

EXPERIENCING PARENTAL CANCER: A CASE STUDY WITH APPLICATION OF NEUMAN'S MODEL

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ABSTRACT

Objective: to understand, in the light of Betty Neuman's Systems Model, the experience of a woman-mother with cancer, and identify the woman-mother's needs and prescribe nursing interventions in classified language.

Method: a qualitative case study of a woman-mother of a teenager experiencing cancer. Data collection carried out in Coimbra, Portugal, in 2021, through a semi-structured interview, supported by a script based on Betty Neuman's Systems Model. Data processing performed based on categorical content analysis.

Results: the analysis of a mother's speech made it possible to identify categories in agreement with the model variables: physiological, psychological, sociocultural, spiritual and developmental. The difficulties most expressed by the mother were fear, changes caused by the disease and parental role performance. The nursing diagnoses were defined based on the focuses "acceptance of health status", "fear", "parental role" and "family coping", associating them with the respective nursing interventions. Interventions focused on support and education.

Conclusion: the theoretical model contributed to understanding and identifying the needs of a mother experiencing parental cancer, facilitating the prescription of nursing interventions in classified language. The model proved to be relevant for future interventions in parents experiencing similar situations.

DESCRIPTORS: Parents. Cancer. Parenting. Nursing. Theoretical models.

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VIVÊNCIA DO CANCRO PARENTAL: ESTUDO DE CASO COM APLICAÇÃO DO MODELO DE NEUMAN

RESUMO

Objetivo: compreender à luz do Modelo de Sistemas de Betty Neuman, a experiência de uma mulher-mãe a vivenciar uma situação de cancro; identificar as necessidades da mulher-mãe e prescrever intervenções de enfermagem em linguagem classificada.

Método: estudo de caso do tipo qualitativo, de uma mulher-mãe de um adolescente, a vivenciar cancro. Colheita de dados realizada em Coimbra, Portugal, em 2021, através de entrevista semiestruturada, apoiada por um guião fundamentado no Modelo de Betty Neuman. Tratamento de dados realizado com base na análise de conteúdo categorial.

Resultados: a análise do discurso da mãe possibilitou identificar categorias concordantes com as variáveis do modelo: fisiológicas, psicológicas, socioculturais, espirituais e desenvolvimentais. As dificuldades mais expressas pela mãe foram o medo, alterações provocadas pela doença e o desempenho do papel parental. Os diagnósticos de enfermagem foram definidos com base nos focos “aceitação do estado de saúde”, “medo”, “papel parental” e “*coping* familiar”, associando-os às respetivas intervenções de enfermagem. As intervenções focaram-se no apoio e na educação.

Conclusão: o modelo teórico contribuiu para compreender e identificar as necessidades da mãe a experienciar o cancro parental, facilitando a prescrição de intervenções de enfermagem em linguagem classificada. O modelo mostrou-se pertinente para futuras intervenções em pais a vivenciar situações semelhantes.

DESCRITORES: Pais. Cancro. Parentalidade. Enfermagem. Modelos teóricos.

EXPERIENCIA DE CÁNCER PARENTAL: ESTUDIO DE CASO CON APLICACIÓN DEL MODELO DE NEUMAN

RESUMEN

Objetivo: comprender, a la luz del Modelo de Sistemas de Betty Neuman, la experiencia de una mujer-madre que vive una situación de cáncer, e identificar las necesidades de la mujer-madre y prescribir intervenciones de enfermería en lenguaje clasificado.

Método: estudio de caso cualitativo de una mujer-madre de un adolescente en proceso de cáncer. Recopilación de datos realizada en Coimbra, Portugal, en 2021, a través de una entrevista semiestructurada, apoyada en un guión basado en el Modelo Betty Neuman. El procesamiento de datos fue realizado en base al análisis de contenido categórico.

Resultados: el análisis del discurso de la madre permitió identificar categorías de acuerdo con las variables del modelo: fisiológicas, psicológicas, socioculturales, espirituales y de desarrollo. Las dificultades más expresadas por la madre fueron el miedo, los cambios provocados por la enfermedad y el desempeño del rol parental. Los diagnósticos de enfermería fueron definidos a partir de los enfoques “aceptación del estado de salud”, “miedo”, “rol de los padres” y “*afrentamiento* familiar”, asociándolos a las respectivas intervenciones de enfermería. Las intervenciones centradas en el apoyo y la educación.

Conclusión: el modelo teórico contribuyó a la comprensión e identificación de las necesidades de las madres con cáncer parental, facilitando la prescripción de intervenciones de enfermería en lenguaje clasificado. El modelo demostró ser relevante para futuras intervenciones en padres que experimentan situaciones similares.

DESCRIPTORES: Padres. Cáncer. Paternidad. Enfermería. Modelos teóricos.

INTRODUCTION

The incidence of cancer has increased significantly in people aged between 20 and 50 years¹. In these age groups, considered of procreation and paternity, the diagnosis of cancer in one of the parents can compromise parental role performance². Considering cancer the second leading cause of death worldwide, with a high annual incidence, the number of families affected by this disease can probably increase²⁻³.

Parental cancer (PC) incorporates the experience of cancer by the person and the family nucleus, resulting in a distressing and disturbing experience in the family, inherent to cancer, its physical and psychological repercussions, insecurity about the future and eventual threat of death, causing suffering and changes in the parent-child relationship⁴. Throughout the disease process, parents who experience PC are focused on protecting their children from worries, facing difficulties in performing parental role, telling the situation and maintaining family dynamics⁵⁻⁶. Concomitantly, they tend to have a decrease in parenting skills, caused by the specific physical and emotional exhaustion of the disease and the complexity of understanding their children's reactions to the disease⁷, which can generate a feeling of failure in the face of their responsibilities. These circumstances can affect parents who experience PC, which, according to Betty Neuman's Systems Model (NSM)⁸, is a stress factor. Given that cancer has repercussions and brings new challenges both to the person and their children, a nursing intervention that includes the dyad is important⁵. However, and despite the PC repercussions, there are no standardized nursing care guidelines for families experiencing this problem⁹. Considering the relevance of this phenomenon for society, it is imperative to study its complexity.

As a conceptual basis for the nursing intervention for parents experiencing PC, NSM was considered⁸. According to the author, the model addresses two essential components, stress and the person's reaction to it⁸.

This study aimed to understand the experience of PC of a woman-mother, in the light of NSM, and to identify a woman-mother's needs and prescribe nursing interventions using classified language.

METHOD

This is a case study, anchored in the qualitative paradigm, referring to the experience of a mother's PC. For developing the study, the COREQ checklist was considered. The present study was guided by author AFS and based on the light of NSM⁸.

The study took place in an oncology hospital in the central region of Portugal. Data collection was carried out on February 2, 2021. The sample consists of a 53-year-old married woman, elementary school teacher, mother of a 16-year-old male teenager and a 20-year-old young adult. The household consists of four elements, the self, the husband and the children.

Patients with cancer, at any stage of the disease, with children from 14 to 18 years of age, absence of cognitive deficits, who understand and speak Portuguese fluently, were included. The Informed Consent Form (ICF) for participation in the study was signed. Patients requiring hospitalization in intermediate care units, immediate postoperative period, clinical complications that made it impossible to verbalize, isolation and terminal stages of cancer were excluded.

Data collection was carried out using an interview guide, based on the concepts and methodological principles mentioned in NSM⁸.

Betty Neuman's Systems Model

NSM considers the person an open and dynamic system, in a relationship of physiological, psychological, sociocultural, spiritual and developmental factors, in continuous and reciprocal interaction with the environment¹⁰⁻¹¹. Through the application of the model to PC experience, it is intended to help parents to preserve, achieve and maintain the stability of their systems. Nursing care focuses on the cancer patient client system, addressing the close dyad/family cohabitants (additional client systems). From NSM, the nurse identifies parents' needs and the stimuli that can generate stress in the dyad: intrapersonal, interpersonal and extrapersonal factors. Based on the assessment, they should plan primary, secondary and tertiary prevention interventions to maintain parents' flexible line of defense and assess the outcome. Figure 1 shows NSM showing the interconnection between stressors.

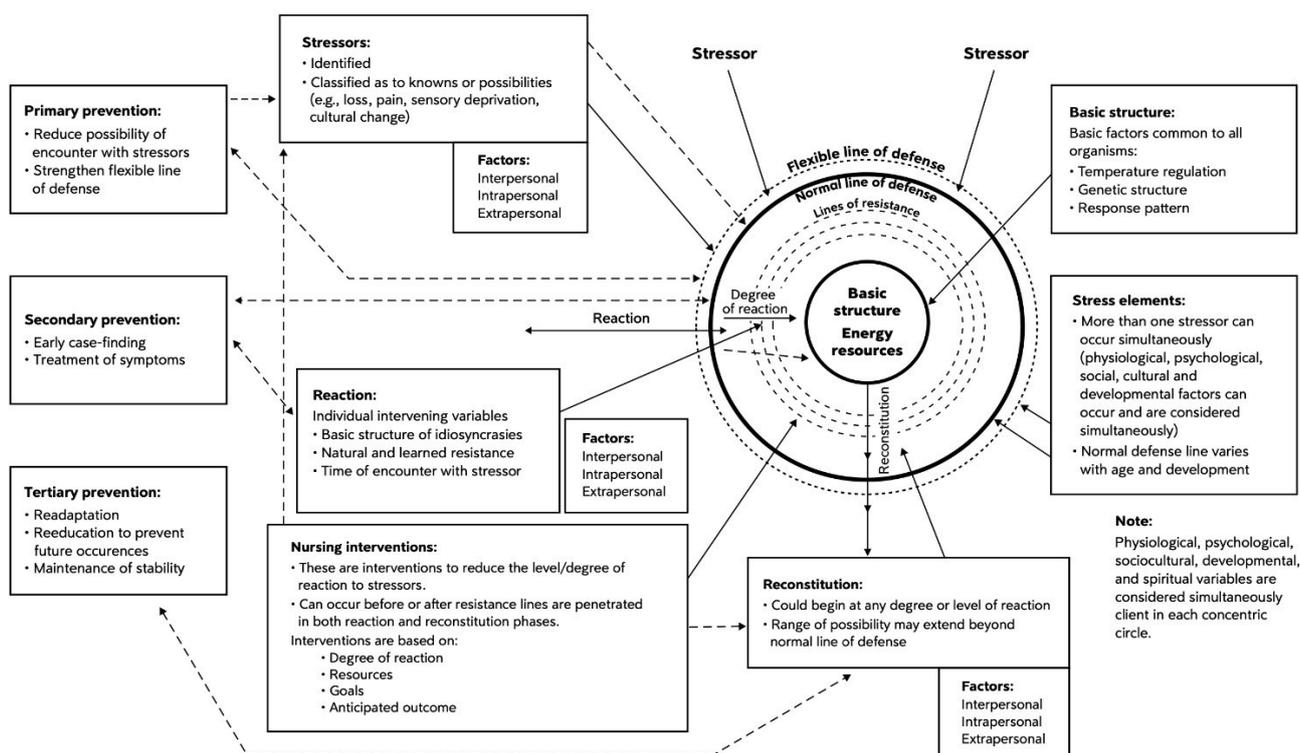


Figure 1 - Betty Neuman's Systems Model^{12:3}.

Data collection took place in a hospital room. The semi-structured interview took place in a calm environment, without interruptions, and lasted 60 minutes, with the presence of the participant and the interviewer. It was recorded in audio format and destroyed after transcription.

Data processing and analysis was carried out through the coding and categorization of data by units of meaning, according to the content analysis framework¹³, and supported by the NSM theoretical framework⁸. Categorization was carried out inductively, identifying dimensions or themes, through discourse analysis¹³. The MAXQDA Software was used to support the categorization.

All ethical assumptions inherent to studies carried out with human beings were complied with, having been approved by the Institutional Review Board of the institution where the investigation was carried out. The mother consented to the participation and recording of the interview and signed the ICF. The participant's statements were coded as M1, safeguarding data anonymity and confidentiality.

RESULTS

According to NSM, the mother's stressor is experiencing PC. The family socioeconomic status did not change, considering the family the social support network. The mother's cancer is an invasive breast cancer, stage 2, diagnosed one year ago. At the time of the interview, he was undergoing neoadjuvant treatments (chemotherapy, hormone therapy and immunotherapy) and in a period of postoperative recovery (mastectomy). Figure 2, based on NSM and appropriate to the case under analysis, schematically depicts the interconnection of stressors, stressors, the three levels of prevention, nursing interventions using ICNP^{®14} terminology, and reconstitution actions. The mother is represented in the center of the model, protected by the lines of resistance, normal and flexible defense. Intrapersonal stressors express the forces that the mother shows in the interaction of caregiving, namely fear, changes in the disease and changes in parental role. With regard to interpersonal factors, the maintenance of the mother's relationships with her husband, children, family and close friends, and some health professionals stands out. In terms of extrapersonal factors, absenteeism due to incapacity, social isolation caused by illness and difficulties in maintaining family dynamics, compromising parental role, stand out. Regarding the physiological, psychological, sociocultural, spiritual and developmental variables, contents of the mother's communication were identified that fit into the categories conceptualized in the model, whose results are presented in Chart 1. According to NSM, nurses identify the etiology of stressors and the interaction of variables, analyzing potential and real effects in order, in partnership with the family nucleus, to design a care plan adjusted to their needs. When assessing the mother's needs, "acceptance of health status," "fear," "parental role" and "family coping" are the nursing focuses in need of intervention. In this regard, a care plan was carried out using ICNP^{®14} taxonomy, with the presentation of the respective coding for the focuses, nursing diagnoses (ND), interventions, diagnostic and assessment activities, and for the expected results (Chart 2). Using classified language supports the decision-making process, promoting systematic documentation and communication between nurses¹⁵.

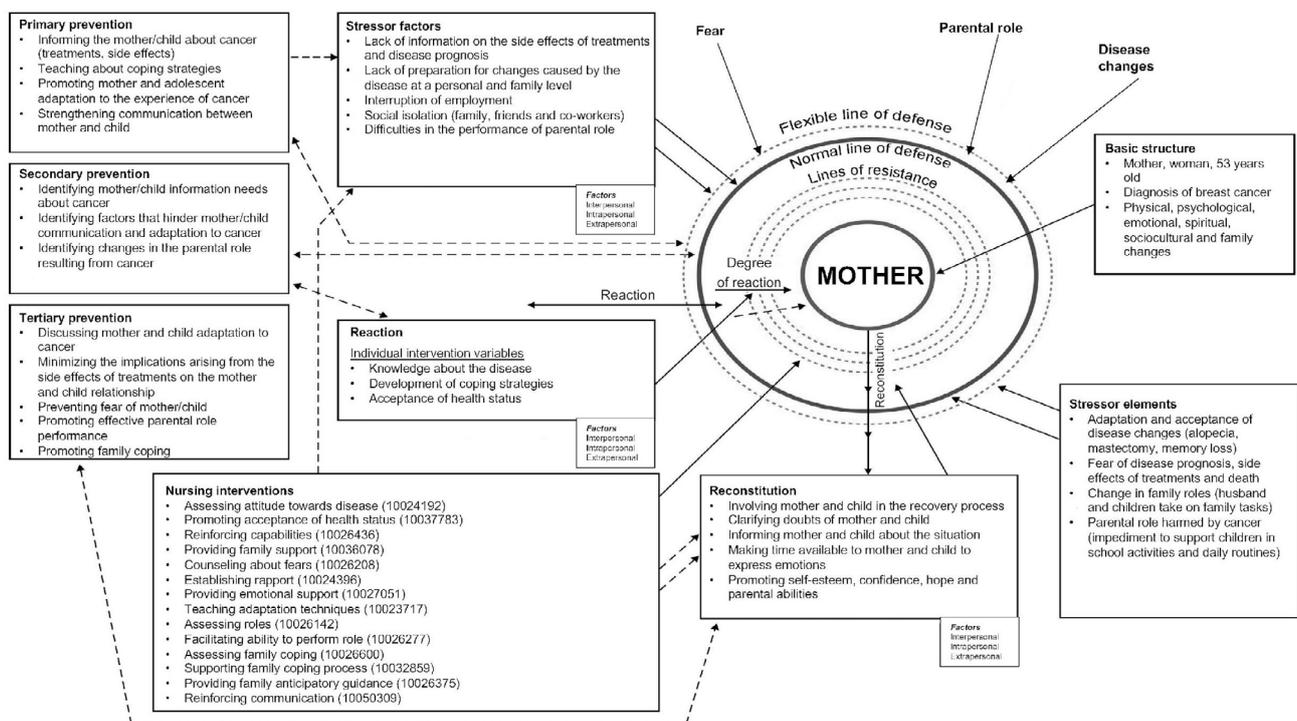


Figure 2 - Application of Betty Neuman's Systems Model to the case under study.

Chart 1 - Domains, categories, subcategories and units of meaning. Coimbra, Portugal, 2021.

Domain	Category	Subcategory	Units of Meaning (UM)
Physiological variables	Changes caused by cancer	Side effects of chemotherapy	<i>I vomited a lot. I have paresthesia of the upper limbs, the taste is altered, I have swelling of the legs and headaches. The effects were being violent, I had no strength. I forget easily, I have no concentration. I don't have energy.</i>
Psychological variables	Emotional changes	Fear	<i>I really thought and felt that I might die. I never verbalized it, but I was afraid for my son. What would become of him, since he's a kid. (...) it was a bit dark.</i>
		Sadness	<i>On a psychological and emotional level, I also broke down (...) I was not very well psychologically. Sometimes I felt an "emptiness", I cried. I'm more emotional.</i>
		Anxiety	<i>The process is very long and causes anxiety. You always have to be getting strength. I was not prepared for this reality, sometimes I felt lost.</i>
	Self-image	<i>I had a hard time falling out my hair. The mastectomy was hard (...) the first time I saw it I was inconsolable. When I get ready, it's coping. I had to grieve and I'm still doing it.</i>	
	Hospitalization	<i>Mentally I wasn't prepared. It cost me because of my son, because he missed me so much. One day, he told me, "When you were in the hospital, I would come home and not study, I would not do anything, I would just wait for you to call me".</i>	
Coping strategies	<i>Talk to family and close friends. I held on tightly to everything I could and tried to speed up the process quickly. I didn't read anything about the treatments, about anything. It was a way to protect myself (...) I never did anything without the physician's guideline.</i>		
Sociocultural variables	Labour changes		<i>I still have a certificate; I didn't have the psychological conditions to be in front of a class. I really had to stop, because the head was no longer there.</i>
	Socioeconomic repercussions		<i>There are many more expenses (...) my husband needed to have a medical certificate. I was no longer able to help my parents who are sick, and I had to turn to support for them.</i>
	Support networks	Family	<i>I had support from my family, they helped me to get the stones out of the way. They said it was beautiful. My family never let me get away from them. (...), my husband started to give me more support and the children as well.</i>
		Friends	<i>My friends gave me the support they could, they supported me in everything (...) I felt that I was not alone (...) I am privileged.</i>
		Health teams	<i>I had support from the family physician, the surgeon, and some nurses. They were available to listen and support me. It was important to trust the team.</i>
Community networks		<i>I never looked for support networks, I didn't sign up for associations. This is my thing and when I have doubts, I ask and clarify.</i>	

Chart 1 - Cont.

Domain	Category	Subcategory	Units of Meaning (UM)
Spiritual variables	Beliefs		<i>I got angry with God and I'm still not reconciled. It's not for thinking why me. Not. I thought no one deserved it.</i>
Developmental variables	Self-care		<i>In the shower they helped me wash my back (...) I didn't feel well, but then it goes away. There is no right time, there is an adaptation.</i>
	Changes in family tasks		<i>I tried to keep the routines, but you can't, because everything changes around us. I was the one who took care of the house and I didn't have the strength to do some things. My husband had to take over and many things I did became his tasks.</i>
	Family relations	Husband	<i>My husband was not quite understanding the situation. After the mastectomy, he sometimes felt like pushing him away, but he never left me. He suffered and so did our relationship. He doesn't like me to cry, he doesn't know what to do. He spent more time at home worrying about me and the children (...).</i>
		Children	<i>The situation [my illness] shook them and my biggest concern was not me, it was them. When my daughter was worse, she guided the situation. My son was scared too, but then over time he matured. I didn't want him to grow up because of this, but it helped him. He was always careful with me, even if he could go out, he didn't come out to protect me. I felt that he was sad in the depths of his soul, worried about his mother.</i>
		Family nucleus	<i>My relationship with my husband and with my children has strengthened. It brought us together much more. We are all for the same goal. It's not just my process, it's the whole family's.</i>
Parental role		<i>I didn't want my children to stop having the quality of life they had. I am a very attentive mother and I accompany my children in their studies, but at times I was more fragile and I did not give them the support they were used to. This situation compromised my role as a mother. I feel a little guilty about that. I didn't have the strength, and at times my son had to orient himself. You didn't have me there to support you.</i>	

Chart 2 - Care plan based on ICNP^{®14} taxonomy. Coimbra, Portugal, 2021.

Focus	Nursing diagnosis	Objective	Outcome criteria	Autonomous nursing interventions	Expected nursing outcomes
Acceptance of health status (10044273)	Impaired acceptance of health status (10029480)	Promote acceptance of mother's health status throughout cancer experience.	That the woman-mother empowers herself with adequate mechanisms to facilitate the process of accepting her health status.	<ul style="list-style-type: none"> - Assessing attitude towards disease (10024192) - Assessing acceptance of health status (10026249) - Promoting acceptance of health status (10037783) - Promoting self-esteem (10024455) - Reinforcing capabilities (10026436) - Providing family support (10036078) 	Acceptance of health status (10023499)
Fear (10007738)	Fear (10000703)	Reduce mother-woman fear during cancer experience.	That the mother-woman mobilize appropriate strategies to reduce fear.	<ul style="list-style-type: none"> - Counseling about fears (10026208) - Counseling about hopes (10026212) - Establishing rapport (10024396) - Providing emotional support (10027051) 	Reduced fear (10027889)
Parental role (10014068)	Risk for impaired parenting (10015198)	Promote parental role of woman-mother during cancer experience.	That the woman-mother empower herself with appropriate mechanisms to perform parental role.	<ul style="list-style-type: none"> - Assessing roles (10026142) - Teaching adaptation techniques (10023717) - Encouraging positive affirmations (10024377) - Facilitating ability to perform role (10026277) - Providing emotional support (10027051) - Assessing self efficacy (10024280) - Assessing fear about being a burden to others (10026254) 	Effective role performance (10027940)
Family coping (10034736)	Risk for impaired family coping (10032364)	Promote family coping and adaptation during parental cancer experience.	That the family take appropriate strategies to promote effective family adaptation and coping.	<ul style="list-style-type: none"> - Assessing family coping (10026600) - Supporting family coping process (10032859) - Providing family anticipatory guidance (10026375) - Reinforcing communication (10050309) 	Effective family coping (10034770)

DISCUSSION

The mother's experience of PC brings her flexible line of defense closer to the normal line. The definition of nursing interventions for each ND aims to reinforce the lines of defense, minimize the consequences of PC and provide the mother's well-being after reconstitution or recovery. At the level of primary prevention, interventions include providing information on the pathology and developing coping strategies, reducing risk factors and promoting adaptation to PC and strengthening and protecting the flexible line of defense¹¹. In terms of secondary prevention, interventions include the assessment of information needs, adaptation difficulties and changes in parental role performance, allowing an early diagnosis. These interventions are intended to reduce the reaction to stressors, through the lines of resistance, mobilizing internal and external resources to maintain energy and achieve stability. Within the scope of tertiary prevention, interventions aim to readaptation to the situation, taking into account the physical and psychological limitations caused by cancer, minimizing the consequences and preventing fear. These interventions start after reconstitution, allowing readaptation, through communication, promoting effective parental role performance and family coping. In PC experience, the factors and stressors that compromised the mother's adaptation were identified. The mother's most recurrent difficulties were fear, the changes caused by the disease and the risk of compromise in parental role performance. These difficulties are referenced in other studies, namely the changes caused by PC, which deteriorate the dyad's quality of life, causing implications at the level of five dimensions: emotional, social, physical, spiritual and financial^{3,16}. The lack of information and preparation for the disease and its repercussions, the interruption of work activity, social isolation and difficulties in performing parental role were the stressors. These findings are in line with scientific evidence, which points to the more effective parents' communication skills, parental role performance, children's emotional/behavioral adjustment and quality of family life are, the less worry, anxiety and depression the sick parent will have¹⁷. The stressors identified were the mother's adaptation and acceptance to disease changes, fear of prognosis, treatments and death, inversion of family roles, and compromised parental role. The more complex the PC experience, the more noticeable the stressors and elements will be, and parents may express anxiety, fear, sadness, family changes, and significant suffering¹⁷⁻¹⁸. Evidence shows that parents need guidance to promote trust and self-efficacy in communication, with nurses playing a leading role in families experiencing PC¹⁸. Considering the identified nursing focuses, the interventions developed aimed at providing social support to families and developing parenting skills, namely emotional availability, communication skills, reducing fear, assisting in the role reversal process, decreasing anxiety and developing coping mechanisms¹⁹.

Despite the recognition of this specific population's needs, health professionals point out barriers to the incorporation of interventions in clinical practice, namely: time pressure; non-inclusion of parental role in clinical assessment; structural and emotional barriers; fear of causing suffering; lack of confidence and lack of knowledge to deal with the situation²⁰. However, the structural assessment of patients' family, identifying the presence of children/adolescents in the household is a duty²⁰, so nursing interventions should include the dyad, supporting parents to deal with their children, alleviating their concerns, and minimizing the impact of PC along the disease trajectory^{20,21}.

The results of this study show the impact of cancer on parental role experience, verifying the importance of nurses in the mother's adaptation to PC.

As limitations, study design stands out, and the case study analyzed can be assumed as limiting in generalization of results. It is recommended to carry out further investigations on PC experience using NSM, with the nursing process implementation and assessment.

The results of this study have potential for application in circumstances of parents with adolescent children experiencing PC. Nursing teams must incorporate interventions that respond to the dyad's and family's needs, highlighting parental role as an integral part of family balance. NSM implementation through systematic nursing interventions that meet the needs of parents can promote adaptation to PC and contribute to minimizing the psychosocial impact resulting from the experience.

CONCLUSION

NSM was found to be adequate for understanding the phenomenon and assessing the needs of a mother experiencing PC, allowing the identification of intra, inter, extra-personal factors, and stressors, enabling care planning based on the model's three levels of intervention, considered applicable and suitable for other parents with cancer disease.

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NOTES

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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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