

## FAMILY DYNAMICS FACE THE RISK OF DEATH - A SYSTEMIC ANALYSIS OF THE HOSPITALIZATION PROCESS

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### ABSTRACT

This study aimed to understand the adaptive dynamics of a family system vulnerable to death and dying. It is a descriptive-exploratory research with qualitative approach, developed in a public hospital, with nine families delimited by data saturation. Data were collected from April to May 2015 by means of semi-structured interview and development of a Family Ecomap and Genogram, analyzed through the Discourse of the Collective Subject. Systemic Thinking was used as theoretical foundation. The results comprehended 5 axes: systemic modulation to overcome the crisis, health team as a partner in the process of healthy coping, social network as a protective element, spirituality as a source of support, and financial resources as necessary sustenance. In conclusion, families express adaptive and resilient systemic interactions face the hospitalization process using resources of their own, of the health team and of the socioeconomic and spiritual support network. Thus, it is inferred that health professionals must enhance their know-how and care practices with the family, and the Systemic approach is suggested as an innovative methodology for a praxis of comprehensive care of families vulnerable to death and dying in the hospital context.

**Keywords:** Death. Family. Care.

### INTRODUCTION

Family is the social foundation of every individual, representing the primary relational institution of the human person. In this way, it emerges as an interdependent unity in which family circle relationships influence one another, so any change brought about in this context will have an influence on each individual, separately and on the system as a whole<sup>(1)</sup>. A family facing illness experiences negative feelings, such as tension and fear, and should be sheltered in the caring process. It is of paramount importance that health professionals turn their attention to these people, understanding their difficult position alongside a loved one that is critically ill<sup>(2)</sup>.

Thus, it is important that professionals are available for interaction and bonding with family members, making the latter attentive to listening, sharing of information and recognition of their attempts to care for the patient. In this sense, interaction will take into account context and family wishes, including relatives in decision-making processes and encouraging them to face the negative situation to which they are subjected<sup>(3)</sup>.

It is thus understood that the family is considered as a whole in which each member of this system is an inseparable and expressive part, necessitating, therefore, a care with a more sensitive and comprehensive consideration for spiritual and biopsychosocial needs face hospitalization and risk of death<sup>(4)</sup>. These conceptions have their origin in Systemic Thinking<sup>(5)</sup>, the framework of this study, which brings the understanding that the family generally attributes to the death/illness of one of its members a stimulus for transformations in their daily life, affecting everyday activities<sup>(6)</sup>.

In this context, the health team, especially nursing, arises as a great partner in the experiencing of changes and resumption of family relationships, as well as grief elaboration. Such a fact points to the prevention of future psychological symptoms in those who suffer a loss because, in addition to contributing to the elaboration of possible feelings of guilt, it allows the re-elaboration of previous conflicting family experiences, with re-significances in the current family dynamics<sup>(7)</sup>. Therefore, the team will be able to contribute to a better communication, enabling the development of resilience<sup>(8)</sup>.

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This communication becomes more revealing when it allows professionals to systematize assistance, not only to patients but to families as well, which, from a systemic point of view, is seen as a whole. In this sense, the set of diagnoses, identified by the Calgary Family Assessment Model (CFAM) in the illness process, shows how hard it is for families and their members to face the hospitalization process and to adapt to the hospital context in the follow-up of one of their members. Therefore, the inclusion of this methodology of multidisciplinary intervention in health units appears as a new and important technological support for the reception of families as they cope with illness and hospitalization<sup>(9)</sup>.

Given the above, this study evidences the relevance of the theme chosen, bearing in mind that this is an expanding area that still requires research and can add knowledge and contribute to the adoption of new methodologies, as well as strategies for the care and reception of families in the hospital environment.

In this sense, the literature review resorted to the following bases: *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS) and the Scientific Electronic Library Online (SCIELO), using the descriptors: “death”, “dying”, “systemic approach”, “family resilience”, “systemic thinking”, “family system”, and “feelings face death”, in Portuguese, within a 10-year cut; it was possible to observe that experiences and research in the area are scarce and, when present, focus on pediatrics, which validates this study.

In view of this, the guiding question chosen for this study was “From the systemic perspective, how does family dynamics develop face death/dying in hospital context?” The general objective was to understand the adaptive dynamics of the family system vulnerable to death/ hospital death; while the specific objective was to recognize the main adaptive resources chosen by families, based on their structural and bonding design, and to identify the meaning of the health team to the healthy coping of families vulnerable to death/hospital death.

## METHODOLOGY

A qualitative study was carried out with mothers of PT children from the Kangaroo Lodge of a public maternity hospital in the municipality of Feira de Santana-BA between May and July 2016. For the participants of this study, the following inclusion criteria were established: residing in the municipality

of Feira de Santana and that the PT child had been discharged before two months of age, and as an exclusion criterion, the child that had some congenital malformation, since it implies other specific care.

The selection of the participants took place in the public maternity hospital, after its had signed consent term and authorize the research in this place allowing data collection of medical records from the KM in the financial sector of this hospital. The mothers were selected according to the inclusion criteria. The data collected were: name of the PTNB mothers, address and telephone contact for contact and to schedule the interviews, if there was interest, and how many days since the child was discharged, to contemplate the inclusion criteria.

Regarding the child, the following data were collected: Gestational age at birth; Current Age; Sex; Weight at birth and at discharge; Time of hospitalization in the NEO-ICU and in the Kangaroo Method.

The households of mothers with children from the KM were initially chosen as data collection field; however, there were difficulties contacting some mothers and scheduling the visit. Thus, the data collection also took place in the waiting room of the outpatient clinic of the public maternity hospital, where the mothers were making several consultations with the PT child, with authorization from the maternity coordination. It was possible to conduct the interview in two households and the other mothers were interviewed in the outpatient clinic of the aforementioned public maternity hospital. In all cases, the researcher explained to the mothers the research objectives and later followed the semi-structured interview script

The interviews were recorded in order to guarantee the reliability of the answers, collecting the sociodemographic data and guiding questions: 1) Tell me how you have been taking care of your child after hospital discharge; 2) How has your child's follow up been occurring after being discharged from hospital?; 3) What do you do when your child has a health problem? After the interviews, the empirical data were fully transcribed and submitted to the thematic content analysis of Bardin<sup>(6)</sup>.

This study was evaluated and approved by the Research Ethics Committee with Human Beings (CEP) of the State University of Feira de Santana (UEFS), under number of C.A.A.E. 53425316.0.0000.0053 and opinion number 1,458,459.

The researchers informed the participants about the objectives of the study and only started collecting the data after their signature of the Informed Consent Form (ICF), one of the interviewees was an adolescent mother, and she was asked to sign the Clarified Assent Form (CAF) and her tutor signed the ICF for Legal Representatives.

The confidentiality and privacy of the employees were ensured through identification codes, replacing their names with fictitious proper names chosen by the interviewees.

## RESULTS AND DISCUSSION

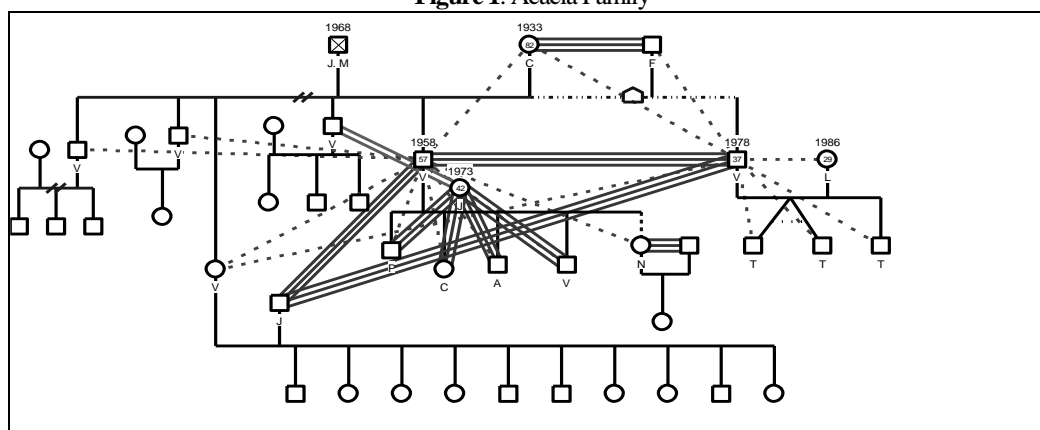
The analysis resulted in 5 axes, the first one being centered on adaptations families go through, and the subsequent 04 being about their support ties. Interviewees included: father, mother, child, sibling;

age between 24 and 61 years old. The main diagnoses of hospitalized patients were: traumatic brain injury, acute abdomen, acquired immunodeficiency syndrome, stroke, sepsis and cancer.

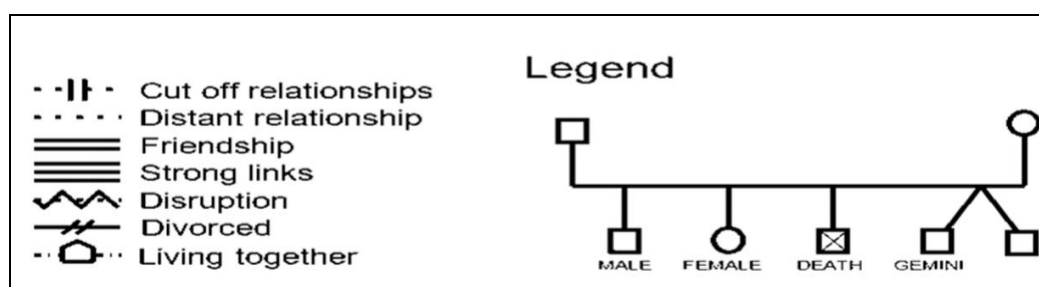
### Axis 1: Systemic modulation as a way to overcome the crisis

Axis 1 evidences the systemic modulation triggered in the family face the hospitalization process and risk of death of a loved one. Initially, the Acacia Family Genogram shows the family's extension and its rearrangements over the years, which reflects on the Ecomap of internal ties, affected by the coping with hospitalization, evidencing the modulation of the family around the patient. An example is the brother, main caregiver, leaving his wife and children in another city to be with his brother at risk of death.

Figure 1. Acacia Family



Source. The authors. Genopro Tool.



I'm very close to my family, they have always been united. Now our family has been shaken: we are going through a process of adaptation, a new experience that we still don't know how it will work and, because of that, we had to change everything, all of our lifestyle because we have a member that needs special care. We sacrifice ourselves spending time here, and we have to leave our children at home, and they take care of each other, but I'm not upset, not at all, because, for me, this is his moment and it's in hardship that we should love more, especially the most fragile ones. So, those who have a more solid structure try to support each other. (DCS 1).

When one of the members of the family system faces hospitalization, the entire family undergoes changes in its dynamics, affecting the whole, which initiates a process of readjustments in its structure and organization. Families try to adapt to this new experience, resizing roles and strengthening themselves in their conditions, seeking support from the other members of the family group and of their social network. Although some members are distant from the family, the latter comes up with new resources necessary to cope with the crisis.

The triggering event of adaptations consists of facing the imminence of death, the feeling of fear, distress and loneliness in this moment of intense emotional exhaustion that involves the risk of death of a hospitalized relative<sup>(11)</sup>. The discomfort experienced by the family shows one's impossibility to move on with his or her personal and family life.

Thus, the hospitalization process, especially when it brings the risk of death, represents a moment in which there is a permutation in the roles played by each member within the family system, an adjustment to new, unknown and increased requirements. In addition, there may be subtle or dramatic changes in the family or household, producing reactions due to

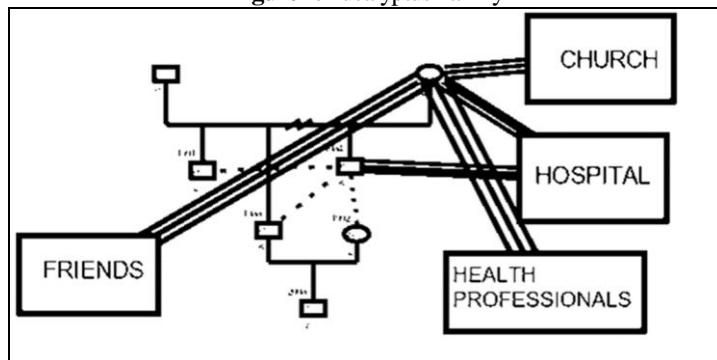
disturbances and concern, which consequently increases the burden of other members experiencing different stages of adaptation<sup>(12)</sup>.

This reorganization face all problems translates one of the mechanisms that the family accesses to find a balance between the changes and the disturbances caused in the system<sup>(13)</sup>. This dynamics should be understood by the health and nursing team so that they can act in a more sensitive and comprehensive way face the needs.

### Axis 2: Health team as a partner in the healthy coping process

Axis 2 highlights how important the family considers the health team to be for a healthy coping with the hospitalization process, which coincides with evidence expressed in the Eucalyptus Family Ecomap. This Ecomap shows a very strong tie between more than one family member and the hospital and health professionals. The DCS converges with the finding by expressing the family's joy for feeling welcomed by the team during the hospitalization, even considering the team to be at the same level as friends.

Figure 2. Eucalyptus Family



Source: The authors. Genopro Tool.

They speak very badly of this hospital because of the large number of patients here, but I don't see it as a bad hospital. What I can say is that, so far, they're taking good care of her, and that's comforting: a very good service, follow-up and nice staff; the technicians, doctors, not to mention the nurses... nutritionists, physiotherapists, they are my friends. (DCS 2).

The first words of the speech, "they speak very badly of the hospital", reveal that, although the hospital is still a subject of dissatisfaction for some, it is possible, against pessimistic expectations, to have a good experience during hospitalization when there is a structure capable of meeting the individuals' needs,

minimizing difficulties<sup>(14)</sup>.

Thus, face the hospitalization process, marked by doubts, fears, insecurity, and other feelings that weaken individuals and families, the sensitization and mobilization of the team to provide a health care integrated with the socio-cultural reality, creates

security ties for them. The professional leaves the place of a stranger, or even a tormentor, to take a sheltering place, committed to directing and supporting these people in such a stressful environment, emerging as resilience ties for the family system.

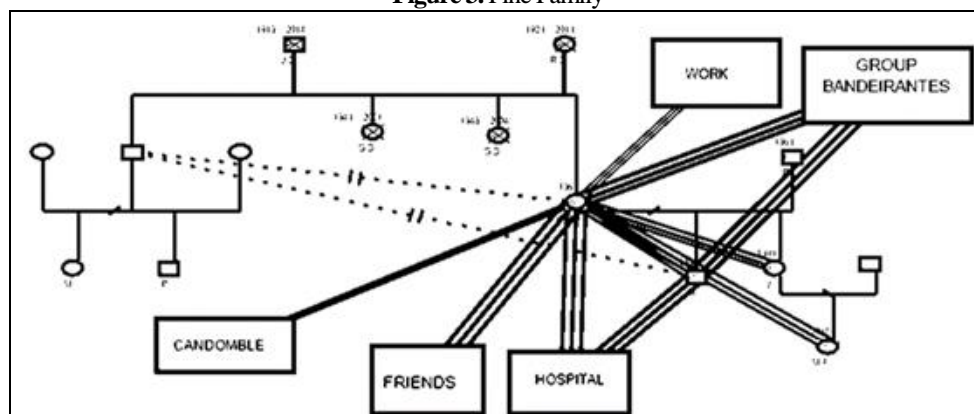
Therefore, the health team needs to maintain a connection with the extension of the patient in order to keep this extension supported and informed so that the hospitalized member and the other constituents of the system can be instrumentalized and assisted, experimenting with dialogue as a tool to exercise tolerance and to respect the specificities that exist among members, positively influencing the health and wellbeing of the system<sup>(15)</sup>. Thus, the importance of the health team as a source of support is evident, noting

that, in this study, it was mentioned more than the social network was, commonly pointed out in research of this nature, which integrates this study in the following axis.

### Axis 3: Social network as a protective element

This axis addresses social network support in a family's life, which is expressed in the Pine Family Genogram and Ecomap, rich in significant social bonds also in DCS 3. Difficulties encountered during hospitalization commonly lead the family to seek support within its social network (work, friends, religion and groups in general).

Figure 3. Pine Family



Source. The authors. Genopro Tool.

Many friends support me. They help us in everything they can. And our community also supports us: the Bandeirantes, who campaigned for diapers for him; my boss, who deals well with my absence; the church, which is with us, present and praying. (DCS 3).

From this perspective, family support will include the whole set of interpersonal ties of the system: the extended family itself, friends, community, work, school, social practices, that is, everything with which the subject interacts, both internally and externally. Thus, the personal social network is defined as the sum of all relationships a person perceives as meaningful or defines as strong and important bonds of their coexistence. On the other hand, it can be stated that the absence of extra-family ties is a risk factor for health, comparable to smoking or lack of physical activity<sup>(13)</sup>.

Another important social support that exists in the hospital itself is the network formed by each accompanying family member, determined by forced cohabitation in the environment of care. The

emotional atmosphere provided by shared experiences in the hospital is oftentimes responsible for affective relationships and behaviors of solidarity, which become a community of emotional support to the family that lives with hospitalization<sup>(16)</sup>.

Thus, the social network will configure, directly or indirectly, as a source of resilience for the coping with adversities present in the environment, causing it to increase its resolving power, encouraging individuals not to move away, because the presence of the illness in a family often deteriorates the quality of interaction with the environment, generating a negative impact on the health of the whole family. As for social network, spiritual support stands out, which emerges in the results as

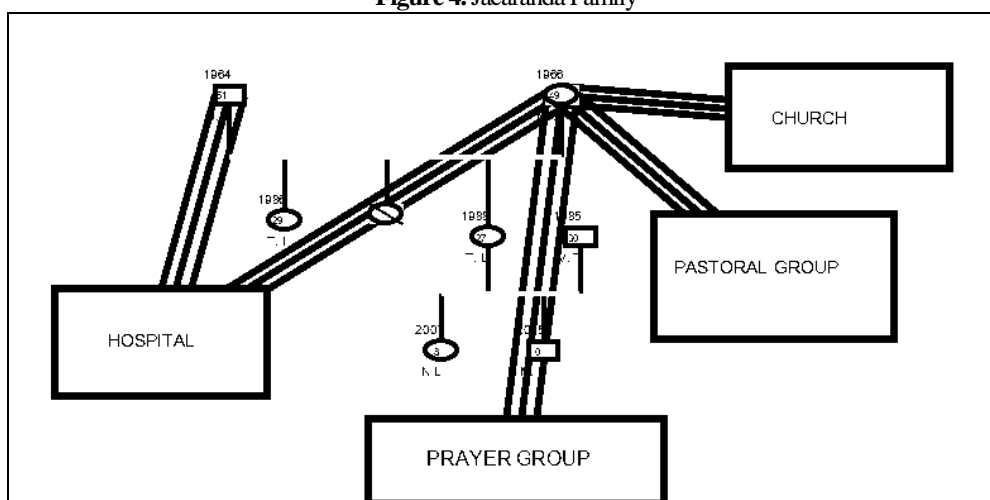
the main social source of support in the coping with the crisis caused by the illness, composing axis 04.

#### Axis 4: Cultivating spirituality as a source of support

In Axis 4, the Jacaranda Family shows in its

Genogram and Ecomap the diversity of ties that show the support of faith and spirituality in the coping with illness and risk of death, a reference also seen in DCS 4, which expresses belief in God as encouragement face the many difficulties encountered in the hospitalization process.

Figure 4. Jacaranda Family



Source. The authors. Genopro Tool.

All this strength comes from God, my support is only in him. I renewed my covenant with God, because before I didn't even feel like praying but now, amid the struggles, I can seek him. She (the patient) always asks if there's not going to be prayer too. Everyone is praying for her at home. (DCS 4).

Cultivation of spirituality is positive in this context. In this way, the importance of caring for the spiritual dimension of the individual is emphasized, since spirituality has a direct relationship with a better ability to deal with illness, health and life. Thus, by helping with the maintenance of spiritual practices, nurses promote health, strengthening coping mechanisms and improving quality of life<sup>(17)</sup>.

Another study found that most families believe that spirituality has helped them cope with the stress of hospitalization. For this reason, it should be emphasized that health professionals must be concerned about the actual insertion of spiritual assistance into the care routine, through academic discussions capable of incrementing the clinic, aiming at the wellbeing of the patient and his or her family, with the latter being an important part in the recovery of the former<sup>(18)</sup>.

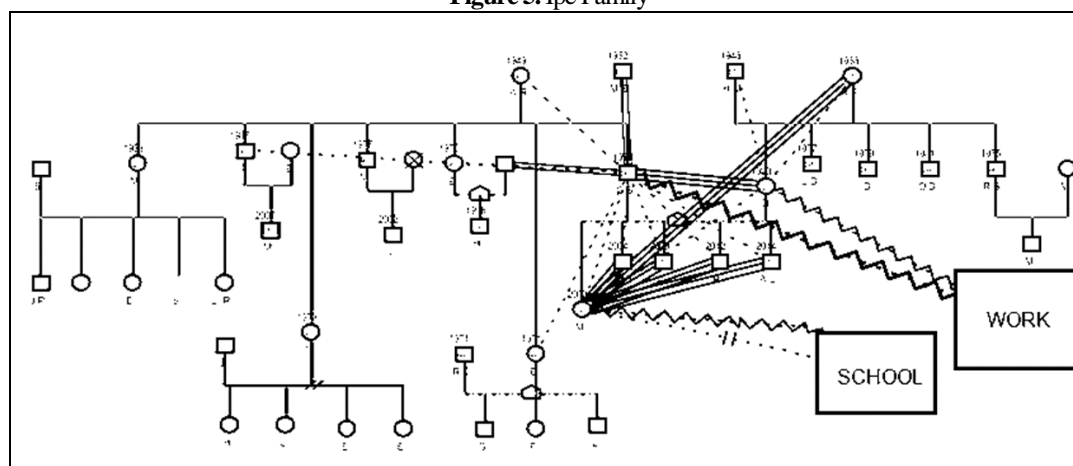
Thus, the relationship between the hospital experience of the companions and the cultivation of

their spirituality results in the soothing of their frailties and fears, in comfort and inner hope, due to the certainty that they are not alone, for believing that there is a greater force that guides them. The connection with this force is established through prayers, making individuals believe that the end of their restlessness and pain is near. For this reason, support to faith and spirituality by the hospital health team is relevant, because prayer groups are a source of support for the care of the family in the health-illness process.

#### Axis 5 - Financial resources as needed sustenance

In Axis 5, the Ipê Family Genogram and Ecomap evidences absence from work, which is the main means of sustenance for the family. Without this sustenance, it is up to the family to resort to external financial support to meet their needs during hospitalization.

Figure 5. Ipê Family



Source. The authors. Genopro Tool.

This is costing me a lot. We don't work properly, worried about the situation. So I had to stop working to be able to stay with him and to support him, even in this financial situation - we have no one. I'm going home walking because I don't have money to go back. Neither the city government supports us, only God! So, for me, it's this situation. It's very exhausting. (DCS 5).

The discovery of an impacting diagnosis about a family member can result in a number of implications, including financial ones, capable of damaging the interpersonal relationships a family's individuals. This contributes to stress, tension and conflict between the members of the system<sup>(19)</sup>, or also reveals the fragility of the family's internal ties, with few resources in its internal structure, as observed through the Genogram and Ecomap.

Therefore, with illness and its consequences, one of the great impacts the family suffers is financial issues, especially when the household provider needs to interrupt his or her work to dedicate himself or herself to the care of a loved one. This context undermines the coping and must be considered by the health team<sup>(20)</sup>.

In view of this understanding, it is the responsibility of nursing to inform families about available resources to help in their financial needs, which is done in partnership with the social service, in an interdisciplinary practice that meets care needs in order to promote, together with the family, the wellbeing necessary to the resilient coping with the difficulty.

## FINAL CONSIDERATIONS

The study allowed observing the dynamic process of readjustments of the researched family

systems by accessing the prominent axes that make up the affirmative resources aimed at overcoming difficulties in the family's process of adaptation. In this sense, internal ties, expressed in systemic modulation, and external ties, represented by health professionals, friends, neighbors, church, support groups, work and others, appeared as a network of meaningful resources, promoters of a greater capacity of resilience capacity by boost the resolving power of the family system.

It is important to emphasize the instrumental amplitude provided by the systemic approach in helping to understand the problems derived from the illness of a family member and the repercussions of the illness and the hospitalization in this context. The family, at its pace, stands as a field of interactions that compose a complex and dynamic system between the patient and the support network, becoming a vital element to the reestablishment of the relations with life, with the adjustments that the illness imposes. Thus, the study showed that the hospitalization of a loved one triggers reactions, both in the family circle and in the staff, and that perceiving, understanding and acting warmly face these reactions strengthen the care condition of family members, boosting the recognition of difficulties as an instrument that gives one strengths to deal with this situation.

In this way, nursing should invest in interdisciplinary paths that enable a comprehensive care, choosing the systemic approach as a fruitful possibility of advancement, making a difference even in adverse situations, permeated by the working process and the frequent devaluation of this profession. It is also worth mentioning the expectation and encouragement to the use of the Genogram and Ecomap in the medical records so that the team develops care strategies for families

and patients face death/dying. The new techniques allow professionals to be closer to families and to have a different perspective to take care of this system.

The limitations of this study derive from the limited up-to-date literature available on this theme and from the restricted study scenario, which may or may not coincide with other realities. Thus, the development of further research in the area is encouraged.

## A DINÂMICA FAMILIAR FRENTE AO RISCO DE MORTE – UMA ANÁLISE SISTÊMICA DO PROCESSO DE HOSPITALIZAÇÃO

### RESUMO

Este estudo objetivou compreender a dinâmica adaptativa do sistema familiar vulnerável à morte e ao morrer. Trata-se de uma pesquisa descritivo-exploratória com abordagem qualitativa, desenvolvida em um hospital público, com nove famílias, delimitadas pela saturação dos dados. A coleta de dados ocorreu no período de abril a maio de 2015 por meio de entrevista semiestruturada e desenvolvimento de Genograma e Ecomapa familiar, analisados mediante Discurso do Sujeito Coletivo. Utilizamos como fundamento teórico o Pensamento Sistêmico. Os resultados envolveram 05 eixos: modulação sistêmica para superação da crise, equipe de saúde como parceira no processo de enfrentamento saudável, rede social como elemento protetor, espiritualidade como fonte de apoio, e recursos financeiros como sustento necessário. Concluímos que a família expressa interações sistêmicas adaptativas e resilientes frente ao processo de hospitalização, a partir de recursos próprios, da equipe de saúde e da rede de apoio socioeconômica e espiritual. Assim, inferimos que os profissionais de saúde devem aperfeiçoar seu saber-fazer e o cuidado junto à família, sugerindo-se a abordagem Sistêmica como metodologia inovadora a uma práxis de cuidados integrais à família vulnerável à morte e ao morrer no contexto hospitalar.

**Palavras-chave:** Morte. Família. Cuidado.

## LA DINÁMICA FAMILIAR FRENTE AL RIESGO DE MUERTE – UN ANÁLISIS SISTÉMICO DEL PROCESO DE HOSPITALIZACIÓN

### RESUMEN

Este estudio tuvo el objetivo de comprender la dinámica adaptativa del sistema familiar vulnerable a la muerte y al morir. Se trata de una investigación descriptivo-exploratoria con abordaje cualitativo, desarrollada en un hospital público, con nueve familias, delimitadas por la saturación de los datos. La recolección de datos ocurrió en el período de abril a mayo de 2015 por medio de entrevista semiestructurada y el desarrollo de Genograma y Ecomapa familiar, analizados mediante Discurso del Sujeto Colectivo. Utilizamos como fundamento teórico el Pensamiento Sistémico. Los resultados involucraron 05 ejes: modulación sistémica para superación de la crisis, equipo de salud como ayudante en el proceso de enfrentamiento saludable, red social como elemento protector, espiritualidad como fuente de apoyo, y recursos financieros como mantenimiento necesario. Concluimos que la familia expresa interacciones sistémicas adaptativas y resilientes frente al proceso de hospitalización, a partir de recursos propios, del equipo de salud y de la red de apoyo socioeconómica y espiritual. Así, inferimos que los profesionales de salud deben perfeccionar su saber-hacer y el cuidado junto a la familia, sugiriéndose el abordaje Sistémico como metodología innovadora a una praxis de cuidados integrales a la familia vulnerable a la muerte y al morir en el contexto hospitalario.

**Palabras clave:** Muerte. Familia. Cuidado.

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