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Structural, Development and Functional Evaluation of Families of Older People Under Palliative Care

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Abstract

Objective: to evaluate the structure, development and functionality of elderly families in end-stage palliative care.

Method: this is a qualitative study, developed with five families, whose data were collected through the interview technique, using two instruments: the genogram and eco-map. The empirical material was analyzed in the light of the Calgary Family Assessment Model.

Results: the data obtained from the family assessment, verified in the structural category, has shown that most families, as to the organization, is from the extensive type and that the female figure is the provider of home. Concerning the development of families, it was observed that every women have caregivers function. In the functional aspect, regardless of household income, elderly patients maintained their satisfactory hygiene conditions.

Conclusion: it is expected that the results of this research can support the planning of nursing care through the complete evaluation of the family, in order to contribute to the development of skills in nursing, to meet the needs of families of elderly patients with disease in the final stage of life.

Descriptors: Nursing; Elderly; Family; Palliative Care; Nursing Models

Introduction

Population ageing is a global and cotemporary phenomenon of demographic transition, with social implications. It is characterized by a significant increase in serious chronic illnesses, which increase the number of dependent people [1] and life-threatening diseases, such as cancer. For this reason, it is necessary directed assistance to the elderly afflicted with terminal illness and to their families, providing them support so they can live with dignity. Thus, palliative care is relevant.

Palliative care is presented as a therapeutic modality with an interdisciplinary approach that improves life quality of patients with advanced and terminally ill chronic disease and provides support to their family. It consists of a set of actions that are aimed to individualized care in order to restore the dignity in human finitude.

Terminal illness leads patients to the final stage of life and is characterized as an incurable, progressive and advanced disease, which does not respond to specific treatments and causes great emotional impact on the patient, family and health professionals and with limited health prognosis from three up to six months [2,3]. Thus, the possibility of losing relative one affects the whole family. In this way, the fear of pain and suffering that involves the finitude of life can be an indicator that, in order to care for the elderly, the family should be included in the care plan of the healthcare professional [4].

The actions of nurses as health team member enables the assistance planning to the family and elderly patients affected by a disease that led to the finitude of life. In this sense, it is highlighted the adoption of theoretical models which leads Nursing in the process of care, in the perspective to evaluate the structure, development and family functioning that the elderly is inserted. Therefore, it is emphasized the Calgary Family Assessment Model expressed by a multidimensional and integrated framework for family assessment, which was presented by Wright and Leahey [5]. This model integrates the structural, developmental and functional dimension and provides an understanding of the family, their internal relations and with the support network, in order to balance the bonds, it observes the family dynamics with the purpose of planning satisfactorily the care for patients and their family.

As previously disclosed, the study was guided by the following question: What is the structure, the development and functionality of families with elderly in terminal stage in

palliative care? In order to answer this proposed question, it was presented the following objective: to evaluate the structure, development and functionality of elderly families in terminal stage under palliative care.

In this context, this research is considered relevant in the field of nursing, because the number of publications in national literature about this theme is still low and meet unique and challenging elements, that seek to make contributions to the application of knowledge. Subsidize the practice of this type of care and sensitize the nurse professional who keeps more contact with the elderly patients and their family to know the difficulties in situations that permeate the disease in terminal phase and find a solution to the problems with their family.

Method

This is a field research with a qualitative approach, conducted by the assumptions of the theoretical and methodological framework of the Calgary Family Assessment Model [5] performed in a hospital, philanthropic institution, located in the city of João Pessoa, state of Paraíba, Brazil. Considering the population of this study, it was part of the research population elderly with terminal disease under palliative care who were hospitalized during the study period and their family caregivers. To select the sample, the following inclusion criteria were adopted: patients aged over sixty, who presented the Palliative Performance Scale score equal to or below 50% and were conscious and oriented at the time of data collection. This scale is used in the eligibility conditions to establish the degree of functionality and complexity of the patient, from a clinical point of view, and aims to provide palliative assistance to patients and their families who need this sort of care [6]. As for the family caregivers, they should be over 18 and be accompanying the patient at the time of data collection. The sample was composed of five families, each represented by the elderly patient with terminal illness and a family caregiver, thus, ten participants. This quantity was considered sufficient because the qualitative research describes meanings of actions and human relations, it is non-noticeable and not procurable in equations, averages and statistics [7].

To render viable the collection of data with the families, it was used the genogram and eco-map, recommended tools for the Calgary Model. For this, it was used the interview technique, based on a predefined script containing relevant questions to the purpose of the study; the recording system unit mp4 to record interviews with the families included in the study; and the field diary to record the notes of the Palliative Performance Scale. Data were collected in the months of August, September and October 2014. The genogram is an organizational chart that depicts family tree and outlines its structure and its history, as well as revealing the health status of each person and the type of relationships between the core. The eco-map is a graphic design with which the nurse can assess the links between family members, through support networks and services used by them [5]. The empirical material obtained was analysed in the light of the Calgary Family Assessment Model [5], considering the categories it proposes-structural, developmental and functional-and discussed based on the literature.

Research was conducted in an ethical and responsible manner and is in full compliance with all relevant codes. We gave every participant a written consent. In compliance with the ethical observances related to research involving human subjects, recommended by Resolution 466/2012 of the National Health Council [8], the project was approved by the Ethics Committee of the Federal University of Paraiba, under CAAE of nº. 33261114.1.0000.5183. To preserve the identity of the elderly participating in the study, they were named with names of the brightest stars in the universe, and family caregivers, precious gemstones names for their unique condition of caregivers, with courage and fortitude that this t job requires require. In the preparation of the genogram, the other family members received fictitious names.

Results

Thus, five families were part of the study: patient Alya and her caregiver Rubi; patient Atria and her caregiver Pérola; patient Alzir and her caregiver Crystal; patient Jih and his caregiver Esmeralda; and patient Gianfar and his caregiver Topázio. To understand and expand the observation focus of the individual for the family, it will be presented the characterization of five families involved in the study in relation to structural, developmental and functional aspects. The genogram was the instrument used to illustrate and detail the structure and composition of each family, and the ecomap to outline the family's relationships with other people and meaningful institutions, as shown in Figures 1-5.

Figure 1 shows, through the genogram and ecomap, the structure of the family of Mrs. Alya (index case), who is natural from Cacimba de Dentro-PB, 71 years old, widow and retired. She was diagnosed with esophageal and stomach neoplasia, she began chemotherapy treatment at a referral hospital in oncology but was unsuccessful. She is currently hospitalized and receiving palliative treatment.

As for the structural aspect of Alya's family, is of the extensive female single parent type, composed by the patient, a brother of 72 years old and her sister-in-law, also elderly, who have ten children, six of which also compose Alya's family core. Rubi is her niece and main caregiver of Mrs. Alya. The patient's family is of low social class, since it only has two minimum wages, resulting from both Mrs. Alya and her brother retirement. They own the house. The level of education of her nephews is very low-are only literate. All living from subsistence agriculture in the countryside of the state.

The family does not maintain relations with the neighbors, because they reside in the countryside and everything is distant and difficult. This geographical situation weakens relations with

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other family members. As for network support of her family, with regard to the Basic Health Unit (BHU), Rubi declares that there are no ties, because of the distance, which complicates to search for care for her aunt. The patient (index case) had three children who died shortly after birth. However, Mrs. Alya likes nephews as they were her children and have a harmonious relation with them, especially with Rubi. The family has a relationship of affection with the hospital staff where the patient is hospitalized and she says he feels esteemed especially by nurses (Figure 1). According to Rubi reports, the entire family member is Catholic, and faith and hope are essential to address the problems, especially those who appeared with the aunt's disease (Alya).

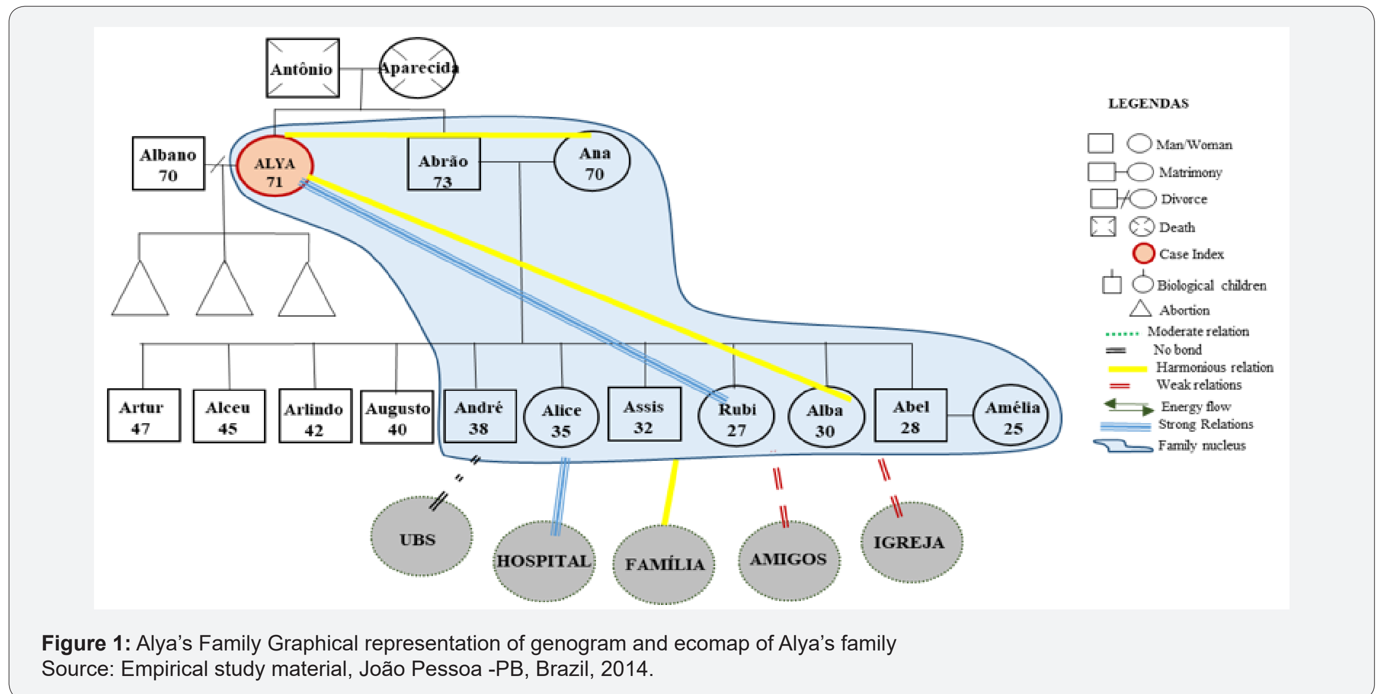

Figure 1: Alya's Family Graphical representation of genogram and ecomap of Alya's family
Source: Empirical study material, João Pessoa -PB, Brazil, 2014.

Regarding the development of the family aspect, it is in the stage which is defined as a family at the end of life, because of the fact that Alya is single, does not have children, is elderly and with terminal illness, although she adore her nephews and consider them as her true children. In this case, it can also be considered in the stage when the children are leaving the house. Rubi says everything changed: the distance

and the financial conditions relative to Alya care. Yet, the family gathers without many problems or conflicts. However, the disease condition of the aunt (Alya) has interfered significantly in the life of Ruby, because it was necessary to modify her daily routine to assist Alya in hospitals. As they live particularly distant, the other family members always call to obtain news about Alya.

As for the functional aspect of Alya's family, her sister-in-law, Ana, and niece Rubi, unique responsible for Alya's hospital care, both play a friend and partner role and also maintain a mutual concern for her brother. These mentioned family members are the ones directly involved in decisions that involve the diagnosis and all aspects related to hospitalization. Relatives residing in the capital of Paraiba or in other states claim that they can not follow her to the hospital environment because they have to work. Rubi says that if all members of the family helped, it would be better and less exhaustive, which creates concern and sadness for Mrs. Alya's brother, since he is elderly and lacks sufficient physical and emotional conditions.

The diagnosis of Mrs. Alya was revealed by the doctor after an endoscopic examination. The notification of the disease without a cure, according to Rubi, was painful. Everyone was sad. Since then, the family faces difficulties and cares for the health of Mrs. Alya. For healthcare, the family relies exclusively with the hospital where the patient is hospitalized. According to Ruby, in the hospital, her aunt receive necessary assistance needed at the moment, but notes that the communication between professionals and the family needs to be improved, both in direct care and for the announcement of the results of diagnostic tests. Ruby concludes by stating that the patient's illness caused a great impact on the family, and everyone have difficulties in expressing their feelings.

Figure 2, which represents the genogram and eco-map, illustrates the structure of the family of Mrs. Atria (index case), who is natural in Belém do Brejo do Cruz state of Paraíba, is 67, widow, illiterate, pensioner and has three children (a man and two women). She was afflicted with uterine and bladder neoplasia and bone metastasis. As she was considered with no therapeutic possibility of cure, she is currently hospitalized in palliative treatment.

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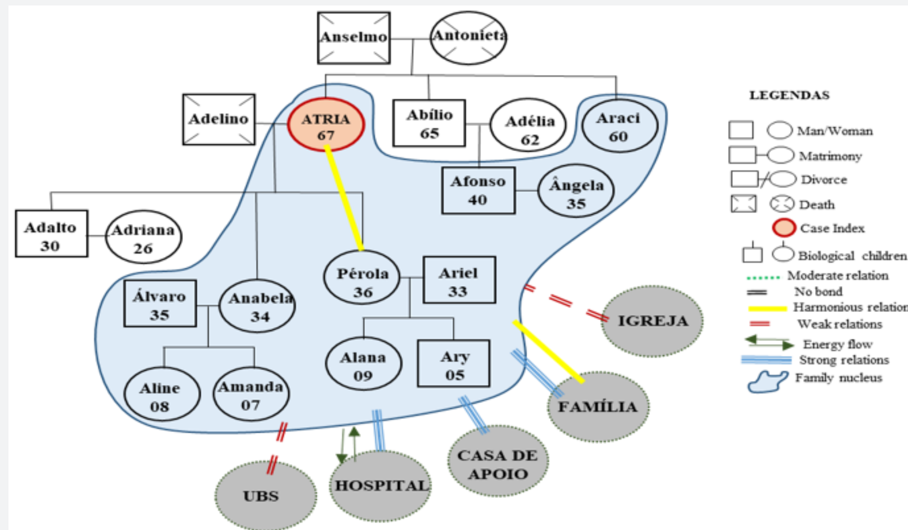

Figure 2: Atria's Family Graphical representation of genogram and ecomap of Atria's family Source: Empirical study material, João Pessoa -PB, Brazil, 2014.

As for the structural aspect, Atria's family is of the extensive female single parent type, composed by her three children, one married son and two married daughters, two sons-in-law, four grandchildren, a nephew with his wife and an unmarried sister. Pearl, her daughter of 36 years, accompanies the patient to the hospital. The family of Atria is of low social class, has three minimum wages resulting from her pension and income from her sons-in-law. According to Pérola, the house they live in is their property and in precarious conditions, said Pearl.

The family relationships are harmonious. According to Pérola, there is a doctor, friend of the family, who lives in João Pessoa collaborating with the expenses. As for the network support of the family, in relation to the Basic Health Unit (BHU), Pérola said that there are no links. Everyone maintain a strong relationship with the hospital where the patient is hospitalized, mainly with professionals, and she feels welcome (Figure 1). Pearl also stated that they are Catholics and prays to find strength for her mother's recovery. Regarding the developmental aspect, Atria's family is in two stages of life: the first, concerning the departure of children from home, with adult children and grandchildren; and the second, defined as a family at the end of life, due to the fact that one of the members is with terminal illness and advanced age. Pérola confirms that everything has changed and that financial conditions have become more difficult. However, despite many difficulties, the family maintains a harmonious relationship. Pérola said that Atria's disease interfere with the daily life of the family because she is the one who cares for her mother at the hospital and leave her children with her mother-in-law.

In regard of the functional aspect of the family, Atria plays a paper of friend and homemaker, being also the economic and emotional sustenance of the family. With regard to the environment in which they live, Pérola expresses that in the place where the family lives there is a lack of missing parks and sanitation, the streets are not paved, hence living conditions are unsatisfactory. As for hospital care, it is distributed between Pérola and the wife of her cousin who lives in João Pessoa because other family members have not enough emotional condition to support the stress. She stresses that the city Council from where she lives maintains a support house to receive sick people and the ones who need to perform examinations in the capital, this one receives her brothers when they come to visit his mother has a welcoming environment. She also comments that it would be much easier if more family members collaborate with care.

Regarding the news of the diagnosis, the doctor communicated Pérola, who informed the family, which became desperate. In addition to the concern with Atria, the family had to change their daily routine to accompany the patient during the treatment, as Pérola had to leave her husband and children to look after her mother in the hospital in João Pessoa. Because she is closer to the mother, Pérola experiences intensely the suffering of her mother. She completes stating that due to the illness of her mother, the family members have approached more to each other, although some members remain distant.

The graphic representation of Figure 3 shows, through the genogram and ecomap, the structure of the family of Mrs. Alzir (index case), who is from Guarabira in the state of Paraíba, she is 62 years old, single and retired. She was diagnosed with breast cancer and began chemotherapy treatment at a referral oncology hospital, but without success. She is currently hospitalized and being subjected to palliative treatment.

Regarding the structural aspect of her family, it is of the extensive female single parent type, composed by one older sister and three nephews, two of them are married, and the wife

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of one of them, Cristal, participates in patient care, especially in the hospital where she is hospitalized. The patient's family is of low social class, they earn three minimum wages, resulting from the retirement of Mrs. Alzir and her sister, and another salary resulting from the job of one of the nephews. The patient has a harmonious relationship with Cristal, that, to go to the hospital, receives financial aid from her mother-in-law for food and transportation. The house in which the family lives in is their property and has reasonable living conditions.

The family relationships are strong and harmonious. As for the family network support, in relation to the Basic Health Unit (BHU), Cristal reports that the relationships are weak and has difficulty when seeking help. Everyone maintain strong relationships with the hospital where the patient is hospitalized, mainly with professionals. The caretaker said she feels welcome, there is a constant flow of energy (Figure 3), the whole family is Catholic and that "faith helps, and religion provides support and hope".

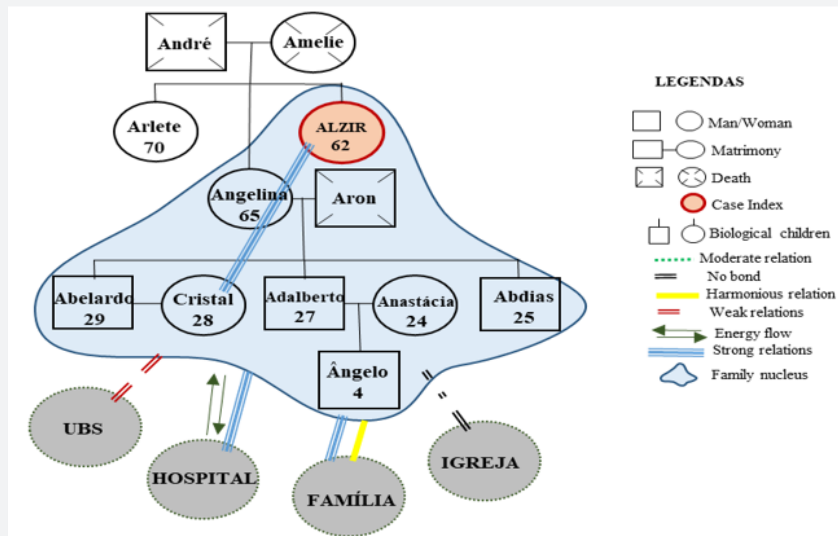

Figure 3: Alzir's Family Graphical representation of genogram and ecomap of Alzir's family Source: Empirical study material, João Pessoa -PB, Brazil, 2014.

With regard to development, the family is at the end of life stage, due to the fact that Alzir is single, does not have children, has a diagnosis of terminal illness and is aging, despite having a great appreciation for her nephews, sons of her sister, and consider them as children. Thus, it should be considered maturation stage of children and the their departure of home. Cristal ensures that everything changed and became was difficult and that the financial situation interferes in the patient assistance. She states that the discovery of Alzir's disease changed completely the family routine and quit her job to care for her: "It affected my life and most of my family, we do everything to assist her, when we cannot do, we pay a person to stay with her in the hospital overnight."

As for the functional aspect of Alzir's family, she plays a homemaker and is comprehensive. With regard to the environment they reside, Cristal ensures that has parks, cobbled streets and sanitation, but the house is small to the number of people. With regard to the hospital care, it is restricted exclusively to Cristal. The sister of Mrs. Alzir shows concern, but due to the fact of being elderly, she has not enough physical and emotional conditions to help. She said that if more family members collaborated with care, it would be very good. As for the news about the diagnosis, Cristal said that part of the family still does not know the real health state of Mrs. Alzir, including Cristal's mother-in-law and the sister of the patient, whose health is fragile. Cristal is the one who communicates with family members and decides about treatment, through the mobile phone, to disclose the information about the patient. Cristal completes saying that the disease Mrs. Alzir did not approached or moved away family members.

The graphic design represented by the genogram and ecomap, which corresponds to Figure 4, illustrates Jih's family structure. The patient (index case) is from Mamanguape in the state of Paraíba, is 71 years old, married, retired and has seven children (five men and two women). He was diagnosed with a malignant melanoma with liver, skin and lymph nodes metastasis. Due to have no therapeutic possibility of cure, he is currently hospitalized in palliative treatment.

As for the structural aspect, the family of Jih is of the nuclear type, composed by him (index case), his wife and his youngest son, who lives with his parents. Esmeralda is 21 years old, Jih's granddaughter and main caregiver, she is the one who most accompany him in the hospital environment. The patient's family is of low social class. According to Esmeralda, the financial situation influences someway in the use of health resources in the assistance for Jih, since the family earns with

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only two minimum wages, from the retirement of Jih and his wife. Their house is family's own property and has reasonable living conditions.

The patient has a harmonious relationship with his granddaughter Emerald. The family relationships are strong and harmonious. As for the family support network, the granddaughter said there were no ties with the Basic Health Unit (BHU) and that the family has difficulties to receive help from the team professionals. Everyone has good relations with the hospital where the patient is hospitalized, mainly with the nurses, for whom feel welcomed. Jih's granddaughter said that they are Catholic and renew their faith in the church (Figure 4).

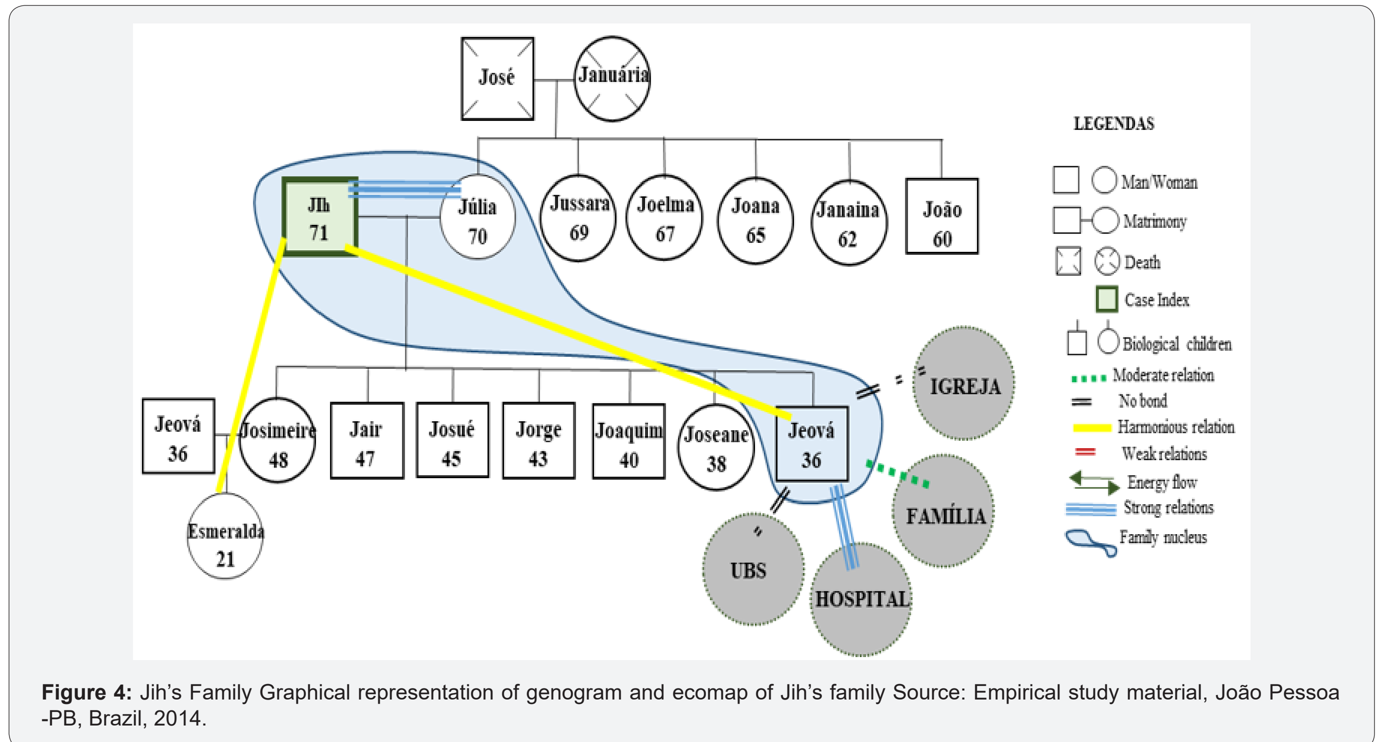

Figure 4: Jih's Family Graphical representation of genogram and ecomap of Jih's family Source: Empirical study material, João Pessoa -PB, Brazil, 2014.

With respect to the family developmental aspect, it has two stages: the first, which is defined as maturation of children and their home departure, with adult children and grandchildren; and the second, as the family in the end of life, because Jih has a diagnosis of a terminal illness and is elderly. Esmeralda emphasizes that Jih's disease interfered in the family daily life because it was necessary that other relatives contributed more for his care in the hospital environment. Esmeralda ensures that the relationship with other family members is moderate and she does not mention any conflictual relationship.

Regarding the functional aspect of the index case, Jih is the head of the family, friend and companion. Because his wife is elderly, hospital care is divided between the two daughters and especially the granddaughter, Esmeralda.

About the diagnosis, Esmeralda said that, when it was revealed, the family was afflicted and who informed Jih was Josimere, one of his daughters. It was very difficult and painful. Esmeralda states that her aunt, Josimere, expresses herself better and she was always ahead of the decisions related to the treatment of Jih. In addition to the concern with Jih, the family had to change its daily routine, as it was indispensable the collaboration of the family member to arrange assistance for Jih at the hospital in João Pessoa. Esmeralda concludes by saying that with the diagnoses of Jih's disease, the family members have approached more to each other.

In Figure 5, through the genogram and ecomap, it is showed Gianfar's family structure. This patient (index case) was born in João Pessoa, capital of Paraíba, he is 67 years old, widower and retired. He was diagnosed with maxillary sinus cancer and initiated chemotherapy treatment at a referral oncology hospital. Since he did not succeed in treatment, he was admitted to palliative treatment.

As for the structural aspect, the Gianfar's family is the of extensive female single parent, composed by him, his mother Dona Gilda who is 82 years old, two sisters-in-law, one of them is Topázio who is Gianfar's main caregiver, and his daughter who is 26 years old. The patient's family is of low social class and their income is three minimum wages, resulting from the retirement of the patient, his sister (Topázio) and his mother-in-law. The house of the family is their own property.

The family has not any sort of ties with neighbours. The family relations with other relatives are moderated. Topázio said that this situation only happens because there no sufficient interest, since the family is composed by elderlies. Regarding

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the family network support, in relation to the Basic Health Unit (BHU), Topázio reports to have strong ties and mentions the doctor and the nurses as family friends. In addition to the health of the Gianfar (index case), there is also his mother, who is diabetic. The family has a relation of affection with the hospital professionals where the patient is hospitalized and say they feel welcome, mainly by the nurses. About religion, Topázio states that the family is Catholic, they to attend Mass every Sunday and watch the Mass on television (TV Aparecida). The family group prays to find comfort to relieve the situation of Gianfar.

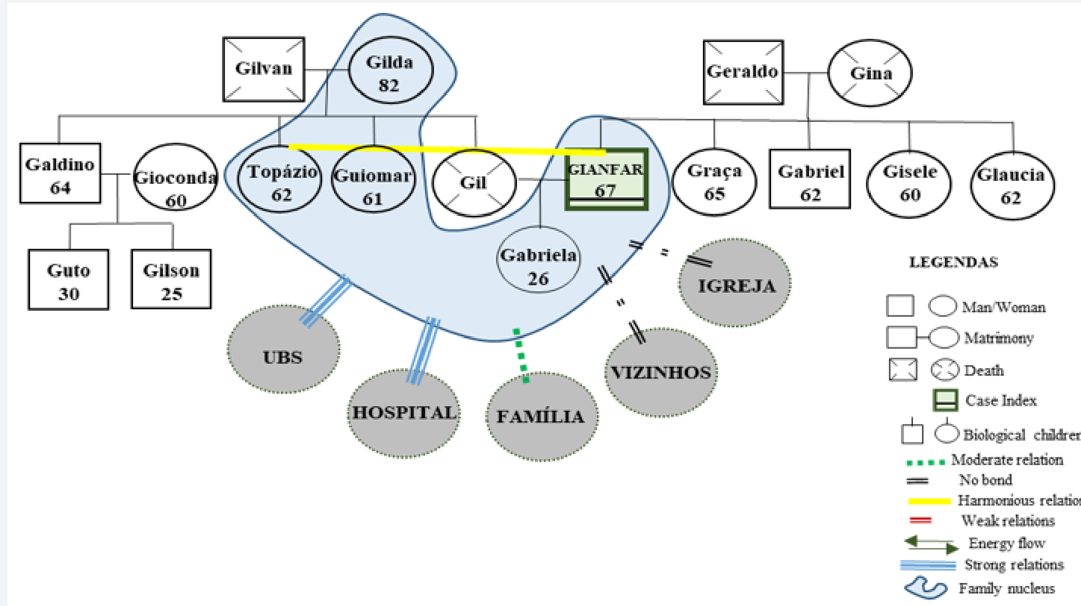

Figure 5: Gianfar's Family Graphical representation of genogram and ecomap of Gianfar's family
Source: Empirical study material, João Pessoa - PB, Brazil, 2014.

Regarding the developmental aspect, the family is in two stages: in the end of life, due to the fact that Gianfar was diagnosed with a severe and terminal disease and he is elderly; and the maturation of children and their departure of home, since Gianfar' daughter is 26 years old. Topázio claims that the Gianfar's illness changed the daily routine of the family, affected them in financial issues and created difficulties to arrange a schedule to care for her brother-in-law. The daughter of Gianfar does not comprehend that she needs to help more at home and in the hospital. Moreover, as other family members live in the countryside of the state, they always call to know about him.

In the case of the functional aspect of the family, Gianfar plays a friend and partner role, Topázio, his sister-in-law, and Gabriela, his daughter, are responsible for taking care of him in the hospital. Topázio decides and resolves everything that involves the family financial issues. Relatives residing in the capital of Paraiba or in the countryside of the state say they can not visit the patient and family because they have to work. For Topázio everything is very tiring and sad. The diagnosis of Gianfar was revealed to the family by the doctor. The notification of disease with no cure, according to Topázio, was painful, and the whole family was sad. Since then, they are facing financial and emotional difficulties. For health care, the family relies exclusively with the hospital where the patient is hospitalized and obtain the necessary assistance, but the communication between professionals and the family needs to be improved, both in the direct care and in the updates of Gianfar's health status. Topázio states that the patient's illness caused a great impact on the family and that everyone has difficulty in expressing their feelings.

Discussion

With the characterization of families of elderly patients with end-stage disease under palliative care it was possible to identify how interactions occur in family life towards the demands that this situation requires. The data were presented, interpreted, and analysed in order to understand these interactions. Therefore, it was used as theoretical reference the Calgary Family Assessment Model.

This model proposes that when assessing a family, the professional must examine its structure, who is part of it, the family affective bonds as well as its context [5]. Regarding the assessment of the structural category, it was found that the family 1 (Alya), 2 (Atria), 3 (Alzir) and 5 (Gianfar) are characterized as of the feminine extensive single parent type, presented in their genograms illustrated in Figures 1-5. This family setting is the one in which only one parent, in this case the mother, lives with the children, other minors who are under their responsibility and other adults or relatives [9]. Only family 4 (Jih) (Figure 4)

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is identified as nuclear, meaning that the family composed by a couple living with their children [10].

Researchers observe that, over time, the family and society have changed together. Thus, society modify culturally, politically, ethically or for equal rights. For instance, these modifications resulted in changes in the social role of women, which led to the gradual establishment of women in the gradually the job market. These changes are reflected in the families, because they are characterized as a source of social metamorphosis [9].

Due to these changes, the female single parent families are currently the reality of a significant percentage of society [11]. In this aspect, the CFAM meets this contemporary formation of family composition and defines the family as "a group of individuals united by strong emotional bonds with a sense of belonging and inclination to participate in each other's lives." The model recommends that the nurse should not restrict the family to consanguinity and marriage criterion, but acknowledge it beyond traditional boundaries. (5:32) Therefore, it is appropriate for Nursing to investigate new ways to establish bonds in the family context and provide them a humanized point of view of the family care with elderly patients in terminal phase.

As for the mutual influence of the family group with institutions that the families maintain a significant contact, all participating families of the research have strong relations with the hospitals where the elderly patients were admitted under palliative treatment. This fact helps the family to understand even more the health status of the patient, as shown in the ecomaps of each family (Figures 1-5). Therefore, four families reported no relationship with the Basic Health Unit (BHU).

In these circumstances, it is noteworthy that, with technological advances in health and cultural changes, such advances have contributed to increase the terminality of life, especially in the hospital setting. However, this process of terminally is independent of the environment where the patient is admitted, therefore, in any situation, it is necessary that the patient receives a dignified and humane treatment. Therefore, it is particularly important that the nursing professionals expand their knowledge and skills to fulfill the demands of the family and the peculiarities of these patients under palliative care [12,13].

With regard to religion and spirituality, families expressed a similar meaning to the religious values and beliefs [5]. In this way, the five families of the study mentioned the Catholic religion as part of the family context, as the ecomap shows in Figures 1-5. The Calgary Family Assessment Model emphasizes that evaluation is more delicate at the time of diagnosis of a potentially fatal disease, especially when there are crisis (attacks) that cause extreme suffering [5]. The study observes that identify religion as a potentially effective tool and detect the spiritual shortcomings (deficiencies) of patients and their families provide to healthcare professionals the ability to plan and promote a comprehensive care for the patient's family in the finitude of life [14].

The evaluation of the developmental category is the family history, the moments of the life cycle of the family and it is modelled by predictable and unpredictable events, such as diseases and disasters. With respect to the stages of the life of families, all of them (1 Alya, 2 Atria, 3 Alzir, 4 Jih and 5 Gianfar) are in two stages. The end of life stage, in which the emotional process of family transition develops from the functional decline of the elderly patient and from the death of family member, and the stage of maturation of the children and their departure from home, as the families of Atria of Jih and Gianfar have children and grandchildren, while Alya families and the Alzir even having no biological or adopted children, consider their closer nephews and nieces as their true children [5].

The Calgary Model emphasizes that the family should explore new options and adjust roles in the family and social nucleus. Dealing with the loss of one family member is a moment to think about life and take care of pending businesses with the internal family and social contacts. It also stresses that the nurse should know the development of the life cycle of the family, and especially lead (conduct) and present conditions for elderly in terminal phase to have the opportunity to apply for specific occupations for their age and interact with every family member (children, nephews, grandchildren, siblings, spouses, etc.), providing support for the family promotes itself (family develops) new arrangements improving the performance of their roles [5]. For families 1, 2, 3, 4 and 5 of this study, the main bonds demonstrated were of friendship and harmony, especially between the patient and the family caregiver. In all families, women were delegated to be caregivers. The bonds refer to affective ties between people and transcend consanguinity and gender.

The functional assessment is the investigation of how family members behave genuinely with each other in relation to the basic aspects of family functioning. All families of this study present difficulties in providing of patient care, which is related to internal financial resources and social support. Regardless of the monthly household income, the families maintained satisfactory conditions of hygiene at the place where the elderly lived and in hospitals and expressed (to have) a harmonious relationship among family members. Nevertheless, financial difficulties and the severity of the disease motivated them to seek hospitalization for their family member, since the disease progressed and pain occasioned suffering compromising the quality of life of the elderly.

It is noteworthy that in addition to relieving pain and suffering, holistic care is essential in assisting patients with end-stage disease. In accordance with this argument (likewise), palliative care has essentially the function of providing a better life for patients and their families, and this type of care confirms

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the importance of active, complete and comprehensive care, because when the disease process leads naturally to the finitude (death), the patient should receive comfort in the physical, psychological, social and spiritual dimensions [15].

All families (1, 2, 3, 4 and 5) had patients with oncological disease in terminal phase and were under palliative treatment in hospitals where the study was conducted. In all of them, the caregiver role is occupied by women: in Alya's family, her niece Rubi; in Atria's family, her daughter Pérola; in Alzir's family, her niece Cristal; in Jih's family, his granddaughter Esmeralda granddaughter, and in Gianfar's family, his sister-in-law Topázio. All caregivers reported overburden in the performance of the role, for they could not count on other family members in providing patient care.

As for family caregivers, with respect to their feelings generated by the care situation, it became clear that if on the one hand the overload of work negatively impacted on their quality of life, on the other hand, the care of hospitalized patients were motivated as a way to demonstrate gratitude to the feelings of love, caring and affection that these elderly dedicated to their families throughout life. Studies observe how distressing is the activity of care, because it is the primary caregiver who is most held responsible for the elderly patient and the burden of caring has several impacts on the caregiver leading to social isolation, reduced or lack of leisure, neglect their own health and physical and mental exhaustion [16,17]. Therefore, it is imperative that health professionals provide palliative care to families and promote actions to exercise harmony, trust and familiarity among its members and the healthcare team in order to exchange experiences that encourage care in both biopsychological and spiritual dimensions in the family system. especially the nurses, because they directly assist the family of elderly with end-stage disease from the diagnosis to the final moment of life.

Final Considerations

The study showed that the care of elderlies in terminal phase influences the structure and dynamics of families, due to situations of uncertainty and concern about the future of limitations, fear and the possibility of imminent finitude(death). Through the Calgary Family Assessment Model, it was possible to have a holistic view of the families of the elderly in the terminal phase treated with palliative care, in which nursing care may contribute to overcome or minimize the suffering experienced by many difficulties, as it contributes with integral care and attention; to evidence the structural, developmental and functional dimensions of the families studied were altered due to the end-of-life disease situation; to understand that the integration of the family into the care plan accelerates the process of accepting the death situation; to live well the last phase of life; as well as to reduce the risk of psychological damage caused by the possibility of losing a relative and by mourning. Thus, it is concluded that the Calgary Family Assessment Model is the ideal for a qualified and humanized care centered on the family as a unit of care.

This study had as limitations the relatively small number of patients participating, because some of those other hospitalized patients were excluded from the research since they presented serious health difficulties imposed by the disease and did not complete inclusion criteria. It is expected that the results of this research may support the nursing care planning based on the integral evaluation of the family and provide care focused on the quality of family life, in the perspective that the group can acquire its own resources to deal with the numerous difficulties of families with elderly people in the final stages of life.

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