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The impact of the hospitalization process on the caregiver of a chronic critical patient hospitalized in a Semi-Intensive Care Unit

O impacto do processo de hospitalização para o acompanhante familiar do paciente crítico crônico internado em Unidade de Terapia Semi-Intensiva

El impacto del proceso de hospitalización para el acompañante familiar del paciente crítico crónico internado em unidad de cuidado intermédio

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ABSTRACT

Objective: To understand the impact of the hospitalization process on the family companion of critical patients admitted to a Semi-Intensive Care Unit (SICU). **Method:** Exploratory research with a qualitative approach, conducted in the months of April to July of 2016 through a semi-structured interview applied to relatives who were accompanying patients hospitalized in an SICU of a high complexity care hospital in Fortaleza. The interviews were submitted to content analysis. **Results:** Three themes emerged through the perception of the family members, which reveal the companion's functioning during the hospitalization period: emotional, familiar and behavioural. **Conclusion:** The companion experiences an intense process of suffering and emotional fragility, causing changes in the family organization. The companion, being a caregiver, is subjected to high levels of stress, having to use coping skills, with; spirituality and social media among the most evident. The companion is an integral care unit for the hospitalized patient and a key piece in the humanization process of health.

Keywords: Semi-Intensive care; Hospitalization; Caregivers; Family.

RESUMO

Objetivo: Compreender o impacto do processo de hospitalização para o acompanhante familiar do paciente internado em Unidade de Terapia Semi-Intensiva (UTSI). **Método:** Pesquisa exploratória de natureza qualitativa realizada de abril a julho de 2016 por meio de entrevista semiestruturada aplicada acompanhantes familiares de pacientes internados na UTSI de um hospital terciário na cidade de Fortaleza. As entrevistas foram submetidas à análise de conteúdo. **Resultados:** Diante da percepção dos familiares emergiram três temáticas, as quais revelam o funcionamento do acompanhante no momento da internação: emocional, familiar e comportamental. **Conclusão:** O familiar vivencia intenso processo de sofrimento e fragilidade emocional, havendo transformações na organização familiar. O acompanhante, enquanto cuidador, fica submetido a elevada carga de estresse, tendo que utilizar-se de recursos de enfrentamento, ficando mais evidentes a espiritualidade e as mídias sociais. O acompanhante é uma unidade do cuidado integral com o paciente internado e peça-chave no processo de humanização da saúde.

Palavras-chave: Cuidados Semi-Intensivos; Hospitalização; Cuidadores; Família.

RESUMEN

Objetivo: Comprender el impacto del proceso de hospitalización para el acompañante familiar del paciente en Unidad de Terapia Semi-Intensiva (USI). **Método:** Investigación exploratoria y cualitativa realizada de abril a julio de 2016 por medio de entrevista semiestructurada aplicada en acompañantes familiares de pacientes internados en la USI de un hospital terciario en la ciudad de Fortaleza. Las entrevistas se sometieron al análisis de contenido. **Resultados:** Ante la percepción de los familiares surgieron tres temáticas, revelando el funcionamiento del acompañante: emocional, familiar y conductual. **Conclusión:** El familiar vive intensamente el proceso de sufrimiento y fragilidad emocional, habiendo transformaciones en la organización familiar. El acompañante, como cuidador, queda sometido a una elevada carga de estrés, teniendo que utilizar recursos de enfrentamiento, quedando más evidentes la espiritualidad y los medios sociales. El acompañante es una unidad del cuidado integral con el paciente y pieza clave en el proceso de humanización de la salud.

Palabras clave: Cuidados Semi-Intensivos; Hospitalización; Cuidadores; Familia.

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INTRODUCTION

The idea of bringing caregivers to the care of hospitalized patients has gained strength in the last few decades, however with the public health policies guidelines, anchored in conceptions based on the Unified Health System (SUS) the notion of integrality gained strength in the beginning of the twentieth century; a concept that refers to possible health promotion actions, risk and injury prevention, and patient care required in each case at every level of system complexity.[1]

The companion was recognized as a facilitator for the recuperation of the patient's health and a catalyst for the rehabilitation process, being able to maintain affective and social bonding and ensure emotional support, due to the importance of having someone in the process of the dynamics of care.[2]

Therefore, the aspects that involve the process of humanization should be part of the routine of all health professionals, especially those working in units that require specialized care, directive actions and in units which have high risk of death, such as the Semi-Intensive Care Unit (SICU).

The Semi-Intensive Care Unit provides care to patients who require continuous medical attention, with permanent attention, rapid decision making, complex care and constant monitoring of the organic functions, in the attempt to reestablish life, similar to an Intensive Care Unit (ICU), differentiating from the latter because it allows the presence of companions in this care process. According to the Regional Council of Medicine of the State of Ceará (CREMEC),[3] through Resolution 26, the SICU is intended for serious or potentially serious patients who do not need to stay in the ICU but are not able to stay in the ward.

The focus of this study are the SICUs which allow the presence of a constant companion, who assists in patient care and provides support to the patient. This initiative was made possible by the efforts to humanize the environment, combining technological resources with humanistic resources - based on the *Programa Nacional de Humanização Hospitalar*/National Program for Hospital Humanization (PNHAH).

The PNHAH program was established by the Ministry of Health in 2001, which aims to encourage and disseminate the practice of humanization in the health sector, as well as to improve the provision of the service to the population. One of their main objectives is the interpersonal relationship between health professionals and the way they relate to the community.[4]

In an attempt to expand the ideas proposed by the PNHAH, which only covered the hospital scope, the National Humanization Policy (PNH) - *Humanize SUS* emerged in 2003, expanding already existing concepts. According to Machado et al.,[5] its objective is to reach the all routines within the SUS health network, through the changes in the sectors, which present an institutional culture, from user service to the strengthening of links from primary health care up to high complexity care.

Thus, "humanizing is the act of offering individuals a quality service through the articulation of technological advances with user embracement, improvement of the care environments

and the working conditions of the professionals".[6:63] Given the amplitude of the concept, these issues enable discussions that go beyond the care provided in order to restore health and open space for reflections on the subjective experience of patients and their families within the hospitalization process.

We emphasize that the companion enters the hospital to provide support to the patient and to maintain the bonds outside the walls of the institution, allowing the reduction of psychological symptoms and participating in the technical activities within the units. However, the caregiver is often still seen by professionals as a supporting figure in the process of becoming ill, especially when we talk about intensive care where care is directed to technical activities.

Thus, we open space in order to enter the subjective world of the relative who abdicates personal issues in the name of caring, which is the maximum that governs the operation of the hospital structure in favor of the improvement of the patient.

The phenomenon of illness, which affects and threatens the continuity of life, can generate varied emotional manifestations. The surprise of becoming a person in need of medical care brings to light the split between being healthy and being sick, inducing discomfort and emotional conflicts for the vast majority of people who are not prepared to deal with this existential experience, or becoming ill.[7]

In the case of the family companion, the focus of the study, in the experience of such processes, many questions emerge in the journey from diagnosis to possible mourning due to death. It is with doubt and fear that patients and relatives are exposed to extremely difficult situations, requiring specialized care to confront the crisis situation that causes various emotional repercussions.

In the case of qualitative studies, we can say that there are gaps in knowledge concerning the companion and intensive care, since most of the materials related to the subject do not address psychological issues experienced by the companions within the SICU. The shortage of both national and international literature on the subject was observed after the main databases were searched in the Virtual Health Library (VHL) portal, using descriptors relevant to the subject.

Given that there are many challenges for health teams, it is therefore imperative to delve deeper into the issue and understand how caregivers are impacted by hospitalization. Thus, from studying the theme, it is expected to acquire a greater understanding and consequent preparation of the health teams, especially highlighting the subjective process experienced by the companion to the health professional who experiences the routine more closely, such as nurses and nursing technicians with the aim to broaden the humanization of care.

Hospitalization significantly affects the relationship between family members, and the disease can generate crises between them, determining actions that must be performed so that the relatives find normality in the changes in which they are experiencing.[8] In other words, illness is part of the dynamics of constant adaptive adjustments between the individual's

environment and their relationships, especially when we talk about chronic diseases, which have an indeterminate duration and unpredictable course, extending for many years and cause caregivers to become overwhelmed.

Each family has its own way of functioning and, therefore, must be approached as a system that maintains significant interdependence relationships among its various subsystems. Therefore, it is a living system relationship, with its balance and imbalance, with its stages of growth and stationary.[9] Faced with events that threaten the functioning of this system, there is an attempt to maintain equilibrium.

Thus, it is worth emphasizing that the psychologist's perspective on these issues opens space for the subjective recognition of human suffering and care beyond the physical body, as well as offering greater clarification to other professionals regarding the processes experienced by the patient's family member. By having more clarity about what is happening with the relative, the team has the possibility to communicate better and succeed in the conduct that requires their collaboration.

In view of this reality, it is important to highlight that the experience of illness in all its subjective implications causes considerate manifestations in the way of life of the individual and in the way individuals relate in the world. Therefore, we must consider subjectivity in a broader sense, visualizing the process of illness and healing not only in the biomedical sense.

Regarding the lack of studies related to the SICU and the aspects that involve the reality experienced by the family member within the unit, it was considered necessary to make an in-depth analysis with the published works on the intensive care spaces in general and the repercussions of this experience in the life of family and companions. In view of the exposed problem, we aim to understand the impact of the hospitalization process on the family of the critical cardiopulmonary patient.

METHOD

An exploratory field study with a qualitative approach performed with family members of patients hospitalized at a SICU at a North/Northeast cardiopneumology referral hospital. We used the theoretical framework of Health Psychology, in particular, classic authors who dialogue with Family Psychology, such as Fátima Abad Sanchez, Froma Walsh and Mônica McGoldrick, who discuss family issues in the face of unexpected crises and losses in the family context.

After the submission of the project to the Research Ethics Committee for Human Beings of the mentioned location, the research was approved, under the number 53400016.6.0000.5039, respecting the ethical principles expressed in Resolution Nr. 466, 2012 12 12 of the National Council of Health.[10]

Following approval, data collection occurred from April to July 2016 through semi-structured interviews, recorded with authorization and with the prerogative of information confidentiality. The material obtained in the recordings was soley used in the research and destroyed after transcription.

All participants were informed about the ethical aspects of the study, ensuring their well-being and dignity as well as confidentiality and anonymity from the moment of their acceptance of the Informed Consent Form. The study participants were selected for convenience according to their availability. The number of interviewees was not pre-established and the interviews were concluded based on data saturation, considering that qualitative research does not work with representativeness.

Inclusion criteria were: relatives of patients hospitalized at the Semi-Intensive Care Unit; family members, regardless of gender, aged 18 and over. The following were excluded from the study: caregiver hired by relatives of the patients and not related to them; relatives of patients from other units of the hospital.

The Bardin Content Analysis was used to ascertain the data, which underwent a detailed organization and evaluation criteria.[11] Thus, the data categorization made it possible to define three categories: hospitalization experience, family dynamics and coping strategies, and some subcategories.

RESULTS AND DISCUSSION

The study was composed of nine family members who were accompanying the patients, being eight women and one man, varying from 21 to 62 years of age and coming from the interior of the state of Ceará or the capital Fortaleza. As a result, we highlight the prevalence of the female relative as the main caregiver in cases of illness, considering that the female figure is interpreted socioculturally as a precursor of care.[12]

According to North American research, women differently from men, are taught from childhood to assume responsibility for the home and the caregiving role in the family, which is why they are in charge of the sick person and are also usually closer to them. Therefore, they are the ones that suffer most from this experience of caring.[13] Corroborating this information, a study carried out in Bahia adds that the availability, sensitivity and desire to care are not sufficient to provide safety to the women during the hospitalization process as a caregiver, as they still suffer from changes in the routine caused by the disease.[14]

In terms of education, incomplete secondary school education prevailed, however, a caregiver who did not present any degree of education was also interviewed. All of them are related by blood to the hospitalized subjects with different kinship from first to third degree. The people interviewed reported having previous experiences in hospital, being an inpatient, caregiver or bedside visitor.

Category - Hospitalization experience
The companion's suffering at the time of hospitalization

It is possible to observe in the reports that before the hospitalization process, the experience of the companions is experienced in a singular way.[15]

Families who experience the phenomenon of illness are often vulnerable due to the impact and uncertainties of the

crisis generated by the disease. By coming into contact with the possibility of death, many feelings - such as fear, insecurity, anguish, loneliness among others - may emerge, disorganizing the family members.[16,17] International studies related to intensive care and family indicate that the members of the system generally experience psychological symptoms that can lead to stress, depression and anxiety,[18-20] which may persist after leaving the intensive care unit, even after hospital discharge.[20] Some reactions of the companions are evident in the following sentences:

> (Cries) Awful! It's difficult because a month has passed. Difficult! [...] She is doing very well, because they (the doctors) expected a recovery in three months and she is recovering in weeks, but despite that, it is still very painful (E1).

> (Cries) Fear! I am afraid of losing her (E9).

Research indicates that reactions due to hospitalization, represented in the discourses such as pain, uselessness, despair and fear, are intensified in ICUs when the family member perceives themselves unable to guarantee continuous contact with the hospitalized patient.[21] However, in the interviews, it was observed that such feelings are associated with the fear of the unknown and the fear of death, since the companions in the SICU have the opportunity to stay and participate in the day and the care of the family member and even so, share their suffering of having a loved one hospitalized.

In addition, the disease can cause harm in all areas of the individual's life.[22] The hospitalization and the illness process can be experienced in such a way that they transpose the emotional barrier and physical reactions can arise, possibly an effect of the poor elaboration of emotions.

> My stomach is sick [...] I'm using a diaper. It's the nerves. [...] I thought it was something I ate, but it is not. It's psychological, it's nerves. It is! It's nerves!! (E7).

It is also noted that the hospitalized patient's state of health interferes with the emotional state of the companion. Some disturbing feelings were evidenced to a greater or lesser degree associated with the state of the patient's health:

> It was worse then! But now it's getting better because it's been really bad, but now we see her getting better, she's already talking [...]. And at that time, how was it? It was desperate, it was so horrible, so horrible, so bad because the doctors almost did not give us any hope [...] (E2).

Despite all this suffering that surrounds caregivers, family members still have to reorganize themselves emotionally in search of intrafamily equilibrium.[23] They will have to cope with the impersonal routine of regulated hospitalization, discipline-centered practice, and the difficulties of performing daily care.

Relationship with the hospitalization team

The data in this category show that the interviewees consider the doctors and nurses to be considerate, trustworthy and feel comfortable regarding the care provided. In some statements, the trust in the professional team and the satisfaction with the service in the SICU is evident:

> The doctor treats us well, the nurses treat us well, the doctor treats us well. Everything is good (E5).

> [...] Here, people only die when they have to die. Because what do the girls do here, right? The nurses, the doctor are good people. They treat us and her well. There's nothing missing for her here. I have nothing to speak bad of here (E6).

> [...] I'm calmer here because I let myself watch, right? I leave the scene and put myself in the place of the companion [...] (E7)

The participants' reports lead us to believe that the care provided generates gratitude in families due to the lack of knowledge of their rights and the role of the professional as a provider of health services.

Articles have demonstrated the fragility of human relationships within the intensive care units since the praxis of care is centered on the logic of the technical work and the physical aspects that involve the daily life of the professionals, going against the parameters that involve the integrality of SUS. Hence, the importance of humanized work in these environments.[2,24]

The results found in North American research reinforce this evidence, emphasizing that the communicative dissonances faced by the family and the health team within the ICU can intensify the feelings of family helplessness and the psychological reactions, as previously reported.

It is worth mentioning that the team members also experience discomfort and uncertainties caused by the patient's treatment and prognosis, experiencing lack of protection and using avoidance mechanisms to prevent contact with the family in order to avoid suffering. In the end, they neglect the subjective needs of their clients. However, it is up to the team to teach, respect the dialogue in the relationship, considering the limits of each one.

According to Calrson et al.,[18] professionals should seek methods and actions that help to improve the relationship and communication between them. Some of the suggested strategies would be the team's awareness about the negative repercussions generated by the lack of communication and the hiring of professionals who work directly with emotional support.

Therefore, it is necessary to improve understanding and communication between family members and patients in order to try to reduce damage caused by the hospitalization process in such environments.

Category - Family Dynamics
Family organization in care

It is known that the caregiver is often moved by a range of emotional contents. In addition, illness usually leads to changes in family dynamics, which will require flexibility in order to restructure and reorganize daily activities.[24] The crisis generated by the discovery of a disease causes a disruption of homeostasis, raising the need for an inter-relational reorganization in the search for a new identity.[23,25]

The process of illness is not an isolated event, it requires maintenance of the family structure in different dimensions of life.[26] The change will require adaptation to the new condition and restructuring of the vital aspects of daily life, which can threaten the integrity of the members due to the unpredictability of the events experienced in the hospital.[27] From the experienced transformations, the participants elucidated the main changes felt by them in the face of this experience:

> When I started to come here, I got fired because the owner thought I was tired and did not want it anymore. [...] So we lose a lot [...] (E3).

> In the old days, I worked as a registered employee at a company. Now, no, I'm working from home to have more time to stay with her (E4).

> Everything changed [...] I'm a manicurist. Now, with mother's treatment, right? Mom's health, I almost never have customers because the time does not match with when I'm with Mom, I have to cancel the client. (E7).

> I had to give up everything in my life to stay with her [...]. work and social life [...]. I left work to be with her [...] (E8).

The decrease in social interaction in the last two participants is noticeable, since the situation has directly influenced their daily life, since both report that they have lost their independence to live because of the patient.

Illness and hospitalization imply inevitable losses and mark the breaking of a pattern of behavior in order to adapt to a new reality. These losses require a bereavement so that one can internalize what is essential and move on.[28]

The article reports that a large proportion of family members are financially burdened due to the abdication of life in favor of providing exclusive care to the patient.[12] In addition to this, hospitalization may entail some expenses that were not previously foreseen.

> [...] you spend a lot. The hospital is free, but not everything is free. Whenever she needs medicine, we buy it. We also spend a lot on transportation - taxi and motorcycle (E3).

> It's difficult because you have to have money to drive. You have to have the money to buy her toilet paper. You have to have (E4)

Complaints related to financial issues were attributed to the difficulties faced due to the expenses incurred in the patient's hospitalization process, which were previously not in the family budget, together with the impossibility of maintaining the ability to work.

Support from the patient's family to the caregiver

How the family deals with the illness depends on each member's history, on how well the family system was emotionally healthy, and the defense mechanisms they use in the seriousness of the situation.

Family support corresponds to the form of support given to the caregivers during the hospitalization process. It was clear that the majority of the participants had a satisfactory support network regarding the participation of other family members in the role of companion/caregiver at the time of admission.

> Her children. [...] We take turns [...] (E2).

> My brother came in last week, he stayed with her. My niece has come, too. Her daughter has come, too. Her sister-in-law has already come. And so, in the end it's me, right? (E6).

> The whole family is engaged. My aunts, my cousins, my sisters. The whole family [...] (E9).

However, family members who work as companions/caregivers and do not count on the support of other family members to take turns at providing care, experience feelings of abandonment and loneliness:[29]

> [...] right here in the hospital, it's just me who stays. [...] People say: I can't for this reason or for that reason [...]. They see that I need help (E8).

> Nobody. And so it makes me feel me a mixture of anger, right? It makes me feel something (E7).

According to the same study,[29] families that can establish taking turns and organize themselves to care for the patient by sharing actions are able to undergo the same situations in an amicable way, since they avoid overwhelming one person. However, even when caregivers take turns and share responsibilities, some family members become overwhelmed:

> When I go home, I don't rest, I go to work. So, I am practically awake for 24 hours straight (E1).

> [...] now, I'm only here, and when I go home, it's to work from home (E3).

It was observed that becoming overwhelmed also appears subtly in the experience of the other participants because of the changes and challenges faced by them when faced with

hospitalization. We corroborate with the assertions that the physical stress associated with the accumulation of roles generates negative impact on the family economy, health and quality of life of its members,[27] as evidenced in the described reality of the interviewees.

In this regard, Passos et al.[14] suggests that the exercise of care requires a disruption in how the caregiver lived their life before the disease. In order to accompany an inpatient it is necessary to break with individuality, in an almost self-destructive movement, since the companion gives up leisure activities and abdicates from work in order to be at the service of the patient.

Category - coping strategy

Although the term coping assumes several meanings in literature, we consider it the design of strategies in order to adapt to situations considered stressful.[30,31]

Thus, coping strategies are actions that we develop with the purpose of solving problems and are related to the diverse creative responses we face in difficult situations. Therefore, the stressful processes caused by illnesses require efforts and mechanisms adapted to the new situations in order to provide the appropriate mental balance.

As a result, the strategy that was most evident in the accounts of the caregiver is related to spirituality. In most interviews, the participants indicate attachment and hope in the conviction of a superior force to overcome the hospitalization process of the family member who is sick:

> [...] I'm asking God for her to be able to go home, I think it can only be that (E2).
>
> It's God. I always bring the bible with me. I read a lot, I pray a lot [...] (E7).
>
> [...] I cling to faith (cries) (E9).

Belief in a higher being, like God, capable of promoting miracles and healing, provides feelings of self-confidence and security for both the patient and the caregiver, making them capable of withstanding the consequences of illness and believing in the regeneration of one's health and relief from suffering.[12,29] "Religiousness is perceived as a form of confrontation, relief from suffering and comfort that takes space from fatality".[23:425] Other studies confirm these data, stating that spirituality offers comfort and a feeling of protection, as well as improving the quality of life of individuals in palliative care.[32]

Nevertheless, some strategies function as cognitive maneuvers in order to change the meaning of the situation, either consciously or not, and serve as a way of negotiating with the emotions of the individual in order to maintain hope, well-being or even self-esteem.[30,31] Thus, some participants relied on electronic media as a strategy to overcome situations, since the caregiver/companion is allowed to use electronic equipment in the SICU:

> I try to distract myself, listening to music for the time to pass quickly. (Cries) listening to music is trying to hide from it (E1).
>
> [...] I watch something on the internet, I have to have the internet to stay here; I use zap (WhatsApp), and face (Facebook), I listen to my novena, watch my soap opera (E2).

It is important to clarify that the dynamics of confrontation may change according to the time and stage of each person. The adjustments made in the face of a certain difficulty must be made in order to modify the threatening condition and adapt to the reality experienced.

FINAL CONSIDERATIONS

The categories that reveal how the family member works in the process of accompanying the illness of a relative in the Semi-Intensive Care Unit were hospitalization experience, family dynamics and copoing strategy.

On the first catgegory, the companions experience the SICU in a painful way, when coming in contact with an uncertain prognosis and with the possible death of the hospitalized relative. Devastating emotions are triggered and behaviors of vulnerability are perceived, which indicates that even if they are in the daily company of the loved one in the routine of the unit, proximity is not a calming factor for the companions. On the contrary, participating in the hospital routine, being exposed to emergency situations can contribute to the companion become emotionally fragile.

Family dynamics require significant transformations, from the changes faced in the daily routine to the form of support found by the systems to support the family member elected as "official caretaker". The latter has high stress levels - often a chronic condition that does not improve even when the companion is absent from the hospital - although there is a significant presence of other family members who take turns taking care of the patient in the hospital, which implies that the role played by the companion goes far beyond the physical presence in the hospital, that is to say, he is responsible for the emotional support of the patient and the family organization.

The interviewed participants needed to use their coping strategy resources in order to be able to adapt to the stressful conditions of the environment, emphasizing spirituality and social media as an instrument to deal with the internal and/or external demands that permeate the care process. Spirituality appears as a means of sustaining hope for patient recovery or even dealing with the possibility of death, while social media functions as a mechanism for emotional - albeit partial - withdrawal from the stressful situation.

It is worth noting that, in relation to the interpersonal relationship with the health team, the participants emphasize the provided care, revealing a feeling of gratitude in the families.

Difficulty in approaching the subject beyond gratitude was observed, which may indicate a good link, but also highlights the difficulty of understanding the health professional as a service provider and health care as a guaranteed right of the citizen. Thus, it is emphasized that the relationship between the two has not been deepened and other investigations are necessary.

We emphasize in this research that it is up to health professionals to consider the family as a support element between the patient and the institution, which is able to maintain ties and make the environment safer and more welcoming, but also as an organism in the process of suffering and adaptation.

It is necessary to rethink the presence of the caregiver in the hospital, which is often still seen as a concession in order to overcome the structural deficiencies of the environment, seeing the subjective needs of the users and the value that the caregiver can add to the hospitalization process.

In view of the above, it is significant, in this research, to include the family as a unit of care, hoping to ratify the importance of a more qualified health care with more humanized care.

REFERENCES

1. Lei n. 8080/90, de 19 de setembro de 1990 (BR). Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. Brasília (DF): Diário Oficial da União; 1990 [Internet]. [cited 2018 Feb 7]. Available from: http://www.planalto.gov.br/ccivil_03/leis/l8080.htm

2. Sanches ICP, Couto IRR, Abrahão AL, Andrade M. Acompanhamento hospitalar: direito ou concessão ao usuário hospitalizado? Ciênc Saúde Coletiva [Internet]. 2013 Jan; [cited 2018 Feb 7]; 18(1):67-76. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232013000100008

3. Conselho Federal de Medicina do Ceará. Resolução n. 26 de 18, de fevereiro de 2004. Define e regulamenta as atividades das Unidades de Terapia Semi-Intensiva [Internet]. Ceará; 2002 [cited 2016 Dec 16]. Available from: http://www.cremec.com.br/resolucoes/res2602.htm

4. Ministério da Saúde (BR). Secretaria de Assistência à Saúde: programa nacional de humanização da assistência hospitalar. Brasília (DF). Ministério da Saúde; 2001.

5. Machado ER, Soares NV. Humanização em UTI: Sentidos e significados sob a ótica da equipe de saúde. Rev Enferm Cent O Mim [Internet]. 2016 Sep/Dec; [cited 2018 Feb 7]; 6(3):2342-8. Available from: http://www.seer.ufsj.edu.br/index.php/recom/article/view/1011

6. Carvalho DO, Santos NNRC, Silva ARV, Carvalho GNC. Percepção do profissional de enfermagem acerca do cuidado humanizado no ambiente hospitalar. Rev Interd [Internet]. 2015 Aug/Sep; [cited 2018 Feb 7]; 8(3):61-74. Available from: https://revistainterdisciplinar.uninovafapi.edu.br/index.php/revinter/article/view/680

7. Lustosa MA. A família do paciente internado. Rev SBPH [Internet]. 2007 Jun; [cited 2018 Feb 7]; 10(1):3-8. Available from: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582007000100002

8. Baleiro CRB, Cerveny CMO. Família e doença. In: Cerveny CMO. Família e... comunicação, divórcio, mudança, resiliência, deficiência, lei, bioética, doença, religião e drogadiçãoSão Paulo (SP): Casa do Psicólogo; 2013. p. 147-62.

9. Machado M. Compreender a teoria familiar sistêmica. Psicologia PT. O Portal dos Psicólogos. 2012 [Internet]. [cited 2018 Feb 7]. Available from: http://unesav.com.br/ckfinder/userfiles/files/Resenha%20do%20texto.pdf

10. Ministério da Saúde (BR). Conselho Nacional de Saúde. Resolução n. 466 de 12, de dezembro de 2012. Diretrizes e Normas Regulamentadoras de Pesquisas com Seres Humanos [Internet]. Brasília: Diário Oficial da União; 2012 [Internet]. [cited 2018 Feb 7]. Available from: http://conselho.saude.gov.br/resolucoes/2012/reso466.pdf

11. Bardin L. Análise de conteúdo. Tradução de Luis Antero Reto e Augusto Pinheiro. 70ª ed. Lisboa: Edições 70; 2011.

12. Encarnação JF, Farinasso ALC. A família e o familiar cuidador de pacientes fora de possibilidades terapêuticas: uma revisão integrativa. Sem Ciênc Biol Saúde [Internet]. 2014 Jan/Jun; [cited 2018 Feb 7]; 35(1):137-48. Available from: http://www.uel.br/revistas/uel/index.php/seminabio/article/viewFile/16076/15812

13. Lin IF, Fee HR, WU HS. Negative and positive caregiving experiences: a closer look at the intersection of gender and relatioships. Fam Relat [Internet]. 2012 Apr; [cited 2018 Feb 7]; 61(2):343-58. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3335398/

14. Passos SS, Pereira A, Nitschke RG. Routine of the family companion during hospitalization of a family member. Acta Paul Enferm [Internet]. 2015 Nov/Dec; [cited 2018 Feb 7]; 28(6):539-45. Available from: http://www.scielo.br/scielo.php?pid=S0103-21002015000600539&script=sci_arttext&tlng=en

15. Menossi MJ, Zorzo JCC, Lima RAG. A dialógica vida/morte no cuidado do adolescente com câncer. Rev Latino Am Enferm [Internet]. 2012 Jan/Feb; [cited 2018 Feb 7]; 20(1):9 telas. Available from: http://www.scielo.br/pdf/rlae/v20n1/pt_17.pdf

16. Santos DG, Caregnato RCA. Familiares de pacientes em coma internados na Unidade de Terapia Intensiva: percepções e comportamentos. Rev Eletr Enferm [Internet]. 2013 Apr/Jun; [cited 2018 Feb 7]; 15(2):487-95. Available from: https://www.fen.ufg.br/fen_revista/v15/n2/pdf/v15n2a23.pdf

17. Passos SSS, Silva JO, Santana VS, Santos VMN, Pereira A, Santos LM. O acolhimento no cuidado à família numa unidade de terapia intensiva. Rev Enferm UERJ [Internet]. 2015 May/Jun; [cited 2018 Feb 7]; 23(3):368-74. Available from: http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/6259

18. Carlson EB, Spain DA, Muhtadie L, McDade-Montez L, Macia KS. Care and Caring in the ICU: Family Members' Distress and Perceptions about Staff Skills, Communication, and Emotional Support. J Crit Care [Internet]. 2015 Jun; [cited 2018 Feb 7]; 30(3):557-61. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4414707/

19. Aitken LM, Rattray J, Kenardy J, Hull AM, Ullman AJ, Le Brocque R, et al. Perspectives of patients and family members regarding psychological support using intensive care diaries: An exploratory mixed methods study. J Crit Care [Internet]. 2017 Apr; [cited 2018 Feb 7]; 38:263-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/28011420

20. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. Am J Crit Care [Internet]. 2012 Nov; [cited 2018 Feb 7]; 21(6):384-93. Available from: https://www.ncbi.nlm.nih.gov/pubmed/23117902

21. Frizon G, Nascimento ERP, Bertoncello KCG, Martins JJ. Familiares na sala de espera de uma Unidade de Terapia Intensiva: sentimentos revelados. Rev Gaúcha Enferm [Internet]. 2011 Mar; [cited 2018 Feb 7]; 32(1):72-8. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472011000100009

22. Seki NH, Galheigo SM. O uso da música nos cuidados paliativos: humanizando o cuidado e facilitando o adeus. Interface (Botucatu) [Internet]. 2010; [cited 2018 Feb 7]; 14(33):273-84. Available from: http://www.scielo.br/scielo.php?pid=S1414-32832010000200004&script=sci_abstract&tlng=pt

23. Schmidt B, Gabarra LM, Gonçalves JR. Intervenção psicológica em terminalidade e morte: relato de experiência. Paidéia (Ribeirão Preto) [Internet]. 2011 Sep/Dec; [cited 2018 Feb 7]; 21(50):423-30. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-863X2011000300015

24. Sanchez FA. A família na visão sistêmica. In: Baptista MN, Teodoro MLM, orgs. Psicologia de Família: teoria, avaliação e intervenção. Porto Alegre (RS): Artmed; 2012. p. 38-47.

25. Fonseca JVC, Rabelo T. Necessidades de cuidados de enfermagem do cuidador da pessoa sob cuidados paliativos. Rev Bras Enferm [Internet]. 2011 Jan/Feb; [cited 2018 Feb 7]; 64(1):180-4. Available from: http://www.scielo.br/pdf/reben/v64n1/v64n1a26.pdf

26. Souza MGG, Gomes AMT. Sentimentos compartilhados por familiares de pacientes oncológicos em tratamento quimioterápico: um estudo de representações sociais. Rev Enferm UERJ [Internet]. 2012 Apr/Jun; [cited 2018 Feb 7]; 20(2):149-54. Available from: http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/4009

27. Martins MM, Monteiro MCD, Gonçalves LHT. Vivências de familiares cuidadores em internamento hospitalares: o início de dependência do idoso. Rev Enferm UFPE On Line. [Internet]. 2016 Mar; [cited 2018 Feb 7]; 10(3):1109-18. Available from: http://pesquisa.bvsalud.org/bvsecuador/resource/pt/bde-29637

28. Walsh F, McGoldrick M. A Perda e a família: uma perspectiva sistêmica. In: Walsh F, McgGoldrick M. Morte na Família: Sobrevivendo às Perdas. Porto Alegre (RS): Artmed; 1998. p. 27-55.

29. Beuter M, Brondani CM, Szareski C, Cordeiro FR, Roso CC. Sentimentos de familiares acompanhantes de adultos face ao processo de hospitalização. Esc Anna Nery [Internet]. 2012 Mar; [cited 2018 Feb 7]; 16(1):134-40. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452012000100018

30. Nascimento CM, Nunes S. Conceito de enfrentamento e a sua relevância na prática da psiconcologia. Encontro Rev Psicol [Internet]. 2010; [cited 2018 Feb 7]; 13(19):91-102. Available from: http://www.pgsskroton.com.br/seer/index.php/renc/article/viewFile/2519/2411

31. Santos QN. Estratégia de Enfrentamento (Coping) da Família Frente a um Membro Familiar Hospitalizado. Uma Revisão de Literatura Brasileira. Mudanças [Internet]. 2013 Jul/Dec; [cited 2018 Feb 7]; 21(2):40-7. Available from: https://www.metodista.br/revistas/revistas-ims/index.php/MUD/article/view/3894

32. Dobratz MC. "All my saints are within me": expressions of end-of-life spirituality. Palliat Support Care [Internet]. 2013 Jun; [cited 2018 Feb 7]; 11(3):191-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/?term=All+my+saints+are+within+me%E2%80%9D%3A+Expressions+of+end-of-life+spirituality