The experience of accompanying a family...



RESEARCH

The experience of accompanying a family member hospitalized for cancer

A experiência em acompanhar um membro da família internado por câncer

La experiencia de acompañar a un familiar hospitalizado por câncer

Claudelí Mistura ¹, Fabiane Weber Schenkel ², Bruna Vanessa Costa da Rosa ³, Nara Marilene Oliveira Girardon-Perlini ⁴

ABSTRACT

Objective: to know the experience of the relative who companions the adult patient with cancer during hospitalization. **Method:** this is a descriptive study with a qualitative approach, performed in a hospital in the countryside of the State of Rio Grande do Sul, in which participated six family members through open interviews. The analysis was by Thematic Content Analysis. **Results:** from the analysis of the information emerged categories those address the arrangements to accompany the sick family member, the hospital structure for the permanence of the companion, relationships with healthcare professionals, the feelings about the disease and the sick family member, and the sources for support the patient and the family companion. **Conclusion:** hospitalization alters the family dynamics, and for the family companion to take care of their sick family member and cope with their difficulties needs to count with the support and help from the family and the health professionals. **Descriptors:** Family nursing, Neoplasms, Hospitalization, Nursing.

RESUMO

Objetivo: Conhecer a experiência do familiar que acompanha o adulto doente de câncer durante a internação hospitalar. Método: estudo descritivo com abordagem qualitativa, realizado em um hospital do interior do Estado do Rio Grande do Sul. Participaram seis familiares, por meio de entrevista aberta. A análise ocorreu pela Análise de Conteúdo Temática. Resultados: da análise das informações emergiram categorias que abordam os arranjos para acompanhar o familiar doente, a estrutura hospitalar para a permanência do acompanhante, o relacionamento com os profissionais de saúde, os sentimentos em relação à doença e ao familiar doente e as fontes de apoio para o acompanhante e o familiar doente. Conclusão: a internação modifica a dinâmica familiar, sendo que para o acompanhante cuidar de seu familiar doente e enfrentar suas dificuldades surgidas necessita contar com o apoio e a ajuda da família, bem como dos profissionais de saúde. Descritores: Enfermagem familiar, Neoplasias, Hospitalização, Enfermagem.

RESUMEN

Objetivo: conocer la experiencia del familiar acompañante de un adulto enfermo de cáncer durante la hospitalización. Método: se realizó un estudio descriptivo con un enfoque cualitativo, realizado en un hospital en el interior del Estado de Rio Grande do Sul, en el cual participaron seis miembros de la familia a través de entrevistas abiertas. El análisis se realizó por Análisis de Contenido Temático. Resultados: del análisis de las informaciones emergieron las categorías que abordan los arreglos para acompañar al miembro enfermo de la familia, la estructura hospitalaria para la permanencia del familiar acompañante, las relaciones de compañerismo con los profesionales, los sentimientos sobre la enfermedad y los pacientes y el apoyo para el familiar enfermo y el familiar acompañante. Conclusión: la hospitalización altera la dinámica de la familia y, para el familiar acompañante cuidar de su familiar enfermo e lidiar con sus dificultades necesita contar con el apoyo y la ayuda de la familia y de los profesionales de la salud. Descriptores: Enfermería de la familia, Neoplasias, Hospitalización, Enfermería.

¹ Nurse, Master student. Federal University of Santa Maria (UFSM). Member of the Research Group Care, Health and Nursing. Email:claumistura@gmail.com ² Nurse, specialist in cardiology. Email: fwsenf@yahoo.com.br ³ Nurse, Master student. Federal University of Santa Maria (UFSM). Member of the Research Group Care, Health and Nursing. Email: bruninha_vcr@hotmail.com ⁴ Nurse, PhD in Nursing, Associate Professor, Department of Nursing and the Graduate Program in Nursing (PPGENF), Federal University of Santa Maria (UFSM), Researcher, member of the Research Group Care, Health and Nursing.Email: nara.girardon@gmail.com. Address: Federal University of Santa Maria Nursing Department Av Roraima, 1000 Building 26 - University City, Neighborhood Camobi CEP: 97105-900 - Santa Maria (RS), Brazil.

INTRODUCTION

eoplasms are considered a public health problem in Brazil, and the number of people with cancer increases considerably each year. The epidemiological statistics indicate that this is the second cause of death in the country. ¹ The region with the highest number of new cases is the Southeast, followed by the South and in third place is the Northeast. ¹

Through this perspective, the possibility of living with a cancer patient has become increasingly common for families. The diagnostic and therapeutic process can be often protracted and uncertain, resulting in frequent periods of hospitalization. In the hospitalization of elderly people, the focus of this study, the presence of the family is characterized mainly by the permanence of a family that came and responsible, in some situations, the care the patient and family for emotional support.

Therefore, having a sick family member hospitalized for cancer is a stressful event for the family, given the circumstances surrounding the hospitalization, change of routine and disturbances imposed on the family routine. Moreover, this situation may represent the need to meet other requirements, depending on which position the patient and escort occupy in the family, especially when they are heads of households, responsible for income, or parents of children who depend on care, among other singularities.¹⁻²

In addition to the aforementioned effects, cancer differs from other pathologies to be associated with the idea of poor prognosis and metaphors dire. Thus, how the family is organized to deal with the situation and meet the demands of care will be influenced by the particular way this conceives the disease, which can be reflected in the actions, behavior, and emotional state and even in the state biological patient and family members.²⁻³

The care provided by the family, in general, are intended to preserve the lives of its members and to encourage them to reach full development, according to his ability and with the conditions of their environment. Accordingly, in situations of illness, the support and help of the family as a whole are essential both for the person who falls ill and for other family members.⁴

The constant presence of a family member accompanying the period of hospitalization can collaborate to improve the health, safety and provide help to qualify the assistance. However, be familiar companion requires immersion in an environment permeated by knowledge and practices specific. This reality is not always favorable, depending on the context and characteristics of living care and hospital structure may promote feelings of insecurity and suffering, especially when the family has worsened their clinical.⁵

The accompanying family needs information, emotional support, space to assuage doubts and anseios6, and a structure that allows comfort and welcome, considering that it

plays a role in helping the healthcare team, regardless of the level of participation in care

Note that the family presence during hospitalization stands out as a fundamental part of care for people with cancer, contributing to the recovery of health, and also qualify for nursing care, as it represents the main source of support. The experience of family caregivers, according to the study is a part of the few pleasures that they assume with resignation, but they do so in solidarity with the sick family.⁷

For the family, caring for a family member who is sick is the possibility to create their own way of dealing with the situation. It is also a way to correspond to the expectations, and socio-cultural and family values of the patient care provided by the family are necessarily.⁷

Accordingly, to provide a full and effective assistance to those involved, it is important to know the process of organizing the family to take care of the hospitalized family⁸ and accompany him.

The knowledge about the experience of families to accompany a family hospitalized for cancer, it is essential for the planning and implementation of strategies and actions that include nursing, too, care to family companion, which, in turn, can contribute to the quality assistance and stakeholder satisfaction. In this context, the development of studies to deepen and broaden discussions about the disease process, considering the perspective of the family group, contributes to the strengthening of nursing.

Thus, considering the above, the present study has the guiding question: How family members live with the experience of accompanying an adult family member hospitalized for cancer? The goal is to understand the experience of the family accompanying the adult cancer patient during hospitalization.

METHOD

The research is characterized as a qualitative and descriptive. Qualitative studies respond to particular issues involving the subjectivity of the subject and that cannot be quantified. Descriptive studies aim to describe the characteristics of a given population and narrate facts and phenomena of a given reality. 10

This research was conducted in two clinical units of a general hospital, large, in the state of Rio Grande do Sul, where people are hospitalized with chronic diseases.

The subjects included in the study were family members who were accompanying adult inpatients diagnosed with cancer in clinical units of the hospital. Six family members participated in the investigation. The number of participants was determined by data saturation, ie, interrupted to capture employees when it found that no new evidence emerged of the information.¹¹

The age of the participants ranged from 32 to 58 years old. All were female. Regarding the family bond, four were wives, one daughter and one aunt. Most were housewives, living in municipalities other than that in which the hospital is located and provided care to the family member. Regarding the diagnosis of cancer of the family, three had lymphoma; one had neoplasm of the esophagus and intestine, one neoplasm of testis and brain metastasis, and another one, leukemia. Most patients were dependent for their activities of daily living.

Data collection occurred through an open interview with the following question: "how is for you to follow (patient's name) during hospitalization?" Data analysis was by qualitative analysis, proposed by Minayo⁹, whose organization has the following steps: preanalysis, material exploration and treatment / inferences / interpretations. During the preanalysis were heard and transcribed all interviews. The exploitation of the material comprised a thorough reading of the interviews, the clipping of the transcripts and the construction of categories. In step treatment / inferences / interpretations, we have presented an interpretive synthesis in which it discussed the results, based on goals and literature anchor used.

The research was conducted in accordance with the ethical principles envisaged in Resolution 196/96 of the National Health Council, which guides the practices in human research. 12 The participants were informed about the purpose of the research, their voluntary participation and confidentiality of information. All signed the Informed Consent Form (ICF), in duplicate, with the remaining one respondent and another with the interviewer. To ensure anonymity, participants were identified with names of flowers.

The study was approved by the Ethics Committee in Research of the Northwest Regional University of Rio Grande do Sul (UNIJUÍ), according to the opinion embodied paragraph n°.128/2009.

RESULTS AND DISCUSSION

The following shows the categories that emerged from the analysis of the data produced: arrangements to accompany the sick family member during hospitalization, the hospital structure for continuing companion; relationship with health professionals; feelings about the disease and the sick relative and sources of support for companion and family sick.

ARRANGEMENTS TO ASSIST THE SICK RELATIVE DURING HOSPITALIZATION

In order to facilitate the monitoring of the family during hospitalization, family members, especially one who is willing to be your companion, seek to accomplish family arrangements that allow the removal of the house for some time. Among these arrangements revealed the delegation of activities performed by him.

Lucky I have my mother who can stay with my son and I have a "Tata" (term used in some regions of Rio Grande do Sul to designate maid or nanny) who takes care of my house. (Libélula)

Some caregivers often try to anticipate the tasks that are possible to facilitate the daily lives of families who remain at home. To do this, turn also to the availability of help from other family members or people from their relationships that jointly and severally undertake to cooperate in some activities.

I have three children who work; the three are single and live with me. Has my husband who stays home because he has trouble ... I'm a bit here, but I leave my stuff forwarded. So, we go with this well, dodging things. (Rosa)

My house is abandoned, because we live in the countryside, we work on the farm for our boss. Glad we have him, which is very good for us and helps us. (Orquídea)

It may be noted that the ways in which families organize themselves are quite distinct. Study participants mentioned that they rely on the help of family of origin (parents), the nuclear family (husband and children) and also other people, as the boss.

Care to a family member diagnosed with cancer is becoming a reality in the lives of many families. To handle this situation, the family group needs to adapt and reorganize itself to meet the demands of the patient and other family members. This change in routine may reflect difficulties in emotional, relational, social and financial, and the need to identify someone who can take responsibility to monitor and care for the family member in case of hospitalization. 13

Arrangements made by family caregivers can be designed predicting a period of time defined for its implementation and defined the family thinks about the admission and progress of treatment. The period of prolonged hospitalization may result in caregiver growing tension, caused by both the risk of exhaustion as by the continuous addition of new tasks over time. 13

The companions generally do not know for sure how long it will need to stay in hospital and begin, immediately, to consider alternatives to the everyday suitability and planning as a way to keep the family functioning and emotional stability and physical, as following report.

If he has to stay in hospital too long, then the child will have to come take care of him. During the week he works. Then, only if he gets the weekend for me to rest a bit, look at my home and my pets, but let's see how things are happening. (Orquidea)

The hospital requires the family to develop strategies and arrangements to continue to meet the needs of your family sick, during hospitalization and at the same time, meet the new demands of care. In a study of family caregivers of hospitalized patients with chronic diseases have been identified factors related to the illness of a family member, such as, home organization and insufficient financial resources, difficulty keeping the house comfortably, ask for help in maintaining the home and sense of overload, configured as defining the nursing diagnosis "impaired home maintenance." ¹⁴

THE HOSPITAL STRUCTURE FOR THE PERMANENCE OF THE ESCORT

Regarding housing conditions of hospital stay for the companion, all respondents reported that it is exhausting to spend the night in the hospital due to lack of a suitable place to rest. Report that in most cases, need to improvise restrooms with mats or blankets, as there is a proper place, even if the rest is for a short period of time.

Look, sleeping here is very complicated, this time I was lucky to have this sofa for me to rest, at least somewhat, but there was another room where I slept on the floor, bringing the comforter from home and slept on the floor. It's bad, uncomfortable, but now I'm sleeping, resting mean better. (Libélula)

Sleeping here is quite bad ... Sometimes I get a room that has a little mattress, giving a stool to sleep, but sometimes we have to improvise, grab a blanket and lie on the ground. (Violeta)

The unpreparedness of the hospital for the inclusion of the family in the context of care may be evidenced by inadequate conditions for physical rest, especially sleep and rest, which constitutes a basic necessity to life. Whereas the clinical condition of most patients is dependent, in need of a companion, the infrastructure, especially the wards, offers inadequate to these, for example, a few simple chairs in a narrow space between beds.

Situations similar to those found in this study were also observed in other hospitals whose conditions have not fostered an environment conducive to family involvement in the care of the sick, but potentiated situations that cause discomfort and suffering for the family companion. 15

With regard to food, the companions to consider the patient to hospital diet are adequate but limited in relation to compliance with certain criteria. They feed, most of the time, with snacks or when someone in the family brings home some food.

I'm already based with snacks, because I do not like the food here. I did not ask for the social worker, because I know there are people who need it more than me. So, I leave to those who need it most. Sometimes I eat lunch outside, but it is very difficult. Sometimes I have breakfast there in the corner bakery. (Libélula)

Note that the companions are fed improperly, because the hospital only offers service snack bar and get the food prepared by the department of nutrition and dietetics you need a permit from the welfare office, as one of the participants mentioned. It is noted that the criterion for the power supply used in hospitals is related to the financial condition of the companion and the patient's age.

However, according to the Ordinance of the Ministry of Health n. 1286/93, the patient is entitled to a companion in the consultations, as well as in admissions and in the latter, if the medical advice requiring the presence of a companion in the hospital, the service contracted for the same hospital may accrue to the account corresponding to the daily accommodation costs and power acompanhante.16 This right companion seems to be still unknown to people in general.

Another aspect was scored in relation to cleaning the inpatient unit, considered by most employees as appropriate, as the team organizes the rooms and bathrooms properly, about twice a day. Even so, it is clear that if the study participants could, they would demand more care and attention to cleaning the inpatient units, especially with the bathrooms.

Hygiene is good. They spend all day cleaning, but could improve a bit. We know they have great service, which is very big here, but they could perfect the little more, especially in bathrooms that sometimes gets a bad smell, because it's a lot of people. (Margarida)

Actions relating to the maintenance of an effective standard of hygiene are priority in the hospital environment, given the implications related to the risk of infection due to neglect this aspect. However, it is clear that the flow of people in the wards is intense and commitment to the organization and care of the environment, it is often precarious, and not always the hygiene sector workers can constantly keep the place clean.

Accordingly, with accompanying hospital study found that the presence of dirt and unpleasant odors in the environment in which the patient lies constitutes a factor that causes discomfort attendant physical, resulting in feeling of discomfort in persons who are at this local. 15

RELATIONSHIP WITH HEALTH PROFESSIONALS

Regarding the relationship with the health professionals with whom they interact, the respondents mentioned the medical and nursing staff. In relation to the doctors, it is identified that, many times, the companions would like more information, ask questions, understand what is happening and what can happen to your family, but most of these professionals did not seem to meet expectations.

The doctor did not tell me the right things, as that will be, so I do not know anything right, just know that he is with a head injury. This doctor does not give me much access. I do not know why he did not tell me if he thinks I do not know or I do not understand, or does not want to talk in front of my husband. (Libélula)

The doctors do not say much, but equal, we do not quite understand what they mean. Until now he did not say much. It makes me worried, nervous, because I do not know

quite sure what is happening, is curable and what we do ... I'm not afraid to know, but I do not want to hide things and do not spare me anything ... (Orquidea)

The imprecision or even the lack of information provided by the professional familiar echoes in the construction of hypotheses related to the reasons for adopting such behavior, which can help to enhance the insecurity and fears in relation to prognosis and disease severity. In the literature review on the communication of the diagnosis in oncology multidisciplinary team identified in the articles analyzed, problems concerning the language used by physicians, stating the desire to receive more information, because even knowing the diagnosis, patients and family did not feel sufficiently informed about their disease and cancer pain. 17

On the other hand, communication of health professionals is an instrument that approximates the caregivers, and, in most cases, can stimulate and / or enhance their participation in the care of the patient¹⁵, ie, the communication is necessary for the family to know more about the condition of his family and, thus, may report information/facts, opinions or feelings about it.²

Health professionals need to realize that families who live daily with a family member with cancer are at risk because chronic disease, due to its characteristics, and especially when not properly controlled, can express different changes and transformations in its context and everyday life, deserving all the attention and respect of these professionals. 18

The family, in turn, need clear and understandable information, because face the illness of one of its members has an impact on the family unit and the strategies used in this process can be an important source for understanding the lived, and from that effectively include family as the subject of care actions.³

Among health professionals, nursing is the most is present in the care of patients in hospital. The role of the nurse within the family's attention, care and respect to maintain a peaceful, warm and safe in meeting the care needs of the person admitted. The humanized care provides a quality service to patients and families, proving to be the best way to deal with people's feelings and understand their difficulties. 19

Observe, to analyze the evidence, that most family shows to be satisfied with the nursing staff because it gets access and affordability you expect to receive in the context of hospitalization. Respondents mention that realize the committed team with the patient and family members, because these establish a solid bond and continuous.

The nursing staff here is excellent; they are very loving, caring, and helpful. They are always ready to help if needed. (Margarida)

When we need nurses (referring to the nursing techniques), they are already there to help. If we call once, they soon come. Are well dear, thoughtful, talk to us, explain things, because most of the time, we do not understand "to" what each thing. (Girassol)

It is important for caregivers of a hospitalized family have as much knowledge as possible about the disease and the evolution of your family, as this makes them safer to play their roles as caregivers. Open communication of the health professional with family helps in understanding and acceptance of the disease and assists in the preparation of complex feelings that arise from the disease. Thus, communication between the patient and the nursing staff is a basic tool for building strategies that aim humanized care. 19

FEELINGS IN RELATION TO THE DISEASE AND THE SICK RELATIVE

The responsibility is to be present and care to sick family member, during hospitalization, can also be a challenge for caregivers, who in addition to feeling physically and emotionally exhausted, have to overcome their own limitations, fears and live with uncertainty about the future.

The stigma of cancer committed family relationships, hindering communication, which is progressively higher, compared to the progression of the disease.²⁰ Culturally, cancer is a disease that causes fear, because it is associated with the prospect of loss and death that afflicts both the family as patients.

It's very sad how a person can get to it. It hurts knowing that in time she cannot be here with us. (Margarida)

I was devastated, because you are not prepared. Now, not long ago, had ended the "chemo", was to be good and everything came back again, the worst thing it is, it seems that it will never have an end. (Libélula)

What a shock it was for us! Wow, how I cried that day! It was very sad. At the time it seemed that there was no more exit, nothing to do. (Girassol)

In this context, it can be seen that the feeling of helplessness and the possibility that the treatment outcome does not match the expected afflict their families. The prospect of treatment failure and the reality observed in other patients who are in a similar situation, dying, the perspective of death as a possibility, as something that can happen; and that breeds insecurity and doubt.

At first I was more hopeful, because he made the "chemo". The first ones were a success, got almost good. Stayed four months without "chemo" and returned all over again ... You know, I see people in the hospital, all dying of cancer ... (Violeta)

The way the family accepts, handles his family and facing the illness and treatment is mostly influenced by the environment and the family relationships, but given the difficulties experienced in the day-to-day, the family ends up feeling ineffective, because he thinks he cannot help the sick family member. 21 Sit often frustrated and lose hope for not knowing how and in what way to help.

The feeling is the worst possible, we feel very frustrated, we cannot help him. Because being there with her husband, lying, hurting and cannot do anything to help. (Libélula)

We feel really bad, because you cannot do much, cannot help, only seeing suffer ... Have to go on and see where all this will take. (Orquidea)

The process of illness and hospitalization situations can trigger anxiety, anguish, fear, and also conflict within the family, since this is a painful experience for everyone. It is noticed that, despite the present feelings, concern for the welfare of the sick person takes the family to develop actions that convey solidarity, understanding and caring. At the same time, demand patience, although sometimes consider that the patient does not recognize the care that you are being dispensed.

He always wants me to stay with him, if I go a bit he gets angry ... Yesterday, there radiotherapy, he got angry because I did not go in there in the room with him, but cannot enter another person, but he does not understand it, says I abandoned like a dog. I do not drop it, I'm always together, just that there are times when I have to eat, go to the bathroom, leaving a little ... (Libélula)

In the context of hospitalization and illness, the person may feel vulnerable, unprotected and helpless against unknown environment and procedures that need to undergo. The accompanying family member represents safety, security and someone who can advocate for him. In the absence of the sick person feels abandoned. For family companion, however, this relationship can become exhausting and stressful.

In a study of families who sought to identify concerns and expectations related to chronic illness in the hospital concluded that the family is in bed for the sick person, that they have the capacity to meet the needs of the patient. The illness and hospitalization are situations that can promote the strengthening of marriage and family relationships, especially when there is affection between them. 18

SOURCES OF SUPPORT FOR THE FAMILIAR COMPANION

One factor mentioned as important and encouraging the study participants for both the person admitted as a chaperone is related to sources of assistance received during the hospitalization period. Able to count on the presence of other family members to the division of labor, company or even visits, helps reduce tension and anxiety.

Here are three sisters and two are outside ... So, we divide thus one gets at night, his niece, who is there, spend the day here, then I can do the chore at home. My other sister, if we exchange the nights ... This sister of São Paulo stayed 20 days here. My other sister who lives in Mato Grosso was one week. (Rosa)

The possibility of having anyone to share the activities of caring for sick family member can be a task less stressful for caregivers, because in addition to available time to perform daily tasks also minimizes fatigue allowing assume the role of escort.

Facing crises from events like illness, the family tends to rearrange each other, often dividing the tasks in order to be a source of support for its members, while maintaining the understanding and respect, valuing and preserving family unity. Diseases like cancer, involving not only the sick person but the whole family group making, from the first moment, turn to the patient, going your direction, extending his hand and articulating to help it.²²

However, when it comes to receiving family visits, the participants of this study mention that these depending on the situation, can cause more grief than joy and discomfort and help, because some do not convey warmth and tranquility. Report also the absence of visits as a factor of suffering for themselves and the patient, who may feel lonely and abandoned.

His mother and his father came today, but just visiting, then they go away, do not get straight here ... (Libélula)

Has one husband who has now come and go away already ... She has two children, but they do not have the courage to see his mother in that state. (Margarida)

His brother comes and just cry, he does not react well to it all. (Libélula)

Another source of support identified as a promoter of comfort and courage was religiosity. Relatives seek in faith the strength to face difficult times. The belief in something greater, capable of providing the necessary support to deal with the difficulties and fears present in the course of illness, strengthens the family holding out hope as well as assists in the process of accepting the disease.

God is whom we have to believe in the first place, otherwise we cannot overcome and to give him strength. We must have faith in God all the time. We have to hold on to something to be able to overcome these difficulties. Not worth fighting and not having faith in God, because He is the first thing. (Orquidea)

If it was God who wanted so I cannot complain, I have to accept, because He always knows what to do. (Girassol)

Faith is an important tool for humans, which helps to overcome the difficulties that appear in day-to-day and, regardless of the adverse situation, people seek in faith and Divine force protection and resources to address it. Believe that they can rely on spiritual forces generates feelings of comfort, so religiosity constitutes a resource used by people to support.

In a study that sought to identify the meaning of medical intervention and religious faith for the elderly patient with cancer found that religious faith is enhanced and results in hope, balance and strength, leading the struggle for life and the serenity to accept the disease, being an ally potentiating the clinical treatment.²³

CONCLUSION

The experience of family accompanying having an adult member is hospitalized for cancer in a condition that requires internal reorganization within the family, so that someone can get away from the daily context and remain beside the sick person in the hospital. This need for reorganization that involves all members of the family explains that illness is a situation that mobilizes the family unit. The removal of a family member to meet the needs of those who are sick depends on the cooperation and solidarity of other relatives and their relationships.

The task of monitoring the family during hospitalization is generally assumed primarily by a family member, who has the closest bond with the patient, carried out this study for wives, daughter and aunt. For them, the experience was exhausting, painful, arduous and, at times, even desperate. The cancer treatment, usually with prolonged and recurrent hospitalizations in later stages, requires the accompanying adaptation to an environment, often without adequate infrastructure to welcome him, being necessary to improvise places to rest and feed.

The relational context with health professionals is marked by unmet expectations of information, especially in relation to physicians, which contribute to feelings of insecurity and uncertainty are strengthened. Regarding the relationship with nursing, there is recognition by the attention and respect afforded to the patient and family availability and commitment to both patient and family.

The results of the study indicate that the presence and sharing activities related to the stay in the hospital for other family members constitute a source of support and decreased burden on the family companion. However, does not always mean the presence of family support and serenity, depending on the relations established before the disease, since the weaknesses and family conflicts tend to emerge in the face of adversity and the threat that the situation is.

Religiosity, regardless of creed, the intensity and the start time is a resource that accompanying family members turn to strengthen during the period of hospitalization, which promotes feelings of comfort and hope helping to accept the prognosis.

Compared to the results obtained in this study, it is clear that, despite the encouragement of the propositions of the National Humanization hospital services still need to implement strategies that effectively ensure the inclusion of the family in the hospital. However, it is possible to realize that nursing has adopted relational attitudes that favor the formation of bonding, trust and security. These considerations reinforce the evidence

present in nursing research that highlights the importance of understanding the perspectives of family members on the experiences arising from the disease process, as a strategy for directing the actions of care to meet the real needs of families.

Although restricted to a specific context and a sample limited to people undergoing cancer treatment, it appears that the experience of family members participating in this research may be representative of situations experienced by other families admitted to other hospitals and other medical conditions. In this sense, the study may contribute to discussions in relation to foster care provided by the health team and in particular by nursing from the perspective of a skilled care and humane.

REFERENCES

- 1. Ministério da Saúde (BR). Instituto Nacional de Câncer José Alencar Gomes da Silva. Coordenação Geral de Ações Estratégicas. Coordenação de Prevenção e Vigilância. Estimativa 2012: incidência de câncer no Brasil. Brasília (DF): Ministério da Saúde; 2011.
- 2. Girardon-Perlini, NMO. Cuidando para manter o mundo da família amparado: a experiência da família rural frente ao câncer [tese]. São Paulo (SP): Escola de Enfermagem da Universidade de São Paulo; 2009.
- 3. Bervian PI, Girardon-Perlini NMO. A família (con)vivendo com a mulher/mãe após a mastectomia. Rev bras cancerol. 2006; 52(2):121-8.
- 4. Sales CA, Matos PCB, Mendonça DPR, Marcon SS. Cuidar de um familiar com câncer: o impacto no cotidiano de vida do cuidador. Rev eletrônica enferm [periódico on line] 2010; 02 dez 2012]; 12(4):616-21. Disponível [citado em em: http://www.fen.ufg.br/fen_revista/v12/n4/pdf/v12n4a04.pdf
- 5. Prochnow AG, Santos JLG, Pradebon VM, Schimith MD. Acolhimento no âmbito hospitalar: perspectivas dos acompanhantes de pacientes hospitalizados. Rev. gaúch enferm. 2009 mar; 30(1):11-8.
- 6. Fraga CR, Espírito Santo FH. A vivência hospitalar do familiar cuidador. Rev pesqui cuid fundam [periódico on line] 2010 out/dez; [citado em 02 dez 2012]; 2(Ed. Supl.):474-76. Disponível em:

http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1016/pdf_176

7. Silva L, Bocchi, SCM, Bousso RS. O papel da solidariedade desempenhado por familiares visitantes de acompanhantes de adultos e Idosos hospitalizados. Texto & contexto enferm [periódico on line] 2008 abr/jun; [citado em 02 dez 2012]; 17(2):297-303. Disponível em: http://www.scielo.br/pdf/tce/v17n2/11

Mistura C, Schenkel FW, Rosa BVC, et al. The experience of accompanying a family...

- 8. Wanderbroocke ACNS. Cuidando de um familiar com câncer. Psicol argum [periódico on line] 2005 abr-jun; [citado em 04 dez 2012]; 23(41):17-23. Disponível em: http://www2.pucpr.br/reol/index.php/PA?dd1=183&dd99=view
- 9. Minayo MCS. Pesquisa Social: teoria, método e criatividade. 30ª ed. Petrópolis (RJ): Vozes; 2011.
- 10. Gil AC. Métodos e técnicas de pesquisa social. 6ª ed. São Paulo (SP): Atlas; 2010.
- 11. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em pesquisas qualitativas em saúde: contribuições teóricas. Cad saúde pública. 2008 jan; 24(1):17-27.
- 12. Ministério da Saúde (BR). Conselho Nacional de Saúde. Diretrizes e normas regulamentadoras da pesquisa envolvendo seres humanos: Resolução nº 196/96. Brasília (DF); 1996. [citado 11 mai 2012]. Disponível em: http://www.ufrgs.br/bioetica/res19696.htm
- 13. Sales CA, Molina MAS, Cardoso RCS. Estar com um ente guerido com câncer: concepções dos familiares. Revista Nursing. 2006 jun; 97(8):878-82.
- 14. Montefusco SAR, Bachion MM. Manutenção do lar prejudicada: diagnóstico de enfermagem em familiares de pacientes hospitalizados com doenças crônicas. Rev eletrônica enferm [periódico on line]. 2011; [citado em 04 dez 2012]; 13(2):182-9. Disponível em: http://www.revistas.ufg.br/index.php/fen/article/view/14201/9619
- 15. Szareski C, Beuter M, Brondani CM. Situações de conforto e desconforto vivenciadas pelo acompanhante na hospitalização do familiar com doença crônica. Ciênc cuid saúde. 2009; 8(3):378-84.
- 16. Ministério da Saúde (BR). Portaria n.1286, de outubro de 1993. Brasília (DF); 1993. 02 2012]. set Disponível http://dtr2004.saude.gov.br/susdeaz/legislacao/arquivo/19_Portaria_1286_de_26_10_1993 .pdf
- 17. Pinheiro UMS. Más notícias em oncologia: o caminho da comunicação na perspectiva de médicos e enfermeiros. [dissertação]. Santa Maria (RS): Programa de Pós-graduação em Enfermagem, Universidade Federal de Santa Maria; 2012.
- 18. Miliorini JP, Fernandes MV, Decesaro MN, Marcon SS. A família no contexto hospitalar: apreendendo os anseios e expectativas relacionadas com a doença crônica. Rev Rene. 2008; 9(3):81-91.
- 19. Morais GSN, Costa SFG, Fontes WD, Carneiro AD. Comunicação como instrumento básico no cuidar humanizado em enfermagem ao paciente hospitalizado. Acta paul enferm. 2009;
- 20. Carvalho CSU. A necessária atenção à família do paciente oncológico. Rev bras cancerol. 2008; 54(1):87-96.
- 21. Silveira RA, Oliveira ICS. O cotidiano do familiar/acompanhante junto da criança com doença oncológica durante a hospitalização. Rev Rene. 2011; 12(3):532-9.
- 22. Bielemann VLM. A família cuidando do ser humano com câncer e sentido a experiência. Rev bras enferm. 2003 mar/abr; 56(2):133-7.
- 23. Teixeira JJV, Lefèvre F. Significado da intervenção médica e da fé religiosa para o paciente idoso com câncer. Ciênc saúde coletiva. 2008 jul/ago; 13(4):1247-56.

ISSN 2175-5361 Mistura C, Schenkel FW, Rosa BVC, et al. DOI: 10.9789/2175-5361.2014v6n1p47

The experience of accompanying a family...



Received on: 02/02/2013 Required for review: No Approved on: 03/10/2000 Published on: 01/01/2014 Contact of the corresponding author: Marilene Oliveira Girardon-Perlini Endereço: Av. Roraima, 1000 Prédio 26 – Cidade Universitária, Camobi CEP: 97105-900 – Santa Maria (RS), Brasil