

CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

INTEGRATIVE REVIEW OF THE LITERATURE

DOI: 10.9789/2175-5361.rpcf.v14.11575

QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH CANCER: AN INTEGRATIVE REVIEW

*Qualidade de vida das mães de criança com câncer: revisão integrativa**Calidad de vida de madres de niños con cáncer: una revisión integradora***Rosana Fidelis Coelho Vieira¹** **Fátima Helena do Espírito Santo¹** **Rosângela da Silva Santos²** **Wanderson Alves Ribeiro¹** **Cristiane da Silva Varejão¹** **Arthur Moreira da Silva Neto²** 

ABSTRACT

Objective: to analyze the scientific evidence in the literature on the quality of life of mothers of children with cancer. **Method:** integrative literature review, carried out in LILACS, Medical Subject Headings (MeSH), CINAHL databases, in English, Portuguese and Spanish, using controlled descriptors in Portuguese: “quality of life”, “cancer”, “family” and “nursing” and their versions in English and Spanish in the time frame from 2010 to 2020. **Results:** twelve complete studies were selected for interpretative analysis that allowed the identification of five categories: affected domains; socio-demographic data and quality of life; spirituality and positive thinking; readapting the way of living; role of the health team. **Conclusion:** studies with the theme quality of life of mothers of children with cancer were concerned with showing that having a child diagnosed with cancer significantly alters the quality of life of mothers, in different aspects: cognitive, emotional, affective and social.

DESCRIPTORS: Quality of life; Neoplasms; Family, Nursing.

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Received: 12/08/2021; Accepted: 12/10/2021; Published online: 10/07/2022

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How cited: Vieira RFC, Santo FHE, Santos RS, Ribeiro WA, Varejão CS, Silva Neto AM. Quality of life of mothers of children with cancer: an integrative review. *R Pesq Cuid Fundam* [Internet]. 2022 [cited year month day];14:e11575. Available from: <https://doi.org/10.9789/2175-5361.rpcf.v14.11575>



RESUMO

Objetivo: analisar as evidências científicas da literatura sobre qualidade de vida das mães de criança com câncer. **Método:** revisão Integrativa da literatura, realizada nas bases de dados LILACS, *Medical Subject Headings* e CINAHL, nos idiomas inglês, português e espanhol, com utilização dos descritores controlados em português: “qualidade de vida”, “câncer”, “família” e “enfermagem” e suas versões em inglês e espanhol no recorte temporal de 2010 a 2020. **Resultados:** foram selecionados 12 estudos completos para análise interpretativa que permitiu a identificação de cinco: categorias: domínios afetados; dados sócios demográficos e qualidade de vida; espiritualidade e pensamento positivo; readaptando o modo de viver; papel da equipe de saúde. **Conclusão:** os estudos com a temática qualidade de vida das mães de crianças com câncer tiveram a preocupação em mostrar que ter um filho com diagnóstico de câncer altera significativamente a qualidade de vidas das mães, em diferentes aspectos: cognitivo, emocional, afetivo e social.

DESCRITORES: Qualidade de vida; Neoplasias; Família; Enfermagem.

RESUMEN

Objetivo: analizar la evidencia científica em la literatura sobre la calidad de vida de las madres de niños con cáncer. **Método:** revisión integrativa de la literatura, realizada en LILACS, *Medical Subject Headings*, bases de datos CINAHL, em inglês, português y español, utilizando descriptores controlados em português: “calidad de vida”, “cáncer”, “familia” y “enfermería”. Y sus versiones em inglês y español em el período de 2010 a 2020. **Resultados:** se seleccionaron doce estudios completos para análisis interpretativo que permitieron identificar cinco: categorías: domínios afectados; datos sociodemográficos y calidad de vida; espiritualidad y pensamiento positivo; readaptación de la forma de vida; papel del equipo de salud. **Conclusión:** estudios com el tema calidad de vida de madres de niños con cáncer se preocuparon por mostrar que tener um hijo com câncer altera significativamente la calidad de vida de las madres, em diferentes aspectos: cognitivo, emocional, afectivo y social.

DESCRIPTORES: Calidad de vida; Neoplasias; Familia, Enfermería.

INTRODUCTION

The concept of quality of life associated with chronic diseases has been modified and has become increasingly comprehensive, mainly because it is associated with well-being, a situation that can suffer consequences directly or indirectly in everyday life, with sudden repercussions in people's lives.¹

Cancer is a chronic degenerative disease² with prolonged treatment needs that can bring about changes in the life of the person and the family. The increased demand that the sick child projects on the mother brings a mutual dependence and reduces the quality of life.³

In Brazil, 620,000 new cases of cancer are estimated for the triennium 2020-2022. Of these, excluding non-melanoma skin cancer cases, there will be 450,000. In the pediatric clientele, 8,460 new cases are expected for the same period.⁴

Studies show that the lower the Human Development Index (HDI), the higher the expectation of cancer.⁵ Pediatric cancer corresponds to a small global cancer rate with an incidence of 0.5% to 4.6% of malignant tumors, 80% in countries with low HDI.⁶

The discovery of cancer in children leads to a maladjustment in the families' daily lives, since it is a disease with a reserved prognosis, still stigmatized and associated with death.⁷ Different reactions and emotions are raised by families when facing the diagnosis of cancer from the beginning of the discovery, throughout the treatment, and even in the achievement of cure, due to the fear of relapse, bringing wear and tear mainly to mothers, the main caregivers.⁸

The different demands of the caregiver at home, in the face of a chronic disease, can influence negative experiences, both

for the caregiver and for those being cared for. The family, and especially the mother, must be seen as a care unit that needs to be welcomed and supported by the nursing team, so that she can play her role of mother and caregiver, because the success of the child's treatment also depends on this interaction.

Considering that mothers are part of the care unit during the treatment of a child with cancer, the following question arises: Is there concern about the quality of life of mothers who have a child with cancer?

METHOD

This is an Integrative Review (IR) of the literature, carried out from May to November 2021. A broad method used in Evidence-Based Practice (EBP), which allows the evaluation of results already obtained in research, through a critical evaluation of the evidence and thus facilitate its applicability in care.⁹

The integrative review was developed following six steps: 1) definition of the review question; 2) search and selection of studies; 3) extraction of data from studies; 4) critical appraisal of studies; 5) synthesis of review results; 6) presentation of the review.¹⁰

The acronym PICO (P: population – child/ cancer/mother; I: intervention – quality of life; Co: context: childhood cancer) 11 was used to elaborate the guiding question.

To search the literature, a prior consultation was made in the Health Sciences Descriptors (DeCS), specific to LILACS databases, in *Medical Subject Headings* (MeSH), and by titles in the CINAHL database, respecting the specificities of each database. The crossing of descriptors was according to the Boolean

operators AND to associate them and OR to distinguish them, specified in Chart 1.

For the selection of articles, the inclusion criteria were: articles in English, Portuguese and Spanish, available in full online, indexed in the period 2010 to 2020, which addressed the theme quality of life of mothers of children with cancer. Review articles, editorials, case reports, reflections or communications and those duplicated in the databases were excluded.

The database search resulted in the identification of 220 articles. After exclusion of duplicates, screening of titles, abstracts, and evaluation of full texts, 12 articles were selected. To increase the quality of systematic reviews and meta-analyses,

we used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) document, which consists of 27 detailed and easy-to-view items in the flowchart of all study phases (Figure 1).¹¹

The studies were evaluated and classified according to their scientific rigor. The synthesis of the articles was grouped in Chart 2 containing the following items: year, author, research design, outcome, and level of evidence.

The level of evidence (NE) was based on the categorization founded by experts from the Agency for Healthcare Research and Quality (AHRQ), 12 ensuring the validity of this review, focusing on the adequacy of the methodology applied (Chart 2).

Chart 1 – Search strategy in the databases. Rio de Janeiro, RJ, Brazil, 2021

Database	Search Strategy
BVS LILACS/BDENF	((Quality of life OR qualidade de vida OR calidad de vida) AND (mother* OR mom OR mae OR madre) AND ((child* OR teen* OR adolescent* OR crianca OR nino) AND (neoplas* OR cancer OR carcinoma* OR tumor* OR tumour* OR malignan* OR oncol*))) AND (instance:"regional") AND (db:(“LILACS” OR “BDENF”))
PUBMED	((Quality of life[mh] quality of life[tiab]) AND (Mothers[mh] OR mother*[tiab] OR mom[tiab])) AND ((Child[mh] OR child*[tiab] OR teen*[tiab] OR adolescent*[tiab]) AND (Neoplasms[mh] OR neoplas*[tiab] OR cancer[tiab] OR carcinoma*[tiab] OR tumor*[tiab] OR tumour*[tiab] OR malignan*[tiab] OR oncol*[tiab])))
CINAHL	((Quality of life AND (mother* OR mom)) AND ((child* OR teen* OR adolescent*) AND (neoplas* OR cancer OR carcinoma* OR tumor* OR tumour* OR malignan* OR oncol*)))

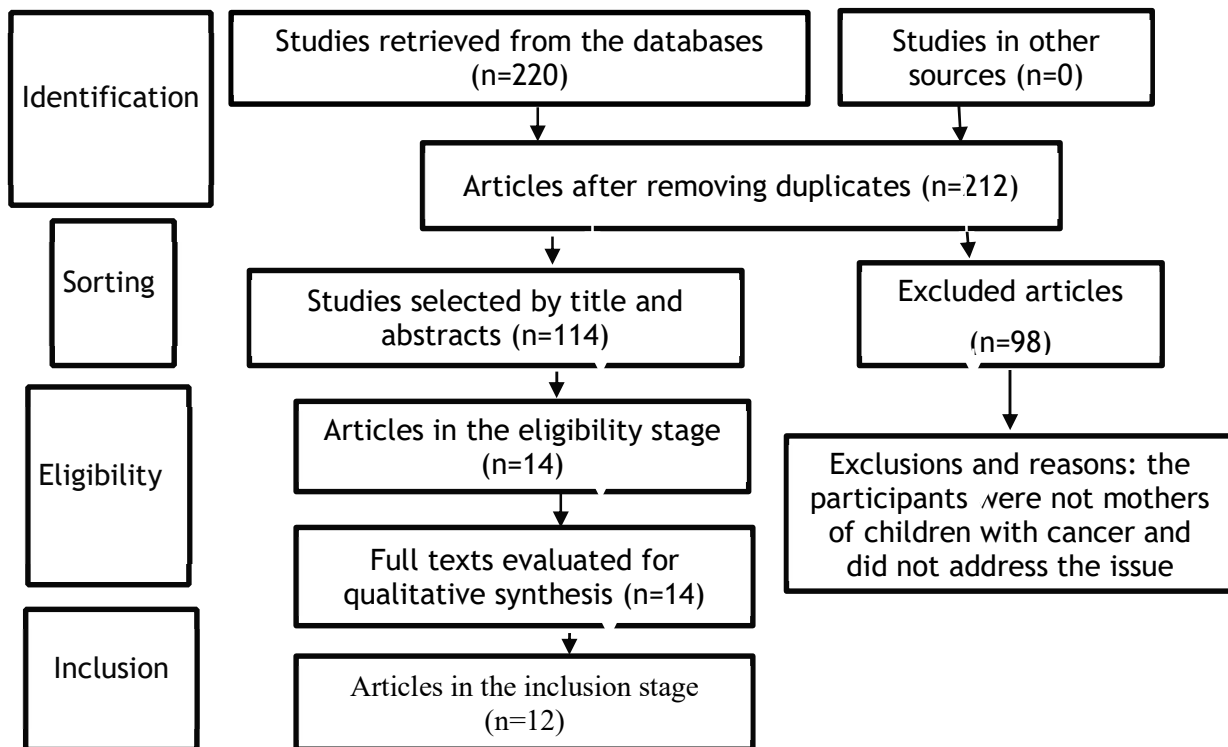


Figure 1 – Flow of the process of selection of studies for review, according to Prism. Rio de Janeiro, RJ, Brazil, 2020

Chart 2 – Summary of the studies selected in the review. Rio de Janeiro, RJ, Brazil, 2021

Nº	Publication Year and Authors	Method	Disposal	NE
1	2020- Ilic, V; Nikitovic, M; Maric, G; Jovanovic, A; Paripovic, L; Bokun, J; Stanic, D; Vukovic, MP; Tepavcevic, DK; Pekmezovic, T.	Cross-sectional descriptive study with a quantitative approach	It showed that QLRS measured by SF-36 in relatives of children with cancer is strongly influenced by depression	2
2	2015- Guimarães, CA; Enumo, SRF.	Qualitative research	Different impacts on families and at different times, duration and stages of the disease, being greater in the family of the child out of therapeutic possibility	6
3	2014- Ghodsbin, F; Asadi, N; JavanmardiFard, S; Kamali, M.	Interventional with selection using convenience sampling and randomly assigned into two groups (intervention and control)	At the first assessment, the mean quality of life scores in the study and control groups were 224.9 and 225.7, which after three months changed to 338.2 and 226.7, respectively. Implement educational and counseling programs for parents, specifically parents of minors with leukemia, to promote caregiving, reduce anxiety and, as a result, improve quality of life.	4
4	2012- Rubira, EA; Marcon, SR; Belasco, AGS; Gaíva, MAM; Espinosa, MM	Cross-sectional descriptive study	The caregivers' QL and care overload are compromised in several domains, and these changes can affect the quality of care provided to children and adolescents and lead to maladjustments in their own health	6
5	2011-Nóbrega, KIM; Pereira, CU	A descriptive, cross-sectional, exploratory study with a quantitative approach	Caregivers' perceived quality of life was moderate. The social domain was the relevant factor for depression, while the physical domain for anxiety.	6
6	2019- Modanloo, S; Rohani, C,S; Shirinabadi,F; Azam; V; Parvaneh; Pourhosseingholi, A.	Cross-sectional descriptive study	All dimensions of family functioning and quality of life reported as unhealthy dimensions. Low quality of life was reported in all domains by parents. Quality of life should be measured at the first meeting with a family of a child with cancer and during follow-up meetings to help plan family empowerment interventions.	6
7	2016- Safarabadi-Farahani, A et al	Randomized, controlled trial	Significant improvement was found within the intervention group in QoL ($p < 0.001$), including improvements in the mental/emotional burden ($p < 0.001$), disruption ($p < 0.001$), and positive adaptation ($p < 0.001$) subscale measures compared to the control group over time. There was no difference between the intervention and control groups on the financial subscale measure after the intervention ($p > 0.05$). Conclusion: The BPI (brief psychosocial intervention) was an effective strategy for improving the quality of life of PCCs. Similar interventions can be planned by professionals to reduce the burden of childhood cancer in PCCCs (primary caregivers of children with cancer)	2
8	2014- Medeiros, EGMS; Leite, RFB, Ramos, DKR; Almeida, LAL	Qualitative study with an exploratory-descriptive approach	Social quality of life, psychological symptoms and personal growth were affected. We conclude that caring for a relative with neoplasia, especially if it is a child, is a challenge for the family. However, it is possible to build good experiences living with the sick child and to view the illness as an opportunity for personal growth.	6
9	2018- Khanjari, S; Damghanifar, M; Haqqani, H	Cross-sectional descriptive-correlational study	The result of examining the relationship between quality of life and demographic characteristics of mothers showed that the level of education, income, and occupation had a statistically significant relationship. Conclusion: The quality of life of the participants in this study was significantly related to RCOPE (religious coping). Mothers with negative RCOPE showed low scores for quality of life, and religious support can improve their quality of life.	6
10	2019- Douki, HE; Elyasi, F; Hasanzadeh, R.	Randomized Controlled Study	The mean depression and anxiety scores recorded, in the intervention group were significantly lower than the group. Conclusion: Positive thinking training reduced anxiety and depression and increased the quality of life of mothers of children with leukemia.	2
11	2014- Sigurdardottir, A. O., Svavarsdottir, E. K., Rayens, M. K., Gokun, Y.	Quasi-experimental intervention study	The favorability score of the site was found to be very high. In addition, although not significant, an increase in mothers' ratings of cancer communication based on the Pediatric Quality of Life Questionnaire (PedsQL) was found after the intervention compared to before. The results suggest that the use of an evidence-based website is feasible, appears to increase cancer knowledge, and may thus contribute to better cancer situation management for families.	2

Chart 2 – Cont.

N°	Publication Year and Authors	Method	Disposal	NE
12	2011- Eyigor, S; Karapolat, H; Yesil, H; Kantar, M	Case control study.	Overall scores for health, vitality, social functioning, and mental health were significantly lower among mothers of children with cancer compared to the scores of mothers of children without cancer. Mothers of children with cancer, who require hospital care, have worse quality of life and psychological health than mothers of healthy children. These results suggest that the current system for treating cancer in Turkish children should also include careful monitoring of the quality of life and psychological health of the mothers providing care.	4

RESULTS

The final sample was composed of 12 scientific articles. Regarding the characteristics of the studies, 63.66% were published in international journals and 36.33% in national journals. The country with the largest number of studies was Iran (25%), followed by Brazil (16.67%), Iceland (16.67%), Turkey (16.67%), Germany (8.33%), the Netherlands (8.33%), and Serbia (8.33%).

As for the research method, there was a predominance of studies with a qualitative approach, with 58.34%, level of evidence 6; 33.33% randomized controlled and well-designed study and 8.33% well-designed cohort study and case control.¹²

The year 2014 showed the highest number of publications on this topic with 25% of the publications. On the other hand, in the years 2010, 2013, and 2017 there were no publications.

It was possible to stratify five thematic categories that stood out with the intentionality of the theme of the guiding question and analyze according to the principles and guidelines of thematic analysis,¹³ namely: affected domains; socio-demographic data and quality of life; spirituality and positive thinking; readapting the way of living; role of the health team.

DISCUSSION

In the category affected domains, seven studies evaluated the quality of life of mothers of children diagnosed with cancer at different stages of the disease, reinforcing that parents of children with cancer need more attention than parents of children with other diseases.

Having a child with cancer dramatically changes the psychological health of these mothers due to fear, anxiety, uncertainty of the future, and the social and financial changes imposed by the treatment from diagnosis to final outcome.^{14–17}

The use of psychosocial intervention measures has been shown to favor meeting the demands of the caregiver of the child with cancer, showing significant improvements in the group of mothers who had this type of support.¹⁸

In the sociodemographic data and quality of life category, the relationship of the sociodemographic factors with the quality of life of mothers of children with cancer was described in four

studies, punctuating situations of unemployment, larger number of children, family disorganization, and scarcity of financial resources as impediments to the access to minimum requirements and important to human dignity, translating into low scores of quality of life.^{19–22}

The loss of income of one of the parents combined with the economic difficulties that emerge from the treatment itself, travel costs, since many live far from the treatment centers, further weaken family relationships, with physical, emotional, and psychological stress.

It is a fact that the cost of cancer treatment grows exponentially due to the need for expensive drugs and technologies, besides the fact that its diagnosis is made most of the time late, causing financial toxicity, and it must be seen with responsibility for the impact it can have on the quality of life of everyone who experiences cancer.²³

In view of these needs, social support plays a fundamental role in reducing the economic impact on these families, so that they can reorganize and direct their resources.

In the category spirituality and positive thinking, the improvement in the quality of life of mothers is closely linked to spirituality and God, as a defensive action to deal with the crisis experienced, and should also be considered by the medical team and nurses.²²

Two articles evidenced that positive thinking reduces the level of anxiety and depression in mothers, improving their quality of life, being effective in increasing happiness.^{22,25}

In the category readapting the way of life, despite the significant change in the routine of life of families since the beginning of the diagnosis, altering their family dynamics, imposing new routines, without possibilities of social interaction, leisure, work, affecting the quality of life, leading them to physical, mental, and emotional exhaustion, a research conducted in Paraíba found that family members experience a new way of facing difficulties after the diagnosis of cancer in the child, with maturation and organizing themselves with the time factor that before the diagnosis was an impediment to be able to take care of their child.^{25,26}

In the category role of the health team, six articles in this review highlighted the relevant role of the health team, namely physicians, psychologists, and nurses regarding the concern with the mothers' quality of life.^{14–18,22,24–28}

The nursing team, by participating for more time with the child and his family during the assistance, becomes fundamental for being able to know and detect the needs and thus, to minimize the traumatic effects, providing information, inserting the family in the whole process, trying to minimize the pain that the illness already gives the child and his family.

CONCLUSION

The research revealed that the studies with the theme quality of life of mothers of children with cancer were concerned with showing that having a child diagnosed with cancer significantly changes the quality of life of mothers in different aspects: cognitive, emotional, affective, and social. The health team must be concerned with creating strategies that can strengthen these mothers in the care of their children with cancer. However, it was possible to conclude with this review that research on this theme still needs to be further developed, providing more expressive data to the scientific community, especially regarding the interventional measures that can improve this scenario.

Therefore, we realize the need for research that develops strategies for the care of mothers who have a child with cancer, since they are the interlocutors of the entire treatment, and therefore need to be strengthened and, equally, cared for.

The greater the bond between child, family, and team in cancer treatment, the better the understanding of the disease and adherence to treatment. In this context, mothers need to be seen as key players.

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