

Family experience living with advanced neoplasm: a glance at the rural population

Experiência de famílias convivendo com neoplasia avançada: um olhar à população rural

Experiencia familiar que vive con neoplasia avanzada: una mirada a la población rural

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ABSTRACT

Objectives: to understand the experience of rural families living with advanced cancer, from Family Management Style Framework's perspective. **Methods:** a qualitative research conducted in seven cities of the northern of state of Rio Grande do Sul in homes of 11 families (27 people). Data collection took place in 2014, using the genogram and narrative interview. Analysis followed Family Management Style Framework's theoretical model. **Results:** the results were organized into three categories based on conceptual components of the referred model: no more normal life: situation definition; attempt to reconcile care and work: management behavior; imminence of the finitude of life: perception of consequences. **Final Considerations:** living in rural context gives families specific ways of dealing with advanced cancer. Understanding the movements undertaken by rural families throughout the experience can guide nursing professionals in planning interventions collaborating with this population's health.

Descriptors: Neoplasms; Family; Rural Health; Nursing; Nursing Research.

RESUMO

Objetivos: compreender a experiência das famílias rurais que convivem com a neoplasia avançada, na perspectiva do *Family Management Style Framework*. **Métodos:** pesquisa qualitativa, realizada em sete municípios da região Norte do Rio Grande do Sul, no domicílio de 11 famílias (27 pessoas). A coleta de dados ocorreu em 2014, utilizando o genograma e a entrevista narrativa. A análise seguiu o modelo teórico *Family Management Style Framework*. **Resultados:** os resultados foram organizados em três categorias, a partir dos componentes conceituais do referido modelo: *não existe mais vida normal: definição da situação; tentativa de conciliar cuidado e trabalho: comportamento de manejo; iminência da finitude da vida: percepção das consequências*. **Considerações Finais:** viver no contexto rural confere à família maneiras específicas de agir diante da neoplasia avançada. Compreender os movimentos empreendidos pelas famílias rurais no decorrer da experiência pode guiar os profissionais de enfermagem no planejamento de intervenções colaborando com a saúde dessa população. **Descritores:** Neoplasias; Família; Saúde da População Rural; Enfermagem; Pesquisa em Enfermagem.

RESUMEN

Objetivo: comprender la experiencia de las familias rurales que viven con cáncer avanzado, desde la perspectiva del *Family Management Style Framework*. **Métodos:** investigación cualitativa, realizada en siete municipios de la región norte del estado de Rio Grande do Sul, en los hogares de 11 familias (27 personas). La recopilación de datos tuvo lugar en 2014, utilizando el genograma y la entrevista narrativa. El análisis siguió el modelo teórico de *Family Management Style Framework*. **Resultados:** los resultados se organizaron en tres categorías, basadas en los componentes conceptuales del modelo referido: *no hay más vida normal: definición de la situación; intento de conciliar cuidado y trabajo: comportamiento de gestión; iminencia de la finitud de la vida: percepción de las consecuencias*. **Consideraciones Finales:** vivir en un contexto rural brinda a la familia formas específicas de tratar el cáncer avanzado. Comprender los movimientos realizados por las familias rurales a lo largo de la experiencia puede guiar a los profesionales de enfermería en la planificación de intervenciones que colaboran con la salud de esta población. **Descriptor:** Neoplasias; Familia; Salud Rural; Enfermería; Investigación en Enfermería.

Descriptors: Neoplasias; Familia; Salud Rural; Enfermería; Investigación en Enfermería.

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INTRODUCTION

Cancer is a public health problem due to the magnitude of the epidemiological data, whether due to its incidence, to the population's quality of life and to its high mortality rate⁽¹⁾. Latin America and the Caribbean are responsible for the incidence of 7.8 cancer cases per 100,000 inhabitants⁽¹⁾. Among the main predisposing factors are mainly the lifestyle and social characteristics of a given population. Rural populations are included, which have particularities in relation to access to health services, cultural actions and aspects related to their routine, which impacts on cancer incidence⁽²⁾.

In countries such as Brazil, where there is a decline in mortality associated with infectious diseases and an increase in chronic noncommunicable diseases, the most commonly diagnosed neoplasms are lung, breast, prostate and colorectal⁽²⁾. This determinant places Rio Grande do Sul in the fourth position in the ranking of cancer incidence among the federative units⁽³⁾.

Within the disease picture, cancer cells tend to be aggressive and difficult to control. They can spread to other regions of the body, causing metastasis when cancer can progress to an advanced stage, with no possibility of remission or cure to the patient⁽⁴⁾.

The word "neoplasm" means "abnormal growth" of a tissue whose reproduction is no longer regulated by homeostatic mechanisms. At the moment patients present signs and symptoms such as pain, constitutional symptoms (asthenia, cachexia, anorexia, fatigue), psychological problems, obstructions in various body regions, sleep disorders and inoperable metastasis diagnosis, there is a definition of advanced and end-of-life neoplasm⁽⁵⁻⁶⁾. Living with a family member under palliative care is a complex experience for families and, in general, also for nursing care, especially when it involves those with socioeconomic deprivation and residents far from treatment centers, a reality of many who live in rural environment⁽⁷⁻⁸⁾.

Families, especially those living in rural areas, need to be cared for due to singularities such as the difficulty of access to health services and the risk factors associated with work activity. Members of a family form a complex system, where each member is a subsystem or individual system and is characterized by being elements in mutual interaction with each other⁽⁹⁾. Considering that the change in one of its members, such as disease diagnosis, affects all the others, there is system imbalance. However, it is known that, through its own internal capacity for reorganization, this family can rebalance itself⁽⁹⁾.

When analyzing families and their psychosocial functioning, researchers⁽¹⁰⁾ identified that quality of life is related to the ability to share feelings and deal with conflicts, characterizing better psychosocial condition. A study with rural families shows that, when they realize their threatened world, they feel the need to develop strategies that enable them to reacquire security to interact with a different reality, including the urban one. This not only makes them oscillate between feeling protected and helpless, but also builds a new way of working to cope with the demands of illness and rural family's life⁽¹¹⁾.

In recent years, studies⁽¹²⁻¹⁵⁾ have been conducted using the adapted Family Management Style Framework (FMSF) model focusing on the experience of adults and their families regarding chronic disease, especially cancer. Investigations addressing the

experience of families with a sick member in the Intensive Care Unit (ICU)⁽¹⁶⁾ were identified from the perspective of FMSF. They also address the research results that refer to family influence on child's nutritional status from interviews guided by the model⁽¹⁷⁾; and studies describing the understanding of family management from the perspective of school age children (eight to thirteen)⁽¹⁸⁾. FMSF has been used to explore family management under various circumstances. Understanding the results obtained through it enables health interventions involving interdisciplinary care focused on the specific demands of families⁽¹⁹⁾.

However, no studies were found that sought to understand the experience of rural families living with advanced cancer from the perspective of this model in nursing. This represents a possibility to broaden the understanding about this family dynamic. Thus, it is possible to identify demands and to propose interventions aimed at the family living in rural areas⁽²⁰⁾. It should be noted that FMSF was originally developed as a support in research conducted by nurses with children and their parents in situations of chronic disease. FMSF proposes the understanding of conceptual components on how families define the disease situation, which management skills are evidenced and families' expectations for the future⁽²¹⁾. Management, in this perspective, is defined as the behavior or effort that families make, directed to care and adaptation to the demands related to the disease⁽²¹⁾.

Considering that FMSF enables nurses to understand how the family unit includes the demands resulting from the illness to their daily lives, the following question emerged: How do rural families, who have an advanced cancer member, experience this experience?

OBJECTIVES

To understand the experience of rural families living with advanced cancer from FMSF's perspective.

METHODS

Ethical aspects

This research was approved by the Research Ethics Committee and recognized by the Brazilian National Research Ethics Commission (CONEP - *Comissão Nacional de Ética em Pesquisa*). It was conducted in view of the ethical precepts regarding research with human beings, according to Resolution 466/12. Participants were personally invited by one of the researchers. They were instructed on the objectives and procedures, guarantee of confidentiality, risks and benefits, free access to the interview recordings and transcripts, and freedom to participate or not in the research. After clarifying these issues, each participant signed the Free and Informed Consent Term, receiving a copy of it. To ensure their anonymity, each participant was identified by their link to the sick person, followed by the use of the letter F for family and numbering from the chronological order of data collection (e.g., Son - F1).

Type of study and theoretical-methodological framework

This qualitative research was anchored in the theoretical framework FMSF⁽²¹⁾. FMSF allows defining the management style,

in accordance with the perceptions and individual behaviors of each family member, in order to know and organize strategies from the family organization⁽¹⁹⁾. The model was adapted to be used in rural or adult families with cancer. This adaptation refers to the replacement of the gaze directed to the child and his family, as well as these terms, by focusing on the adult or elderly person and their family. The conceptual components that make up the essence of FMSF have been retained. As a method, narrative research was adopted to understand the experience of rural families living with advanced cancer. It was accomplished by understanding the unfolding of actions and events over time; plot, including meanings, causes, and consequences of the facts and factors that give rise to worry, suffering, and annoyance.

Methodological procedures

The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to support the rigor and credibility of the research. This occurred by describing aspects such as study design and data analysis, along with the detailed research method⁽²²⁾.

Data collection and analysis was conducted by two researchers who contributed to this process from their respective experiences on the theme and the method used. It is noteworthy that an interview was conducted as a way of familiarization with the process of collecting and evaluating the questions elaborated, which was disregarded in analysis *corpus*. Interviews were conducted without interruption, all participants remained until the end of the interview.

Study setting and data source

The study site corresponds to seven cities based in the northern region of the state of Rio Grande do Sul, Brazil. To locate families with potential to participate in the study, Primary Health Care nurses of these cities were consulted for information on patients with advanced cancer. After the selection of probable participants, Community Health Agents were asked by the nurse to visit families with one of the researchers, in order to invite them to the study.

As inclusion criteria, these families should reside in rural areas; have a link with the health unit belonging to PHC network; have knowledge of disease diagnosis and the clinical situation of the family member. At least two family members should be involved during the interview, one of them being the patient himself. Exclusion criteria were: family members under 18 years old and family or patient who did not present cognitive conditions (unconsciousness, difficulty in comprehension and oral verbalization, lack of lucidity or allo-psycho-orientation) and/or clinics (pain, nausea, vomiting or other discomfort) to participate in the interview.

11 families, comprising 27 people who had, during the data collection period, one of its members with advanced cancer participated. All families intentionally invited agreed to participate and then composed the research sample, established by data saturation, complying with the following steps: 1. Availability of "raw" data records; 2. "Immersion" in each record; 3. Compilation of individual analyzes for each interview; 4. Gathering the themes or types of utterances for each pre-category or new category; 5. Data coding; 6. Allocation of themes and types of statements in a table, aggregating them for each (pre) category and highlighting when

the first occurrence occurred; 7. Verification of theoretical saturation for each pre-category or new category, which occurs when new themes or types of utterances are not consistently added after further interviews; 8. Saturation visualization, which occurs when the table is transformed into a graph, allows, for each category analyzed, a visual observation of "saturation"⁽²³⁾. Interviews were analyzed and the results evaluated by the researchers, in order to define the moment to stop the collection, considering that the research problem and the objectives could be satisfactorily answered. According to the modality listed for data collection and analysis, transcripts were not returned to participants for validation.

Collection and organization of data

Data collection took place during 2014 and interviews were conducted at home, according to family preference. The choice of which members would participate in the interview was a family decision, and there was no limit to the number of participants. Initially, participants were asked to build the family genogram. Following this, the narrative interview was conducted⁽²⁴⁾, starting from the following point: "Please tell me the family life experiences since the disease started until today". Interviews were recorded and lasted between 45 minutes and one hour and 50 minutes.

Data analysis

After the interviews, they were fully transcribed. The narratives analysis was performed following the thematic analysis technique steps⁽²⁵⁾: pre-analysis, material exploration, treatment of the obtained results, and interpretations. Data appreciation was guided by the conceptual components of FMSF: situation definition, management behavior and consequence perception. They also guided the presentation of the following results.

RESULTS

Most of the sick people were over 60 years old, ranging from 46 to 81 years old. The average age was 63 years old. Among the 11 families interviewed, a narrative was obtained of nine sick people (two wives, three husbands, nine sons or daughters, one sister and three daughters-in-law). The work activity developed by rural families ranged from planting soybeans, corn and wheat, swine farming and cattle raising. When operating with FMSF, adapted for this study, we sought to identify aspects of how the rural-resident family unit, including patient himself, manages advanced cancer.

No More Normal Life: Situation Definition

The first conceptual component of FMSF called "situation definition" concerns the meaning and the way family members view the sick person and the disease. These aspects are important as they influence the behaviors and actions employed to manage the disease and incorporate it into the family routine. When families face the illness of one of their members, they look for answers. They aspire to know what the patient has, to then define the situation they are in and, later, to be able to act. What drives the search for answers is the anguish and anxiety felt by family members. These

are comprised between the period from the beginning of disease suspicion until diagnosis confirmation and prognosis elaboration.

I wanted to know what she had. Where the physician went, I ran after. Until I reached him and asked: Dr. What do you think the mother has? (Daughter1, F3)

Families consider different hypotheses for the onset of cancer and relate them to lifestyle habits in order to know its cause. Such conjectures are also linked to past events that refer to the memory of situations similar to the present one. Families also see advanced cancer as unfair or as a situation that the sick and family members should not be experiencing, as a serious thing that harms everyone and kills.

She [daughter] began to say that she thought she also had an illness like her father's. She said 'I think I'm just like dad' (Wife, F1)

I don't know why cancer is like this: either it hurts or it kills! Why does it hurt people so much? So much... that the family can no longer have a life! No more normal life. (Daughter-in-law, F9)

Ideas about disease management capacity make the family and patient's view of the ease or difficulty of complying with a treatment regime noticeable and intervene in their ability to effectively manage the disease situation. When having a treatment schedule, families need to reorganize their routines in order to provide the necessary care to patients.

Some difficulties faced by the families participating in this study refer to care management involving physical problems. Management occurs when patients have impaired physical mobility and need help with walking, eating and hygiene. Other obstacles relate to access to health services: the city of residence of the family is geographically distant from the oncology reference service in which the treatment is performed. In these situations, commuting generates tiredness and physical exhaustion, both in the family and in the patient, hindering care management, undermining its effectiveness, being seen as a sacrifice.

It is a sacrifice! Now we haven't even taken him to the bathroom anymore. We couldn't get him up. I got tired on that trip. I took him there at the chemotherapy clinic. I got tired and he got tired. (Wife, F1)

Despite the difficulties, families see treatment as an investment in patient's life. Regardless of prognosis, they understand that it is necessary to do everything possible for the patient to obtain protection to rehabilitate his health. This perspective adopted by families not only contributes to the proper management of the situation but also justifies the sacrifices made.

The other week came the result of the exam. They [family members] freaked out, wept, painted the seven. It was a desperation [cry]! (Sick person, F2)

They [siblings] panicked ... all of them. (Sick person, F8)

Families recognize that there is family imbalance with advanced cancer shown by emotional shock when they receive the news of the disease. However, they also confirm that mutual help between

family members is a mechanism that enables the restoration of balance in this environment. Courage and willpower are cited as instruments that the family uses to cope with the situation. In the families' view, it is necessary to face the disease with the mutuality of the family, through reciprocity and sharing feelings and concerns.

We get worried, get scared! It's not easy! We were always doing for each other! If one is not well, the others help. We want to help, cannot make the person sad ... There is always one or the other here, then it cheers her up. (Sister, F8)

Courage and will ... and having the willpower to help too... (Daughter-in-law, F5)

Do what? They have to support on each other... (Husband, F10)

Mutuality refers to the idea that families share feelings and situations. The shared perspectives, based on the demands made explicit by the patient, contribute to bringing family interrelations closer.

Attempt to Reconcile Care and Work: Management Behavior

This conceptual component addresses the principles that model rural household behaviors for advanced cancer management and the ability to develop a routine in the face of disease-related demands. This routine involves goals, priorities and values, which now direct the approach and specific strategies for disease management. Families express that the bonds of affection and commitment that unite their members help in coping with cancer and are values that carry with them in the path of illness.

I can say that I take care of her [mother-in-law] more than my own mother. (Daughter-in-law, F9)

We get along very well. I think ... I can't complain about him [...] there's no way to feel isolated here! There is no danger! (Sick person, F2)

Through love, families justify their management behavior towards the disease. Usually, this feeling also justifies the attachment that family members have for each other, because without their presence there is no justification for care.

Love, faith and courage, because I always say, we have to love the person, because if you do not love, you will not seek, it will not help. (Daughter2, F3)

Among the family management strategies, there is the protection of the patient from the truth about the prognosis of the disease, or from advanced disease diagnosis.

When the physician said it was cancer, I said "Don't tell mom, or she'll die sooner!" I would say, "She will die before! If she knows, she will die!" (Daughter 2, F3)

They didn't want to tell me! They were hiding, and I said, "It's no use!" They whispered! In fact, they don't talk to ... protect, but it's no use, today or tomorrow one finds out. (Sick person, F11)

Families feel that telling a sick family member that he has advanced cancer can hurt him, so that he may lose hope of living.

Therefore, they prefer the truth to be concealed. The patient, in turn, sees the family's attempt to omit the diagnosis as a protective attitude. However, in his view, such behavior becomes useless given the fact that the disease manifests and becomes noticeable as it progresses.

In relation to spirituality, family seeks the sick's well-being, which happens by joining forces so that stability returns to the family system. Faith in God is cited as the main generator of hope in the family. Through promises or novenas, faith and prayer are fundamental for spirituality to manifest. Family needs spiritual support to manage the disease and face the reality of advanced cancer with comfort and support.

We put it in God's hands and He is the one who will do it, I always say! They [sisters] said, "from asking so much, she [mother] is still there". (Daughter, F3)

Management brings an appreciation of families regarding how much they have developed a routine, strategy related to coping with the disease and how they have incorporated them into daily life. They needed to undertake changes, such as the abandonment of rural work, by both the sick and family members.

I can't do it anymore, I didn't do anything else on land... (Sick person, F4)

Now he [father-in-law] will have to discard the animals ... in the case of milk, he will have to finish. Because there's no way, there's no time. And there comes a time that you can't take it anymore, tiredness is great. (Daughter-in-law, F9)

Respondents report that work causes tiredness in those who perform it and the well-being of all needs to be prioritized at this time, sometimes causing the abandonment of rural activities. There is still the sale of goods. Families feel that they are no longer able to work without the patient's help and also because they need financial resources to meet the demands of treatment such as transportation and housing in urban centers on days of appointment, exams, and medication.

On the other hand, there are families who do not abandon rural work because it is the only source of income. They depend on them to cover all family expenses, including treatment. Assuming the need to be on the farm makes them geographically distant from the sick person, especially when she travels to the treatment center. However, they are reassured that they promote the financial stability of all.

I never went with her, not once. I went there to visit her, but I never went along ... I couldn't go! There are the milk cows! (Husband, F11)

I stayed at home helping, taking milk, helping around here ... then it was just me, because they went and someone had to stay. (Daughter-in-law, F9)

When a rural family member becomes ill, work on the property must continue and family members need to organize to continue activities. The requirement that someone stay on the farm and not accompany his or her sick family member to the place of treatment in order to continue work is also seen as a helpful tool.

Imminence of the Finitude of Life: Perception of Consequences

The third conceptual component is intended to elucidate the dimension that advanced cancer occupies in family life and the impact this will bring to the future of family life. Families' lifestyle before illness brought them more moments of harmony than the current reality. Stability and control loss over daily life in relation to previous and commonly performed activities generates disharmony in family dynamics.

We were a very happy couple! We work, we raise our children! These complications happened ... And I don't have the strength to help him anymore, and then I get angry, I get hate. The happiest time of our lives was when we were young. I wanted to be born again and have that life to do our things again. (Wife, F7)

Feeling angry is linked to one of the stages that illness imposes. The disease harms, threatens and unbalances the family as a whole. Health is related to youthfulness and strength to work, to raise children and to fight disease and life.

By considering the hypothesis that someday the family member may die, the family can imagine the future and may enter into a process of denial of death. This predictability does not please them when they realize that sooner or later the sick relative will die.

They [children] do not accept. But if God wants, you [children] will not prevent! I put the cards on the table, I don't like lies! If it comes to us to leave [die] you will have to have the courage to face it! No one wants him to die; wants him to stay! ... I say, "we have to have courage and help each other and when mom asks, be here with dad! Not that you don't like it, that you feel bad ... In life or death, we have to help each other! No one will be without help"! (Wife, F7)

Note that it is difficult for family members to accept the foreshadowing of death that advanced cancer brings. At the same time as the family reflects on this possibility, the patient himself also narrates what, in his conception, seems to be his approach to the end of life and the possible consequences that this fact may generate for the family.

I feel obligated to be present with them, understand? [crying] Not me dying, or anything ... But missing them! Cause I know they need me, for them I suffer [cry]. (Sick person, F2)

I remember that before the surgery, I asked that if anything happened, they would take care of her [daughter]! That's who I thought the most! (Sick person, F11)

Sick family members express concern for family members about the consequences their death may cause. It is noticed that there is a feeling of care towards family members, protection to them and willingness to be able to be well without their presence.

Family expectations for the future refer to a conjecture about the implications of the disease for everyone's life. It is possible to verify that there are shared perspectives of hope about the future of both the patient and the family.

I want God to give her health. And for me too, to take care of her! (Husband, F10)

You can't give up ... you have to have hope! (Son, F5)

Hope is driven by the desire for the sick family member to achieve healing and the family to be able to move into a more comfortable position than that imposed by advanced disease. However, some family members express hopelessness about a good prognosis, sometimes feeling downcast or discouraged.

So-and-so [husband] is often discouraged. And it cannot happen! It's not because I'm sick that we will let things fall ... we go on! If God wants it, so be it! Why advance suffering early? I think you have to look at it like this: if you have to die of cancer, you die of cancer! No one is eternal. When time comes, we will die! (Sick person, F2)

Patients' attitude can be a source of encouragement to other family members, which is one of the bases for maintaining hope and accepting the possibility of death in the future. Patients' will is that death should not be evoked early, so that this suffering may not be anticipated.

From the moment that confirmation of advanced cancer hangs over the family, there is the idea of death as a fact to be lived in the near future. From this perspective, peer into the concreteness of the dying process. This notion, explicit and sometimes implicitly perceived, sometimes permeates family interactions and has an impact on family organization and balance. In addition, this issue generates a new challenge, experienced in different ways, given the family's experiences and future expectations.

DISCUSSION

Experiencing, as a rural family, advanced cancer is a revelation of a challenge. From the impact of advanced disease diagnosis and death proximity, families seek to adapt to the new situation and the various feelings that emerge from an uncertain future. Caring for rural families with advanced cancer denotes efforts to the nursing professional. Nurses should know and value the specificities/singularities of living in the countryside, and pay attention to the demands arising from aspects that include access, displacement and adherence to or attachment to health services and treatment.

Situation definition requires the positioning of the family facing the needs that are presented. Events that bring about major changes in life, especially unexpected ones, challenge the presumed individual world, triggering a crisis in which the subject tends to be restless, tense, anxious and indecisive until the necessary changes are made⁽²⁶⁾.

A study that analyzed parents and children in illness states that, in order to have a definition of the child's situation, parents consider their role in family life, as well as their symbolism and emotional meaning for all⁽²⁷⁾. Projecting this evidence for this study, it is clear that, for families who experience the illness of an adult or elderly member, there is a significance arising from the matriarchal or patriarchal role that this person has in the family. Therefore, actors are required to determine the positioning and definition expected by other.

With the emotional shock caused by illness, feelings such as uncertainty, distrust, disbelief and fear are identified, and this contributes to the construction of disease vision. Families undergo various changes: environmental, relational, physical and mental health and in relation to activities of daily living. Recognizing the

negative factors, the members rediscover themselves in the face of the disease, reporting that they feel stronger and special, and it can be noticed the approach between them⁽²⁸⁾.

Families usually devote themselves to caring for the sick so that they feel better physically and emotionally. To this end, initiatives that seek to manage pain, fatigue, body care, hygiene and diet stand out⁽²⁹⁾. Caring for and coping with the disease shows not only lower quality of life for the family experiencing cancer illness compared to families who do not live with this disease in their environment, but also greater predisposition to develop anxiety, depression and anguish⁽³⁰⁻³²⁾.

The progressive involvement of family members with the patient and with each other makes them incorporate new perceptions of relationships and commitment to building more personal human connections⁽³³⁾. As the disease and symptoms progress, so does the discomfort of the family and the sick⁽³⁴⁾. The lower the degree of functionality of the patient, the greater the discomfort⁽³⁵⁾. Mutuality is also manifested by attitudes and words of support and involvement. Faith leads families to see care as part of their journey, connects family to God, which makes them find comfort and security, allowing better acceptance and adaptation⁽³⁶⁻³⁸⁾.

Family establishes bonds of trust, empathy, affection and affection, building new relationships with neighbors, close friends or distant relatives. Coping with adversity together is crucial to the proper functioning of the family system and provides a new way of life⁽³⁷⁾. Families redefine their priorities based on the patient's needs, taking advantage of the opportunity to be in constant contact with this family member to reaffirm the bonds of love⁽²⁷⁾.

Based on the management approach adopted by rural families, it is observed that, even knowing that each family is unique, it presents behavioral singularities and needs specificities in nursing care. In practice and research with families, there is a tendency to manage the disease according to certain rules governing ideas about the ability to develop the demands of the disease to restore family balance⁽³⁹⁾. Family structure and relationships can have a positive or negative impact on the patient and family during times of difficulty or adversity, causing different coping strategies depending on the stage of the disease⁽⁴⁰⁾.

Living with advanced disease in rural context may expose families to the need to cope with complex transitions in the roles, relationships, activities of daily living and mental health of patients and caregivers. Creating, adapting, and changing routines are efforts aimed at striking a balance between individual and family needs⁽⁴¹⁾. In the present study, families were found expressing the need to stay at home and once those who choose to accompany the patient in their treatment. In the latter case, this decision determines family members to interact with a different and urban reality, which broadens the context in which experience takes place⁽¹¹⁾. Due to geographical variations between place of residence and treatment, rural households tend to have higher financial expenses than urban households for cancer treatment. Living in rural context also interferes with access to health services, especially at the end of life, such as advanced cancer⁽⁷⁾.

Realizing the worsening health of the sick relative, despite all efforts made to provide quality care, the family is disorganized and its stability is affected by uncertainty, distrust, disbelief and fear⁽⁴²⁾. Approaching the possibility of death, families may begin the early

mourning phase. However, such a period may be permeated by the hope of recovering the patient. About 30% of patients and families still feel possible cancer cure, despite clinical evidence and expert opinion⁽³²⁾. Expectations of the future refer to the view that families will find suffering ahead, but there may be hope that something will reverse this condition. Usually, patients and their families respond to advanced disease in four ways: hopelessness and despair; conformism in accepting an uncomfortable or unfavorable situation of the disease; false hope for unrealistic results; and hope in punctual or instantaneous moments, such as time spent with family. This last situation is due to the acceptance of the terminal disease prognosis⁽⁴³⁾.

Hope validation for disease cure is not up to nursing. However, there are practices that promote hope for improved comfort. It is evident that home visits and palliative home interventions can positively influence families experiencing cancer progression, reinforcing the focus on improving communication and social support⁽³⁸⁾. This, specifically in rural context, could contribute to making the family feel more supportive of what is defined in the conceptual component "perceptions of consequence".

Study limitations

Among the study limitations, the number is representative of the experience of a certain rural population that have similar characteristics, not corresponding to other families that have other cultures or live in different locations from those surveyed. Regarding the model used in data analysis, FMSF, being initially aimed at children and their families, there is no deepening in research with adult relatives. Therefore, this restricted comparison and discussion of results with other investigations.

Contributions to nursing

The end-of-life context of rural population, as addressed in this research, made it possible to understand the family dynamic

adopted in this system. It highlighted practical contributions so that this process is less painfully experienced by families. Subsidies that support nursing and interdisciplinary care, such as understanding the situation from the family perspective, can strengthen care strategies. These strategies aim to reestablish family balance and seek new alternatives in the face of factors that hinder the healthy functioning of the family.

FINAL CONSIDERATIONS

The definition of the situation that families and patients make for themselves involves the creation of meanings that will guide the conduct adopted by them. This occurs considering the experiences already lived, especially those involving other cases of cancer in the family. Situation management involves body and emotional care, aiming at protection as family members seek to preserve the patient from knowing the truth. This management is also supported by negative and positive feelings. These feelings sometimes influence balance, sometimes lead to family system imbalance. A new philosophy, based on love, is adopted as a justification for attitudes in this context, permeating relationships and strengthening bonds of affection.

Living in rural areas can hamper the family's ability to manage the disease, sometimes due to its geographical distance to the place of treatment; and, at other times, for the sacrifice demanded by families in face of patients' needs. The decision whether or not to abandon rural work may be an imposition, depending on the family's financial and work context. Expectation about families' future leads them to losses and gains. Losses involve lack of stability, imbalance, suffering from the changes imposed by the disease and, finally, the possibility of loss of the sick relative. Gains occur through learning from this experience and the possibility of bringing the family together towards a common goal, strengthening and strengthening the bonds of affection, mutuality, complicity and strengthening of bonds.

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