ORIGINAL ARTICLE

REVISTA
ENFERMAGEM ATUAL
IN DERME

THERAPEUTIC LETTERS: NURSING INTERVENTION WITH FAMILIES OF PATIENTS UNDER PALLIATIVE CARE

CARTAS TERAPÉUTICAS: INTERVENCIÓN DE ENFERMERÍA CON FAMILIARES DE PACIENTES EN CUIDADOS PALIATIVOS

CARTAS TERAPÊUTICAS: INTERVENÇÃO DE ENFERMAGEM COM FAMÍLIAS DE PACIENTES EM CUIDADOS PALIATIVOS

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Submission: 05-04-2024
Approval: 27-02-2025

ABSTRACT

Objectives: to promote nursing intervention to family caregivers with chronic sadness who experience anticipatory grief of patients in palliative care based on therapeutic letters and to analyze the nursing intervention proposed based on the report of family caregivers with chronic sadness who experience anticipatory grief of patients in palliative care, in light of the Chronic Sadness Theory. **Method:** this is field research with a qualitative approach, carried out in a reference hospital for patient care in palliative care, with ten family caregivers. Nursing intervention was carried out with therapeutic letters. At the end of the meetings, semi-structured interviews were carried out with the study participants. The empirical material was categorized using the thematic content analysis technique. **Results:** it was possible to identify four thematic categories: ‘Valuing the family caregiver’, ‘Providing the family’s emotional bond’, ‘Strengthening the therapeutic relationship’ and ‘Effective coping strategies. **Discussion:** after overcoming the difficulties, the families felt strengthened by the letter they received from the nurse. The coping strategies were effective in dealing with the sadness resulting from the grieving process and provided comfort. **Final Considerations:** the findings evidenced in the literature corroborate the results of this study and reinforce the use of the Theoretical Model of Chronic Sadness to support the planning of nursing care in the context of palliative care.

Keywords: Palliative Care; Anticipatory Grief; Sadness; Nursing Care; Therapeutic Letters.

RESUMEN

Objetivos: promover la intervención de enfermería a cuidadores familiares con tristeza crónica que experimentan duelo anticipado de pacientes en cuidados paliativos a partir de cartas terapéuticas y analizar la intervención de enfermería propuesta a partir del relato de cuidadores familiares con tristeza crónica que experimentan duelo anticipado de pacientes en cuidados paliativos. cuidado, a la luz de la Teoría de la Tristeza Crónica. **Método:** se trata de una investigación de campo con enfoque cualitativo, realizada en un hospital de referencia para la atención de pacientes en cuidados paliativos, con diez cuidadores familiares. La intervención de enfermería se realizó con cartas terapéuticas. Al final de las reuniones se realizaron entrevistas semiestructuradas a los participantes del estudio. El material empírico fue categorizado mediante la técnica de análisis de contenido temático. **Resultados:** fue posible identificar cuatro categorías temáticas: 'Valoración del cuidador familiar', 'Proporcionar el vínculo afectivo de la familia', 'Fortalecer la relación terapéutica' y 'Estrategias de afrontamiento efectivas'. **Discusión:** después de superar las dificultades, las familias se sintieron fortalecidas por la carta que recibieron de la enfermera. Las estrategias de afrontamiento fueron efectivas para afrontar la tristeza resultante del proceso de duelo y brindaron consuelo. **Consideraciones finales:** los hallazgos evidenciados en la literatura corroboran los resultados de este estudio y refuerzan el uso del Modelo Teórico de Tristeza Crónica para apoyar la planificación de los cuidados de enfermería en el contexto de los cuidados paliativos.

Palabras Clave: Cuidados Paliativos; Duelo Anticipado; Tristeza; Cuidado de Enfermera; Cartas Terapéuticas.

RESUMO

Objetivos: promover intervenção de enfermagem ao cuidador familiar com tristeza crônica que vivencia o luto antecipatório de paciente em cuidados paliativos com base nas cartas terapêuticas e, analisar a intervenção de enfermagem proposta a partir do relato do cuidador familiar com tristeza crônica que vivencia o luto antecipatório de paciente em cuidados paliativos, à luz da Teoria de tristeza crônica. **Método:** trata-se de uma pesquisa de campo com abordagem qualitativa, realizada em um hospital de referência no atendimento ao paciente em cuidados paliativos, com dez cuidadores familiares. Foi realizada intervenção de enfermagem com cartas terapêuticas. No final dos encontros, foram realizadas entrevistas semiestruturadas com os participantes do estudo. O material empírico foi categorizado utilizando-se a técnica de análise de conteúdo temática. **Resultados:** foi possível identificar quatro categorias temáticas: ‘Valorização do cuidador familiar’, ‘Proporcionar o vínculo afetivo da família’, ‘Fortalecendo a relação terapêutica’ e ‘Estratégias eficazes de enfrentamento. **Discussão:** ao superar as dificuldades, as famílias se sentiram fortalecidas pela carta que receberam da enfermeira. As estratégias de enfrentamento foram eficazes para lidar com a tristeza decorrente do processo de luto e lhes proporcionaram conforto. **Considerações Finais:** os achados evidenciados na literatura corroboram os resultados deste estudo e reforça a utilização do Modelo Teórico da Tristeza crônica para subsidiar o planejamento da assistência de enfermagem no contexto dos cuidados paliativos.

Palavras-chave: Cuidados Paliativos; Luto Antecipatório; Tristeza; Cuidados de Enfermagem; Cartas Terapêuticas.

INTRODUCTION

Palliative care is an active comprehensive care approach that aims to improve the quality of life of people of all ages with severe health-related suffering due to serious illness, and especially those nearing the end of life, as well as their families and caregivers. It is provided by a multidisciplinary team with a holistic approach to meet the bio-psycho-social and spiritual needs of patients and their families, including grief counseling, if indicated(1), such as anticipatory grief.

Anticipatory grief is a specific feeling of grief before the death of a terminally ill family member in response to loss. Throughout the course of the illness, family caregivers witness the gradual cognitive, social and physical deterioration of a very important family member who is seriously ill. It is essential that the palliative care team provides timely and appropriate care to prevent complications, such as complicated grief after death(2).

As an integral part of the multidisciplinary palliative care team, nurses promote comprehensive and humanized care, and enable patients to have an end-of-life experience characterized by dignity, compassion, and support for family caregivers and grieving caregivers(3,4), which are crucial in end-of-life care. Caregivers may be overwhelmed by the responsibilities associated with care, with several negative consequences for their health(5) and develop chronic sadness.

Chronic sadness is persistent and associated with mourning. It is recurrent, permanent, periodic, and potentially progressive. It is seen as a normal reaction to loss, which may be to a single event or ongoing (progressive). Generally, people who experience chronic grief use internal and external strategies to cope with a circumstance or during the experience. However, if these strategies are ineffective, the disparity created by the loss will continue to intensify and may progress to a state of pathological mourning or depression(6).

It is worth noting that there are several therapeutic approaches that can help family caregivers to go through complex situations involving the process of anticipatory grief, such as therapeutic letters. A study refers to the use of therapeutic letters as an intervention strategy with a specific intention: to “involve clients in therapy, promote cooperation and find solutions to the problems presented” (7:3). Family caregivers of patients in the final phase of life in palliative care have specific demands that end up reflecting on their well-being and family dynamics. Therefore, the use of therapeutic letters as a nursing intervention for people who experience situations of emotional impact with repercussions in the various spheres of their lives becomes undeniably necessary.

This theme is relevant in the context of Nursing because it will enable the production of new knowledge on the topic investigated, which will result positively in the assistance to family caregivers of patients in the final phase of life. Furthermore, this study is justified by the perspective of promoting nursing intervention that will guide palliative care practice, with the possibility of obtaining satisfactory results in relation to the real needs of family caregivers in the process of anticipatory grief of patients in palliative care.

However, there is little published research on this topic in the Brazilian literature. Hence the interest in conducting this study, which had as its guiding thread the following guiding questions: how to promote nursing intervention to family caregivers with chronic sadness who experience anticipatory grief of a patient in palliative care? and how to analyze the proposed nursing intervention?

To answer the questions described above, the following objectives were listed for the study: to promote nursing intervention to family caregivers with chronic sadness who experience anticipatory grief of a patient in palliative care based on therapeutic letters and to analyze the proposed nursing intervention based on the report of the family caregiver in light of the Theory of Chronic Grief.

METHODS

This is a field research with a qualitative approach. The qualitative approach seeks the singularities and meanings of the phenomenon with which it proposes to work, which is expressed through beliefs, values, opinions, representations, forms of relationship, symbologies, uses, customs, behaviors and practices(8).

It is worth mentioning that, in order to maintain methodological rigor, the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used. The COREQ checklist was developed to promote explicit and comprehensive reports of qualitative studies. The criteria included in the guide can help researchers report important aspects of the research, study methods, study context, findings, analyses and interpretations(9,10).

The study was carried out in a hospital located in the city of João Pessoa - PB, characterized as a reference service for the care of patients with incurable diseases and eligible for palliative care. To collect the data, the Burke/Eakes Chronic Sadness Assessment Instrument, a version adapted to Brazilian Portuguese, was used, as well as a semi-structured interview technique, based on a previously prepared script containing questions related to the study objectives.

The sample consisted of family caregivers, selected based on the following criteria: they must be the primary family caregiver of the patient in palliative care, over 18 years of age; they must be accompanying the patient at the time of data collection; the family caregiver must be at very high risk of chronic sadness, according to the instrument used to assess chronic sadness, with a score ranging from 70 to 139 points; and they must express interest and availability to participate in the study. Family members who did not directly participate in the patient's care were excluded from the study. Thus, the sample was represented by ten family caregivers, who were gradually included in the research.

To collect the data, the Burke/Eakes Chronic Grief Assessment Instrument, a version adapted to Brazilian Portuguese, and the semi-structured interview technique were used, based on a previously prepared script containing questions related to the study objectives. The data were collected from January to March 2020.

For the nursing intervention, therapeutic letters were used, which were delivered during the meetings. Sending therapeutic letters is recommended during the nurse's meetings with the families(11). These letters should briefly contain what was discussed in the meetings and highlight values attributed by the family. They also contribute to forming bonds, because they have a sense of transparency between the professional and the family(12). In this study, the strategy of sending “closing letters” was used in order to offer a summary of the conversations between the nurse and the family caregiver to help elaborate on anticipatory grief, as a way of positively scoring the end of the meetings. To carry out this phase of the research, therapeutic letters were prepared following the model and recommendations of Moules, Wright and Leahey(12,11).

The focus of the meetings was on well-being in the sense of the person as a whole, including their physical, psychosocial and spiritual dimensions. It involved understanding the experiences, concerns and perspectives of the family caregiver, combined with affective, cognitive and emotion-regulating nursing actions that focused on the processes and experiences of caregivers during the course of changes, in which health and the perception of well-being are intended results.

It is worth mentioning that in the literature of the health area, several terms have been used to describe this type of relationship, including helping relationships, intentional relationships, nurse-client relationships and therapeutic alliances(13). In this research, the terms used were: therapeutic encounter, nurse-family caregiver relationship and helping relationships.

The meetings that resulted in the therapeutic letters were scheduled and held at the hospital where the patient was hospitalized and accompanied by his/her family caregiver. Five meetings were held with each family caregiver, each lasting 30 to 45 minutes. At the fourth meeting, the therapeutic letters were delivered, and at the final meeting, an interview was conducted with the family caregiver, individually, in the hospital chapel, at the participants' choice, with the aim of understanding the experiences regarding the therapeutic nursing letters received by the caregivers.

The interviews were transcribed in full to categorize the empirical material. The thematic content analysis technique was used to process the collected data. 14 This technique includes the following phases: pre-analysis, a phase in which the collected data (interviews) were transcribed in order to make them operational; exploration of the material and treatment, inference and interpretation of the data. In the material exploration phase, the raw results are organized in a way that makes them meaningful and valid and were analyzed in light of the Theory of Chronic Sadness. The treatment of the results, inference and interpretation, consists of treating the results. This is the moment of intuition, reflective and critical analysis to interpret the findings of the research in question. The research was initiated after the project was submitted for consideration by the Research Ethics Committee of the Lauro Wanderley University Hospital of the Federal University of Paraíba (CAAE: 26539619.5.0000.5183) and the issuance of an approval report according to Consolidated Opinion number: 3,787,780. All the operationalization of this study followed the ethical observances contemplated in Resolution No. 466 of 2012, of the National Health Council,15 to guarantee the confidentiality of the information and the anonymity of the participants. Thus, fictitious names were assigned by the participants themselves, such as: Acacia, Love, Affection, Hope, Sunflower, Jasmine, Lily, Saudade, Fleur de Lis and Gratitude.

RESULTS

Ten family caregivers of patients in palliative care participated in this study, aged between 40 and 61 years old, eight of whom were female; eight were married, one was divorced and one was in a stable union. Regarding race/ethnicity, nine identified as mixed race. Regarding education, six had completed high school; three had higher education; and one had incomplete high school. Regarding family income, seven participants reported a monthly income of three to five minimum wages, and three reported a monthly income of one to three minimum wages. Nine of the participants identified as Catholic and one reported as Protestant.

Regarding the assessment of chronic sadness, according to the results of the scores of the Burke/Eakes Chronic Sadness Assessment Instrument, a version adapted to Brazilian Portuguese, one family caregiver presented a score of 72; three, a score between 74 and 80; five, a score between 93 and 97; and one with a score of 101. Thus, all participants with a score between 70-139 were at very high risk of chronic sadness.

In this study, the therapeutic letters were designed to be useful to the family caregiver who experiences anticipatory grief and presents characteristics of chronic sadness and with an increasing need for care and support. The letters sent to the family caregivers are presented in Table 1.

Table 1 – Summary of the therapeutic letters sent by the nurse to the family caregiver who experiences anticipatory grief and presents characteristics of chronic sadness - João Pessoa, PB – Brazil, 2021.

Dear Acacia, greetings! **[...] I learned that since your mother's cancer was diagnosed, you have been directly involved in her care, that this has been a challenging journey and that your family faces this journey together. [...] You teach daily about strength, courage and faith, in the face of imminent death, and demonstrate an exceptional ability to face this challenge, and emerge with courage and sensitivity and your faith in God is the essential resource you need to restore your strength and determination [...].**
Dear Love, greetings! **[...] You show so much love for your son, I was very touched by the stories you tell about how dedicated you are to caring for him since he was struck by the disease, sharing openly your worries and fears, about how your life has changed and how it has been the most challenging and difficult journey you have ever faced as a parent. [...]. Because of your strong spiritual beliefs, you have opened yourself up to the possibility of finding a sweet way to live with your son. Your ability to feel joy, to smile and to embrace hope will help him find meaning in this experience [...].**
Dear Caring, greetings! **[...] You found the courage to talk about painful issues about your experience of suffering and the uncertainty of your daughter's illness and the future. I found a fearless mother to face an arduous struggle in search of a treatment for her daughter that would alleviate the suffering of the lost battles. [...]. In the search to get closer to God, you find the strength to understand the experience of being the mother of a daughter with a chronic and progressive illness and to endure her journey with great patience and love [...].**
Dear Hope, greetings! **[...] First of all, Hope, as soon as I met you, I noticed that people really admire your kind nature. [...] You have strengths, and the ones I admire most are your sense of humor, your love and loyalty to your family, your interest in helping others, and your willingness to speak your mind to me. [...] I admire your persistence in ensuring the best comfort for your mother. [...] You have great strength and ability to deal with problems. I was amazed at your resilience. [...] Your trust in God to overcome difficult times [...].**
Dear Sunflower, greetings! **[...] You have expressed concerns about how to deal with your father's illness and shared some of your feelings of sadness and grief that you have been struggling with since your grandmother's death. [...] You have been very courageous in revealing your fears and anxieties regarding the final stage of your father's illness and your recent loss. [...]. [...]. You have reported that you feel much better after talking to your family and that you have expressed your sadness at your father's passing and that you now feel more supported and have participated in prayer times with your wife [...].**
Dear Jasmine, greetings!

[...]. I noticed that your sister Azaleia felt angry and sad, which is understandable in the final phase. [...]. However, even though you are exhausted, you have fought with great determination, understanding and affection. In addition to trying to keep the family together to celebrate her birthday. It was so beautiful to see your family united in celebrating her birthday. These feelings can only be filled with love. It is incredible how each of you found different and unique ways to support each other on this journey [...].
Dear Lily, greetings! **[...] The health challenges you face when caring for your aunt Amélia are impressive. [...] The adjustments you made during your aunt's hospitalization are difficult, so don't feel guilty. You closely monitor the entire treatment and provide all the care together with the caregiver. When your aunt needs you, you are truly by her side, with great affection and care. [...] I noticed that you care a lot about your aunt's religiosity and spirituality, and that is admirable!**
Dear Flor de Liz, greetings! **[...] You have found the strength to engage in some difficult and painful conversations about your experience, both because of the complexity of your sister Rosa's illness, with all its physical and emotional weaknesses and limitations, and because of the uncertainties of the future. [...] I admire your persistence in ensuring your sister's well-being. [...] I realize the great impact that Rosa's illness has on your life, such as the overload of the role of caregiver and your concern with moments of uncertainty, anger and suffering. [...] You [...] reaffirm your faith daily and strengthen your ability to give new meaning to care and life [...].**
Dear Gratitude, greetings! **[...] You are the person who made your family's life easier to live amid the suffering caused by the illness of your husband, whom you called Lindo. [...]. The affection and support you dedicate to caring for your husband reflect the loving way you praise him for his strengths and abilities to adapt to each limitation that the disease inflicts. It is admirable to see your courage and wisdom to solve problems. I am confident in your ability to give new meaning to your life [...].**
Dear Missing You, greetings! **[...] Your journey is challenging, because you suffered the loss of your beloved father, previously faced the grief and managed to reorganize your life with great courage and sensitivity. [...]. I noticed that you are aware of the fragility of this situation by openly expressing deeply painful questions about the future. [...]. The care and concern for your family, in addition to your faith and positivity, create a climate of trust, which reduces fear and anxiety [...].**

Source: Research data – 2020.

In the content analysis process, three thematic categories emerged from the report of the family caregiver with chronic sadness who experiences the anticipatory grief of a patient in palliative care: ‘Valuing the family caregiver’, ‘Providing the family’s emotional bond’ and ‘Strengthening the therapeutic relationship’. In addition to these, it was possible to code a category, based on the concept of the Theory of Chronic Sadness: ‘Effective coping strategies’.

Valuing the family caregiver

Complex situations, such as recognizing that chronic sadness is a response to anticipatory grief associated with the imminent loss of a loved one with a rapidly progressive and end-of-life illness, can make family members, especially the primary caregiver, feel vulnerable in the face of suffering and the role they must assume during hospitalization. And even if they learn to care for themselves and their sick family member, mobilized by profound changes that occur in this process, they will only achieve satisfactory results if they receive effective support in some way.

Through therapeutic letters, the nurse presents a summary of the meetings and the opportunity to present to the caregiver their strengths and reinforce the changes made in the care they are providing to their loved one. In the family members' reports, it was clear how much they felt valued, special and respected due to their qualities as caregivers, expressed in the following reports:

> My family is very close, but sometimes I felt so alone, so unmotivated, it seemed like I had ceased to exist. [...] I couldn't stop reading your letter. I cried and smiled at the same time. I cried because you listened to my sadness. I smiled because someone cared about me, listened to my few joys, valued me, praised my way of taking care of my mother, my dedication and my love for her (Acacia).
>
> When I read the letter I felt valued. [...] I felt that my dedication, my journey alongside my son was valued (Love).
>
> We have faced a lot together [...]. The letter strengthened me. [...] It is so good to feel valued in the midst of so much sadness (Affection).
>
> I was sad and tired and receiving this letter was very important to me. [...] I felt special (Hope).
>
> I felt very important because you cared about me. I was feeling alone (Sunflower).
>
> When I received the letter [...] I felt so special, supported [...] we feel very valued (Jasmine).
>
> It's a lot of consideration for me and I needed it, you know. I felt very important. It's great to be treated with respect and kindness. (Liz Flower).
>
> No one has ever written to me like that. [...] I get emotional every time I read it, it was very important for me to receive a letter (Sunflower).

Therapeutic letters are a source of information for families to visualize what is happening in the patient's relationship with the family caregiver and the assistance offered.

Promoting family emotional bonds

At the same time as assuming the responsibility of caregiver, the family member finds it difficult to show his family that he also needs to be cared for and protected. Given the situation, it seems that there is a distancing in family relationships, due to the suffering and fear generated by the disease, whose progression is rapid, and death is imminent, and the responsibility that is placed on his role as caregiver. The therapeutic letters have a positive result in the family relationship, since the caregiver read the letters as a family, which allowed them to reestablish the relationship in a united way and with mutual support, as can be seen in the following reports:

> I asked my wife to read it too and then she hugged me really tight, it was as if she was apologizing for not understanding me [...]. We hugged for a long time and I confess that I held back tears. [...] I felt comfortable and protected (Love).
>
> I sat down with my mother, my husband and my other two children and we read the letter together. It was a very difficult moment [...]. We are in this fight together (Affection).
>
> [...] I showed the letter to my children and it was really nice, I felt so welcomed (Hope).
>
> I felt motivated and my heart was relieved. I was feeling defeated with so many losses in my family. [...] I read the letter with my family, [...] I learned that I need them to get through so much suffering (Sunflower).
>
> My sister has depression and calls me every day, so I told her that I had received a letter that praised me and had so many beautiful things about me, I read it to her. After that, I read it to my husband and to my neighbor. Everyone liked it and even my brother, who didn't care much about me, read the letter and he thanked me for taking care of our mother (I miss him).

Family caregivers have become an integral part of care. Nurses should strive to ensure that family caregivers and other family members have a common and accurate understanding of the patient's condition and prognosis. They should routinely validate the role of the family caregiver and be sensitive to their distress and how they will manage the end-of-life situation of their loved one.

The nurses' approaches to how family caregivers were coping consisted of encouraging and allowing expressions of sadness in order to work to understand and even overcome them. Others understood positive reactions to strengthen trust in the therapeutic relationship between the nurse and the family caregiver.

Strengthening the therapeutic relationship

Therapeutic letters are a resource that helps nurses to strengthen bonds from the moment the family caregiver feels understood and their needs are met. When analyzing the participants' statements about the care provided by the nurse, it was observed that they felt satisfied with the attention, dedication and respect provided to them, as shown in these reports:

> I have been taking care of her ever since my mother got sick and no doctor has ever asked if I was okay or if I needed help and you cared when I was sad and you helped me (Acacia).
>
> You took care of me like other professionals take care of my daughter, with a lot of affection (Caring).
>
> You listened to me and helped me trust myself and the people who love me (Hope).
>
> I want to say that today I am a different person [...]. You are a very special person to me. [...] You were very attentive (Sunflower).
>
> I am very grateful for the time you dedicated to helping me solve my problems, I was suffering a lot (Jasmine).
>
> I felt guilty and judged for having to work and leaving someone else to take

> care of my aunt and you very calmly helped me overcome this guilt (Lily).
>
> When I needed you most you appeared [...] we fought a lot and now things have improved a lot, I am calmer. You were a ten (Liz Flower).
>
> I kept looking at the clock waiting for you to arrive, I even called you once, remember? I thought you weren't coming anymore. I had a lot to say (I miss you).

The nurse-caregiver meeting made it possible to open up paths for the clear manifestation of their intentions in the helping relationship, through new channels of expression, such as therapeutic letters. The use of letters facilitates the helping relationship, they summarize the person's progress in the therapeutic process, giving them a broad view of the changes and achievements.

Effective coping strategies

Despite having unique experiences of anticipatory grief, chronic sadness was experienced. Based on the Theory of Chronic Sadness, coping strategies are divided into internal and external and may or may not be effective. The most useful and applied internal coping strategies were acceptance and spirituality. The latter included prayers and trust in God, according to some reports presented:

> Today I feel stronger, more courageous to accept this whole situation [...] my faith in God strengthens me (Acacia).
>
> It's difficult, I know that my son's illness has no cure, but I can now accept it [...] God helps me deal with my fears and my pain (Love).
>
> The trust I have in God [...] helps me overcome difficult times (Affection).
>
> I know that my mother's time is approaching. [...] the faith I have in God comforts me (Missing her).

During the meetings, the caregivers chose to accept the end-of-life situation of their family member and their faith in God strengthened them, which helped them prepare emotionally to fully assume the responsibility of caring for their family member. They reported that, by accepting the end-of-life situation, they were able to follow the nurse's advice and recommendations, which also benefited the patient.

The external coping strategies were family support, as mentioned in the category ‘Strengthening family ties’; the attention provided by the nurse, shown in the category ‘Strengthening the therapeutic relationship’; and the support provided by all the professionals at the hospital where the patients were hospitalized, mentioned in the following statements:

> The hospital professionals are concerned about doing the best they can. [...] they are welcoming (Hope).
>
> It is a welcoming hospital, the professionals are friendly and that gave me confidence (Sunflower).
>
> The doctor and nurses talk to my sister and I can see that she feels good about it and so do I (Flor de Liz).
>
> It is a good environment [...] we feel good. They take care of my husband with affection (Gratitude).
>
> I have made friends with everyone here at the hospital. [...] They are dedicated and take care of people with great care (Miss them).

Some study participants noted that they feel welcomed in the hospital environment and that the multidisciplinary team provides attentive, friendly and dedicated care, which instills confidence and well-being in caregivers.

All participants spoke of their individual growth in this process, the unique bonds they developed with their loved ones and other family members, their ability to find peace in unexpected situations and their spiritual maturity as a result of their experiences with chronic sadness.

DISCUSSION

Among the study participants, it was found that the majority were women (mother, daughter, niece, and wife). Regarding the attribution to the female gender, as the promoter of care in most cases, particularly when it comes to illness, among other issues that are related to this female attribution. Caring is a task that requires attention, patience, and constant dedication. According to a survey conducted in 2019 on anxiety related to death in palliative care, in a sample of 111 family caregivers of palliative patients, the majority were female (82.9%) (16).

Findings related to gender differences in the experience of chronic sadness between mothers and fathers showed that chronic sadness is permanent in mothers, while fathers tend to resolve their suffering. Even though the roles of parents have evolved over time, it continues to be reported that mothers continue to be the main caregivers of children in most instances(17).

It is worth noting that when it came to financial issues, a caregiver related feelings of guilt to the need to work and not participate fully in caring for her aunt. It is important to consider that the process of illness has several social determinants related to living conditions, and coping with the disease is directly related to the socioeconomic and cultural contexts in which patients and their families live(18). Therefore, it is important to consider information about the family's socioeconomic conditions and include them in discussions with the health team, considering the possibilities of support and support network available to meet their needs.

In the family member's care experience, there were specific triggers that made chronic suffering intense, with feelings of anger, guilt, fear and sadness. These emotions are reported in the therapeutic letters. According to the Theory of Chronic Sadness, triggers are factors or events (developmental milestones) that are mainly related to the family caregiver's responsibility. And the useful strategies promoted by nurses include providing information, helping the family caregiver assimilate this entire process, being empathetic and compassionate(6,17), such as therapeutic letters.

Regarding the category – Valuing the family caregiver, it concerns how much the caregivers felt valued in the interaction with the nurse. When overcoming difficulties, the families felt strengthened by the letters they received from the nurse. It is worth noting that the reciprocal nature of the relationship between the nurse and the family caregiver is particularly unique to each relationship. In this interaction between the nurse and the family caregiver, there is a tone of “being together”, which is created by trust and mutual respect(12).

A study warns that caregivers need to maintain their health and need support to do so. The high demands of care lead to a decline in personal health. One of the central objectives of interventions aimed at caregivers is to support them in building relationships and in open communication with their family members and loved ones. Therefore, the goal is for caregivers to feel comfortable communicating feelings such as anxiety and other symptoms and ensure that they can get the help they need to alleviate them(19).

In the category – Providing the family with emotional bonds, it refers to the readjustment of the emotional bonds that the family members were able to reestablish with the other members of their family, provided by the nurse-caregiver interaction, perceived both in the statements and in the therapeutic letters.

It is worth mentioning that the caregiver is a vital element, due to the essential role he/she plays in the disease process and the active participation in all aspects, accompanying the patient and seeking alternatives to better care for him/her, from the diagnosis of an advanced chronic disease and rapid progression until the end of life. It is considered that, in a disease that threatens the continuity of life, the family functions as a unit that is moved by the type of suffering of the family member(20).

The family should be seen as an independent and creative unit, sharing its own values and experiences, power and affection, aiming to improve the quality of life of the family group. The use of letters demonstrates the involvement of nurses in the care of sick family members, giving new meaning to the relationships established through the provision of strategies, the promotion of relationships at different levels through the establishment of objectives related to care, as well as the communication established with all those involved(21,22).

In Nursing, the writing of therapeutic letters is a little-known intervention in family nursing practice(22) and little used as a strategy in the training of nurses to build relationships, at least at the national level. A study(23) indicated that the writing of therapeutic letters is generally not included in the regular Nursing curriculum. However, the faculty encouraged the creativity of the students and motivated them to write therapeutic letters to patients. It was shown that letters are a powerful teaching strategy to promote student learning in clinical nursing education and help them develop their relational skills to know and understand the patient, and that this activity helped the clinical faculty to identify students who had difficulties relating to their patients.

The category - Strengthening the therapeutic relationship - revealed that during the process of interaction with family caregivers, there was mutual cooperation, that is, they came together in favor of a common goal, which is fundamental to achieving better results. Research has shown that, for a caregiver, the experience of caring for a family member with cancer is associated with several problems and challenges related to care. In this sense, deeply understanding the tribulations can be a step towards solving the problems faced by family caregivers of these patients. Therefore, health planners must consider the challenges and suffering faced by family caregivers and prevent them through appropriate interventions(24).

It is worth noting that when preparing therapeutic letters, the patient and the professional write and construct the story that the person tells when they are in therapy and, after being written, the expression is externalized and implies the construction and deconstruction of stories of experiences lived by people, with the aim of rediscovering and valuing the relationship between thoughts and the construction of new meanings. It is a flexible tool and, in some cases, the letters can be written by the professional to the person or from the person to the professional(25).

The letters were used as instruments to help people process the mourning of their loved ones. Thus, it should be considered that, for this style of intervention, the therapeutic capacity lies in the management of discourses surrounding loss and mourning, in order to deconstruct the meanings that were maintained and integrate those that emerged in the process. It is by analyzing, reflecting and listening with empathy to the different stories told by clients that it is possible to bring about changes(25).

Regarding the category of Effective coping strategies – sick people and their families will face numerous difficult situations throughout their lives, as well as in moments of greatest stress due to the nature of the loss and the process of chronic grief. Professional assessment and reassessment will be required at various junctures in life in connection with the acquisition of appropriate services. Thus, it was possible to observe that the nurse used effective methods to help the family caregiver cope with the anticipatory grieving process.

The internal coping strategies that resulted from the nurse-caregiver interaction were: accepting the end-of-life situation of their family member and spiritual strengthening. The external coping strategies were family support, the bond created by the therapeutic relationship or helping relationship and the support of all professionals at the hospital where the patients were hospitalized.

People with chronic progressive and potentially life-limiting diseases and their families need specific palliative care and psychosocial and spiritual support should be a priority. Therefore, professional caregivers must understand the needs of patients and their family caregivers who experience anticipatory grief throughout the various stages of the disease and be able to provide support for grief at any time after the patient's death(26).

The anticipatory grief of the family caregiver can be resolved through well-established processes, if worked on appropriately(27). The multiple losses experienced by family caregivers, such as the fact that one of the family members acquires a rapidly progressive chronic disease that generates limitations and physical, emotional and social suffering, are described in the Chronic Sadness Theory as the first antecedent of chronic sadness(28). Although it is seen as a normal reaction, chronic sadness can progress to a pathological state, such as depression, if coping strategies are ineffective.

A published study(29) notes that despite their experience, mothers who care for children with chronic diseases discovered different ways of dealing with chronic sadness. These coping strategies included crying - for them, crying caused an emotional release of physical fatigue and tension resulting from accumulated emotions that included disappointment, fear, frustration and despair; preparing for the long process of their child's therapy; thinking positively; keeping busy and asking God for strength and guidance. The coping strategies offered by the professional helped them to move through the experience, which allowed them to see their child's future with optimism and positivity.

In a study that used the Burke/Eakes Chronic Grief Assessment Instrument to identify women with chronic grief and help them overcome postpartum loss, it was possible to identify coping strategies, such as spiritual beliefs and family and social support, as effective in dealing with loss and finding comfort(30). These findings discussed in the literature are similar to those evidenced in this research.

Regarding the implications for clinical nursing practice and research, the use of therapeutic letters is a low-cost intervention, whose construction process is relatively simple. However, in this case, a certain complexity was considered, since anticipatory grief is considered a unique experience, with deeply painful consequences. It has been shown to have significant beneficial effects, arousing interest in introducing therapeutic letters as an independent intervention for nurses or to complement assistance in existing palliative care services.

FINAL CONSIDERATIONS

This study, which involved ten caregivers who presented a score indicating a very high risk of chronic sadness, revealed that the use of therapeutic letters has many intentions and purposes. In this study, they were designed to be useful to family caregivers who experience anticipatory grief and present characteristics of chronic sadness and a growing need for care and support. In addition, interpersonal relationships were developed during the meetings.

The participants felt chronic sadness resulting from the anticipatory grief process and it was necessary to help the caregiver develop effective internal and external coping mechanisms to overcome anticipatory grief and prevent chronic or permanent grief. With the support of the nurse, the feeling of anticipated loss experienced was effectively managed.

The findings evidenced in the literature corroborate the results of this study and reinforce the use of the Theoretical Model of Chronic

Sadness to support palliative nursing practice for planning holistic care.

As a suggestion for practice, nurses are advised to understand the process of anticipatory grief in the context of palliative care and to use care strategies to provide assistance that helps people cope with difficult situations and give new meaning to their lives.

The extent to which this study can be generalized has limitations, since only ten people participated in it and other important family members were not included. It is suggested that further studies be conducted with a larger number of caregivers and other groups, using therapeutic letters and the Theory of Chronic Grief in Nursing in the context of palliative care.

REFERENCES

1. Radbruch L, Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S et al. Redefining palliative care. a new consensus-based definition. J pain symptom manage. 2020; 60(4):754-64. doi: https://doi.org/10.1016/j.jpainsymman.2020.04.027

2. Cheung DSK, Ho KHM, Cheung TF, Lam SC, Tse MMY. Anticipatory grief of spousal and adult children caregivers of people with dementia. BMC palliative care. 2018; 17(1):1-10. doi: https://doi.org/10.1186/s12904-018-0376-3

3. Cross LA. Compassion fatigue in palliative care nursing: a concept analysis. J hosp palliat nurs. 2019; 21(1): 21–28. doi: 10.1097/njh.0000000000000477
4. Pereira SM, Hernández-Marrero P, Pasman HR, Capelas ML, Larkin P, Francke AL. Nursing education on palliative care across europe: results and recommendations from the EAPC taskforce on preparation for practice in palliative care nursing across the EU based on an online-survey and country reports. Palliative Medicine. 2021;35(1):130-41. doi: https://doi.org/10.1177/0269216320956817

5. Becqué YN, Rietjens JA, van Driel AG, van der Heide A, Witkamp E. Nursing interventions to support family caregivers in end-of-life care at home: A systematic narrative review. Int j nurs stud. 2019;97(3):28-39. doi: https://doi.org/10.1111/jan.14326

6. Ari ES, Abayomi OO, Daniel GO, Achema G, Elijah E, Mangdik CE. Chronic sorrow among internally displaced persons in plateau north-central Nigeria: a phenomenological study. J nursing care reports. 2021;2(1):1-8. Available from: https://unisciencepub.com/storage/2021/06/Chronic-Sorrows-Among-Internally-Displaced-Persons-in-Plateau-North-Central-Nigeria.pdf

7. Bell JM, Moules NJ, Wright LM. Therapeutic letters and the family nursing unit: a legacy of advanced nursing practice. J fam nurs. 2009;15(1):6-30. doi: https://doi.org/10.1177/1074840709331865

8. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. Rev pesq qual. 2017; 5(7):1-12.

9. Buus N, Perron A. The quality of quality criteria: replicating the development of the Consolidated Criteria for Reporting Qualitative Research (COREQ). Int j nurs stud. 2020;102(3):103452. doi: https://doi.org/10.1016/j.ijnurstu.2019.103452
10. Souza VRDS, Marziale MHP, Silva GTR, Nascimento PL. Tradução e validação para a língua portuguesa e avaliação do guia

COREQ. Acta Paul Enferm, 2021;34:eAPE02631. doi: 10.37689/acta-ape/2021AO02631

11. Wright LM, Leahey M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. 5 th. São Paulo: Roca; 2012.

12. Moules NJ. Therapy on paper: Therapeutic letters and the tone of relationship. Journal of Systemic Therapies. 2003;22(1):33-49.

13. Bardin L. Análise de conteúdo. 70 ed Lisboa: edições; 2012.

14. Kornhaber R et al. Enhancing adult therapeutic interpersonal relationships in the acute health care setting: an integrative review. J multidisciplinary healthcare. 2016;9(2):537-48.

15. Ministério da Saúde (MS). Conselho Nacional de Saúde. Resolução n. 564, de 6 de novembro de 2017. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Diário Oficial da União 2017. Disponível em: http://www.cofen.gov.br/resolucao-cofen-no-5642017_59145.html

16. Abreu-Figueiredo RMS, Sá LO, Lourenço TMG, Almeida SSBP. Ansiedade relacionada à morte em cuidados paliativos: validação do diagnóstico de enfermagem. Acta Paul Enferm. 2019;32(2):178-85. doi: https://doi.org/10.1590/1982-0194201900025

17. Coughlin MB, Sethares KA. (2017). Chronic sorrow in parents of children with a chronic illness or disability: an integrative literature Review. J pediatr nurs. 2017;37(2):108-16. doi:10.1016/j.pedn.2017.06.011

18. Frossard A. Os cuidados paliativos como política pública: notas introdutórias. Cad EBAPE BR. 2016;14(spe):640-55. doi: https://doi.org/10.1590/1679-395114315

19. Moss KO, Kurzawa C, Daly B, Prince-Paul M. Identifying and addressing family caregiver anxiety. J hospice palliative nursing. 2019;21(1):14-21. doi: 10.1097/NJH.0000000000000489

20. Cavalcanti AES, Netto JJM, Martins KMC, Rodrigues ARM, Goyanna NF, Aragão OC. Percepção de cuidadores familiares sobre cuidados paliativos. Arq ciênc saúde. 2018;25(1):24-8. doi: doi.org/10.17696/2318-3691.25.1.2018.685

21. Andrade GB, Pedroso VSM, Weykamp JM, Soares LS, Siqueira HCH, Yasin JCM. (2019). Cuidados paliativos e a importância da comunicação entre o enfermeiro e paciente, familiar e cuidador. RPCFO. 2019;11(3):713-7. Disponível em: http://ciberindex.com/c/ps/P113713

22. Marcheti MA, Mandetta, MA. Cartas terapêuticas como intervenção de enfermagem à família da criança com deficiência. CIAIQ2016, v. 2, 2016.

23. Freed PE, McLaughlin DE, Battle LS, Leander S, Westhus N. Therapeutic letters in undergraduate nursing education: ideas for clinical nurse educators. Nurse educ today. 2010;30(5):470-75. doi: https://doi.org/10.1016/j.nedt.2009.10.009

24. Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. Scand j caring sci. 2018;32(1):309-16. doi: https://doi.org/10.1111/scs.12463

25. Lizardo JDG, Fadda SMN. Intervención narrativa en duelo infantil por separación de pareja estudio de caso. Revista Electrónica de Psicología Iztacala. 2019;22(2):42-9. Disponível em: https://www.iztacala.unam.mx/carreras/psicologia/psiclin/vol22num2/Vol22No2Art11.pdf

26. Fox S, Azman A, Timmons S. Palliative care needs in parkinson’s disease: focus on anticipatory grief in family carers. Ann palliat med (Online). 2020; 9(Supplement 1), 34-43. doi: http://dx.doi.org/10.21037/apm.2020.02.04

27. Kübler-Ross E. Sobre a morte e o morrer: O que os doentes terminais têm para ensinar a médicos, enfermeiras, religiosos e aos seus próprios parentes. 10 ed. São Paulo: WWF Martins Fontes, 2017.

28. Eakes GG. Chronic sorrow. In: Alligood MR. Nursing theorists and their work-e-book. 9th ed. Elsevier; 2017. 609-25p.

29. Cabatan MCC, Danar JAJ, Mitra JLS, Adriano MAG, Martinez CYP. (2010). Filipino mothers’ experiences of chronic sorrow. Phillip J Ocup Ther [Internet]. 2016;4(1):34-45. Available from: https://www.researchgate.net/publication/301479264

30. Rahayu DS. Chronic sorrow theory application" to overcome the feeling of loss due to infant mortality in post-partum women. JMCRH. 2019;2(1):100-6. doi: https://doi.org/10.36780/jmcrh.v2i1.70

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Declaration of conflict of interests

Nothing to declare.

Funding and Acknowledgements

No funding

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