

## Care provided by the father to the child with cancer under the influence of masculinities: qualitative meta-synthesis

*Cuidado paterno ao filho com câncer sob influência das masculinidades: metassíntese qualitativa*  
*Cuidado paterno del hijo con cáncer bajo la influencia de las masculinidades: metasíntesis cualitativa*

Naiara Barros Polita<sup>1</sup>, Willyane de Andrade Alvarenga<sup>1</sup>, Ana Carolina Andrade Biaggi Leite<sup>1</sup>,  
Jeferson Santos Araújo<sup>1</sup>, Louise Bittencourt Paes Abreu dos Santos<sup>II</sup>, Márcia Maria Fontão Zago<sup>1</sup>,  
Francine de Montigny<sup>III</sup>, Lucila Castanheira Nascimento<sup>1</sup>

<sup>I</sup> Universidade de São Paulo, School of Nursing of Ribeirão Preto, Postgraduate Program in Nursing. Ribeirão Preto, São Paulo, Brazil.

<sup>II</sup> Universidade Federal do Rio de Janeiro, Department of Nursing. Macaé, Rio de Janeiro, Brazil.

<sup>III</sup> Université du Québec en Outaouais, Département des Sciences Infirmières. Gatineau, Quebec, Canada.

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### ABSTRACT

**Objective:** To synthesize and interpret findings and conclusions of qualitative research addressing the experience of the father in the care of the child with cancer. **Method:** Meta-synthesis of 16 qualitative studies from six databases, analyzed through taxonomic analysis. **Results:** Child and adolescent cancer have several repercussions on the daily life of the father, especially related to the stigma around the disease, the fear of the unknown and the social and family role. Faced with the illness and the need to care for the child, the father seeks to recover normality in the family and transitions between hegemonic masculine behaviors and practices culturally recognized as female. **Final Considerations:** The complex experience of the father, influenced by masculinities, was evidenced. The limitations regard the restricted understanding of the contextual specificities of the experiences, due to the limited characteristics of the parents and children described in the studies. The knowledge produced is useful to promote involvement of fathers in the care of the child, as well as to strengthen and assist him in this task.

**Descriptors:** Fathers; Pediatric Nursing; Qualitative Research; Cancer; Family Nursing.

### RESUMO

**Objetivo:** Sintetizar e interpretar resultados e conclusões de pesquisas qualitativas sobre a experiência do pai no cuidado do filho com câncer. **Método:** Metassíntese de 16 estudos qualitativos capturados em seis bases de dados e analisados por meio da análise taxonômica. **Resultados:** O câncer infantojuvenil impõe inúmeras repercussões ao cotidiano do pai, sobretudo relacionadas ao estigma da doença, ao medo do desconhecido e ao papel social e familiar. Diante da doença e da necessidade de cuidado do filho, o pai busca resgatar a normalidade na família e transita entre comportamentos hegemonicamente masculinizantes e práticas reconhecidas culturalmente como femininas. **Considerações finais:** Evidenciou-se a complexa experiência paterna influenciada pelas masculinidades. As limitações referem-se à restrita compreensão das especificidades contextuais das experiências, pelas escassas características dos pais e filhos descritas nos estudos. O conhecimento produzido revela-se útil para promover o engajamento paterno no cuidado do filho, bem como fortalecê-lo e auxiliá-lo nesta tarefa.

**Descritores:** Pai; Enfermagem Pediátrica; Pesquisa Qualitativa; Neoplasia; Enfermagem Familiar.

### RESUMEN

**Objetivo:** Sintetizar e interpretar resultados y conclusiones de investigaciones cualitativas sobre la experiencia del padre en el cuidado del hijo con cáncer. **Método:** Metasíntesis de 16 estudios cualitativos recogidos en seis bases de datos y examinados mediante análisis taxonómica. **Resultados:** El cáncer infantojuvenil repercute considerablemente en la vida cotidiana del padre, sobre todo con relación al estigma de la enfermedad, al miedo a lo desconocido y al papel social y familiar. Ante la enfermedad y la necesidad de

cuidar del hijo, el padre busca rescatar la normalidad en la familia y transita entre comportamientos hegemónicamente masculinos y prácticas reconocidas culturalmente como femeninas. **Consideraciones finales:** Se puso en evidencia la compleja experiencia paterna influenciada por las masculinidades. Las limitaciones se refieren a la estricta comprensión de las especificidades contextuales de las experiencias por las escasas características de los padres e hijos descritos en los estudios. El conocimiento producido puede llegar a ser útil para promover el compromiso paterno en el cuidado del hijo, así como fortalecerlo y ayudarlo en esta tarea.

**Descriptores:** Padre; Enfermería Pediátrica; Investigación Cualitativa; Neoplasia; Enfermería Familiar.

CORRESPONDING AUTHOR

Lucila Castanheira Nascimento

E-mail: lucila@eerp.usp.br

## INTRODUCTION

Since the twentieth century, changes in family settings have been contributing to the emergence of new conceptions about the roles occupied by family members. These changes have redefined the responsibilities of fathers, requiring from them greater involvement in household tasks, interaction and participation in the care and education of the children<sup>(1-2)</sup>. Thus, fatherhood has taken on new values and concerns<sup>(3-4)</sup>. When there is a child with a chronic illness in the family, the father is crucial for the process of family adjustment, aimed at including the disease and maintaining balance in family life<sup>(5)</sup>.

Health professionals acknowledge the important role of the father in the care of the child. However, they find it difficult to include him in this task, since usually it is the mother that occupies the leading role, with the father on a secondary position<sup>(3,6)</sup>. Therefore, in order to help fathers to develop the necessary skills for this care, it is important to provide an assistance that understands their needs and concerns and contemplates their personal characteristics and socio-cultural context<sup>(3,7)</sup>.

The defense of masculinity stands out among the paternal characteristics, since being a father and caregiver is a challenge experienced by many men in global, regional and local contexts. On an anthropological approach, masculinities are multiple, as are the cultures in which they are inserted. So, among fathers, hegemonic, complicit, subordinate and marginalized behaviors that guide them in their daily actions of caring for the child coexist<sup>(8)</sup>.

In the specific context of child and adolescent cancer, studies describe how the family deals with the changes and how those changes impact the family organization and the relationship between the family members, who experience the child's health condition with anguish, doubt and fear<sup>(9-10)</sup>. Physical, social and emotional overload repercussions are part of the experience of family members who face childhood cancer, especially the father, who deals with his masculine roles in the family and in society<sup>(11)</sup>. Qualitative studies have been conducted to investigate the experience of the father and other family members with the child or adolescent's cancer diagnosis<sup>(9,12-14)</sup>.

Given the above and the importance of further investigate fathers' experience of care, the present study is proposed with the purpose of synthesizing and interpreting results and conclusions of qualitative research addressing the father's experience in the care of the child with cancer. This meta-synthesis is intended to provide suggestions for the individualized care of the father and the family based on empirical, qualitative evidence, as well as to identify gaps in the literature and in the clinical practice.

## METHOD

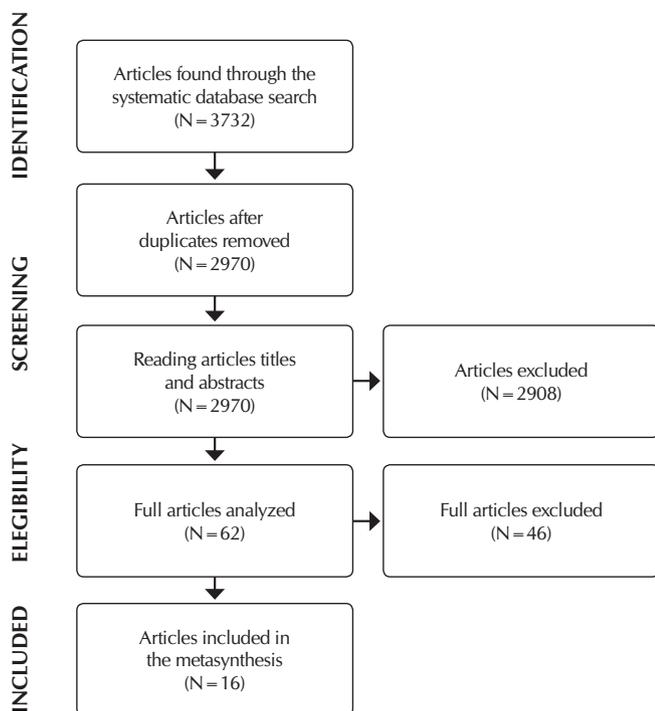
This is a qualitative meta-synthesis, a design characterized by synthesis and interpretation of the findings of qualitative studies of a given area, aimed at obtaining a broad conceptual understanding to transcend the existing studies and allow the formulation of a set of new discoveries<sup>(15)</sup>. To do so, the approach proposed by Sandelowski and Barroso was adopted<sup>(15)</sup>, which includes the following steps: elaboration of the research question, systematic identification and selection of articles, evaluation of the articles selected, data extraction and elaboration of the synthesis. ENTREQ (*Enhancing Transparency in Reporting the Synthesis of Qualitative Research*) recommendations were used for this qualitative synthesis<sup>(16)</sup>.

A literature search based on the research question "What is the father's experience in the care of the child or adolescent with cancer?" was conducted to find original qualitative studies addressing this experience, in order to better understand it. The search was conducted by two independent reviewers from March 2016 to May 2016 in six databases: PubMed, Scopus, Web of Science, CINAHL, CUIDEN and LILACS. The search was limited to Portuguese, Spanish and English-language and to research published from 1995 to 2015. The descriptors and the keywords 'father', 'child', 'adolescent' and 'cancer', selected based on the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH), were combined with Boolean operators (AND, OR).

The articles included were those with qualitative methodologies and descriptive/exploratory studies with qualitative analysis of the data, conducted with fathers and addressing their experiences in the care of the child or adolescent with cancer (their practices, behavior, beliefs, values and feelings). Studies conducted with the father and other family members were included if the results concerning the father were presented and analyzed independently. Mixed methods studies with qualitative data presented and analyzed separately from quantitative data were also included. Studies that described the experience of fathers of children and adolescents with cancer along with the experience of fathers of children this age in other conditions were excluded from the analysis.

A total of 3732 studies were identified in these databases, as shown in Figure 1, which followed PRISMA recommendations<sup>(17)</sup> to describe the literature search process. Of these, 762 duplicate articles were excluded, leaving 2970 articles. Then the titles and abstracts were read independently by the two reviewers, observing the inclusion and exclusion criteria. The Kappa index<sup>(18)</sup> was calculated to measure the agreement between

the two reviewers and obtained a value of 0.97, indicating substantial agreement. As a result of this process, 62 articles met the eligibility criteria. The articles were then read in full and 46 of them were excluded because they were not primary studies ( $n = 16$ ); were based on a quantitative approach ( $n = 5$ ); included other family members, without individual presentation of the results for each of them ( $n = 24$ ); addressed paternal experience with childhood cancer along with sickle cell disease ( $n = 1$ ). Thus, the final sample of this meta-synthesis consisted of 16 articles.



**Figure 1** – PRISMA flowchart<sup>(17)</sup> of the literature search process

The quality of the articles was analyzed independently by the two reviewers using the Critical Appraisal Skills Program (CASP)<sup>(19)</sup> – an instrument that consists of a checklist for the evaluation of qualitative studies. The instrument contains 10 questions that evaluate the description and relevance of the objective, the adequacy of the qualitative methodology, the research design, the recruitment strategy, the data collection, the adequacy of the relationship between researcher and participant, ethical issues, data analysis, presentation of results and contributions of the study. The discrepancies between the evaluators were discussed in meetings until consensus was reached. Methodological quality was not a reason to exclude studies, due to the limitations of evaluating this aspect and the contributions of the findings to the topic, which is still incipient in the Brazilian scenario<sup>(20)</sup>.

The articles included were reread by two authors, and the data extraction process was done using a form based on the question adopted in this meta-synthesis and in the general characteristics

of the studies: year of publication; authors; country of origin; area of study; objectives and methodological aspects (study design, participants and data collection procedures); and the findings about the fathers' experience with the child's cancer. The taxonomic analysis with constant comparison and reciprocal translation of in vivo and imported concepts, proposed by Sandelowski and Barroso<sup>(15)</sup> was used for data analysis and elaboration of the synthesis. For the definition of the categories and the interpretive synthesis of the data, the properties and variations suggested by the findings, the underlying concepts, the conceptual semantic relations explicit or implicit in the findings, and the concepts imported from the literature were considered to integrate the findings and express the result in a central concept<sup>(15)</sup>. The codes based on the data were compared and organized into taxonomies according to their similarities, which were analyzed using in vivo concepts from the results and concepts imported from medical anthropology and the anthropology of masculinities. The codes were then compared to each other and grouped into categories.

The process of codification and categorization was done individually by two authors and later compared to discuss disagreements. To complete the synthesis and to maximize its validity, two other authors, with experience in qualitative research and anthropology, carefully reviewed the adjustment of codes and taxonomies, as well as the concepts related to the categories.

## RESULTS

The final sample consisted of 16 studies<sup>(21-36)</sup>. As shown in Chart 1, the articles were published between 2001 and 2013 in six different countries: Australia ( $N = 4$ ), the United States ( $N = 4$ ), Canada ( $N = 4$ ), Brazil ( $N = 2$ ), China ( $N = 1$ ) and Ireland ( $N = 1$ ). The studies used phenomenology ( $N = 6$ ), grounded theory ( $N = 3$ ), mixed methods ( $N = 2$ ) and qualitative description ( $N = 5$ ). Four of them<sup>(21,29,31,36)</sup> did not specify the theoretical framework adopted and were named as generic qualitative<sup>(37)</sup>. Data were collected through interviews ( $N = 13$ ), focus group ( $N = 1$ ) or the combination of both ( $N = 2$ ).

The 16 studies included a total of 171 fathers of children with cancer, from newborns to 18-year-olds, at different stages of the disease and the diagnosis. Most studies did not sufficiently describe the father figure, since only five of them characterized it as represented by the biological father, adoptive father, stepfather or grandfather. Only seven studies focused on a single type of cancer, mostly on acute lymphocytic leukemia. Most of them included fathers of children in unspecified treatment phase and diagnosis of different cancers.

The overall quality of the studies included in the meta-synthesis was satisfactory (Table 1). All of them demonstrated consistency between objective and methodology. Four did not report the recruitment strategy; four did not describe the ethical aspects of the research; and most did not mention reflexivity aspects, that is, the researcher's critical analysis of his relationship with the participants and the possibility of bias ( $N = 14$ ). Only one study did not sufficiently inform the steps of the data analysis.

**Chart 1** – Characteristics of the original studies included in the qualitative meta-synthesis, Ribeirão Preto, São Paulo, Brazil, 2016

First author, year and country	Design	Data collection	Characterization of fathers
Chesler, 2001 United States <sup>(21)</sup>	Descriptive/ Generic qualitative	Semi-structured in-depth interview and focus group	N = 167; age not specified. Fathers mourning, fathers of children in different stages of treatment or survivors/cured. Children with various oncological diagnoses.
Liaschenko, 2001 United States <sup>(22)</sup>	Descriptive/ Generic qualitative	Semi-structured interviews	N = 12; age = 36-59; biological fathers. Fathers of children from 8 to 20 years old, on therapeutic and non-therapeutic cancer treatments.
McGrath, 2001 Australia <sup>(23)</sup>	Phenomenology	Unstructured interview	N = 4; age not specified. Fathers of children on treatment for acute lymphocytic leukemia (ALL), from newborns to 16-year-olds.
Neil-Urban, 2002 United States <sup>(24)</sup>	Phenomenology	Focus group and semi-structured interviews	N = 10; age not specified. Seven biological fathers, two stepfathers and a grandfather of children on cancer treatment.
Jones, 2003 Canada <sup>(25)</sup>	Grounded theory	Focus Group	N = 10; age = 35-56. Seven biological fathers, two stepfathers and a grandfather of children between three and 16 years old on cancer treatment.
McGrath, 2003 Australia <sup>(26)</sup> <sub>a</sub>	Phenomenology	Unstructured interview	N = 6; age = 24-54. Fathers of children between 17 months and 18 years old on ALL treatment.
McGrath, 2003 Australia <sup>(27)</sup> <sub>b</sub>	Phenomenology	Unstructured interview	N = 6; age = 24-54. Fathers of children between 17 months and 18 years old on ALL treatment.
McGrath, 2004 Australia <sup>(28)</sup>	Phenomenology	Unstructured interview	N = 6; age = 24-54. Fathers of children between 17 months and 18 years old on ALL treatment.
Clarke, 2005 Canada <sup>(29)</sup>	Descriptive/ Generic qualitative	Unspecified interview	N = 16; mean age = 44. Fathers of 10-year-old children in different stages of cancer treatment.
Hill, 2009 Ireland <sup>(30)</sup>	Phenomenology	Semi-structured in-depth interview	N = 5; age = 31-42. Biological fathers of children in ALL remission aged between 18 months and 7 years at the time of diagnosis.
Nicholas, 2009 Canada <sup>(31)</sup>	Grounded theory	Semi-structured interview	N = 16; mean age = 43. 14 biological fathers, a stepfather and an adoptive father of children between one and 17 years old on cancer treatment.
Wills, 2009 China <sup>(32)</sup>	Descriptive/ Generic qualitative	Semi-structured in-depth interview	N = 9; mean age = 38. Fathers of children newly diagnosed with ALL, aged between nine months and 14 years.
Dupas, 2012 Brazil <sup>(33)</sup>	Grounded theory	Semi-structured interview	N = 5; age not specified. Fathers of children on cancer treatment.
Nicholas, 2012 Canada <sup>(34)</sup>	Mixed method	Unspecified interview	N = 21; age not specified. Fathers of children with brain tumor on different treatment modalities.
Hensler, 2013 United States <sup>(35)</sup>	Mixed method	Questionnaire and unstructured interview	N = 25; age not specified. Fathers of surviving children with a mean age of 11 years.
Silva, 2013 Brazil <sup>(36)</sup>	Descriptive/ Generic qualitative	Semi-structured interview	N = 11; age = 27-53. Fathers of children on cancer treatment.

Note: ALL = Acute lymphocytic leukemia

**Table 1** – Results of the quality assessment of the articles, Ribeirão Preto, São Paulo, Brazil, 2016

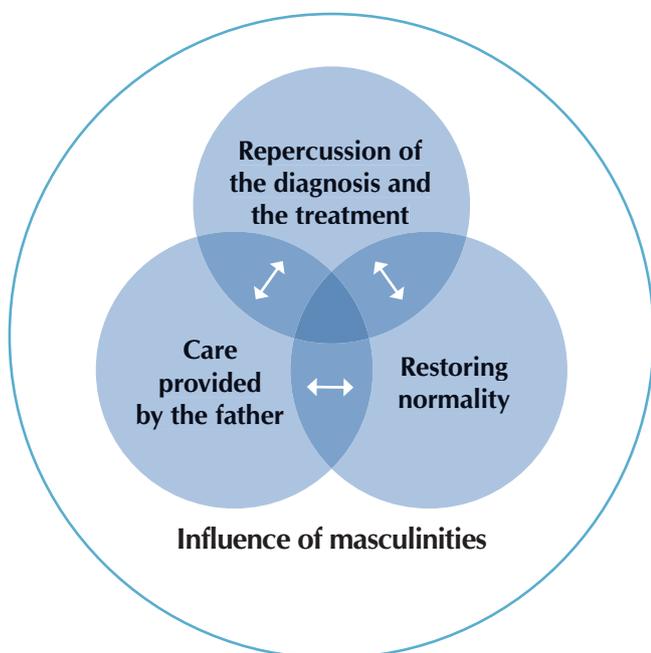
Question	Yes*	Partially reported *	No*
1. Was there a clear statement of the aims of the research?	16 <sup>(21-36)</sup>	0	0
2. Is a qualitative methodology appropriate?	16 <sup>(21-36)</sup>	0	0
3. Was the research design appropriate to address the aims of the research?	12 <sup>(23-26,28-31,33-35)</sup>	4 <sup>(22,27,32,36)</sup>	0
4. Was the recruitment strategy appropriate to the aims of the research?	2 <sup>(27-32)</sup>	10 <sup>(21,23,25-26,29-34)</sup>	4 <sup>(24,27-28,36)</sup>
5. Was the data collected in a way that addressed the research issue?	10 <sup>(22,25-26,29,31-36)</sup>	6 <sup>(21,24-27,34)</sup>	0
6. Has the relationship between researcher and participants been adequately considered?	0	2 <sup>(32-34)</sup>	14 <sup>(21-31,33,35-36)</sup>
7. Have ethical issues been taken into consideration?	10 <sup>(21,26,28,30-36)</sup>	2 <sup>(22-23)</sup>	4 <sup>(24-25,27,29)</sup>
8. Was the data analysis sufficiently rigorous?	10 <sup>(21,23,25-26,28,30-32,34-35)</sup>	5 <sup>(22,24,29,33,36)</sup>	1 <sup>(27)</sup>
9. Is there a clear statement of findings?	16 <sup>(21-36)</sup>	0	0
10. How valuable is the research?	16 <sup>(21-36)</sup>	0	0

Note: (\*) Number of studies.

### Knowledge synthesis

The analysis of the studies led to the elaboration of three categories that qualify fathers' experience in the care of the child with cancer: 'Repercussions of the child's diagnosis and treatment of cancer for the father', 'Care provided by the father to the child with cancer'; and 'Restoring normality in the experience of the child's cancer'. Of the 16 articles analyzed, 13<sup>(21,23-34)</sup> were represented in all categories.

Figure 2 illustrates the categories and shows that the repercussions of childhood cancer for the father, his search for normality and the care he provides to the child are not isolated. Masculinities are embodied in all aspects of this paternal experience. The influence of masculinities is the central concept that encompasses the three categories and the interactions between them, contributing to the way the diagnosis is received, to the father's actions to deal with the child and the new situation and to the construction of care.



**Figure 2** – Representative categories of the father's experience of caring for the child with cancer and their relationships, under the influence of masculinities

### Repercussions of the child's diagnosis and treatment of cancer

The results showed that child and adolescent cancer have considerable emotional and social repercussions for the father<sup>(21-25,27-34,36)</sup>. Feelings such as sadness<sup>(21,25,34)</sup>, revolt<sup>(31)</sup>, guilt<sup>(21,23,32)</sup>, powerlessness and unpreparedness<sup>(28,31)</sup> were present on the period of diagnosis and during treatment. The diagnosis of the child's cancer, unexpected for the father, and the way it was described as painful, unpredictable, indiscriminate, shocking and devastating<sup>(25,31,33,36)</sup> reflect the meanings attributed to cancer and show the stigma around the disease. The conceptions about the disease along with the diagnosis contributed to this news being received as a shock<sup>(28,32-33,36)</sup> that caused sadness<sup>(21,25,34)</sup>, revolt<sup>(31)</sup>, a

feeling of losing control of the situation<sup>(28,31)</sup> and questions about the real meaning of life<sup>(24)</sup>. Some fathers felt guilty<sup>(21,25,32)</sup> and powerless<sup>(28,31)</sup> for not being able to prevent the cancer from reaching their families.

Uncertainties regarding the child's illness, treatment and future arose<sup>(22,24-25,30-32)</sup>, contributing to the feeling of anguish and the fear of an early death of the child<sup>(21,25,28,31-33)</sup>. Some fathers presented physical symptoms of stress and anxiety, such as dry throat, difficulty sleeping and decreased appetite<sup>(31)</sup>. They also showed concern about work activities and finances keeping them distant from the child, which, together with the strong desire to be close to the children during the treatment, caused tension<sup>(23,26,31)</sup>.

Some described discomfort in their first contact with the hospital environment, as a result of seeing the suffering and exhaustion of children and parents, and remembering the possibility of losing their children<sup>(27)</sup>. They mentioned the lack of privacy in a predominantly female environment and demonstrated difficulty in experiencing the invasive, difficult and painful procedures and emotional stress to physically restrain their children during procedures<sup>(27)</sup>. The fathers showed empathy with the child's pain, comprehension of the child's refusal to treat, and difficulty in establishing limits for the child<sup>(27)</sup>.

Intra and extra familial interactions also faced repercussions of the child's cancer treatment. The increased responsibilities of fathers and mothers brought by the diagnosis of cancer and its treatment led to abrupt changes in family dynamics and, consequently, in the relationship between spouses, causing intimacy difficulties<sup>(25)</sup> and marital discord<sup>(23)</sup>. Some said they did not have enough support from the spouse, but the course of their experience made the couple more united and able to offer mutual support. However, due to the focus on the child, the intimacy of the couple remained impaired<sup>(24)</sup>.

They perceived the social support of co-workers only in the beginning of the experience<sup>(21)</sup>, but were satisfied with the support of family members and healthcare teams<sup>(21,25,28)</sup>. They valued nurses and social workers<sup>(25)</sup>. In this aspect, the groups of parents who deal with child and adolescent cancer had an important role, since they provided a space for making new friendships and sharing ideas and experiences<sup>(31)</sup>. This exchange brought comfort, relief and hope<sup>(25,32)</sup> and, above all, contributed to reduce the distance, isolation and despair felt by them<sup>(31)</sup>.

### Care provided by the father to the child with cancer

The care provided by the father to the child with cancer was influenced by the masculinities related to the roles of men in today's society<sup>(21,23,25,27-34,36)</sup>. Thus, the father assumed identities and stereotypes consistent with the image of a strong man, who shows no weakness and is responsible for the protection and support of the home and the family. Concern about providing subsistence and offering protection to the family was present throughout the experience and guided the fathers' actions<sup>(21,25,28,31-34,36)</sup>.

Most studies<sup>(21,23-25,28-29,31-34,36)</sup> showed that the father experienced difficulty to express and share his emotions with his wife, children and friends. Backed by the stereotype of masculinity

that “men don’t cry”, the father omitted his feelings and fought his tears in order to show strength and to be a source of support and protection for his wife and child<sup>(21,23,25,28-29,31)</sup>. Some tried to deal with the situation independently and in individual comfort spaces<sup>(28)</sup>, which generated difficulties in finding emotional support. Others realized that the strategy of hiding emotions was ineffective and detrimental to health in the long term<sup>(25)</sup>. In general, after the cancer of the child, the fathers’ sense of responsibility about the family and their effort to maintain harmony were intensified<sup>(33)</sup>.

Their protective instinct turned them into hyper protective defenders of their children<sup>(24-25,27,36)</sup>. They were more attentive to the clinical changes and the care provided to the child during hospitalization, fearing possible errors of the health care team. Some took on the care of their healthy children, collaborating with the wife during hospitalizations and adapting to new routines<sup>(26)</sup>. Others actively participated in the hospital and home care of the sick children<sup>(24-25,27,29,36)</sup>, assuming the role of caregivers. Two studies<sup>(29-30)</sup> pointed out that the fathers occupied a side role, attributed to a joint decision of the mothers and the medical team, since the researchers perceived that attention and information were first provided to the wives, which generated dissatisfaction and impaired the relationship of the fathers with the health professionals<sup>(29-30)</sup>.

### Restoring normality in the experience of the child’s cancer

Studies showed that despite the suffering caused by the disease, the father sought to re-signify the child’s illness. In this aspect, the positive experiences of this process and the development of strategies to recover normality within the family were highlighted<sup>(21-22,24-25,27-30,33,35-36)</sup>.

The cancer diagnosis changed the perspective of the father, who came to value his relationship with his wife. Consequently, this promoted a flexibility of roles and, in the long term, contributed to a greater physical and affective bond with the relatives<sup>(32-33,35)</sup>.

There were also changes in the worldview and in the behavior of the father, who established a relation of partnership with the mother; presented optimism, confidence and greater participation in the care of the child with cancer<sup>(33)</sup>, contributing to strengthen the bond between father and child<sup>(21,27,33)</sup>. Even with the uncertainties and fear of losing the child or adolescent<sup>(21-22,24-25,28,30-33)</sup>, the fathers demonstrated hope they would heal<sup>(28)</sup>, which, along with their need to control the situation<sup>(24-25,27-28,31,36)</sup>, motivated them to use their own resources<sup>(23,25-26,28-31,36)</sup> and mobilize social support<sup>(23-24,29-32,36)</sup>.

Another relevant factor for the fathers was the comfort found in religion and spirituality, which provided new meanings, consolation for pain and relief of fear<sup>(31)</sup>. In this aspect, the painful experience strengthened faith and beliefs, intensified their relationship with a higher being and increased their participation in religious activity, aiming to understand and deal with the disease<sup>(31-35)</sup>. The fathers reassessed their personal values throughout this experience, caring more about quality family time<sup>(35)</sup> and becoming more sensible, aware and committed<sup>(21,23,31,35)</sup>.

Despite the initial suffering and shock caused by the therapy and the hospital environment, they adapted to the hospital routines<sup>(27,29)</sup>, sought information about the child’s illness<sup>(23,27,30)</sup>

and, over time, were stronger and able to keep company to the child in the hospital<sup>(27)</sup>. They pointed out the need to seek resources for treatment in other places, due to the scarcity of specialized home care<sup>(25)</sup>, and also demonstrated concern for maintaining the family routine<sup>(28,30)</sup> and adopting healthy life habits and attitudes<sup>(31)</sup> to support the child’s care.

## DISCUSSION

This review provided a synthesis of the experience of the father in the care given to the child with cancer, allowing a comprehensive description of this experience. The three categories elaborated demonstrate how the diagnosis of a child with cancer and the therapeutic process impact the father and affect their relationships and their physical and emotional health. This meta-synthesis also showed how fathers care for their sick child, with protection and a firm attitude, as well as their strategies for restoring normality and coping with the situation. All these factors are connected and influenced by masculinities, equally affected in this process.

The findings of this meta-synthesis are backed by other reviews addressing the psychosocial difficulties and demands of childhood cancer and its treatment<sup>(10)</sup> and the physical symptoms of stress and tension potentially related to the negative beliefs about this kind of cancer<sup>(12)</sup>. In common sense, cancer is seen as a “damned”, serious and life-threatening disease<sup>(9)</sup>. This conception along with ignorance about the disease contribute to the diagnosis being received as a shock and with anguish, revolt, guilt and fear of an early death, making the father feel powerless and unprepared due to the sensation of losing control of the situation. In addition, the way the father deals with his child’s illness is closely related to his masculinities, the central aspect of this meta-synthesis. The need for control over the body and the specificities of the masculine gender are hegemonic characteristics of masculine behaviors; thus, controlling the adversities of life, health, and their dependents is something expected from men so that they can be recognized as dominant, strong and virile<sup>(38)</sup>.

A narrative review of the literature<sup>(5)</sup> that aimed to identify the contributions of the father to the management of chronic health conditions in childhood corroborates the findings regarding the influence of masculinity in the father’s ability to deal with the child’s diagnosis and, consequently, in the care offered to the child. For some fathers of children with chronic diseases, stress was associated with the responsibilities and the need to keep a firm attitude, socially valued in male behaviors<sup>(5)</sup>. In this review<sup>(5)</sup>, most fathers failed to express feelings of sadness and vulnerability to friends, family, professionals and wife, which made them receive insufficient support for their needs.

However, this meta-synthesis showed that, despite the difficulty in exposing emotions, most of the fathers received adequate support from family members and health professionals and little support from co-workers. This divergence of results may be related to the negative beliefs and the emotional and social impact of cancer, which contribute to a greater mobilization of family and society.

It is important to highlight that the demystification of cancer is necessary, but it requires caution and adequate communication between health professionals, parents, families and society. It is possible to change beliefs and practices while meeting and respecting the worldviews of health professionals and of the group of parents<sup>(39)</sup>. However, we should not try to instill our conception into the culture of the other, instead we must detach from our conception so that the vision of the other about his own understanding find its space<sup>(39)</sup>. In this aspect, the health care team has an important role in promoting social support, by informing and assisting the father to obtain the necessary resources to deal with the illness. In general, in this meta-synthesis, the father demonstrated satisfaction with the support received by nurses, social workers and other members of the multi-professional health team.

A qualitative study<sup>(14)</sup> conducted with ninety couples who were biological parents of children with cancer supports the findings of this meta-synthesis regarding the repercussion of the child's cancer in the father's social interactions, especially the marital relationship. The authors pointed out that the couple's relationship is affected since the onset of the symptoms and the search for the health service, because, at that moment, the attention and concern turn to the sick child, which affects the couple's intimacy and sexuality<sup>(14)</sup>. The study highlighted the geographic, physical and affective distance between the partners caused by the separation required during the treatment of the child and by the stress related to the new responsibilities, the changing of roles in the family and the need to be always alert and watch the child. It is worth noting that, despite the damage to the intimacy of the couple after the illness, some spouses reported greater union and mutual commitment<sup>(14)</sup>.

Based on the findings of this meta-synthesis it is possible to infer that the way the father deals with the cancer of his child is also influenced by the social standards of defending gender stereotype with masculine actions. It is important to point out that the attributes and values shared by men and women change throughout history and contribute to the construction of the care provided to children, especially during their illness, since they are a set of interpretable symbols that influence attitudes and behaviors<sup>(39)</sup>. The results demonstrated the father's concern with his role as provider and protector of the family, a characteristic of a stereotype of hegemonic masculinity, which, consequently, characterizes them as people with difficulty expressing their emotions.

The studies analyzed demonstrated that fathers have a secondary position in the care of their children and receive different information and attention from health care professionals, who privileged mothers, reaffirming their role as primary caregivers. Another review<sup>(5)</sup> corroborated these findings, since the participants, fathers of children with chronic health conditions, received second-hand information and did not get attention from health professionals. This finding was not expressive in this meta-synthesis; however, it is relevant, since the lack of information contributes to the sensation of losing control of the situation, the fear of death and failure of the treatment, the non-adherence to treatment and difficulties in caring for the

child. Despite the social conception of gender, the role of the father in Western societies has been changing in recent years, especially after the insertion of women in working life, when new family arrangements emerged<sup>(1-2)</sup>. These modifications have contributed to the greater involvement of the father in the care of the sick child and adolescent, which was evidenced in this meta-synthesis.

The meta-synthesis showed that the father initially suffers with the negative repercussions of the child's illness, but, throughout the trajectory, he builds his experience seeking to restore normality in the family. Similar results were found in Cox's study<sup>(13)</sup>, which showed that both parents are impacted by the diagnosis of their children's cancer and both feel like they lost control of the situation and are powerless when faced with the disease, which leads them to seek normality and develop new ways of caring for the child.

The concept of normality varies culturally and is based on the beliefs shared by a particular group about the proper way for an individual to conduct his life in relation to the others<sup>(40)</sup>. When trying to recover normality in the family, the father tries to restructure the standards valued by society. For that, he develops strategies such as maintaining the family routine, adapting to hospital routines, adopting healthy eating habits and attitudes, seeking the support of the wife, the health professionals, friends and groups of parents and seeking comfort in religion. These attitudes resignify their lives and help them to learn the necessary care for the sick child. As the father inserts himself into the cultural context of health professionals and other parents who deal with similar situations, he acquires new knowledge and practices of these groups, which contributes to the construction of care.

In this aspect, this meta-synthesis showed the importance and effectiveness of groups of parents in similar contexts as a support strategy. It should be emphasized that the nurse can promote these meetings and develop other actions that stimulate socialization and exchange of experiences, to broaden and strengthen the social network of these individuals.

In general, despite the suffering, the fathers face positive experiences that contribute to their empowerment. The child's illness and the changes resulting from this process promote transformations in their worldview, behavior and, above all, in male paradigms and in the re-evaluation of symbolic values, so that they begin to value the relationships with their wives and children and the importance of living at the present. These results are in agreement with another review<sup>(11)</sup>, in which parents reported positive facts related to this experience, such as the strengthening of family bonds, closer relationship with the child, development of maternal and paternal abilities, and changes in life values.

This meta-synthesis analyzed how the cancer of the child leads men to transforming the practices attributed to their gender. On the one hand, there is the representation of masculine identity, which is linked to the codes of honor that are culturally promoted by men who value hegemonic behavior (the father as provider of the house, worker, virile and dominant). And, on the other hand, there is a rearrangement of roles, transcending these values and placing men in roles considered by

Western culture as feminine. This way, the father, in opposition to an image of more traditional masculinity, is placed in a context of partnership, not antagonistic to female behavior, but incorporating some actions historically assigned to the mother, such as caring for children and for the house.

Another modification demonstrated in this meta-synthesis was the strengthening of faith and beliefs of the father, who searches for meanings, consolation and relief of pain and of the fear of death in religion and spirituality. Religion is a system of symbols capable of establishing powerful moods and motivations by formulating general conceptions of the world, the self and the relation between them<sup>(39)</sup>. Thus, in addition to helping the father to find comfort and assign meanings and seek explanations for the child's illness, religion and spirituality also stimulate him to overcome adversity. In this context, the importance of spiritual care is emphasized, since it can help the father to comprehend and accept the disease and encourage him to overcome fears and adverse situations.

### Limitations of the study

In order to provide a basis for the investigation of the care provided by the father to the child with cancer, a broad perspective of this experience was adopted, including studies developed with fathers of children diagnosed with cancer, in different phases of treatment, of different nationalities, ages and with different father figures. However, the influence of the different characteristics of the father and of the cancer on the experience of father care was not assessed. This analysis could have broadened the understanding of the contextual specificities of the experiences, due to the few characteristics of parents and children described in the studies, such as type of neoplasia and phases of the disease, with different treatments, prognoses and repercussions. This meta-synthesis was conducted with rigor, and the quality of the studies included was objectively evaluated through the CASP checklist. Despite the inclusion of studies with some deficiency of methodological rigor, their findings brought wealth of information and complexity to the synthesis. Evaluating the impact of excluding inadequately reported studies from the final meta-synthesis reflects the strength of the resulting synthesis<sup>(17)</sup>.

### Contributions to the nursing area

The results of this meta-synthesis open perspectives for future studies and point out gaps, such as the need for other

investigations to focus on the father figure and seek to assess the experience of other figures who assume the father role, such as stepfather, uncle and grandfather, in nontraditional family configurations. Other phases of the disease, in addition to diagnosis and treatment, also deserve to be investigated, and data should be analyzed based on anthropological perspectives on culture and masculinities.

This meta-synthesis contributes to guide the delivery of qualified care to the father of the child or adolescent with cancer, in order to strengthen and assist him in this care, and also to achieve greater effectiveness of therapy and to meet the family demands for the inclusion of the disease. Health professionals, especially nurses, can have an important role for the demystification of cancer and for helping fathers to obtain the necessary resources for their active engagement in the care of the child, considering his masculine identities.

### FINAL CONSIDERATIONS

This research provided the synthesis and interpretation of the knowledge published in the last 20 years about the experience of the father in the care of the child or the adolescent with cancer. This is a complex experience, mainly influenced by masculinities originated from a culture that define identities and roles for men. Childhood cancer was represented as a serious and unexpected illness for the father, with strong repercussions in his daily life and generating changes in his relationships and way of life. The attitudes and postures assumed in the face of illness and of the need to care for the child were influenced by the culture and the social role assigned to the father. To deal with the new situation, he sought strategies, relying on the need to restore normality, and shifted between hegemonic masculine behaviors and practices considered as feminine in Western culture, building an identity of partnership.

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