

Feelings of children when witnessing parents' illness

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ABSTRACT

This study aimed to learn the experiences of children who witness their parents' illness due to cancer. This is a descriptive, qualitative study, with six children between 10 and 12 years of age, children of cancer patients assisted by a support institution. The data were collected from July to August 2015, based on the guiding question: "How do you feel about your father/mother's illness?" From the analysis, two categories emerged: Recognizing the disease and the possibility of the parents' death and, Growing as a child and living as an adult: the repercussions of parents with cancer in their children's lives, which reveal that children understand cancer and the possibility of death of their parents, being also affected by the disease. By experiencing the fears and repercussions of cancer, children need assistance by the family and health team during their parents' illness.

Descriptors: Neoplasms; Child; Parenting; Pediatric Nursing; Qualitative Research.

INTRODUCTION

Cancer has become increasingly present in families around the world, which can be due the increasing disease aggressiveness, which is now considered the second cause of death in Brazil⁽¹⁾, in addition to the alarming estimates that calculate a total of 596,000 new cases of cancer in Brazil between 2016 and 2017⁽²⁾.

In addition, the development of amplified technologies to diagnose and improve the means of treatment⁽³⁾, allow the early diagnosis and increase of the survival. This directly affects the increasing number of currently neoplasms cases. For that matter, the diseases are diagnosed early, and people are getting ill

increasingly younger and, at reproductive age. Given this scenario, the literature points to the following problems: the parents illness of children who still are in childhood and school age, needing care⁽⁴⁾.

When a parent is diagnosed with a cancer, their parental role can be affected by modifying child-care routines, capacity to be zealous, and consequently destroying the home⁽⁵⁾. Thus, the impact of cancer on children's lives is extremely shocking, as they are directly affected by the worsening of their parents' health. Although children and adolescents show good acceptance of their parents' illness, a study of children of mothers with cancer has shown that they can develop important emotional problems, especially when parents have high anxiety and do not talk about their illness with their children⁽⁶⁾.

It is worth emphasizing that the family often prefers to protect the child from worries about everyday problems, forgetting that children constantly receive information through their interaction with the world and that, according to their cognitive level, they are able to create representations of what is happening around them⁽⁷⁾. In this sense, the parents' fear of revealing the real diagnosis to their children is due to a desire to protect them from suffering because they believe that their children can go through the same fears they face, causing them to partially transmit the information⁽⁸⁾.

However, a study in Saudi Arabia with children and adolescents between the ages of five and 16, whose mothers had breast cancer, has shown that discussing the cancer diagnosis with the children has improved the way they treat their mother, as well as positive effects on their personality as a whole⁽⁴⁾. In addition, the existence of an honest and gradual dialogue between parents and children establishes a relationship of trust between them, which enables positive results for children's self-confidence in the future⁽⁸⁾.

Faced with such considerations, we questioned "how do children feel when witnessing their parents' illness due to cancer?", Exploring the child's feelings and knowledge about a neoplasm may be critical for healthcare professionals, since they can provide care for parents who take care of their children during illness. The family institution, as the first reference of a person in his/her life and main source of support in times of illness, should be the health team's focus of attention, which is committed to assist all its members to deal with the conflicts inherent to illness at home⁽⁹⁾.

Moreover, children should be prepared for their future by organizing their feelings in order to understand how they perceive the cancer of their parents. Therefore, this study aims to understand the perception of children who experience their parents' illness due to cancer.

METHOD

This is a qualitative study, which allows us to unveil subjectivities, meanings, values and attitudes of the human being's experiences, focusing on the individual and society in a profound and non-quantifiable way⁽¹⁰⁾.

Six children of father or mother with cancer assisted by a support philanthropic institution, located in the Northwest of Paraná, Brazil, participated in this study. The children were located from the family register in the support institution, with the inclusion criteria of being from 10 to 12 incomplete years of age,

characterized as a child according to the Statute of the Child and Adolescent⁽¹¹⁾, with father or mother actively treated for at least six months of cancer treatment, living in the city of the institution and aware of their parents' illness. The parents of the children confirmed the last criterion before any contact with the children. Incomplete address to locate the family, or the death of the father or mother of the child was considered exclusion criteria.

From the search of family registers in the institution, 24 children matched the age group, but we could establish telephone contact with only 15 families. At that moment, we explained the objectives of the research, and verified if the children were aware of the disease and excluded two families who had not revealed the illness to their children. Among the 13 remaining families, seven parents refused to participate, therefore six interviews occurred, with an average duration of 30 minutes each.

Interviews took place in the families' residences; three to four family meetings were necessary to create a bond with the children, until they felt comfortable staying alone with the researcher and told their experiences and feelings quietly. In addition, the parents were asked to leave at the time of the interviews, so that the children would have more freedom in exposing their innermost feelings, often not revealed to their parents. Data collection occurred between August and October 2015, based on the guiding question: "How do you feel about your father/mother's illness?" In order to continue and deepen the children's story, we used support questions such as "Explain me better about ...", "Tell me more about ..."

The interviews were recorded in a digital recorder and later transcribed in full. The Thematic Content Analysis⁽¹⁰⁾ guided the data analysis, which are pre-analysis, exploration of the material and treatment of results, inference and interpretation. From the analysis, two thematic categories emerged - Recognizing the disease and the possibility of the death of the parents and, - Growing as a child and living as an adult: the repercussions of the cancer of the parents in the children's lives, which were discussed from the current literature about the subject.

As this research involves human beings, we considered the ethical aspects defined by Resolution No. 466/2012 of the National Health Council, approved by the Standing Committee on Ethics in Human Research of the State University of Maringá (COPEP UEM), Opinion No. 1,166,696, of 4/13/2015. The parents of children under 18 years signed the Free and Clarified Consent Term (FCCT). The children, in turn, registered their assent to participate in the research, signing in the specific space in the FCCT already signed by those responsible.

Children's anonymity was preserved through the use of identification codes (C1, C2, C3,..., C6), followed by their respective ages.

RESULTS AND DISCUSSION

The speeches of six children who experience their parents' battle against cancer composed the results of this study. Of these, four were male and two were female, with ages between 10 and 12 incomplete years. Among the parents, five were mothers and only one was a father. The type of cancer varied between the

throat, thyroid and breast, and the latter was the most prevalent, with four cases. The analysis emerged into two categories, presented as following.

Recognizing the disease and the possibility of the death of the parents

When living with cancer in the residence, all family members get closely involved in the new routine that the disease establishes, generating unusual feelings due to the new challenge and causes physical and psychic exhaustion to those involved in the treatment⁽¹²⁾. Likewise, children who experience cancer in the family also perceive their parents' illness and live with the repercussions that their vehemence causes in the family environment, designing their ideas and understanding about cancer and its repercussions.

In this study, children's recognition of parents' cancer, in general, started from previous conceptions, adapted to what they could physically visualize in them. The children demonstrate that the conceptions they have about cancer are due to the knowledge they have acquired through their family members, at their residences or by seeking into their means of information, as the speeches show:

[...] Is cancer a bacterium inside? I think cancer is a bacterium, which is why it causes hair to fall, and it eats here (the cheek), because my father was like that. (C6, 11 years)

[...] I did not know what cancer was. It's been a while since I've heard information on television. (C1, 11 years)

[...] There are several types, skin cancer, hair cancer ... I don't know much about it. I see it on TV. (C2, 10 years)

The children receive information regardless of their relatives' will, because they seek the understanding, they create their meanings by their own means, even if innocently reported. Such construction is a reflection of the child's ability to acquire knowledge, which interacts with the world and creates his/her perceptions⁽⁷⁾.

In addition, the adaptive processes developed by children are specific to their age group, so that they react differently to the adversities imposed by everyday life⁽¹³⁾. Thus, despite the candor involved in their thinking, they demonstrate to be aware of the severity of the disease and understanding about the consequences it entails.

Through the narratives, we noticed that the revelation of the parents' disease was perceived through physical signs that manifested during the course of the disease. Hair loss was the most stigmatized physical repercussion, especially when it came to the mothers, being thus remarkable in the trajectory of the disease evolution for the children, as they portray:

[...] Oh it was sad. Because at first, when she found out she had the disease, she thought it was nothing. She thought it was normal. But then she did the exams, discovered more,' until she lost her hair, she went bald, that hurt! To see my mother bald. (C5, 11 years)

[...] I was afraid because her hair began to fall. Then I realized she had cancer. (C2, 10 years)

[...] She had warned me before she lost her hair, if she had not warned I would have not been okay [...]. If she had not told us that her hair would fall we would think she was going to die, because her hair started to fall, she was going to have to remove her breast. (C3, 11 years)

The loss of hair by a woman has repercussions on her self-identity, since it symbolizes sexual attractiveness, cultural identity and physical health, being stigmatizing and significant for women as for those who surround them⁽¹⁴⁾. When the hair starts falling, it is a moment of uncertainties that comes along with pain, fear and distress. For children, this is the confirmation that their parents are ill, is when they perceive the weakness and the repercussions that the disease can cause.

In addition, the speeches demonstrate that understanding the cancer is also intertwined with the possibility of death. Unlike the adults' dodges, children verbalize death as being linked to the disease, and do not hesitate to talk about it:

[...] It is a disease that kills, which is very bad, I do not know how many percent of cure, of chance that one has to survive. (C1, 11 years)

[...] Because I think most people with cancer die, they end up dying. I saw it on the internet, a person had died of cancer. My friend also said that his grandfather died of cancer. (C4, 10 years)

[...] She could die because of this thing, some women have already died of cancer, I know because I saw it and my mum told me and she called me to watch the report. (C3, 11 years)

We hesitate to recognize death in our society and, consequently, to talk about it⁽¹⁵⁾. The children, in revealing the awareness of the possibility of death, find themselves tied to the experiences of those who have already gone through this journey and, in a still naive way, reveal the fear of losing their parents, even without saying that death would reach them.

Therefore, cancer still has the negative social stigma of death sentence, of threat to social life, and of the thought that from the diagnosis, life changes completely when getting ill⁽¹⁶⁾. In addition, the patient and family are exposed to a storm that affects them mainly in the emotional aspect, being evident their overload in the most impacting moments of the disease, as the diagnosis⁽¹⁷⁾. Such experiences and repercussions for children will be explored in the next category.

Growing as a child and living as an adult: the repercussions of parents' cancer in their children's lives

Cancer in the family generates the need for specific and differentiated care for the patient, which often involves the abdication of plans, desires in contrast to the need for unique dedication to the patient and his/her needs⁽¹²⁾. Cancer affects not only the patient but also the family, fundamentally affecting all its members.

In the course of the disease, cancer treatments become more complex and parents cannot hide the moments of distress and suffering from their children. In such a way, children are potentially affected by the imbalance at home, realizing the repercussions and feelings that a daily illness has imposed on their lives:

[...] At school the grades decreased because of this. In the second year, they lowered their grades. Because I felt sad to see my mother like that. I lost the desire to study, then my grades decreased. (C5, 11 years)

[...] Because if the mother is ill, what child will be happy? Are you going to study in peace? To study? (C1, 11 years)

[...] I got a bit sad to see my father having to do chemo and stuff, because I saw him before but today it is not the

same thing. I see him like this, ill and everything, and before he was happy. (C6, 11 years)

Children express in their speeches that their well-being is directly related to their parents' well-being and, however much they try to hide their anguish, children perceive them and take part of that suffering. Children are affected and cannot perform their daily activities as before, attained by this transformation in their lives. The experience of the disease leads to great and diversified emotional conflicts, being permeated by moments of extreme anxiety⁽¹⁸⁾. This situation carries with it a load of sufferings and expectations for all persons involved⁽¹⁹⁾.

Consequently, the perceptions that the child experiences when living with cancer at home are strong and effusive, so that the deep marks left by the illness make them modify their behavior and approach their parents, because they understand that their presence and their care is essential at this time, as shown below:

[...] I've changed ... Quite a lot, in behavior and staying at home, because of my mother. Because of my mother, because if she was lying down and needed something, I would be close to help her [...]. I used to go out in the morning, then I would run back to school, and after getting home from school, I would leave again. On Saturday and Sunday I would leave in the morning and return only at night. Not anymore, I get home from school, then I do not go out. (C3, 11 years)

[...] I stopped going out, stopped messing around at school, because if I made a mess, my mother would not be able to go to school (C2, 10 years)

Given the speeches, the children feel the need for their parents' care and, at the same time, perceive themselves as responsible for them, through the need of their help - the roles are reversed, and the child is now provider of care. Although it is not necessary, and in many cases this need is not even uttered, children view it as a role assigned to them and, if they are proud of their actions, they act naturally. These attitudes are also found in a study carried out in Saudi Arabia, which reinforces this child's tendency to approach and concern towards parents when they face cancer⁽⁴⁾.

In the moving speech of one of the children, we observed that him, in addition to modifying his daily attitudes on behalf of parents, showed affection and love for them, expressing through his words his sadness at the possibility of death, thinking how much his life would be painful without them.

[...] I began to obey more, to hug more, to kiss more. Because if you lose your mother, what will happen to you? You're going to be cut in half. Like, if she passes away, she takes half the heart way. That's not good ... (The boy's voice is choked, silent). (C1, 11 years)

Benevolence permeated by love towards the other is the extreme possibility of relating to a person and performing a real care, in which the world is left aside, to return to this level⁽²⁰⁾. Despite all the mishaps faced, cancer has transformed these children's lives and strengthened them, causing them to develop a new look at themselves and their bonds. From the illness of the father or mother, these children have learned a new way of being and relating, adding value to health and unity in the family, as well as recognizing the importance and the unique love that is expressed between parents and children.

FINAL REMARKS

The results of this study demonstrate that children have their own mechanisms of constructing their own reality, demonstrating that they have an understanding of the cancer of their parents, besides the possibility of death, which is imminent of the disease worsening. Understanding parents' illness mobilizes children for care, which transforms their lives for the zeal, care, and responsibility that flourish amid the innocence of being a child and the burdens of adult life.

We note that experiencing cancer within the family allows family unification, develops new looks in their members, directing them to perceive life in another way. We could observe that children have their own strength and, despite little experience and little knowledge, they react firmly to obstacles, and face difficulties in an exemplary way. They have shown that despite their young age, they have principles and courage, which is contrary to the fragile image that society has over them, that is, the fact that they experience illness and its repercussions in an extreme and so close way lead them to mature early.

Although few studies explore this aspect of care, it is possible to affirm that families, and especially children, need assistance during the parents' illness, aiming at actions to the healthy development of these beings. Nursing, in particular, being at the forefront of caring for the patient and the family should be prepared to support such children, who demonstrate the need for individual and holistic attention to their doubts, fears and longings.

This study contributes to a better understanding of experiences of children living with their parents' illness due to cancer, making it possible for the health team to approach and assist children and their families. Therefore, the need for new qualitative studies in this area to deepen and broaden the knowledge on the subject is emphasized.

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