





ORIGINAL ARTICLE

ADOLESCENTS EXPERIENCING PARENTAL CANCER: A QUALITATIVE STUDY

HIGHLIGHTS

1. Analysis of the needs of adolescents experiencing parental cancer.
2. Adolescents demonstrate emotional, educational and psychosocial needs.
3. Development of nursing intervention programs.

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ABSTRACT

Objective: to analyze the needs of adolescents experiencing parental cancer. **Method:** an exploratory and descriptive qualitative study. Data collection was carried out through semi-structured interviews in 2021. The convenience sample was composed of adolescents aged 14-19, with parents with oncological disease in the treatment phase, followed in a Portuguese oncology hospital. Data processing was carried out using content analysis. **Results:** from the analysis of the 13 interviews, five domains emerged: Coping with the disease; Knowledge about the disease; Previous experiences with the oncological disease; Experiencing parental cancer; and Somatic changes. The results show that adolescents experiencing parental cancer have emotional, educational and psychosocial needs. **Conclusion:** this study allowed us to understand adolescents' needs, understanding the difficulties experienced and the challenges that the experience entails. The results will support the design of a nursing intervention program for the dyad experiencing parental cancer.

DESCRIPTORS: Adolescents; Parents; Neoplasms; Nursing; Qualitative Research.

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INTRODUCTION

Cancer incidence is increasing worldwide, with a greater number of new cases in people aged 30 to 50¹, an age at which many have dependent children². The experience of cancer in people with dependent children, known as parental cancer (PC), is a growing phenomenon². PC is a stressful life event for patients with cancer and their children, influencing the entire family nucleus, causing changes in routines and relationships, role reversal and socioeconomic difficulties³, which can affect the development of children and adolescents. Children of parents with cancer experience more emotional and behavioral problems, because their parents' care and support are compromised due to the disease process³.

In adolescence, having a parent with cancer can negatively affect psychosocial adjustment, causing lower quality and satisfaction with life as well as changes in school performance and post-traumatic stress^{2,4}. Adolescents are considered more susceptible to experiencing PC⁵, as they have a greater perception of the parental disease. However, their needs are not always met by the sick parent². Parents, due to the burden of the disease, have more difficulty supporting and identifying atypical behaviors in adolescents, and expect health professionals to support their children in dealing with PC. However, inexperience in the area, the gap in knowledge and the non-inclusion of adolescents in the parental illness process in adult hospitals constitute barriers to support⁴.

Despite the relevance of this phenomenon and the impact on the dyad, there are no guidelines for nurses regarding the dyad that experiences PC. However, some authors point out the need to implement interventions in these families^{2-3,6}.

This study aimed to analyze the needs of adolescents experiencing PC.

METHOD

This is a descriptive, exploratory qualitative study, based on the Adolescent Adjustment to Parental Cancer Theoretical Model⁷ (MTAACP - *Modelo Teórico do Ajuste dos Adolescentes ao Cancro Parental*). According to this model, the diagnosis of PC causes psychological and social stress in children, and the factors that contribute to the adaptation of adolescents can be classified as moderators and mediators⁷.

The COnsolidated criteria for REporting Qualitative research (COREQ) checklist was considered⁸. The study was carried out in an oncology hospital in the central region of Portugal between February and September 2021. Adolescents between 14 and 19 years of age, children of cancer patients without cognitive deficits, who understood and spoke Portuguese, were included. Adolescents whose parents needed hospital admission in intermediate care units, immediate post-operative and isolation and terminal stages of the oncological disease were excluded. Participant recruitment occurred by convenience through parents.

We used the semi-structured interview guide¹⁰, based on the MTAACP⁷. Data collection took place in a virtual environment through the Zoom Colibri platform, due to the pandemic period. After the researcher was introduced to adolescents by their parents, the interviews were carried out only in the presence of the participant and lasted an about 40.15 minutes (maximum 60 minutes and minimum 22 minutes). Video-audio was destroyed after its transcription. The interviews were carried out until data saturation. The study authors have experience in qualitative research and are experts in pediatric nursing and in the care of adults with oncological pathology.

Through inductive reasoning, data were coded and categorized into segments

according to Bardin's content analysis framework¹¹, supported by MAXQDA Analytic Pro 2022 software.

Research was approved by the Research Ethics Committee of the institution where the study was carried out (TI25/2020). Adolescents and their legal guardians consented to participate and record the interview and signed the Informed Consent Form. Participants' statements were coded in order to safeguard anonymity and confidentiality, identifying the interviews by the letter "I", then numbered in the order in which they were carried out.

RESULTS

A total of 13 adolescents participated, with an average age of 15.77 years. The choice of intermediate and late adolescence (14 to 19 years old) is justified by the greater vulnerability of this population to experiencing PC^{2,5,9}. Adolescents mostly attended the 3rd cycle and secondary education. The parent was mostly the mother, and they were all in the treatment phase (Chart 1).

Chart 1 - Characteristics of study participants. Coimbra, Portugal, 2021

Interview code	Age	Sex	Education year	Parent	Parents' age	Parent tumor type
I1	16	Male	11 th	Mother	50	Breast
I2	14	Female	8 th	Mother	42	Breast
I3	14	Male	8 th	Mother	46	Breast
I4	15	Male	8 th	Mother	45	Cervical
I5	14	Female	7 th	Mother	38	Breast
I6	15	Male	10 th	Mother	51	Breast
I7	14	Female	8 th	Father	51	Liver
I8	16	Male	10 th	Mother	58	Rectal
I9	18	Female	1 st year of degree	Mother	44	Breast
I10	17	Female	11 th	Mother	46	Breast
I11	17	Male	Vocational education	Father	62	Rectal
I12	17	Male	11 th	Mother	49	Breast
I13	18	Female	12 th	Mother	57	Breast

Source: Authors (2023).

From the analysis of the 13 interviews, five domains emerged: Coping with the disease; Knowledge about the disease; Previous experiences with the oncological disease; Experiencing parental cancer; and Somatic changes (Figure 1).

DOMAINS	COPING WITH THE DISEASE	KNOWLEDGE ABOUT THE DISEASE	PREVIOUS EXPERIENCES WITH THE ONCOLOGICAL DISEASE	EXPERIENCING PARENTAL CANCER	SOMATIC CHANGES
Categories Subcategories	Response to parents' cancer diagnosis Shock Denial Revolt and Anger Hope Acceptance	Information about cancer and treatments	Shock from previous losses	Taking on new responsibilities Carrying out household chores Changes in routines Accompanying the sick parent to the hospital Entry into the world of work Economic difficulties Relationship with the sick parent Support for the sick parent Strengthening the relationship with the sick parent Coping strategies Distraction Isolation Work School and leisure Changes in academic performance Changes in concentration Changes in extracurricular and recreational activities Support, listening and sharing Return to normality Axiological growth	Sleep and rest Body weight
	Expression of emotions Fear Sadness Anxiety Joy with recovery				

Figure 1 – Domains, categories and subcategories. Coimbra, Portugal, 2021

Source: Authors (2023).

The “Coping with the disease” domain arises from the aggregation of the “Response to parents’ cancer diagnosis” and “Expression of emotions” categories.

In “Response to parents’ cancer diagnosis”, participants highlighted “Denial”, “Shock”, “Revolt and Anger”, “Hope” and “Acceptance”.

(...) I didn't want to think that my father was very sick. I thought he was going to have surgery, but I didn't think it was anything serious. (I11)

(...) when they told me it was cancer, I was in shock (I8), (...) amazed, because I wasn't expecting it and I thought what the worst could happen. (I6)

(...) I felt angry because I thought, “With so many people in the world, why did it have to happen to my mother?”. (I1)

As time passed, thoughts began to be more hopeful. (I13)

At first, I was sad, but over time, I managed to cope better. (I7)

In the “Expression of emotions” category, adolescents demonstrated “Fear”, “Sadness”, “Anxiety” and “Joy with recovery”.

I felt some fear, because I already know what it's like to have cancer (...) I'm afraid that this will go in a bad direction, that my mother might die (I2), (...) that something could happen bad with my mother, that the outcome would be less good. (I10)

Not wanting to show too much sadness, but it had a big impact (I8), (...) I was very sad and shaken (I4), (...) the day my mother told me, I spent the rest of the day to cry. (I9)

I've been feeling a lot of anxiety (...) and all those crazy thoughts. (I9)

I think that now, towards the end, more the joy of everything passing (I2), (...) I felt joy when I saw her well. (I1)

Parents' "Knowledge about the disease" affected adolescents' experience of the situation, identifying the "Information about cancer and treatments" category. Some adolescents showed a lack of information; others showed that they had the necessary information; and others showed that they did not know how to act when they found out about the disease.

At first, I couldn't understand what my father's situation was. (I7), (...) I didn't know what could happen (I5), (...) I didn't really understand what it was. (I8)

We were always kept informed by my mother (...) my mother knew and then I knew from her (...). (I10)

When I found out about my mother's illness, I didn't know what to say (I6), (...) I didn't know what to do (I7), (...) I'm still trying to understand what the best behavior is what should I have (I9), (...) what should we say, what can we do to help. (I13)

Regarding the "Previous experiences with the oncological disease" domain, some adolescents showed "Shock from previous losses".

My grandfather had cancer and passed away (...) and that left an impression on me. (I5), A musician in my band died this year with cancer (...), and I was devastated when I found out. (I10)

The "Experiencing parental cancer" domain emerges from eight categories: "Taking on new responsibilities"; "Economic difficulties"; "Relationship with the sick parent"; "Coping strategies"; "School and leisure"; "Support, listening and sharing"; "Return to normality"; "Axiological growth".

The "Taking on new responsibilities" category emerges from the aggregation of the "Carrying out household tasks", "Changes in routines", "Family support", "Accompanying the sick parent to the hospital" and "Entry into the world of work" subcategories.

I started doing more things that I hadn't done before: preparing food, picking up the clothes, vacuuming (I10), (...) helping with tasks that my mother needed because she couldn't make much effort (I3), (...) every weekend we clean the house (...) we have compensated for the work she did. (I8)

Everything has changed in our routines (I9), (...) there are foods that we no longer eat, because my mother has to pay more attention [to the foods she can eat] (I5), (...) I had to go earlier to school, because my mother had to go to the hospital for treatments and I had to ask my grandparents to pick me up. (I10)

My mother can't support us as much and we have to be the ones to support her (I1), (...) I have to spend more time with her, because she might need something (I4), (...) sometimes, I sit next to her [sick mother], talking or studying (I8), (...) I felt more responsible for my younger sister, I had to help her more. (I5)

When there was an appointment, I went with my father so my mother wouldn't miss work. (I11)

(...) I started working so I could get my license and buy a car to have transport for my family. (I11)

In the “Economic difficulties” category, some adolescents mentioned not having had support, while others mentioned that they had had economic support.

(...) externally to the family, we have not had any monetary (...) support (I9), (...) the hospital provided support with transport, which was a good thing. (I11)

The “Relationship with the sick parent” category brings together the “Support for the sick parent” and “Strengthening the relationship with the sick parent” subcategories.

(...) my responsibility has increased in terms of caring for my mother (I6), (...) I worry if she needs help (...) I feel more protective (I12), (...) there was a bit of a role reversal, now I am the caregiver. (I9)

(...) the disease always changes the relationship. We have always had a good relationship, but lately it has been better (I11), (...) the relationship has become closer, we are more united. (I12)

To face PC, some adolescents developed “Coping strategies”, namely “Distraction”, and others opted for “Isolation” or “Work”.

(...) I spent my time busy with technology (...) so I distracted myself a bit so I wasn't always thinking (I5), Sharing and contacting friends was important (...) it distracted me, we talked about other things (...). (I13)

I preferred to get away for a bit, to be isolated to see if it would get better and then I would go to my mother's side (I1), One thing I did was go to my room, I closed myself there (I3), (...) when I feel saddest (...) sometimes I close the blind. (I2)

(...) I tried to get a job after school so I wouldn't be at home so much. (I11)

Adolescents reported that PC interfered with “School and leisure”. At school, “Changes in academic performance”, “Changes in concentration” and “Changes in extracurricular and recreational activities” were noted.

At school, I used to miss a lot to take care of my father (I11), (...) my grades dropped a little (I1), (...) I forgot to do a geography assignment. (I5)

My concentration was compromised and reduced (I4), (...) I wasn't listening to anything that was going on in class, I was thinking about the situation. (I10)

In training, I don't feel like going so much anymore (...) it can be demotivating (I2), (...) I started playing less, to spend more time with my family (I3), (...) I used to play online with my friends and talk loudly. Now, I haven't been playing, because my mother has to sleep. (I8)

The “Support, listening and sharing” category emerged from the speeches of adolescents who highlighted the need for support.

(...) It would help a little if I told them what I was feeling and gave me some advice (I1), (...) I can't even understand my own feelings, I needed help with that too (I9), (...) I think that It's always good to share this with someone who knows and can help me. (I8)

They particularly valued the support of nurses, family, professors and friends.

(...) It was good to talk to a nurse, to be able to vent (I5), (...) I feel relieved to express what I feel (I9), (...) talking to a nurse served to share what is happening to me, in my heart, I feel lighten me up. (I13)

Family members started to worry a little more about me, they call more often, asking how I am (I1), (...) I know that, if I need to talk, I can count on my family (...) in terms of rides and things like that, (...) I know I can count on my grandparents and uncles. (I10)

Some professors also talked to me about the situation I was going through [mother's illness], and worried if I needed anything. (15)

(...) my friends have been a great support (...) they told me everything would be fine, so I wouldn't worry so much (112), (...) having the right friends at the right time. (16)

However, others reported a lack of support from friends.

I felt like my friends weren't very supportive, I don't have very close friends at school either. (15)

During the PC experience, adolescents highlighted "Return to normality".

(...) After she [mother] got better, everything tends to go back to normal (16), (...) as time went by, it was as if it was, it's not all normal, because it's not, but it's as if was there (13), (...) now we try to do the routine normally again. (19)

As a result of the experience, participants demonstrated "Axiological growth".

I feel like I have grown, and continue to grow, because of this situation. I feel that there is an added responsibility for knowing that my mother is experiencing this process (113), (...) my maturity has increased (...) I have grown in mental terms and maturity. (18)

In the "Somatic changes" domain, there were repercussions on "Sleep and rest" and changes in "Body weight". Adolescents reported that they lost weight, but others reported that they gained weight.

In the beginning, I had more difficulty letting myself sleep, sometimes also because of anxiety (11), I haven't slept all night for a few months (...) lately, I've been waking up many times during the night (19), At the beginning of the situation, I started to have insomnia (16), (...) with my father's situation, I felt a lack of sleep. (111)

When I found out about this, I lost a lot of weight. I lost about six kilos without realizing it. (110)

There were days when I woke up feeling hungry, there were others when I woke up without any hunger at all (...) I think I've gained a bit of weight, so much so that I need to lose weight. (111)

The analysis of the results obtained allowed the identification of emotional, educational and psychosocial needs in adolescents who experience PC (Figure 2).

DOMAINS NEEDS	COPING WITH THE DISEASE	KNOWLEDGE ABOUT THE DISEASE	PREVIOUS EXPERIENCES WITH THE ONCOLOGICAL DISEASE	EXPERIENCING PARENTAL CANCER	SOMATIC CHANGES
EMOTIONAL	✓		✓	✓	✓
EDUCATIONAL		✓		✓	✓
PSYCHOLOGICAL				✓	

Figure 2 - Needs of adolescents experiencing parental cancer. Coimbra, Portugal, 2021

Source: Authors (2023).

DISCUSSION

When adolescents are faced with a parent's diagnosis of cancer, they experience a stressful event¹². When facing PC, participants showed denial, shock, revolt and anger, hope and acceptance. Other authors¹³ report that, when adolescents discover the diagnosis of PC, they are in shock and feel grieving. The expression of adolescents' feelings was similar, regardless of the type of cancer and sex of their sick parents. However, scientific evidence indicates that the sex of sick parents, the response to diagnosis and the consequent adolescents' emotional, behavioral and somatic manifestations can be exacerbated in children of the same sex as their parents.¹⁴.

Some adolescents demonstrated hope and acceptance throughout the PC experience, a finding that corroborates other authors who mention that children of parents with cancer live "trapped" between hope, acceptance, fear, sadness and anxiety¹³. The phases experienced by adolescents when confronted with PC fit into the paradigm of the Kübler-Ross theory¹⁵ in relation to the diagnosis of chronic diseases, death or mourning, starting with denial and ending with acceptance. Many adolescents experience fear regarding the diagnosis and repercussions of PC, such as death^{4,13}. However, they do not always express this within the family, corroborating other authors who state that children keep their fears secret to protect their parents.¹³ Another consequence of PC in adolescents is anxiety, and they can develop high levels of anxiety, depressive symptoms and post-traumatic stress^{2,4,16}, which can dissipate over time or persist in the long term⁴. Some participants expressed joy with their parent's recovery, as reported in other studies⁴.

Knowledge about cancer and information about treatments and prognosis are referred to in the literature as the need most recognized by adolescents, however, it is often not met^{2,5,17}. Some participants referred to the need for information; others had the necessary information; and others did not know how to act when they found out about the disease. It is known that children prefer to be informed by their parents; however, they are generally overwhelmed, finding it difficult to talk about the situation^{4,17}, so they expect health professionals to inform. Although the guidelines recommend addressing information needs, support for families affected by PC is limited, due to the lack of inclusion of parental role in care provision¹⁷. The importance of nurses meeting adolescents' need for information is highlighted¹⁶.

Previous experiences with the oncological disease, according to MTAACP, can compromise adolescents' adjustment to the PC⁷ experience. When previous experience includes the death of a family member with cancer, it can influence how they act and respond to similar situations in the future⁷. Some participants reported previous experiences of cancer, mentioning that these losses had a significant impact on them. These results highlight the need to assess the previous experiences of adolescents, reinforcing the need for information and emotional support¹⁶.

The PC experience led participants to take on new responsibilities, such as carrying out domestic tasks, changing routines, accompanying the sick parent to the hospital and entering the world of work, demonstrating the relevance of psychosocial intervention in these families. It can be seen, as mentioned by other authors, that the experience of oncological disease affects family dynamics, with role reversal seen by adolescents^{2,18}. A study points to role reversal as a consequence that PC has on family life patterns, which can be difficult for both parents and adolescents to face². This role reversal can harm the quality of family life, with emotional, social, physical, spiritual and financial consequences¹⁸.

Some adolescents mentioned a lack of economic support, while others reported having benefited from this support. Although economic difficulties are most frequently cited by parents as a consequence of PC, some authors² report that adolescents may need professional assistance to face the socioeconomic consequences⁶.

The experience of PC can affect the relationship with the sick parent²; study participants

reported strengthening the relationship. The majority changed their behavior after the diagnosis, demonstrating greater emotional support and being closer to the sick parent. Acceptance of the disease by the parent and the prior existence of a positive relationship between the dyad favor adolescents' adaptation to the changes caused by PC¹². On the other hand, the quality of the dyad's communication¹⁹⁻²⁰, associated with "warm parenting", can play a protective role in adolescents' adjustment, promoting effective coping and strengthening existing relationships¹².

Adolescents have different coping mechanisms when experiencing PC, including talking about the situation and confronting it, or blocking the topic¹³. Participants adopted different coping strategies, such as distraction (physical and recreational activities), isolation and work. It is recommended that adolescents engage in sporting and social activities, trying to do something fun that allows them to relieve stress². Allowing quality time with the sick parent is seen as an essential strategy in promoting adjustment to PC¹³.

Other repercussions that PC has on adolescents are changes in school life and leisure, which can have an impact on academic performance^{2,12-13}, with low school performance, adding to the responsibility of helping parents and taking on domestic tasks²¹. Participants showed changes in academic performance and concentration, which are explained by the pressure of having a parent with cancer².

In the PC experience, support, listening and sharing are considered fundamental. Some adolescents showed a need for support; others had support from nurses, family, friends and professors; and others had a lack of support from friends. The need to feel supported by their families and talk openly about PC is supported by some studies^{2,6}. It was found that participants shared the situation with family, professors and friends, but some reported a lack of support from friends, which could be due to the difficulty of sharing the situation. One way to promote sharing is to encourage discussion of PC within the family and enable recreational/therapeutic approaches that promote psychosocial support, development of skills based on acceptance therapies and commitment in the face of realities of uncertainty and unpredictability².

Some adolescents reported that they had support from nurses, considering that the interview was important to clarify doubts and freely share what they felt. Other authors⁶ mention that some adolescents prefer the support of external people with whom they can talk, as their concern for their parents and the need to protect them prevent them from sharing their thoughts. Health professionals must communicate with adolescents, demonstrating understanding of their feelings, keeping them informed, honestly, throughout the PC trajectory⁶. Some authors say that parents are adolescents' first choice. Others report that this population wants health professionals to be aware of their needs and provide them with greater support, considering that, initially, it may be embarrassing, but the experience and training of health professionals help them to deal with negative emotions²². Study participants also suggested that nurses could support them, saying that the interview had a therapeutic nature of listening, support and sharing. These results emphasize the need for intervention, for this specific population, in a hospital environment.

Participants expressed a desire to return to normality, as mentioned by some authors⁶, who emphasize that adolescents feel the need to control their lives, attend school and relate to their peers, maintaining normality.

PC influences the development process of adolescents, as they live under pressure, fight for independence and are faced with the need to support their parents on a physical and emotional level¹⁸. This process accelerates the axiological growth of adolescents, contributing to their maturation²³, their ability to adjust to adversity²⁴ and the development of resilience⁴. Some participants in this study reported that their experience resulted in an opportunity for growth with greater appreciation for life.

In a study that analyzed the experience of an adolescent with PC in light of the, different nursing focuses were identified: "knowledge", "sadness", "fear", "anxiety", "adaptation"

and “family coping”, for which autonomous interventions promoting adjustment were prescribed, helping to minimize the impact of the situation²⁵. In the case of the study participants, it is possible to see that these focuses apply in most situations, highlighting the relevance of nursing interventions.

One of the consequences of PC in adolescents are somatic changes^{2,4,6,26}. Some symptoms can persist over time, causing health problems related to low levels of self-esteem, behavioral difficulties, substance abuse, self-harm and attempted suicide⁶. Some participants revealed changes in sleep and rest, and body weight. These findings corroborate those of other authors⁷.

Through analysis of results, it was possible to identify that adolescents who experience PC are faced with emotional, educational and psychosocial needs. Emotional needs are the predominant ones, followed by educational and psychosocial needs. In a study that aimed to map intervention programs for children/adolescents and parents experiencing PC, it was concluded that the prevalent interventions are of a psychoeducational type²⁷. These types of interventions are suggested to respond to the needs demonstrated by the adolescents in the study²⁷.

When coping with the disease, emotional needs become evident, making support during the diagnosis phase and in the PC experience crucial, preventing possible somatic changes. Educational needs must be met when learning about the disease during the diagnosis phase and throughout the PC experience. In this process, adolescents’ psychosocial needs must be equally met, considering a joint intervention with the dyad.

It was found in this study that the needs arose both during the diagnosis phase and during PC, justifying a differentiated nursing intervention, adapted to each adolescent, considering the disease stage and the time since diagnosis, as the repercussions of PC occur throughout the disease trajectory. The consequences can be seen in the long term, and interventions must extend to follow-up²⁷. The importance of developing nursing intervention programs adapted to adolescents’ needs is reinforced.

The limitations of this study are related to its geographical limitation. It is suggested that other investigations be developed in different populations. Knowledge of adolescents’ needs will support the construction of a nursing intervention program aimed at dyads living with PC in hospitals, where parents are accompanied.

CONCLUSION

This study made it possible to understand the experience and identify and analyze the needs of adolescents experiencing PC as well as understanding the difficulties experienced. Adolescents expressed emotional, educational and psychosocial needs, for which nurses must implement interventions that promote adjustment and minimize consequences.

This study contributes to the advancement of knowledge in the area, particularly about the needs of adolescents and children of parents with cancer, where evidence to date is scarce.

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