

## SOCIAL SUPPORT AND FAMILIES OF CHILDREN WITH CANCER: AN INTEGRATIVE REVIEW

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Pedro ICS, Galvão CM, Rocha SMM, Nascimento LC. Social support and families of children with cancer: an integrative review. Rev Latino-am Enfermagem 2008 maio-junho; 16(3):477-83.

*This study aimed to search available evidences in literature about social support to families of children with cancer. An integrative review was elaborated and the articles were searched in PUBMED, WEB of SCIENCE, CINAHL, PsycINFO and LILACS, using the key words: social support, cancer, child and family, between 1996 and 2006. Fifteen articles were selected and the analysis of these publications allowed for the identification of three themes: social support and the trajectory of cancer, social support to healthy siblings and social support to fathers and mothers of children with cancer. Data indicated a lack of consensus among researchers about the use of the term social support and that there is a need for greater methodological rigor in the conduction of these studies. Acknowledging the clients' support needs is important to plan nursing care and guide research development, whose results can be used in practice.*

DESCRIPTORS: social support; neoplasms; child; family; pediatric nursing

## APOYO SOCIAL Y FAMILIAS DE NIÑOS CON CÁNCER: REVISIÓN INTEGRADORA

*La finalidad de este estudio fue buscar las evidencias que se encontraban disponibles sobre el apoyo social a familias de niños con cáncer. Se realizó una revisión integradora y los artículos fueron buscados en las bases de datos PUBMED, WEB of SCIENCE, CINAHL, PsycINFO y LILACS, con las palabras clave: social support, cancer, child y family, en el período de 1996 a 2006. Fueron seleccionados quince artículos. El análisis permitió identificar tres temáticas: apoyo social y la trayectoria del cáncer; apoyo social a los hermanos saludables; y, apoyo social a los padres y madres de niños con cáncer. Los datos indicaron que falta consenso entre los investigadores al respecto del uso del término apoyo social y que es necesario realizar estudios con un mayor rigor metodológico. Reconocer las necesidades, que tiene la clientela, de recibir apoyo es importante para planificar el cuidado de enfermería y dirigir el desarrollo de investigaciones, cuyos resultados puedan ser aplicados en la práctica.*

DESCRIPTORES: apoyo social; neoplasias; niño; familia; enfermería pediátrica

## APOIO SOCIAL E FAMÍLIAS DE CRIANÇAS COM CÂNCER: REVISÃO INTEGRATIVA

*O estudo teve como objetivo buscar evidências disponíveis na literatura que abordem o apoio social aos membros de famílias de crianças com câncer. Elaborou-se revisão integrativa e a busca dos artigos nas bases de dados PubMed, Web of Science, CINAHL, PsycINFO e LILACS, com as palavras-chave social support, cancer, child e family, no período de 1996 a 2006. Selecionou-se quinze artigos e a análise desses permitiu a identificação de três temáticas: apoio social e a trajetória do câncer, apoio social aos irmãos saudáveis e apoio social aos pais e mães de crianças com câncer. Os dados indicaram falta de consenso entre os pesquisadores em relação ao uso do termo apoio social e a necessidade de maior rigor metodológico na realização dos estudos. Reconhecer as necessidades de apoio é importante para se planejar o cuidado de enfermagem e direcionar o desenvolvimento de pesquisas, cujos resultados possam ser desenvolvidos na prática.*

DESCRITORES: apoio social; câncer; criança; família; enfermagem pediátrica

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## INTRODUCTION

Advancements in modern science and technology have contributed to the progress of cancer treatment, so that children and their families can go through a longer experience of the disease. To help them in the cancer trajectory, social support is an important ally.

Social support can be considered "an interaction process between people or groups of people, who through systematic contact establish bonds of friendship and information, receiving material, emotional, affective support, contributing to mutual well-being and constructing positive factors in prevention and health maintenance. Social support highlights the role individuals can play to solve daily situations in crisis moments"<sup>(1)</sup>. However, most studies have looked at social support generically, and not as the main object of their research, turning comparisons and applications more difficult. In addition, studies on social support in Pediatric Oncology originate in adult-based theories. Research on the effects of social support on child cancer patients are still in the initial stage, which does not permit empirical determinations on the importance of this resource for children with cancer and their relatives<sup>(2)</sup>.

In view of the above, this study aims to look for evidence available in literature about social support for family members of children with cancer, from their perspectives, in the last ten years, so as to synthesize knowledge in the area as a base for care delivery to these clients.

## METHOD

To achieve the research objective, the integrative literature review was selected as the research method, with the following steps: problem identification (elaboration of guiding question, establishment of key words and criteria for inclusion/exclusion of articles), article selection, definition of information to be extracted from reviewed articles (objectives, methodology and key conclusions), as well as their analysis, discussion and result interpretation and, finally, knowledge synthesis<sup>(3-5)</sup>.

In view of the research problems: a) cancer is a public health problem; b) it becomes increasingly necessary to include the families in care and in the

therapeutic diagnosis process; c) social support can serve as an important tool to help people experiencing the trajectory of cancer; the following guiding question was established for the review: "What scientific knowledge has been produced about social support given to family members of children with cancer, from their perspectives?". The inclusion criteria were: the study theme of the publication should be questions about families or relatives of children with cancer in dealing with some kind of social support; presenting social support as the central focus and object of the study; publications in English, Spanish and Portuguese, published between January 1996 and July 2006; publications with abstracts available at and indexed in PubMed, digital databases produced by the National Library of Medicine (USA) in the field of Bioscience; Web of Science, which refers to a set of databases (Science Citation Index, Social Science Citation Index, Arts and Humanities Citation Index, Current Chemical Reactions and Index Chemicus), compiled by the ISI (Institute for Scientific Information); CINAHL (Cumulative Index of Nursing and Allied Health Literature), which joins the main scientific productions in nursing; PsycINFO, a reference in psychology, behavioral sciences and education, and LILACS, which covers scientific publications in health from Latin America and the Caribbean. Publications whose research subjects were only adolescents were excluded, as the authors of this review were only interested in research with child cancer patients younger than twelve and their relatives.

The following key words were used: *apoio social* (social support), *família* (family), *criança* (child) and *câncer* (cancer). Care was taken to use the key words that are considered as descriptors in the DECs (*Descritores em Ciências da Saúde*) and MeSH (Medical Subject Headings). The PubMed and Web of Science databases permitted an advanced search with the four key words at the same time; the remainder, however, allowed for crossed searches with only three words at the same time. Therefore, in the CINAHL, PsycINFO and LILACS databases, mutual combinations of key words were necessary.

To select the publications, each title and abstract was read exhaustively to confirm if they addressed the guiding research question and attended to the established inclusion and exclusion criteria. Table 1 shows the distribution of the publications included in the review and their selection phases.

Table 1 - Distribution of bibliographic references from PubMed and Web of Science, according to the key words

Database	Key words (concomitant crossed search)	Obtained references	References exclusively on social support as described in abstract	References exclusively on social support after reading of full article
Pubmed	social support/ child/ cancer/ family	184	15	12
Web of science	social support/ child/ cancer/ family	21	2	1

In Pubmed, 184 references were found, 18 of which were published in languages the inclusion criteria did not cover: seven French, three German, two Polish, two Japanese, one Italian, one Korean, one Russian and one Chinese. Among the 166 remaining publications, the abstracts of ten were not available; five focused on adolescents as research subjects, 12 studied adult cancer and six were not related to cancer. Then, 133 publications were left, of which only 15 exclusively addressed social support, that is, social support was the main study object. After reading the full version of these 15 articles, three were excluded: one did not look at social support from the perspective of family members of children with cancer, but from that of the health professionals who dealt with them; and the other two did not contain social support as the main study object. One of them focused on the healthy sibling's life during one year of treatment for the child with cancer, and the other on the integration process of the child at home and in the community immediately after the treatment.

Twenty-one references were found in the Web of Science, six of which were repeated in PubMed. Among the 15 remaining publications, one focused on adolescents as research subjects; another looked at adult cancer, and four did not refer to cancer. After reading the abstracts of the nine remaining abstracts, it was found that only two indicated social support as the main study object. However, the reading of the full version revealed that one of them focused on how the parents deal with the disease experience over time. Hence, only one of the selected articles was included.

For the search in CINAHL and PsycINFO, first, the key words social support, cancer and child were used and next, the word child was replaced by family. The other two words – social support and cancer – were not excluded as publications with themes different

from our guiding question could appear. The same logic could not be used in LILACS, because the first crossed search, described above, had only produced one article and, therefore, out of concern that an article would be missed, combinations like: "cancer x child x family" and "social support x cancer" were used.

Table 2 - Distribution of bibliographic references from CINAHL, according to the key words

Database	Key words (concomitant crossed search)	Obtained references	References exclusively on social support as described in abstract	References not yet selected through other bases
CINAHL	social support/ cancer/ child	37	6	1
CINAHL	social support/ cancer/ family	114	2	0

In the first crossed search, 37 references were found. The abstract of six contained social support as the main study object; however, five of these publications had already been found in the PubMed search, while the sixth was later repeated in the PsycInfo database. In the second crossed search, 114 references were found, however, without any new study, as publications complying with the inclusion criteria had already been selected. Most studies discarded in this search referred to adult cancer.

Table 3 - Distribution of bibliographic references from PsycINFO, according to the key words

Database	Key words (concomitant crossed search)	Obtained references	References exclusively on social support as described in abstract	References not yet selected through other bases
PsycINFO	social support/ cancer/ child	73	11	8
PsycINFO	social support/ cancer/ family	217	3	0

Seventy-three references were located in the first crossed search. In 11, social support was the main study object, but one was repeated in PubMed; one in Pubmed and CINAHL, and another in CINAHL only. Access to five of the eight references not found in any other database was not possible, because these were two books and two dissertations, both published in English and not issued in Brazil; as to the fifth publication, the article was requested via COMUT (Programa de Comutação Bibliográfica), but access could not be obtained until the moment of publication. After reading the full version of the three remaining

articles, two were excluded: one focused on the experience of Greek mothers during their children's terminal phase, and another only described the relation between of the mother - child with cancer dyad. In the second crossing, 217 references were found, but only three complied with the inclusion criteria and had already been selected. Most studies excluded in this crossed search referred to cancer in adults, mainly in women.

Table 4 - Distribution of bibliographic references from LILACS, according to the key words

Database	Key words (concomitant crossed search)	Obtained references	References exclusively on social support
LILACS	cancer/ child/ family	26	0
LILACS	social support/ cancer	11	0
LILACS	social support/ child/ cancer	1	0

In LILACS, 38 references were found, but one was repeated due to the combinations made. Among the 37 remaining references, six looked at health professionals who took care of children with cancer; eight addressed adult cancer; one was not related to cancer, and five abstracts were not available. All 17 remaining publications did not address social support as the main study object.

Table 5 - Distribution of references included in the integrative review, according to database, publication year, origin, authors, activity area and study design

Database	Year	Origin	Author	Activity area	Study design
Pubmed	1997	China	Martinson et al.	Nursing/ Medicine	Descriptive-exploratory
PsycINFO/ CINAHL	1997	USA	Varni et al.	Medicine	Descriptive-exploratory
Pubmed	1998	Greece	Vasilatou-kosmidis et al.	Medicine	Experience report
Pubmed/CINAHL	2000	USA	Murray JS.	Nursing	Critical literature review
Pubmed/CINAHL	2000	USA	Murray JS.	Nursing	Methodological research
Pubmed/CINAHL	2001	USA	Murray JS.	Nursing	Descriptive-exploratory
Pubmed/PsycINFO	2001	Australia	McGrath P.	Medicine	Phenomenological study
Pubmed/CINAHL	2002	USA	Murray JS.	Nursing	Descriptive
Pubmed	2002	England	Simms et al.	Nursing/Recreation Work	Experience report
Pubmed	2002	USA	Neil-urban et al.	Nursing	Phenomenological study
Pubmed	2003	USA	Suzuki et al.	Psychology/Medicine	Literature review
Web of science	2003	Singapore	Rosaleen O.	Social Work	Descriptive
Pubmed	2004	Canada	Kerr et al.	Nursing	Literature review
Pubmed/ PsycINFO/CINAHL	2004	Canada	Barrera et al.	Psychology	Correlation study
PsycInfo	2006	Sweden	Norberg et al.	Psychology/Medicine	Correlation study

The analysis of the selected publications allowed for the identification of three themes: social support and the trajectory of cancer, social support to healthy siblings and social support to fathers and mothers of children with cancer, described below.

At the end of the trajectory described above, in total, 15 articles were selected, which addressed the guiding question and also complied with the previously established criteria.

## RESULTS

The analysis of the 15 selected articles showed that eight had been elaborated by nursing researchers, sometimes in partnership with other professionals, such as physicians and recreationists. A certain level of homogeneity was found in the articles' distribution in terms of publication year, with an average of two publications on social support as the main study object. With respect to the countries of origin, the United States led the number of publications; despite some studies with other origins, English was the predominant language.

As to the study design characteristics, among the 15 studies included in the review, six used a quantitative methodological approach, with three exploratory-descriptive, two correlation studies and one methodological research; four studies used the qualitative methodological approach, with two phenomenological and two descriptive studies; two experience reports and three literature reviews, one of which was a critical literature review<sup>(4, 6-7)</sup>.

### Social support and the trajectory of cancer

Diagnosis and/or relapse of the disease tend to be the most difficult phase for the families of children with cancer<sup>(8-9)</sup>. At that moment, in general,

they need more *emotional* support and, during the treatment, they also look for *informational support*<sup>(10-12)</sup>. After receiving the diagnosis, the families start to seek and receive the different types of social support, which favor their adjustment in this trajectory<sup>(11)</sup>. However, it was found that the support offered tends to decrease over time due to the duration of treatment<sup>(9)</sup>. Social support is essential to help the families to deal with the shock of the diagnosis and the subsequent demands posed by treatment until the end, whether this means cure or death<sup>(12)</sup>.

#### Social support to healthy siblings

The healthy siblings' answers are determined by their individual temperament, life experiences, culture, developmental age, age of the sick child, closeness of the relation between the sick and the healthy child, and also by how the family responds to the situation<sup>(13)</sup>. Emotional, instrumental and informational support are considered the most beneficial support types for healthy siblings<sup>(14-15)</sup>. Some of these supports have useful mechanisms that teach them to deal with the situation: participation in support groups, talking about the subject; receiving information; open communication with the family; getting involved in care for sick siblings, as well as visiting them in hospital and keeping contact with them at this place, whether by phone or letters. Moreover, time should be spent with the healthy siblings and they should be charged with small responsibilities at home, such as taking care of a pet, in order to acquire a sense of importance<sup>(13)</sup>.

Reducing social support for healthy siblings can cause psychosocial problems, such as: resentment, rage, fear of death, jealousy, guilt, isolation<sup>(13)</sup>, anxiety, depression and behavioral problems<sup>(13, 16)</sup>. Not all healthy siblings develop behavioral or emotional problems but, when this occurs, it is difficult to identify and intervene adequately<sup>(16)</sup>, mainly when the necessary theoretical reference frameworks and technical instruments for this purpose are missing. Adequate means to survey data, as well as to assess different subjects' perceptions – parents and healthy siblings<sup>(17)</sup> and a theoretical reference framework are essential to help pediatric nurses to apply the social support concept in their clinical practice with healthy siblings of children with cancer<sup>(18)</sup>.

As to the characteristics of this concept, these include: attributes, antecedents and consequences. The following attributes can be mentioned: emotional, instrumental, informational and appraisal support. Antecedents of social support include: social network, social engagement and social climate. And, finally, favorable consequences entailed by different support types: increased self-esteem; better ways of dealing with the disease; increased knowledge and understanding of the disease and help for siblings to examine and interpret the situation more appropriately<sup>(18)</sup>.

#### Social support to fathers and mothers of children with cancer

The fathers and mothers of children with cancer can have different responses to adapt to the disease. To give one example, Chinese fathers frequently report symptoms like appetite and weight loss, sleeping difficulties, followed by headaches, dizziness and, finally, colds; Chinese mothers, on the other hand, presented more symptoms than fathers<sup>(19)</sup>. In general, men suffer more from isolation and receive less social support than men<sup>(20)</sup>, perhaps because mothers demonstrate greater anxiety, which is why they seek more support than fathers<sup>(21)</sup>. In practice, individual variations should be taken into account with a view to the better elaboration of a family-centered care plan, although making gender differences is not appropriate, that is, both fathers and mothers should be offered the same support, independently of gender<sup>(21)</sup>.

The sources of support offered to these clients include partners<sup>(9,19)</sup>, family, friends, employees, hospital team and other parents experiencing the same situation<sup>(9)</sup>. Suggestions to increase the support offered to families include: offering care through trained volunteers; involving people who guide the families in the initial stages of treatment and giving opportunities for them to get to know children whose treatment was successful<sup>(9)</sup>; developing support groups for parents<sup>(9)</sup>, either in hospital<sup>(20)</sup> or electronically, besides encouraging the use of new technologies: Internet access and use of videogames to start dialogues about cancer between children and parents<sup>(22)</sup>. Through the range of available interventions, nurses and other health professionals can play an important role by increasing these interventions, as well as by offering Access to different kinds of support to children with cancer and their families<sup>(22)</sup>.



## DISCUSSION

The analyzed data reveal that, when looking at the country of publication, the United States lead the ranking of publications in which social support was the main object of study. In Brazil, on the other hand, no research was published with this focus between 1996 and 2006. There is an urgent need for further research in this area, so as to understand the relation between social support and Brazilian families of children with cancer, as cultural and socioeconomic differences can interfere in this process.

The review revealed how difficult it is to work with the "social support" theme. Initially, in the search for articles, it could be perceived that the databases selected articles that were not always in line with the social support concept, as some authors called any type of "help" a synonym of "social support". This demonstrated that the social support concept is not very clear yet<sup>(23-25)</sup>, as many researchers have not established an operational definition of social support as a base for practice<sup>(18, 23)</sup>. Only one<sup>(18)</sup> of the fifteen articles included in this review intended to analyze its concept.

Different approaches to the term "*apoio social*" (social support) were found, and also its diverse types: *sistema de suporte*/ support systems<sup>(19)</sup>; *questões de apoio*/ support issues<sup>(9)</sup>, *necessidade de apoio*/ supportive care needs<sup>(10)</sup>; informational and emotional needs<sup>(10)</sup>; *apoio psicossocial*/ psychosocial support<sup>(22)</sup>; informal social support<sup>(11)</sup>; practical support from informal social network<sup>(11)</sup>; *cuidados de apoio*/ supportive care<sup>(12)</sup>; *apoio social percebido*/ perceived support<sup>(8,21)</sup> and received support. A clearer definition of this concept will favor its applicability in research<sup>(26)</sup>.

It should be highlighted that greater rigor in research development is needed, mainly in terms of method description. One study was found<sup>(19)</sup> that used

scales but did not present any related references; another<sup>(22)</sup> performed a literature review without describing how it was conducted, giving the impression of a mere collection about cancer, although this did not invalidate the authors' contribution to scientific knowledge in the area.

## CONCLUSIONS

Providing social support to the family members of children with cancer is a part of integral nursing care delivery. Social support frequently tends to decrease over time, but its offer should not be excluded, as the different phases the children and their families face have their own characteristics and relatives do not always express the difficulties they experience. To allow nursing to substantially contribute in the course cancer imposes, planning appropriate services and care, based on the needs in each phase of the disease, it is important to have instruments that help in the identification of social support types that will favor these clients, such as: adequate communication, interviews, genogram, ecomap, among others. Future research should try to understand what these families need most during the cancer trajectory, either the family as a whole or each member of the family core, whether healthy or ill and whether present or not in the hospital environment.

Nowadays, science and technological advances have provided a wide range of available interventions. Therefore, both nurses and other health professional should pay special attention to this process, in order to offer access to different kinds of support to children with cancer and their families. Acknowledging the actual support needs of family members of children with cancer is important for the coherent and adequate planning of nursing care, as well as to help and direct intervention areas that need to be developed, tested in research and put in practice.

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