

# The (re)organization of the family care center after facing the impact of the chronic situation of cardiovascular disease

*A (re)organização do núcleo de cuidado familiar diante das repercussões da condição crônica por doença cardiovascular*

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**ABSTRACT** This article aimed to understand the (re)organization of the family care center a result of cardiovascular disease chronic condition. This is a case study guided the approach conceived as in the Calgary Assessment Model in the Family. The unit of analysis was a family experiencing the cardiovascular disease chronic condition of one of its members. It was that, as the daily routine adapts to the changes generated by the hospitalization a new family configuration of daily living is set up. The implementation of strategies that include the family in hospital discharge planning is suggested.

**KEYWORDS** Family relations. Caregivers. Chronic disease. Cardiovascular diseases.

**RESUMO** Este artigo objetivou compreender a (re)organização do núcleo de cuidado familiar diante das repercussões da condição crônica por doença cardiovascular. Trata-se de estudo de caso norteado pela abordagem familiar concebida como Modelo Calgary de Avaliação na Família. A unidade de análise desta pesquisa foi uma família que vivencia a condição crônica por doença cardiovascular de um de seus membros. Evidenciou-se que, conforme o cotidiano se modifica pelas mudanças geradas com a internação, começa uma nova configuração no modo de vida da família. Sugere-se a implementação de estratégias que envolvam os familiares no planejamento da alta hospitalar.

**PALAVRAS-CHAVE** Relações familiares. Cuidadores. Doença crônica. Doenças cardiovasculares.

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## Introduction

In recent decades, the predominance of Chronic Noncommunicable Diseases (NCDs), caused a demographic transition with a potential to significantly change the epidemiological profile of Brazil (WHO, 2003).

According to the Ministry of Health (2011), NCDs are the leading cause of death worldwide yielding a high number of premature deaths and loss of quality of life, compromising work and leisure activities, and causing an economical impact for families, communities and society in general.

These chronic conditions usually require ongoing management over a long period of time. Thus, according to Weis *et al.* (2013), such overloads evoke numerous consequences also for the family of the ill person, as people with chronic conditions are dependent on this social environment for the continuity of care. The need for the constant presence of a family member to manage the necessary care of the patient requires the reorganization of family structure, and often the family assumes the role of primary caregiver during the whole course of the disease.

Among the NCDs, cardiovascular diseases (CVDs), defined as diseases affecting the heart and arteries including heart attack, stroke, cardiac arrhythmia, ischemia and angina, have a high prevalence, often present associated complications and have considerable impact on morbidity and mortality of the population (WHO, 2003).

The chronic illness condition causes numerous repercussions both in the patient's life and in his/her family, because the continuous and prolonged care necessary for disease control and the prevention of sequelae is taken over by the family. In the event of a crisis caused by a disease process, the family will initially experience a decline in their ability to function, causing changes in respect to emotions, finances and power relations that lead to a process of family reorganization (MARCON *ET AL.*, 2005).

Thus, the 'family' subject has been widely discussed, and in the nursing field, it has been an object of study since the 1950s, with its peak in the 1990s in Brazil. However, the concept of 'family' is complex and is influenced by the historical, social and cultural environment in which it is enclosed; family relations, to some extent, affect the health and disease process of its members, as well as the interpretation of the experience of each family member facing this process (MATTOS, 2008).

To Elsen (2005), the family acts as a health system for its members, overseeing, making decisions, monitoring and evaluating the health and illness statuses of its components. As such, it reaffirms its position as a care unit for its members, infusing their actions towards health professional guidelines with its cultural universe and interactions with the environment.

Given these considerations, some questions arise about the impact endured by a person and his hospitalized relative and the way each family member responds to the changes demanded by the situation. The purpose of this article is to understand the (re)organization of the family care center on the repercussions of a cardiovascular disease chronic condition.

Understanding the implications and significance that emerge from the care needs required by a chronic illness experience, and identifying the resources used by the family contributes to a greater support be given by the health team to family care. Therefore, a more effective care and a better quality of life can result for the family and for the patient.

## Methods

This is a qualitative study of descriptive exploratory nature conducted by a case study methodology. Data was collected using semi-structured interviews, field notes and document analysis.

The study was approved by the Human

Beings Ethics and Research Committee of the University Hospital Júlio Müller (CEP / HUJM) and by the study institution (UFMT), under No. 344.973 as recommended by the National Health Council Resolution 466/2012, protecting participants in respect to confidentiality of information, as well as privacy and anonymity.

As study subject, a family experiencing the cardiovascular disease chronic condition of one of its members was selected. Inclusion criteria were family members living in Mato Grosso, who were experiencing an adult or elderly relative with cardiovascular disease for admission to the medical clinic of the University Hospital Júlio Müller. Through active search, we met Mr. Cravo, who agreed to participate in the study along with his family members (fictitious names were used to preserve the anonymity of the participants).

During data collection, the observation of participants from the studied family was carried out through a direct approach and contact with its members during hospitalization. The observations were made during a meeting with Mr. Cravo and his daughter Tulipa, and in three other meetings with family members who were directly caring for Mr. Cravo: his wife Mrs Rose, two daughters and a granddaughter. All interviews took place in the health care facility where Mr. Cravo was hospitalized. During these meetings, the behavior of each family member was analyzed individually and within the group, identifying the individuals that were most engaged in care, the most affected by the new condition, and the family relations with the social environment. In the interviews, the actions and emotions of the patient and his family were captured, and the information of the subjective aspects were recorded in a diary.

The semi-structured interviews were conducted with the ill person and his family. As a theoretical framework for understanding the familiar phenomena, we used the Calgary Family Assessment Model

(CFAM), which was designed to assess and propose specific interventions in the family universe. It consists of a multidimensional and systematic structure that comprises three main categories of family functioning: structural (composition, organization and characteristics of family members), developmental (stages, tasks and bonds) and functional (activities, communication and family roles) (MONTEFUSCO; BACHION; NAKATAMI, 2008). Thus, the interview with the person experiencing the cardiovascular disease chronic condition was conducted seeking his own perspective of the family concept and composition. Based on that information, interviews with family members followed.

For better understanding the studied phenomena, the Genogram and Ecomap were designed to allow visualization of the family dynamics' elements in its various existential interfaces. The interviews took place from October to December 2013, scheduled according to the availability of each of the participants, after signing the Informed Consent form. All interviews were recorded and later verbatim transcribed.

For the data processing, we used content analysis (thematic mode) proposed by Bardin (2009), defined as a set of communication analysis techniques, which allow us to analyze the meanings (thematic analysis) or significances (lexical analysis).

This method uses the Rule of Representativeness in the pre-analysis steps; the material is explored, and results are processed and interpreted. In the pre-analysis, reading has a flexible characteristic, which enables the formulation of objectives and initial assumptions that will guide the final interpretation. In the exploration of the material, we perform: transcription of the recordings; highlight of important sentences; grouping of phrases and themes and generation of categories. From exploratory procedures, it is possible to grasp the connection between the different variables and develop new hypotheses. At the end

of the analysis, content interpretation and categorization is performed (BARDIN, 2009).

In our analysis three categories emerged: 'Hospitalization impact on the family of the ill person', 'Family and spirituality as the care element' and 'The (de)tour to achieve care'.

## Results and discussion

Mr. Cravo is a calm and gentle man, who in the initial contacts showed some resistance to talk because of his speech problem as a result of cleft lip and palate correction; sometimes, when not understood, he would get frustrated and stop talking. The first contact with him was in the medical ward where he was admitted and he was accompanied by his daughter Tulipa. After a few meetings, Mr. Cravo got more receptive, often told stories and laughed about situations occurring in hospitalization; he always got emotional when speaking of family.

Mr. Cravo is a native of Paraná, has 83 years of age, is of German descent, literate, worked with carpentry, and later as a construction worker before retirement. He has been married to Mrs. Rosa for 53 years, has four children (three girls and a boy), eight grandchildren and four great-grandchildren. Since the diagnosis of cardiovascular disease, the family has been trying to generate and manage Mr. Cravo's care, even with him being resistant to treatment and hospitalization. Mr. Cravo deals with associated complications of the chronic disease, recurrent hospitalizations and limited movement due to

fatigue and dyspnea.

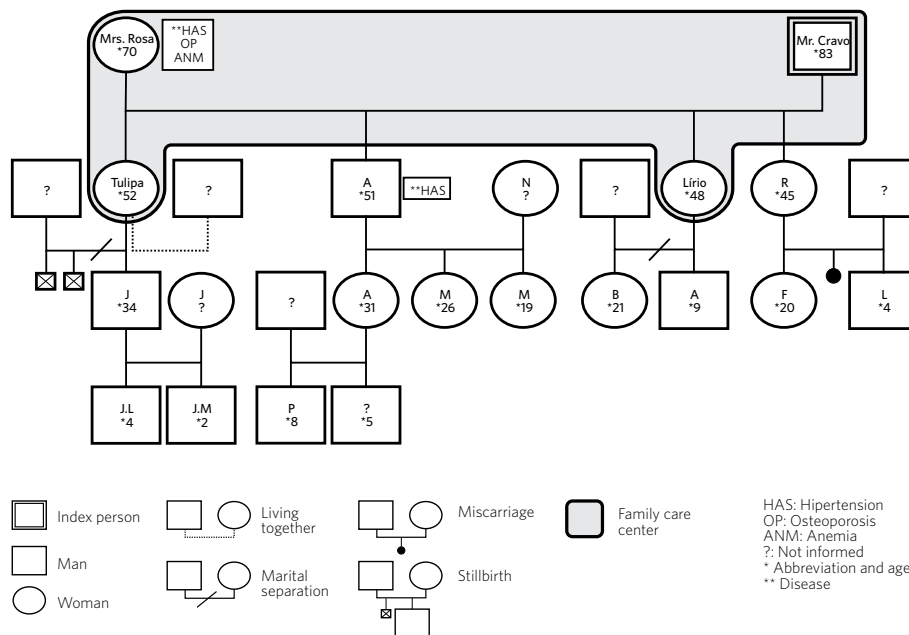
Mr. Cravo and his wife live in a house they own in the west of Cuiabá (MT) since several years. Their two youngest daughters live in the same neighborhood, the eldest daughter on an acreage in the municipality of Chapada (MT) and their son in Várzea Grande (MT). Cravo has little interaction with neighbors. His leisure is limited to family meetings and sitting on the porch, people-watching.

Mr. Cravo attends Catholic church sporadically to accompany his wife; three of his children are also Catholic and a daughter is evangelical. The family sees faith as a coping and fighting strategy in the continuity of treatment.

The analysis of this experiment was carried out through the construction of the genogram, provided in *figure 1*, and the ecomap, as shown in *figure 2*, which assist in the capture of the man's illness experience within the family and community contexts. The family has been involved in his care, which provides elements for understanding its daily living in connection with illness from cardiovascular disease.

The genogram allowed the visualization of the family nucleus and helped understand the rearrangements made to produce care. Despite being a group of eleven members only two of them were available for the support network. Mr. Cravo's family organized themselves to generate care through the rotation between his wife and two daughters, who had their daily life rearranged to be part of Mr. Cravo's care core, as shown in *figure 1*.

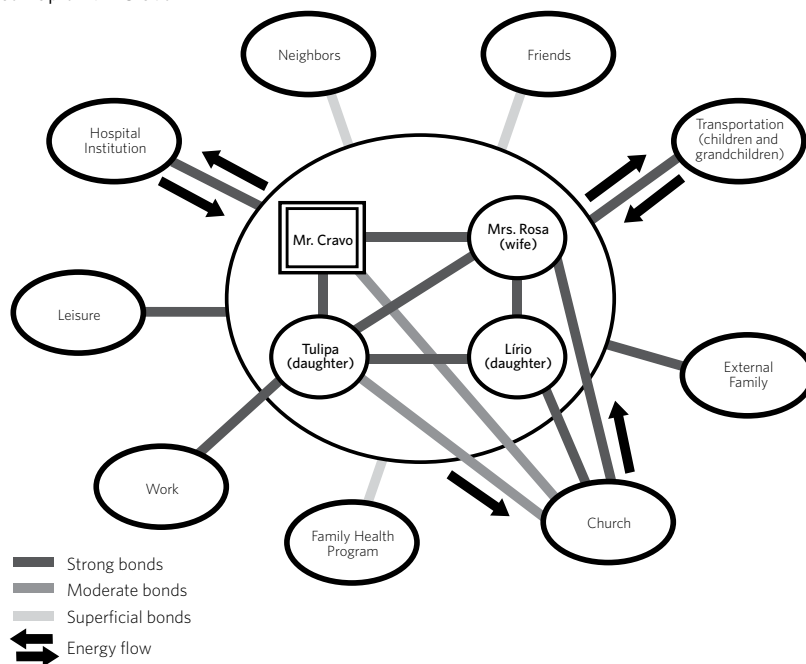
Figure 1. Genogram of Mr. Cravo's family



Source: The authors.

Mr. Cravo's family ecomap was designed considering the intra-family ties and the relations established by the support network, as shown in figure 2.

Figure 2. Ecomap of Mr. Cravo



Source: The authors.

The strong ties between Cravo and his family are grounded in the support network that enables transportation, provides emotional support and in-hospital assistance when the disease gets worse or with the appearance of complications. This raises the attention to the fragile connection of the Primary Care in the proper monitoring of cardiovascular diseases. This aspect could receive extra attention during discharge planning through the counter-referral system. The moderate bond to Tulipa is due to the fact that her duties as a wife and mother eventually hinder a greater involvement in Mr. Cravo's care, and this is in agreement with Correa *et al.* (2014) when they state in their study that:

[...] From the narrative content [...], it was noted that the care network subjects [...], depending on the motion imprinted by the production and pursuit of care, can be characterized as 'active supporter' and 'passive supporter'. The former, that is, those who present themselves as active supporters, are the people who maintain a more constant and routinely interaction with the elderly; as for the passive supporters are those with uneven and less frequent interaction. Thus, it is understood that the active supporters are those establishing close emotional and helpful 'ties' with the ill person and the passive supporter are those that need to be 'triggered' in specific moments of the illness experience of the elderly. (CORREA ET AL., 2014, P. 349).

### **The impact of hospitalization on the family of the ill person**

When hospitalization occurs unexpectedly, the family endures a great impact on their lives, associated to schedule disruption and fear of the unknown. Situations experienced within this context affect the emotions and the care dynamics that underlie family relationships. Family arrangements have to be

remodeled and adapted to new needs, which is sometimes accompanied by insecurity and emotional suffering. Thus, Mr. Cravo's daughters were surprised by the hospitalization of their father, describing in their narratives the well-being and productivity before admission.

*It was hard, it was very sad, you know ... it was not easy. [...] He was a very strong man, you know... my father until then was tending, cleaning the yard, then suddenly, there, you know, every little thing comes down, out of nowhere, everything stops, everything changes. (Lily).*

*Oh it was a very big shock... at the time my father was 61, still young, and then it was a great shock for the whole family, you know... (Tulipa).*

The impact of hospitalization not only affects the ill person, but it is extended to all family members, imposing changes and demanding the reorganization of family dynamics to incorporate into daily activities the care that the disease and its treatment require (CARVALHO, 2008) or whatever activities the person who is going through the illness can no longer perform. In the study, the actions taken by the relatives of the ill person are considered and decided in accordance with the implications of the hospital admission in the family's and in the individual daily life, with substantial emotional bond between family members.

*... our life gets very disrupted, you know... it's not the same... We try to... to split more, you know... as I have my husband taking care of the restaurant we work together, but because he's with his mind busy there, and so I'm not that worried, you know. (Tulipa).*

*Now, I don't make any projects or plans, nothing more, you know... [laughs] it's hard, I'm living day by day, you know, today is today, tomorrow*

*is another day, because I can not even make plans or projects for tomorrow, only for today. (Lirio).*

Thus, the narratives express the way each family member responds to the stress caused by the hospitalization. In this regard, it is important to emphasize the relevance of the other family members' participation favoring a support and care network for this member. Mr. Cravo's hospitalization caused a greater emotional breakdown in the family's male members, as can be observed in the speech below.

*Everybody's shaken, disrupted, the first to break down were the men... men disrupted first, my brother had high-pressure twice, two cardiac arrests, has been hospitalized, has gone out. The other one also... yes, he spent one night here... the day dad got very ill, the next day he could no longer work, spent the whole day motionless... he could not work... the whole family is dysfunctional, all is very difficult. (Lirio).*

This data corroborates the studies that show the woman still is the primary person responsible for care, particularly in cases of illness. Traditionally, the caregiver role falls upon women, whether mothers, daughters or wives, justified by the fact that for a long time, women did not engage in professional activities outside the home, and bear a profile of more frequent, intense and affective participation (GRATÃO ET AL., 2012).

Hospital admission is experienced according to previous episodes that are interpreted as they take place. The experiences are recognized by family members as positive or negative depending on their earlier admission occurrences (CALVETT; SILVA; GAUER, 2008).

*... He had been already admitted other times, you know?... but it was not as difficult as now, this time was more difficult than before, you know... (Lirio).*

*...It is being more difficult but we will win, and win once more. (Tulipa).*

This fact can make the caregiver relative feel fear about the situation they are in, and how they will deal with this feeling will be heavily influenced by their own experiences, knowledge, and ethical and personal values, which will orient their conduct (ALCANTARA, SHIRATORI; PRADO 2008). The disease promotes an exhausting process and, as occurs with the hospitalized person, the family also faces difficulties in coping with the illness situation of one of its members.

Hospitalization due to the aggravation of chronic disease, according to Lustosa (2007), leads to a disruption in the previous way of life, a loss of the familiar daily living, a risky situation, often translating into an important and significant transition, even death, which, in our culture, frightens greatly.

Death is associated with loss and, consequently, to pain and loneliness for people who is surrounded by it (RODRIGUES, 2006). In this regard, the family experiences the feeling of alertness and a sense of impending danger associated with the impotence and distress, revealing the vulnerability and lack of preparation at the possibility of the death of a family member.

All interviews were very emotional, and several times the conversation had to be paused, as tears would take over the responders' voice. While all feared the loss, only the daughter Tulipa, expressed this in words.

*... Fear of losing him... is so great that... we do everything to bring him back, you know [crying] [...] even knowing that one day he'll have to leave (everybody will leave)... but we don't accept it... we don't want it, don't accept it. (Tulipa).*

People, in general, have difficulty accepting death as a natural process of life, especially if it is a circumstance in which a relative

is hospitalized for worsening of a chronic condition.

The situation experienced and reported by family members about hospitalization is similar to the claim by Elsen (2005) that hospitalization affects the family organization and daily life in a greater or lesser degree. Some families can overcome the difficulties of hospitalization and get organized to accompany the person. The organization becomes important for these families, as daily life goes on outside the hospital premises, and as chronic conditions go through exacerbation periods and/or there's an increased demand for care, an increasing need for rearrangements in family dynamic occurs, so that the essential necessities can be provided with the loss of autonomy. Thus, it is the duty of the nursing staff to stimulate the arrangement of a support network with the potential to offer humanized care also to the relatives of the hospitalized person.

### Family and spirituality as care elements

By analyzing the interviews and field notes, we found that in the event of a chronic condition of illness, a support network is organized, and the family plays a very important role in coping with hospitalization.

During the interviews, the support from other family members during hospitalization was reported, confirming the involvement of the whole family facing the illness of one of its members; some assume the role of companion in the hospitalization period, and the others guarantee support, creating a network of effective care, minimizing concerns about home and work duties, strengthening the bond among family members and using it as a mechanism to cope with the illness of a family member.

*... We always had this union among the family, you know?... then after illness the care was higher, anything is a reason for worrying. (Tulipa).*

*... it's more about family really, right?... more the family, the children, grandchildren, right?... (Tulipa).*

*... In the case, like, if he goes... in pain, there is a greater concern, then everyone runs, right, everyone runs to see what it is going on, you know?... (Tulipa).*

The support needed for the situation caused by the disease is continually facing the family, and with that, this support system must be balanced to meet the moment's required needs.

The family system, when faced with the imminent danger of the disease, requires that members maintain homeostasis of the daily activity with the mobilization of domestic and external resources, assigning meanings to the disease and its limitations. (FORGES; SOARES, SILVA, 2008, P 275).

For Ramos *et al.* (2008), the family is the pillar of patients' support to face difficult situations resulting from disease and it allows these people to fight, become optimistic and not perceive themselves as being alone.

When people are faced with the illness condition of a family member, the need to seek support and strength to overcome the arising problems emerges. During the interviews, comments involving spirituality and references to the church, God and faith as mediators are observed, and these aspects are related to the person's own balance and well-being in relation to the treatment of the ill person. In this regard, the relative mentioned:

*... God help him improve and get well! [...] Church, that we have faith on, and everything, right, I reached much grace... oh glory! (Mrs. Rosa).*

*We're praying a lot, you know, believing in God. It is a lot of praying, much prayer, you know, only*



*the Lord! We believe is the Lord who will raise him up... to trust God. Because I have to trust God. Because if I do not trust God who will I trust? [Laughs]... Who will I trust, my God?... (Lirio).*

According to the aforementioned transcripts, Milanesi *et al.* (2006) understand that to face suffering, there is also the need to provide support, represented not only by the family but also by faith in God. Therefore, having faith is to believe that there is still hope of improvement and return to normal daily activities.

*We're praying a lot, right, we are believing in God, is much praying, you know, only the Lord, we believe that it is the Lord who will raise him up, we are praying for doctors' wisdom, yes praying. Praying campaign to really get my father out of here, you know, that's my hope, it's just praying now. (Lirio).*

Through the testimonies, some important elements in the balance maintenance of the ill person and their family during their hospital experience were noted. The pursuit of support and comfort is found within the union and family ties, as well as in the exercise of faith and prayer, showing that these are mediating factors that assist in the care coping. Therefore, it is necessary to understand that the family system and spirituality are part of people's lives and their consideration is essential in the care planning (GUERRERO, 2011).

## The (de)tour to achieve care

In Mr. Cravo's health and disease process, the trajectory traveled by him in the pursuit of care and his status of living with a chronic illness could be observed. Mr. Cravo toured the public and the private health care systems, according to his needs. He moved between different systems without using the

referral and counter-referral strategy of the Unified Health System (SUS). This led to the conclusion that the pursuit of care was based only in the resolution of acute exacerbation of the chronic condition. Therefore, one can observe the various implications of the chronic illness, which effects fall on the person and his/her family. When asked about the consultations and routine monitoring of the chronic disease, we get the following statement:

*They're not done... Just when needed... we almost have to force him to go... [laughs]... 'come on, come on, because we will take you anyway... wanting you or not, you are going'. (Tulipa).*

*When he's not well, we find a closer hospital, you know, an emergency unit at the hospital that provides first aid. [...] As he was really bad three weeks ago, the nearest was hospital A, you know... then we looked for the emergency care of hospital A. (Tulipa).*

It was observed that Mr. Cravo as well as his relatives see the care provided by the hospital as the reference care, mainly based on the biomedical model, disregarding routine visits to monitor the chronic condition in the primary care programs within SUS.

*Oh, we get a lot of support here in the hospital, you know, as... here, when he's admitted here we know that everybody's taking good care, all the needed tests are being done, you know, so we get very confident when he is here. It's useless to go to a private hospital that has only a specific doctor, he sees the patient and tells you 'you got this', and does not do other exams, lung tests, heart, other things, you know... and here we feel a great sense of security... we like it a lot here... (Tulipa).*

Because the health care is focused on the exacerbation of the disease, the access to this type of service would be difficult due to the

health services organization. Thus, the pursuit of care has been affected by the mediation that seeks to make it a more effective and efficient access (MUFFATO ET AL., 2013). This can be noted in the following transcript:

*... then when the chest pain got strong, then he asked for help, and then we rushed to the hospital with him, he was in the hospital A [private], then we called Dr. Flowers, who is taking care of him, then we were referred here, you know. (Tulipa).*

*[...] we looked for Dr. Flowers, as she is my son's cousin, you know... (Tulipa).*

*Then he was brought from hospital B [private], all was paid for as private and the doctor from hospital B is his cousin Mrs. Flowers, who helped us put him here, hospitalized... she really gave us a helping hand, the cousin of my grandson. (Mrs. Rosa).*

*The Inamps team [National Institute of Medical Assistance and Social Welfare] came there because my granddaughter worked at the university [private] and her mother was employed at Inamps. (Mrs. Rosa).*

Above is noted the action of the mediator assisting with access to the public health service, evidenced by the agile way that Mr. Cravo is transferred from the private to the public hospital. This happens every time Mr. Cravo has an exacerbation of the chronic condition and requires hospitalization.

Muffato *et al.* (2013) report that mediators help with an easy flow into public health services through friendships, violating the bureaucratic and slow dynamics that

permeates the public system, joining efforts to increase care potential of ill people and related family.

## Final considerations

In trying to understand the care rearrangements within the family when facing the impact of a cardiovascular disease chronic condition, it was observed that as the routine is modified due to the changes generated by hospitalization, a new configuration in the family's way of life is set up. Hospitalization presents with different meanings for each family member, depending on previous experiences. The present does not exist without the past, which projects a present future framed in previous experiences.

It was noticed that Mr. Cravo and his family built their care network guided by the biomedical model. Also, they faced the adversities generated by the fragility of bonds with possible support networks and family cohesion. The understanding of the family reorganization process and the tools applied to approach the family provided a reflection on the need of improving the multidisciplinary team intervention. The identification of the feelings and needs experienced by the family of hospitalized people is of major importance. Furthermore, we recommend the implementation of strategies that value and involve family members in hospital discharge planning based on the meanings and significance of their experiences about the disease/care process, and aimed at care continuity and monitoring of the ill person. In this study, this assistance was not evidenced by the nursing team during the hospitalization. ■

## References

- ALCANTÁRA, L. M.; SHIRATORI, K.; PRADO, L. M. Rompendo paradigmas: o cuidado de enfermagem na uti e sua relação com o processo saúde-doença. *Rev. Edu Meio Amb e Saúde, Manhauçu*, v. 3, n. 1, p. 41-50, 2008.
- BARDIN, L. *Análise de conteúdo*. Lisboa: Editora Persona, Ed. 70, 2009.
- BRASIL. Ministério da Saúde. Plano de ações estratégicas para o enfrentamento das doenças crônicas não transmissíveis (DCNT) no Brasil 2011-2022 [Internet]. Brasília, DF: Ministério da Saúde, 2011. Disponível em: <[http://bvsms.saude.gov.br/bvs/publicacoes/plano\\_acoes\\_enfrent\\_dcnt\\_2011.pdf](http://bvsms.saude.gov.br/bvs/publicacoes/plano_acoes_enfrent_dcnt_2011.pdf)>. Acesso em: 28 jun. 2016.
- CALVETT, P. U.; SILVA, L. M.; GAUER, G. J. C. Psicologia da saúde e criança hospitalizada. *Psic.*, São Paulo, v. 9, n. 2, dez. 2008.
- CARVALHO, C. S. U. A necessária atenção à família do paciente oncológico. *Rev. bras. Cancerologia*, Rio de Janeiro, v. 54, n. 1, p. 97-102, 2008.
- CORREA, G. H. L. S.; BELLATO, R.; ARAUJO, L. F. S. Redes para o cuidado tecidas por idosa e família que vivenciam situação de adoecimento crônico. *REME*, Belo Horizonte, v. 18, n. 2, p. 346-355, abr./jun., 2014.
- ELSEN, I.; MARCON, S. S.; SILVA, M. R. S. O viver em família e sua interface com a saúde e a doença. *Texto Contexto – enferm*, Florianópolis, v. 14, n. especial, 2005.
- FRAGUAS, G.; SOARES, S. M.; SILVA, P. A. B. A família no contexto do cuidado ao portador de nefropatia diabética: demandas e recursos. *Esc. Anna Nery Rev. Enferm*, v. 12, n. 2, p. 271-277, 2008.
- GRATÃO, A. C. M. *et al.* Sobrecarga e desconforto emocional em cuidadores de idosos. *Texto Contexto – enferm*, Florianópolis, v. 21, n. 2, p. 304-312, jun. 2012.
- GUERRERO, G. P. *et al.* Relação entre espiritualidade e câncer: perspectiva do paciente. *Rev. Bras Enferm.* Brasília, DF, v. 64, n.1, p. 53-59, 2011.
- LUSTOSA, M. A. A família do paciente internado. *Rev. SBPH*, Rio de Janeiro, v. 10, n. 1, p. 3-8, 2007.
- MARCON, S. S. *et al.* Vivência e reflexões de um grupo de estudos junto às famílias que enfrentam a situação crônica de saúde. *Texto contexto – enferm.*, Florianópolis, v. 14, n. especial, p. 116-124, 2005.
- MATTOS, M. *A experiência em família de uma pessoa com diabetes mellitus e em tratamento por hemodiálise*. Cuiabá, MT. 2008. 170 f. Dissertação (Mestrado em Enfermagem) – Universidade Federal de Mato Grosso, Cuiabá, 2008.
- MILANESI, K.; COLLET, N.; OLIVEIRA, B. R. G.; VIEIRA, C. S. Sofrimento psíquico da família de crianças hospitalizadas. *Rev. Bras. enferm.*, Brasília, DF, v. 59, n. 6, p. 769-774, dez. 2006.
- MONTEFUSCO, S. R. A.; BACHION, M. M.; NAKATAMI, A. Y. K. Avaliação de famílias no contexto hospitalar: uma aproximação entre o Modelo Calgary e a Taxonomia da Nanda. *Texto Contexto – enferm.*, Florianópolis, v. 17, n. 1, p. 72-80, mar. 2008.
- MUFFATO, L. F. *et al.* Mediação nas redes para o cuidado de pessoa e família que vivencia o câncer colorretal. *Texto contexto – enferm.*, Florianópolis, v. 22, n. 2, p. 407-415, jun. 2013.
- ORGANIZAÇÃO MUNDIAL DE SAÚDE (OMS). Cuidados inovadores para condições crônicas: componentes estruturais de ação. *Relatório Mundial*. Brasília, DF: Ministério da Saúde Brasil, 2003.
- RAMOS, I. C. Portador de insuficiência renal crônica

em hemodiálise: significados da experiência vivida na implementação do cuidado. *Acta Scientiarum. Health Sciences*, Maringá, v. 30, n.1, p. 73-79, 2008.

RODRIGUES, J. C. Tabu da morte. *Cad. Saúde Pública*, Rio de Janeiro, v. 23, n. 9, p. 2248-2252, set. 2007.

WEIS, M. C. *et al.* A experiência de uma família que

vivencia a condição crônica por anemia falciforme em dois adolescentes. *Saúde debate*, Rio de Janeiro, v. 37, n. 99, p. 597-609, dez. 2013.

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