidance to ensure the rights of their children (Figure 3, Scene 1). In this scene, the social position occupied by Assis and the repercussion of his actions in other "dimensions" stand out, because what motivates him in the search for knowledge is his close and intimate relationship, besides the affection he feels for his children. We perceive that, rather than remaining in a given social place – the association – his proactive attitude led him to move through different places, such as legal institutions.

This perception is corroborated by the experience of Olavo, a semi-literate man used to a simple rural life, who, affected by his close relationship with his son, "took the lead" in the search for his right to health, going to legal institutions and following the outcomes of legal actions (Figure 1, Scene 2), besides caring for his son during hospitalizations,

consultations and daily life. In this scene, given the proximity of the father-child care relationship, Olavo occupies a relational and affective position, from which his attitudes and dynamic actions reverberate in other places, increasing his potential for care. This situation led us to consider that circulation through spaces that may have greater decisiveness for the care of the child, even if outside the geographical area of the rural man's life, is motivated by the affection felt for the person cared for.

Baltasar reports that, faced with his son's illness, he went through several paths to provide him with the necessary therapies (Figure 2, Scene 1). Then, realizing that he would not be attended, he organized documents that could prove these needs and accessed legal services to ensure his rights. This movement is categorized in the physical and circulation dimension of care, but reverberates the concern and zeal of the father-child affective relationship, which enhances the search for care in places that diverge from their daily circulation.

This situation is in accordance with other authors, who point out that participatory fatherhood is a resumption of an affection that is intrinsic to the human being⁽²⁰⁾. This way, the fathers/men are capable of loving, being moved, suffering along and finding joy with their children, becoming warm and tender, prone to create deeper and deeper bonds with those they care for.

CONCLUSION

In this study, we highlight the participation of the father/man in the dimension of care in different life situations, especially in the manifestation of a chronic illness in one of his children. It is fundamental to understand the senses and meanings attributed to this experience, recognizing the value of men in various ways of producing care.

We realize that, faced with the many needs of care presented by their children, men immersed themselves in various contexts, here considered as "dimensions of care", whether in the relational, social, affective or physical and circulation dimensions. In these different "dimensions" they had to overcome difficulties and social and cultural barriers in a society that does not see men as usual providers of care, that is, this care is an attitude different from the socially conceived one. The proactive attitude of men regarding the needs of their children is what leads the father, along with his family, to seek the best for the health of his children, motivated by the affection in the father-son relationship.

We emphasize that the "dimensions" of care by men go beyond the conception of geographic space, since they are related to the organization of the family daily life and the multiple rearrangements necessary for the search, production and management of this care. In this context, the trajectories followed by the man and by the family are responses to the confrontations resulting from the chronic illness of their children.

The image presentation of the diagrams allowed us to understand that the "dimensions of care by men" are not fixed or exclusive, but reverberate on one another, mobilizing different resources and possibilities in the modeling of care for each of these men. We consider this care as very personal and situational.

We consider that important elements have been provided for the reflection on the position of men in the care of the children, enabling professionals and health policy makers to conveniently conceive practices to support this care, especially when related to situations of chronic illness.

RESUMO

Objetivo: Compreender o cuidado pelo homem na situação crônica de adoecimento de um ou mais de seus filhos, a partir do "lugar" em que tal cuidado acontece. **Método:** Pautou-se pela abordagem compreensiva, a partir da (re) vista ao banco de dados de pesquisa matricial à qual o estudo se vincula, com relevo a três experiências de adoecimento selecionadas, em que o homem se posiciona de forma efetiva no cuidado familiar: dois filhos com anemia falciforme; filho com adrenoleucodistrofia e filho com agravos concomitantes (câncer e doença renal). **Resultados:** O diagrama analisador de cada família possibilitou compreender as diferentes formas de cuidar, explicitando a relação que se estabelece entre os diversos lugares do cuidado pelo homem: social; afetivo/relacional e físico/de circulação, bem como as reverberações entre esses lugares no cuidado como um todo. **Conclusão:** Tal compreensão se mostra importante para que os profissionais de saúde considerem e respeitem a pessoalidade, a dignidade e a singularidade de cada família, conferindo também visibilidade ao cuidado moldado significativamente pelo homem, amparando-o, então, nesse processo.

DESCRIPTORIOS

Criança; Doença Crônica; Cuidadores; Relações Pais-Filho; Relações Familiares.

RESUMEN

Objetivo: Comprender el cuidado por el hombre en la situación crónica de enfermedad de uno o más de sus hijos desde el "lugar" en que ocurre dicho cuidado. **Método:** Se pautó por el abordaje comprensivo, a partir de la (re) vista al banco de datos de investigación matricial a la que el estudio se vincula, con relieve para tres experiencias de proceso de enfermedad seleccionadas, en que el hombre se posiciona de modo efectivo en el cuidado familiar: dos hijos con anemia falciforme; hijo con adrenoleucodistrofia e hijo con agravamientos concomitantes (cáncer y enfermedad renal). **Resultados:** El diagrama analizador de cada familia permitió comprender las distintas formas de cuidar, explicitando la relación que se establece entre los diferentes lugares del cuidado por el hombre: social; afectivo/relacional y físico/de circulación, así como las reverberaciones entre esos lugares en el cuidado como un todo. **Conclusión:** Dicha comprensión se muestra importante para que los profesionales sanitarios consideren y respeten la personalidad, la dignidad y la singularidad de cada familia, otorgando también visibilidad al cuidado forjado significativamente por el hombre, amparándolo, de ese modo, en dicho proceso.

DESCRIPTORIOS

Niño; Enfermedad Crónica; Cuidadores; Relaciones Padre-Hijo; Relaciones Familiares.

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