Child cancer recurrence: a study about the mother's experience¹

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Abstract: A relapse in pediatric oncology is experienced by mothers as a critical and threatening event. The diagnosis of the disease relapse implies in a new beginning of the treatment and the potential of failure and child loss. This study aimed to understand the mother's experience of her child's treatment phase. In this qualitative design study, a 39-year old mother participated in a semi-structured interview regarding aspects of her child's treatment trajectory, the resonances in family relationships, and the confrontation of the possibility of death. A thematic content analysis was used to analyze the data. The results indicated themes related to the attribution of meaning to the experience, the perception of injuries in the relationship scope, and a constant threat of loss. Understanding the mother's experiences can favor the planning of psychological interventions that support the attribution of a new meaning to the sickness-health process, as well as provide a preparation for the family regarding end-of-life care.

Keywords: neoplasms, recurrence, family, grief, Psychology.

Introduction

Childhood cancer is understood as the set of diseases in which there is a cellular growth and chaotic multiplication in several parts of the body (Brasil, 2008). Although it is a rare disease, which corresponds to 1% to 3% of malignant neoplasms in the general population, pediatric cancer represents the second cause of mortality among children and adolescents from 1 to 19 years old in all regions of Brazil. Currently, it is the first cause of death by disease in childhood, which reinforces the need for more studies and an improvement in health services regarding oncological care (Brasil, 2014).

With the advance of medical technology, diagnosis and methods of treatment of childhood cancer have been improved, and the possibility of healing became a reality. To increase healing rates, early diagnosis and timely care are essential measures to determine the extension and the quality of survival (Menezes, Passareli, Drude, Santos, & Valle, 2007; Pritchard-Jones et al., 2013).

Despite continued efforts and recent advances, the attention to pediatric oncology continues to be permeated by constraints and, as a general rule, the treatment entails the family – here understood as the care unit –into stress and

threat experiences. The diagnosis of cancer is experienced under the stigma of "fatal disease", still present in the collective imagination, which imposes challenges to face the treatment period (Valle, 1997). Throughout the cancer care process, the family is faced with several specific demands of treatment (medical consultations, examinations, hospitalization) that need to be aligned to aspects of professional and social life (Long & Marsland, 2011). Care with the healthy brothers is also a focus of attention, primarily by the impact of shared experience of illness perceived in its development process, notably in the social and school areas (Cheron & Pettengill, 2011). Another important aspect associated with the change of family routine are the changes in roles and responsibilities in family functioning, in addition to the impact on parental marital relationship (Da Silva, Jacob, & Nascimento, 2010; Morelli, Scorsolini-Comin, & Santos, 2013), and the ability to adapt the family due to the diagnosis is also an important factor to face the child in treatment (Long & Marsland, 2011).

The situation of disease recurrence is defined as the reappearance of cancer after a period of remission (DeVita Jr., Lawrence, Rosenberg, DePinho, & Weinberg, 2011). This phase of treatment usually comes with feelings of frustration, high levels of anxiety-state and stress in the parents, as well as a continuing uncertainty about the survival of the child (Grootenhuis & Last, 1997; Wijnberg-Williams, Kamps, Klip & Hoekstra-Weebers, 2006). The relapse diagnosis demands a reorganization of the family context to deal with their fears and position themselves in relation to the new treatment protocol to be started (Arruda, 2013; Arruda-Colli, Perina, & Santos, 2015; Vivar, Canga, Canga, & Arantzamendi, 2009).

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Hinds et al. (1996) conducted a prospective study to explore the process experienced by the parents before the first cancer recurrence of their children and map the coping strategies used. Parents highlighted their efforts to overcome the initial impact of the communication of the relapse and make decisions about treatment, considering limits, risks, and the feeling of helplessness due to the emerging situation. The possibility of death would strongly oppose to the desire of the treatment effectiveness, arousing experiences of anticipated grief, being the search for security, the strengthening of the sense of control, and the communication with the health team important health coping strategies used in this context.

The oscillation between the hope of the child's preservation and the tangible threat of death seem to influence the search for the cure, the decisions related to the treatment and the expectations regarding the child's prognostics (De Graves & Aranda, 2008; Espíndula & Valle, 2002; Hockenberry-Eaton, Dilorio, & Kemp, 1995). Preparing for the loss emerged as a coping strategy and acquisition of sense of control, as well as the search for normality maintenance and the focus on life in the present moment, the hyper surveillance, and the search for information to increase the sense of security and alleviate the fear of a new relapse. Understanding the fears and hopes experienced by families in this critical time of treatment may assist in the identification of challenges to be faced with the support of the health team, as well as in promoting open communication, aiming at encouraging the coping status (De Graves & Aranda, 2008).

Literature shows that the losses experienced in the process of treatment, the possibility of therapeutic failure, and therefore of early loss of the child can lead to the experience of anticipated mourning (Cardoso & Santos, 2013; Menezes et al., 2007). Anticipatory grief can be understood as an intense emotional expression, which involves the process of grief, coping strategies and psychological reorganization on the imminent loss of a loved one, and the recognition of other associated losses permeated by the need to deal with death uncertainty and the preparation for the loss, often contrasting with the hope (Al-Gamal & Long, 2010; Hottensen, 2010).

In a comparative study of the experience of early mourning performed with 1,040 parents of children with cancer from Jordan, few parents reported to be at peace with themselves and with their living situation (Al-Gamal & Long, 2010). The authors highlighted that symptoms of despair, hopelessness and worthlessness were most intense in the experience of parents of newly diagnosed children than those who performed the treatment at least for six months. The authors defended the adoption of health care actions that involve discussing with the parents the feelings raised by the illness of their child so the possibilities for action and tackling the challenges posed by childhood cancer are expanded.

The illness of a loved one brings changes to the family unit as a whole, but the psychosocial interventions are mostly outlined with a focus on the child or the

caregiver-family member. Considering the emotional demands of the family and the patient-caregiver relationship is important in the process of making sense of the sickness-health-care process, but few studies focus on the possibilities of interventions directed at both (Hinds, Feetham, Kelly, & Nolan, 2012). Providing support to the care unit for the management of stress and improved family functioning can promote the re-signification of the existential issues related to the illness, to life and death (Carvalho, 2002; Oliveira Santos, & Mastropietro, 2010; Robb & Hanson-Abromeit, 2014).

Considering the lack of literature that addresses the psychosocial aspects faced by the family during the experience of pediatric oncological disease recurrence (Espíndula & Valle, 2002; Silva Teles, & Valle, 2005), and also the need for more studies that allow to capture the experience of the caregivers, especially at the time of worsening of the disease, this study aimed to understand the maternal experience during this phase of the child's treatment.

Method

This is a descriptive and exploratory study, with a cross-sectional design. It is characterized as a clinical-qualitative research, chosen as methodological strategy that provides access to the senses and meanings assigned to phenomena associated with the health-disease process (Turato, 2003). The phenomenology was used as a theoretical foundation, allowing to investigate the experiences of a family caregiver before the child's cancer relapse, paying attention to the emotional aspects involved and the meanings of life and death engendered by the critical situation. As proposed by Husserl, we sought to return to the things themselves, in direct and spontaneous contact with the experience, without the use of empirical mediators to access the essence of human life and its subjectivity (Forghieri, 1993; Goto, 2008).

Participant

During a period of one year (July 2011-June 2012), relapse cases of children aged between 5 and 12 years who were being treated in the health service unit were identified. The inclusion criteria for the participation in the study were: having a child in outpatient or inpatient treatment regimen in the hospital unit; being responsible for the child in treatment of cancer relapse and presenting herself to the health service unit as the main caregiver; presenting coherent and spatial and time-driven speech. The exclusion criterion was the presence of losses in the sphere of understanding and/or communication that could interfere the implementation of the interview.

The participant was selected from a *corpus* consisting of eight dyads who agreed to collaborate and who have completed their participation in the study (Arruda, 2013; Arruda-Colli, Perina, & Santos, 2015). The mother chosen for this study proved to be a key informant, as she allowed

us to outline the situation investigated in this study in great detail.

Location

The survey was conducted in a national reference center for cancer treatment for children and adolescents, located in a large city in the Southeast region of the country.

Procedures

To meet the objectives of the study, a semi-structured interview was conducted in a private place inside the hospital institution, with an approximate duration of 60 minutes. So that the participant could freely express her perceptions on the issue investigated, a script was prepared for the interview, covering aspects of the therapeutic trajectory of the child, resonances in family relationships, and facing the possibility of death. The interview was guided by the following main issues: (1) Talk about the development of your child, since his/her birth until today; (2) Tell me how was the illness and treatment process of your child; (3) How are the family relationship and the family routine?

The participant did not agree to the audio recording of the interview, saying she would be more comfortable in the situation without using the recorder, but allowed the researcher to take notes during the conversation and showed to be cooperative throughout the time. Immediately upon termination, the memory transcription of the material was performed, seeking to preserve the report as faithful as possible. That material was later submitted to a theme content analysis (Triviños, 1992; Turato, 2003). Initially the pre-analysis was performed, making a floating reading of the full content of the interview. Then the units of meaning were identified by semantic approach. This step could identify relapses and inflection points in the accounts obtained about the experience lived by the participating mother in relation to cancer relapse. Finalizing the material organization process, the units identified were grouped into thematic categories, and discussed based on the literature researched. After a thorough analysis, we outlined the main elements that emerged from the maternal reports, as well as those considered as potential markers of the family caregiver needs that must be considered in the proposed intervention program considering the psychological counseling aimed at parents of children in treatment for cancer relapse.

Ethical Care

It is important to stress that ethical care outlined in CNS resolution no. 466/2012 of the National Health Council, which regulates research involving human beings in Brazil (Brazil, 2012), since the preparation of the project and its approval by the Research Ethics Committee of the institution (Protocol 05/2010), as well as on the collection and systematization of data were

taken. Fictitious names were assigned to the participant and their family members to protect their identities and to preserve anonymity.

Results

The participant, herein referred to as Paula, is 39 years old, married to Paul and mother of two children: Patricia, 12 years old and Pablo, 7 years old. The contact with this mother was established during the hospitalization of the son, which occurred after the first cycle of chemotherapy, as part of a treatment of recurrent clinical stage IV neuroblastoma.

After careful reading of the research corpus, three thematic categories that allowed us to limit the maternal experiences of cancer relapse of the child emerged: "Faced with the imponderable and seeking to make sense of the experience", "Facing losses on the relational sphere", "Experiencing the relapse of the son with the perspective of death".

Facing the imponderable and seeking to make sense of the experience

To address the issue of diagnosis, the mother expressed about the initial media reactions, as well as their frustrations on what she called "the reality of treatment".

It was awful! We never imagined that Pablo could have cancer ... And we thought that it would be treated and we would be free! And we're here until today...

Before the increased sense of vulnerability and lack of control that she experienced with the illness of her son, Paula recovered her children's life story, including the planning and the desire that permeated the pregnancy, as well as the stressful events experienced, seeking to obtain explanations that could give meaning to the occurrence of cancer in her son.

He was very welcome and awaited for the whole family. And that's what makes me ask: "Why a cancer?". I never imagined that a child so desired would have so many issues ...

In this excerpt we can observe the maternal feelings of bewilderment with the initial diagnosis that mingle with the finding of the paradoxical emotional experiences provided by the childhood cancer: between love and the fear of loss, between the son she protected and the vulnerable son.

The absence of full explanations, which could give meaning to the illness and calm the anxiety aroused by the contact with the unknown seems to have created a huge void of meanings. Similarly, understanding the suffering of the child during the treatment (which involved chemotherapy, radiotherapy and surgery) seemed to awaken his mother conflicting feelings in relation to the risks involved in treatment and their desire to control the threatening situation.

The treatment is very harsh, it is very exhausting, too much pain. And the BMT [Bone Marrow Translplant] is too risky for Pablo because he had fungus, it is complicated.

But he feels the difference, feel that issue that "he cannot". I'm going to deprive him of the other foods too? I take care, but I think a little won't hurt ...

From the mother's reports, we can see the impact of the diagnostic communication and the invasive procedures on the composition of meanings and senses. Data reinforces the importance to pay attention to the quality of the communication among team-patient-family, as well as to the feelings and emotions arising, to encourage the caregiver to face the course of treatment.

Facing losses on the relational sphere

Due to the oncological diagnosis of the youngest son, the family moved from the Midwest region of the country to the countryside of the state of São Paulo, in search of better treatment resources. Such change brought consequences for the family routine, with direct impact in various psychosocial aspects, such as ditching from the social network of support, of work, and of family bonds.

The money weighs, but what weighs more is the relationship, because if one does not support the other, there's no way ...

The relationship established with other patients and their families along the hospital coexistence was recurrent in the mother speech, and constitutes another significant source of social support. Paula valued the perceived social support and empathy established, despite the high emotional costs experienced in clinical worsening situations of other children, which seemed to remind her of the tangible possibility of the death of the other, as well as of her own son.

We met other kids who underwent the treatment along with Pablo, which began with him, but died. And it's hard because we become very close here. One knows what's going on with the other, keeps cheering for each other, but suffers along as well.

The value assigned to the union as a strengthening bond to face the battle of the treatment of her son is observed, as well as a veiled desire to be cared for, with all the conflicts that such situation provides. The prolonged absorption in tasks related to the care of the child also had an impact on the marital relationship, leading to a friction in the couple's life as a result of the decreased sex drive.

He [her husband] must understand me as a mother... You can't just express desire while seeing your son suffer. The participant also highlighted the implications of the illness situation of Pablo in the care she provides to her healthy daughter, recognizing the difficulties of dividing the focus of her attention, totally dedicated to the son's health care.

It is difficult to share the time and care between the two [children]. Patricia is jealous, she also wants us close, and ends up not having much... Because this is a treatment that requires a lot of care, attention, cleaning and feeding care ... She ends up without us ... We try, but there's no way ...

This report highlights the awareness that the balanced division of care and attention among the kids was hindered after Pablo's disease, which leads to facing the negative reactions of the healthy daughter. It seems to amplify latent feelings of guilt and helplessness, enhancing her perception of failure as a mother. Socially, the mother role is commonly associated with caring for their offspring and protecting them against the misfortunes of life. In this sense, both the illness of the child as the perceived impact on the development of the healthy daughter seem to arise a feeling of failure in performing the maternal role.

Experiencing the relapse of the son with the perspective of death

The diagnosis of cancer relapse is experienced as a rupture of the maternal projections in relation to the temporality of healing and family reorganization. The recurrence demands re-adjustment, which requires a repositioning of the patient and the family member in the new beginning of the treatment, denoted as fighting "a new battle for life".

Then, when we think we will ... we were going home and re-organize ourselves, comes another strike. Do you think we can handle it? He stayed five months off therapy and now we will start it over.

The relapse referred the mother to the initial period of research and diagnosis, however it involved greater affective mobilization. The uncertainty fueled by skepticism about the success of the treatment was patent in some parts of the speech, leading to feelings of hopelessness and helplessness to reflect on the possibilities of care and her position as a mother.

We are going to give him everything, do everything, but deep down I know it's no use. I do my part as best as I can, because I don't want to feel guilty. I want to make sure I did everything in my power and I know I am.

Paula demonstrates the desire to be able to reach the end of their fight with the certainty of having "fought the good fight", i.e. with the feeling of having done everything in her power to give her son appropriate treatment conditions and a dignified quality survival. However, amid the angst on the severity of the child's health, feelings of helplessness and the tendency to self-blaming when facing her lack of control over the situation remain dormant.

On the anticipatory experience of the temporality of death, Paula reflected on values and ways of connecting with her son, and related them to the care process. She mentioned the transitory character of life, the issue of the uncertain time of staying in this world, and the appreciation of living in the present, overlooking the need to organize to welcome the experience of finitude.

In the initial diagnosis, I protected him too much. No one could touch Pablo. He stayed in his room and we avoided touching him to the fullest. Kissing him, then, no way, because the doctor said that it could contaminate him. Now, in the second treatment, I feel like doing everything today, as if there won't be enough time if we leave it for later... I tell Paul to be prepared. We need to be prepared.

In this bleak scenario, death infiltrates in maternal reports sometimes in an insidious way, and sometimes clearly and explicitly. Paula claims to be prioritizing the present instead of any future plans. The threat of loss is intense and compelling, being experienced sometimes with awe, sometimes as a possibility to obtain a tangible relief for the suffering experienced.

But I'd rather he would die than have to go through this again. Not that I want to, on the contrary, but I know how difficult it is to treat it. I don't want him to suffer, to get too bad. It's a very big threat.

The scenario of relapse seems to work as an operator that brings new parameters for the mother's assessment on the life of the child and his winding route of treatment. It is also a time to reset expectations and future projects, especially when uncertainty stands as opposed to the viability of the cure. In this sense, the abbreviation of suffering arises as a critical to the experience lived by the mother, conducting her way to perceive and face the need of a new treatment.

Discussion

In this study, it was possible to notice that the diagnosis of Pablo was accompanied by maternal feelings of vulnerability and lack of control over the vital events which appear to have been enhanced by the news of the relapse. Despite the difficulties highlighted in the process of acceptance, the resumption of the treatment resulted in the reorganization of the family dynamics and the strengthening of the affective bonds. The family seemed to be in the process of preparing the initial communication of the recurrence, seeking to regroup to face the new step of treatment, using the affectionate closeness and the strengthening of the bonds of union as sources of support and security to adapt to the new situation emerging (Menezes et al., 2007).

Considering the family crisis situation, the participant showed having a perception of the relationship between the illness and the impact on the family dynamics, demonstrating her concern for the development of the healthy daughter and with the impact on the marital relationship. Such maternal concern is consistent with recent studies, both related to stressing events faced by the couple and their implications for the marital and parental dynamics (Da Silva et al., 2010; Wijnberg-Williams et al., 2006), as in the sense of family union strengthened by the need to face the treatment period (Morelli et al., 2013). The impact of the illness in the development of the healthy siblings has also been a focus in the literature of the area, and the provisioning of emotional care and the construction of an open dialog to facilitate the preparation of the resulting stress was recommended (Cheron & Pettengill, 2011).

The diagnosis of relapse was accompanied by feelings of sadness and frustration of expectations, which increase the sense of threat and the experiences of helplessness, vulnerability, and lack of control over the events. In a similar way to the study of De Graves and Aranda (2008), the oscillation between the hope of healing, with actions directed to treatment and overcoming adversity, and the existential threat imposed by the possibility of death, strengthened by the experience of failure in the first treatment, of the fatal outcome of the children taking the same treatment and the uncertainties concerning the prognosis, was perceived. Thus, the relapse of the disease is also characterized as a critical period that potentially makes the experiences of loss closer to consciousness, deserving specialized attention to emotional care (Arruda, 2013; Arruda-Colli et al., 2015).

The period of cancer relapse treatment was marked by the sense of a new beginning, permeated by uncertainties and memories of the first treatment. The contact with the known part of the initial treatment was opposed to the unknown part represented by the new condition of the disease and its new treatment possibilities. Forghieri (1993) argues that, even before what is "known", uncertainty is revealed while opening to the future, its risks and possibilities requiring the confrontation with the difficulties and constraints in search of the existential health. Consistent with what is described in the literature (Carvalho, 2002; Espíndula & Valle, 2002; Hinds et al., 1996), Paula shared similar concerns to the ones in the first treatment, and using the experiences of the past as support for the construction of meaning in the present, since the future is uncertain, shady or inscrutable (Valle, 1997).

The idea of death emerged in the maternal speech with strong meaning of failure, which seems to hinder its development. However, in contrast, in some moments it emerged as possible breath, acquiring a meaning of relief for the end of the suffering that it would bring about the current stage of illness. The mother also expressed being ready to inhabit a future that she did not choose for herself, but it did not seem so unpredictable and unknown as before. The impossibility of choice and guidance towards the future brought

about by serious illness and, in this study, compounded by the presence of relapse, seems to have amplified the maternal feelings of inability to care for her child, evoking experiences of helplessness which hamper the provision of meaning to existence (Valle, 1997). The obtained data corroborate the importance of widening the care in pediatric oncology beyond the individual scope, also considering the interdependence of the natural experiences of family members in the planning of psychological support interventions (Hinds et al.., 2012; Oliveira et al., 2010; Robb & Hanson-Abromeit, 2014).

Final Remarks

This study enabled us to explore the experiences of a mother facing her son's cancer relapse, covering aspects of the confrontation of the course of treatment of a child, the resonances in family relationships, and the confrontation with the possibility of imminent death. It is assumed that longitudinal randomized studies can contribute to better understand maternal experiences in this critical period of the children's treatment. Despite the cross-sectional design used in this study, the findings obtained contribute to the understanding of the maternal experience in the situation of cancer recurrence.

The inability to rely on the audio records can also be considered a limitation of this study. However, considering

the delicate nature of the subject under investigation, which deals with people in a moment of intense pain due to the worsening of the children's medical condition, it is essential to understand the refusal of the participant to allow for the recording due to the meanings possibly attributed to the recorder and its implications for the conduct of the interview. Respecting the limits imposed by the mother and to preserve her emotional comfort, measures have been taken to minimize the influence of disturbing factors that could compromise the collection and analysis of data through the use of notes recorded throughout the interview and a transcript of the interview in full immediately after its completion.

In this sense, the results highlight possibilities for the health care professional to take a sensitive approach to the needs of the family and can assist in the planning of psychological interventions that promote ways of handling the peculiarities of the disease and its psychosocial resonances. We should pay attention to the quality of the communication in times of diagnosis and critical situations in the course of illness, which becomes essential to promote the family organization to face the situation and the integral care to cancer patients. In this perspective, further studies are needed to explore the interventions that can effectively contribute to improving family-centered care.

A recidiva do câncer pediátrico: um estudo sobre a experiência materna

Resumo: A recidiva em oncologia pediátrica é experienciada pelas mães como um evento crítico e ameaçador. O diagnóstico da recaída da doença implica a retomada do tratamento e o confronto com a possibilidade de fracasso terapêutico e perda do filho. Este estudo teve por objetivo compreender a experiência materna nessa fase do tratamento do filho. Neste estudo de abordagem qualitativa, uma mãe de 39 anos participou de uma entrevista semiestruturada envolvendo aspectos do percurso terapêutico de seu filho, ressonâncias nas relações familiares e confronto com a possibilidade de morte. Os dados foram analisados por meio da análise de conteúdo temática. Os resultados evidenciaram temáticas relacionadas à atribuição de sentido à experiência, percepção de prejuízos na esfera relacional e constante ameaça da perda. Compreender as vivências maternas pode favorecer o planejamento de intervenções psicológicas que auxiliam a ressignificação do processo saúde-doença e preparam a família para o cuidado no final de vida.

Palavras-chave: neoplasias, recidiva, família, luto, Psicologia.

La récidive du cancer pédiatrique: une étude sur l'expérience maternelle

Résumé: La récidive en Oncologie Pédiatrique est expérimentée par les mères comme un événement critique et menaçant. Le diagnostic de la récidive implique la reprise du traitement et la possibilité de faire face à un échec thérapeutique et à la perte de leurs enfants. L'étude a été réalisée dans le but de comprendre l'expérience maternelle à cette étape du traitement de l'enfant. Dans cette étude qualitative, une mère de 39 ans a participé à un entretien semi-structuré qui couvrait les aspects des voies thérapeutiques de son enfant, leur impact dans les relations familiales et la possibilité faire face à la mort de l'enfant. Les résultats ont été analysés en utilisant une analyse de contenu thématique, et ont révélé des difficultés liés à l'attribution de sens à l'expérience, la perception de la récidive par la sphère familiale et la menace constante de la perte. Comprendre les expériences maternelles peut favoriser la planification des interventions psychosociales mises en place pour encadrer le processus santé-maladie et préparent la famille pour l'expérience de fin de vie.

Mots-clés: neoplasmes, récurrence, famille, deuil, Psychologie.

La recurrencia de cáncer pediátrico: un estudio acerca de la experiencia materna

Resumen: La recurrencia en oncología pediátrica es experimentada por las madres como un evento crítico y amenazante. El diagnóstico de la recurrencia de la enfermedad implica en recomenzar el tratamiento y enfrentar la posibilidad de fracaso terapéutico y la pérdida del hijo. Este estudio buscó comprender la experiencia materna de esa etapa de tratamiento del niño. En este estudio cualitativo, una madre de 39 años participó de una entrevista semiestructurada involucrando aspectos del recorrido terapéutico de su hijo, resonancias en las relaciones familiares y confronto con la posibilidad de muerte. Los datos fueron analizados mediante el análisis de contenido temático. Los resultados revelaron asuntos relacionados con la atribución de significado a la experiencia, percepciones de perjuicios en el ámbito relacional y la constante amenaza de la pérdida. Entender las experiencias maternas puede facilitar la planificación de las intervenciones psicológicas que ayudan la resignificación del proceso de salud-enfermedad y preparan a la familia para el cuidado en el final de la vida.

Palabras clave: neoplasias, recurrencia, familia, luto, Psicología.

References

- Al-Gamal, E., & Long, T. (2010). Anticipatory grieving among parents living with a child with cancer. *Journal of Advanced Nursing*, 66(9), 1980-1990. doi: 10.1111/j.1365-2648.2010.05381.x
- Arruda, M. N. F. (2013). A recidiva do câncer pediátrico: vivências da criança e do cuidador-familiar (Master's dissertation). Faculdade de Filosofia, Ciências e Letras de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto.
- Arruda-Colli, M. N. F., Perina, E. M., & Santos, M. A. (2015). Experiences of Brazilian children and family caregivers facing the recurrence of cancer. *European Journal of Oncology Nursing*, *19*(5), 458-464. doi: http://dx.doi.org/10.1016/j.ejon.2015.02.004.
- Brasil. Ministério da Saúde. (2008). Câncer da criança e adolescente no Brasil: dados dos registros de base populacional e de mortalidade. Rio de Janeiro, RJ: Instituto Nacional do Câncer.
- Brasil. Conselho Nacional de Saúde. (2012). *Resolução nº 466, de 12 de dezembro de 2012*. Brasília, DF. Retrieved from http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf
- Brasil. Ministério da Saúde. (2014). *Estimativas 2014:* incidência de câncer no Brasil. Rio de Janeiro, RJ: Instituto Nacional do Câncer.
- Cardoso, E. A. O., & Santos, M. A. (2013). Luto antecipatório em pacientes com indicação para o transplante de células-tronco hematopoéticas. *Ciência & Saúde Coletiva*, 18(9), 2567-2575. Retrieved from http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232013000900011&lng=en&tlng=pt. 10.1590/S1413-81232013000900011.
- Carvalho, M. M. (2002). Psico-oncologia: história, características e desafios. *Psicologia USP*, *13*(1), 151-166. doi: 10.1590/S0103-65642002000100008
- Cheron, M. F. L., & Pettengill, M. A. M. (2011). Experiência do irmão sadio em relação à doença e hospitalização do irmão com câncer. *Acta Paulista de Enfermagem*, *24*(5), 605-610. Retrieved from http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002011000500002&lng=en&tlng=pt. 10.1590/S0103-21002011000500002.

- Da Silva, F. M., Jacob, E., & Nascimento, L. C. (2010). Impact of childhood cancer on parents' relationships: An integrative review. *Journal of Nursing Scholarship*, 42(3), 250-261. doi: 10.1111/j.1547-5069.2010.01360.x
- De Graves, S., & Aranda, S. (2008). Living with hope and fear: The uncertainty of childhood cancer after relapse. *Cancer Nursing*, *31*(4), 292-301. doi: 10.1097/01. NCC.0000305745.41582.73
- DeVita Jr., V. T., Lawrence, T. S., Rosenberg, S. A., DePinho, R. A., & Weinberg, R. A. (Eds.). (2011). *Cancer: Principles and practice of oncology*. Philadelphia, PA: Lippincott Williams &Wilkins.
- Espíndula, J. A., & Valle, E. R. M. (2002). Experiência materna diante da iminência de morte do filho com recidiva de câncer. *Pediatria Moderna*, *38*(5), 188-194. Retrieved from http://www.moreirajr.com.br/revistas. asp?fase=r003&id materia=1916
- Forghieri, Y. C. (1993). *Psicologia fenomenológica:* fundamentos, métodos e pesquisas. São Paulo, SP: Pioneira.
- Goto, T. A. (2008). *Introdução à psicologia fenomenológica:* a nova psicologia de Edmundo Husserl. São Paulo, SP: Paulus.
- Grootenhuis, M. A., & Last, B. F. (1997). Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology*, *6*(2), 115-128. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11462229
- Hinds, P. S., Birenbaum, L. K., Clarke-Steffen, L., Quargnenti, A., Kreissman, S., Kazak, A., . . . Wilimas, J. (1996). Coming to terms: Parents' response to a first cancer recurrence in their child. *Nursing Research*, 45(3), 148-153. Retrieved from http://www.ncbi.nlm. nih.gov/pubmed/8637795
- Hinds, P. S., Feetham, S. L., Kelly, K. P., & Nolan, M. T. (2012). "The family factor": Knowledge needed in oncology research. *Cancer Nursing*, 35(1), 1-2. doi: 10.1097/NCC.0b013e31823b561f
- Hockenberry-Eaton, M., Dilorio, C., & Kemp, V. (1995). The relationship of illness longevity and relapse with self-perception, cancer stressors, anxiety, and coping

- strategies in children with cancer. *Journal of Pediatric Oncology Nursing Official Journal of the Association of Pediatric Oncology Nurses*, 12(2), 71-79. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/7612200
- Hottensen, D. (2010). Anticipatory grief in patients with cancer. *Clinical Journal of Oncology Nursing*, 14(1), 106-107. doi: 10.1188/10.CJON.106-107
- Long, K. A., & Marsland, A. L. (2011). Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Review*, 14(1), 57-88. doi: 10.1007/s10567-010-0082-z
- Menezes, C. N. B., Passareli, P. M., Drude, F. S., Santos, M. A., & Valle, E. R. M. (2007). Câncer infantil: Organização familiar e doença. *Revista Mal-Estar e Subjetividade*, 7(1), 191-210. Retrieved from http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1518-61482007000100011&lng=pt&nrm=iso&tlng=pt
- Morelli, A. B., Scorsolini-Comin, F., & Santos, M. A. (2013). Impacto da morte do filho sobre a conjugalidade dos pais. *Ciência & Saúde Coletiva, 18*(9), 2711-2720. Retrieved from http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232013000900026&Ing=en&tlng=pt. 10.1590/S1413-81232013000900026.
- Oliveira, E. A., Santos, M. A., & Mastropietro, A. P. (2010). Apoio psicológico na terminalidade: Ensinamentos para a vida. *Psicologia em Estudo*, *15*(2), 235-244. Retrieved from http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-73722010000200002&lng=en&tlng=pt. 10.1590/S1413-73722010000200002.
- Pritchard-Jones, K., Pieters, R., Reaman, G. H., Hjorth, L., Downie, P., Calaminus, G., . . . Steliarova-Foucher, E. (2013). Sustaining innovation and improvement in the treatment of childhood cancer: Lessons from highincome countries. *Lancet Oncology*, 14(3), 95-104. doi: 10.1016/S1470-2045(13)70010-X

- Robb, S. L., & Hanson-Abromeit, D. (2014). Review of supportive care interventions to manage distress in young children with cancer and parents. *Cancer Nursing*, *37*(4), E1-E26. doi: 10.1097/NCC.000000000000000095
- Silva, G. M., Teles, S. S., & Valle, E. R. M. (2005). Estudo sobre as publicações brasileiras relacionadas a aspectos psicossociais do câncer infantil: período de 1998 a 2004. *Revista Brasileira de Cancerologia*, *51*(3), 253-261. Retrieved from http://www.inca.gov.br/rbc/n_51/v03/pdf/revisao4.pdf
- Triviños, A. N. S. (1992). *Introdução à pesquisa em ciências sociais: a pesquisa qualitativa em educação*. São Paulo, SP: Atlas.
- Turato, E. R. (2003). Tratado de metodologia da pesquisa clínico-qualitativa: construção teórico-epistemológica, discussão comparada e aplicação nas áreas da saúde e humanas. Petrópolis, RJ: Vozes.
- Valle, E. R. M. (1997). *Câncer infantil: compreender e agir*. Campinas, SP: Psy.
- Vivar, C. G., Canga, N., Canga, A. D., & Arantzamendi, M. (2009). The psychosocial impact of recurrence on cancer survivors and family members: A narrative review. *Journal of Advanced Nursing*, 65(4), 724-736. doi: 10.1111/j.1365-2648.2008.04939.x
- Wijnberg-Williams, B. J., Kamps, W. A., Klip, E. C., & Hoekstra-Weebers, J. E. H. M. (2006). Psychological adjustment of parents of pediatric cancer patients revisited: Five years later. *Psycho-Oncology*, 15(1), 1-8. doi: 10.1002/pon.927

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