

Social Support Perceived by Family and Caregivers of Children with Cancer

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Abstract: Social support to caregivers and family members can contribute to the construction of coping strategies in pediatric cancer diagnosis scenarios. To identify the state of the current literature concerning social support perceived by families and caregivers of children with cancer was the aim of this study. This is an integrative literature review performed in the LILACS and PubMed databases. We selected 10 articles that met the following inclusion criteria: academic articles published from 2014 to 2018, in English, Spanish and/or Portuguese, available in full and as open access, and addressing social support to the family and/or caregivers of children with cancer. The content of the selected articles was organized into the themes “Social support from interpersonal relationships” and “Social support from the health network”, which consider social support as a relevant and significant element in coping with the context of the family living the experience of having a child with cancer. The selected studies showed family members, parents of other children experiencing a similar problem, co-workers, as well as teachers and colleagues of other children as important sources of support. The health network was also an essential source of support, in the assistance, information, instruction, emotional and mediation dimensions of the community resource network. Thus, according to this integrative review, caregivers and family can be supported in different ways, both material and immaterial, and by people who belong to the most diverse social roles.

Keywords: Child, Family, Neoplasms, Social support.

INTRODUCTION

Cancer is a well-known disease with increasingly developed treatments, and it brings with it a demand for care. On the other hand, it is still considered a disease loaded with social representation, which often demonstrates the weaknesses and difficulties of coping both on the part of the patient and of relatives and friends.

Cancer involves not only the sick being as its biological aspects, but all its social relations. When the patient is diagnosed regardless of age, gender, family structure and economic status, a true care network needs to be structured for successful treatment in all its dimensions.

Cancer is estimated to be the leading cause of death and the most important barrier to increasing life expectancy in all countries of the world in the 21st century, as cancer incidence and mortality are growing

rapidly worldwide [1]. Also according to the aforementioned source, estimates indicated that there would be 18.1 million new cancer cases and 9.6 million cancer deaths in 2018. Cancer is a major cause of morbidity and mortality in all regions of the world regardless of the level of human development [1].

Diagnosis of cancer in children affects the family structure in that the child requires differentiated care due to its dependence on an adult for treatment and intense support for side effects. In addition, when cancer affects children, the disease brings with it more impact and, with or without hospitalization, can be experienced as a crisis for them and their family [2].

A study by Schardong *et al.* showed that the increase in anxiety level may be a reality experienced by parents of children with cancer [3]. Parents of children with cancer can have significant impairment in their emotional state, such as depression, stress and anxiety, so it is essential to assist parents in coping with the disease and alleviating their suffering as they are essential for the emotional support of children undergoing cancer treatment [4].

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Social support is understood to be a reciprocal process in relation to any information or support offered to people, implying a positive effect for the recipient [2]. Social support to the family of children with cancer should be carried out through a policy of both oncology hospitals and the public sphere. The fragility of caregivers who handle with children with cancer should be recognized as a necessary matter to alleviate distressing situations for this population, and actions should be effectively conducted to provide full support to these caregivers.

Given this context and assuming that supportive work for families and caregivers exists for a demand that is present in reality, it is still a rarely reported subject in the literature, and as such this study seeks to identify the current state of affairs concerning social support perceived by families and caregivers of children with cancer.

METHODS

This is an integrative literature review, a study that is characterized by the gathering and analysis of research seeking to synthesize the knowledge produced [5] and configuring itself as a facilitating instrument for the use of research results in health service practices [6].

For this integrative review, the following steps were followed: determination of the theme and the guiding question of the study; selection of inclusion and exclusion criteria; search in the academic literature; categorization and evaluation of selected studies; interpretation and presentation of the synthesis [6].

The guiding question of the study was: "What is the current state of affairs concerning social support perceived by families and caregivers of children with cancer?". The following inclusion criteria were adopted: academic articles published from 2014 to 2018, in English, Spanish and/or Portuguese, available in full and as open access, and addressing social support to the family and/or caregivers of children with cancer. As an exclusion criterion, it was defined that literature review articles would be excluded.

The searches were performed in the LILACS and PubMed databases, in August 2019, using the descriptors available in the Health Sciences Descriptors (DeCS): criança, neoplasias, família, apoio social; and in Medical Subject Headings (MeSH): child, neoplasms, family, social support. In the searches performed, the association between the descriptors occurred with the use of the boolean operator AND.

Figure 1 presents the searches performed in the LILACS and PubMed databases:

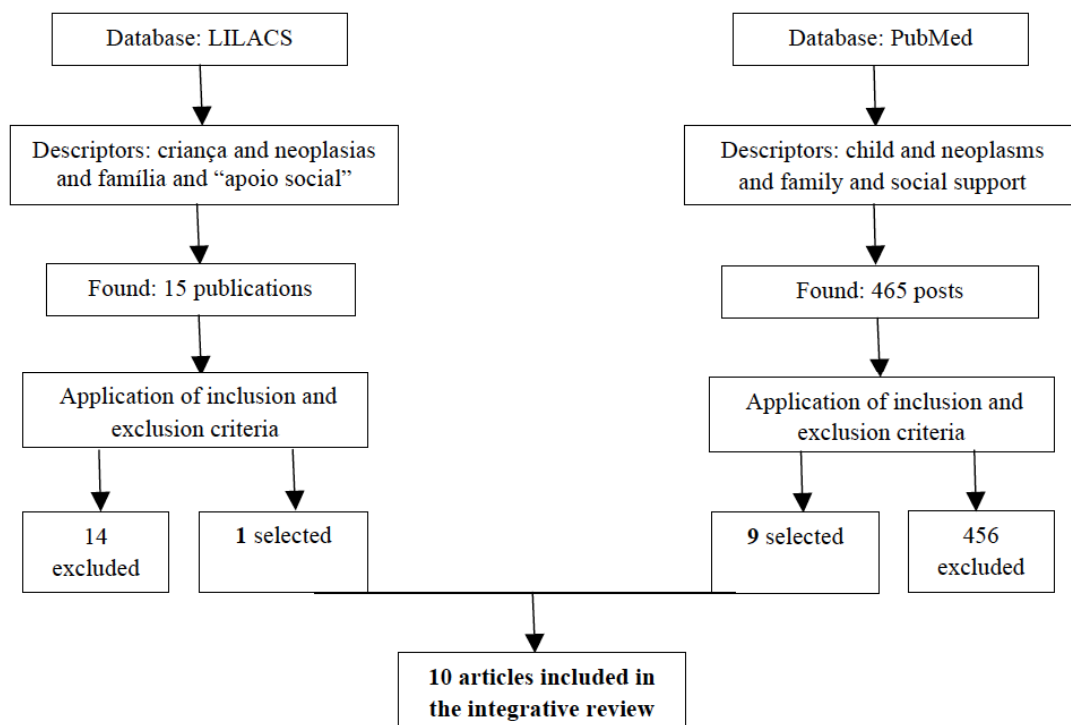


Figure 1: Searches performed in the LILACS and PubMed databases.

In order to collect information from the selected articles, an instrument was constructed containing the following questions: authors, year and journal of publication, title, objective(s), type of study and contributions of social support to family and/or caregivers of children with cancer.

After exhaustive reading, the content of these studies was organized into themes through the use of content analysis, thematic modality [7].

RESULTS

Table 1 shows the studies selected in this integrative literature review.

In a brief characterization, the articles were published from 2014 to 2018, where 2015 notoriously included more articles, with the publication of five articles. Three selected articles were published in Brazilian journals and seven in foreign journals. Of the selected articles, five are from the United States of America, two from Portugal, one from Brazil, one from Sweden and one from China. Regarding the type of study, the studies found were diverse, including quantitative, descriptive and correlational; quanti-qualitative; cross-sectional; longitudinal; multicenter; case-control design; and qualitative studies.

The results were organized into two themes: Social support from interpersonal relationships; Social support from the health network.

SOCIAL SUPPORT FROM INTERPERSONAL RELATIONSHIPS

Faced with the child's illness, caregivers and family may face profound changes in life [11, 16]. Intense feelings may arise when parents experience situations of child suffering [11]. There is a need for strategies to reduce parental anxiety, emphasizing the potential of social support [13].

The child's diagnosis may be accompanied by a greater union between family members [16]. During the treatment period, the family also appeared as an important source of support for caregivers of the child with cancer, especially the main caregiver [16]. In this way, parents can feel welcomed and supported by the family.

This overload can be felt by caregivers [16]. When at home, parents stress the importance of interaction and time spent with the family as a source of emotional support [11]. Relying on grandparents' support in

caring for the child's siblings was also essential [11]. Social support has enabled parents to strike a balance between pre-existing responsibilities, such as work and household chores, and the new caregiving role [12].

Relatives, friends, co-workers and employers were also cited as sources of support for parents of children with cancer [11]. Situations of economic overload can weaken families facing pediatric cancer [9]. In one of the selected studies, the support of co-workers was shown to be one of the sources of financial support [12]. This social support can minimize the possible economic repercussions of the child's disease [9].

In the early stages of treatment, mothers may report losses such as friendships and family moments, but also building friendships with other parents who experience pediatric cancer [17]. In these relationships, there is mutual support between the parents of the pediatric cancer patient [17], with possible repercussions in reducing psychological distress [10].

Emotional and informative support from other parents of cancer patients also appeared in one study [12]. This support had personalized characteristics since it came from people who were experiencing similar situations, sharing feelings and information [12].

Social support is essential for facing the new reality experienced. As such, actions that contribute to the satisfaction of parents with the social support received should be elaborated for the beginning of treatment for pediatric cancer [10]. Assistance in identifying possible sources of support can contribute to increasing parents' social support network [10].

The repercussions of the disease may affect the siblings of the child with cancer [14]. By analyzing aspects related to the social functioning of these siblings, a study [14] identified similarities in peer relationships, but decrease in school performance and activities participation [14]. This scenario highlights the importance of social support to the siblings of the pediatric cancer patient. Thus, when experiencing cancer, siblings and their needs should be considered and communicative processes must be established, as well as supportive and caring strategies [15].

Another aspect verified is related to the support received by children with cancer. As sources of child support, parents mentioned siblings, friends, peers, and teachers in school [11]. In the hospital setting, the play area and school staff were also cited as sources of child support [11].

Table 1: Distribution of References Highlighting Year of Publication, Authors, Journal, Title, Objective(s), Type of study and Social Support Contributions

Year	Authors	Journal	Title	Objective	Study type	Social support contributions
2018	Marques, Araújo, Sá [8]	Rev Bras Enferm	The impact of cancer on healthy siblings	To identify the variables that influence the impact of cancer on healthy siblings.	Quantitative, descriptive and correlational.	Association between social support received by family and reduced impact of cancer on healthy siblings was observed.
2017	Marques [9]	Rev Gaúcha Enferm	The family of the child with cancer: socioeconomic needs	To identify the socioeconomic variables that influence the families of children with cancer.	Quantitative, descriptive and correlational	Social support is associated with the reduction of the economic impact of the disease on the family of the child with cancer.
2016	Harper <i>et al.</i> [10]	Psychooncology	Satisfaction with support versus size of network: Differential effects of social support on psychological distress in parents of pediatric cancer patients	To investigate the direct effects of social support on parents' distress, and to investigate the buffering (or indirect) effects of each dimension of social support.	Longitudinal study	For parents of pediatric cancer patients, satisfaction with social support may act as an attenuator of psychological distress.
2015	Ångström-Brännström <i>et al.</i> [11]	PLoS ONE	Children Undergoing Radiotherapy: Swedish Parents' Experiences and Suggestions for Improvement	To describe parents' experience when their child undergoes radiotherapy treatment, and to report parents' suggestions for improvements during radiotherapy for their children.	Multicenter study	The emotional and practical support received by parents of different social actors (such as family, friends, co-workers, and hospital staff, for example) appears to be essential in scenarios of intense life transformations originated by pediatric cancer and treatment.
2015	Gage-Bouchard <i>et al.</i> [12]	Soc Sci Med.	The Architecture of Support: The Activation of Pre-existing Ties and Formation of New Ties for Tailored Support	To examine differences in the resources, information, and support parents coping with pediatric cancer accessed from different types of network contacts.	Quali-quantitative	The support received by parents resulted in several supports, such as contributions to balance the different roles performed (work, domestic commitments and new responsibilities for child care), financial relief, adaptation to their new reality, knowledge and coping with the child's disease.
2015	Chen <i>et al.</i> [13]	Medicine	Type D Personality Parents of Children With Leukemia Tend to Experience Anxiety	To access anxiety and type D personality (TDP) in parents of children with leukemia, and to determine the mediating effect of social support and coping style on the relationship between TDP and anxiety.	Cross-sectional study	Considering that social support and positive coping may partially explain the link between anxiety and type D personality, they become important strategies for expanding the social support received by parents of pediatric leukemia patients.
2015	Alderfer <i>et al.</i> [14]	J Pediatr Psychol	The Social Functioning of Siblings of Children With Cancer: A Multi-Informant Investigation	To examine social functioning among siblings of children with cancer.	Case-control design	The peer relationships of siblings of pediatric cancer patients, in scenarios filled with stressors from the disease, may be an important resource.

2015	Rosenberg <i>et al.</i> [15]	J Pain Symptom Manage	Long-term psychosocial outcomes among bereaved siblings of children with cancer	To describe: (1) the prevalence of risky health-behaviors, psychological distress, and social support among bereaved siblings; (2) potentially modifiable factors associated with poor outcomes.	Dual-center, cross-sectional	Factors related to the loss of opportunity to say goodbye to the sibling, the lack of preparation to cope with the death of this family member, dissatisfaction with the communicative process, and/or the negative impacts on relationships tended to be associated with lower social support scores and higher suffering in siblings bereaved by pediatric cancer patients.
2014	Andrade <i>et al.</i> [16]	Psicol. ciênc. prof.	Quality of Life and Work Overload of Caretakers of Children with Cancer	To verify the relationship between quality of life and burden in caregivers of children with cancer and treated at a support home.	Quali-quantitative	During treatment, social support may function as a source of support for the child's caregiver, helping to cope with overload-related difficulties, for instance.
2014	Neu, Matthews, King [17]	J Pediatr Nurs	Exploring Sleep-Wake Experiences of Mothers during Maintenance Therapy for Their Child's Acute Lymphoblastic Leukemia	To explore sleep-wake experience of mothers of children in maintenance treatment for Acute Lymphocytic Leukemia.	Qualitative study	For mothers of pediatric patients undergoing treatment for acute lymphocytic leukemia, social support is among the interventions that can help them cope with sleep-wake difficulties.

SOCIAL SUPPORT FROM THE HEALTH NETWORK

Family and caregivers of children with cancer can also count on other sources of social support, such as health professionals. Bonding with health professionals can be important for parents [12]. These professionals can act as intermediaries in the support network, enabling the construction of channels for access to resources and new network bonds [12].

By integrating the support network, health professionals, especially nurses, can play a role in strengthening family care [9]. Individualized guidance provided by the health team in addition to individualized care were valued by parents [11]. Child care permeated by attention, empathy and respect is valued by parents [11].

Another important aspect is the possibility of coexistence with the health team and the establishment of dialogical and trusting processes that allow for the expression of concerns and the clarification of doubts [11].

Thus, professionals working in the health care network, as they are a source of social support, can perform various actions, especially the provision of information [11], the connection with possible support

systems available [10], stimulating interaction between parents and favoring the construction of a sense of community [12].

Considering that the social support received by families may act as a protective factor, contributing, for example, to reducing the possible implications of cancer on healthy siblings, the health professional should seek to identify the needs of the family and their families support systems in moments of care [8].

The look must still be directed to the clinical environment, seeking to identify available resources as well as the efforts of the health team [10]. The planning of interventions must be adapted to the needs of each family [8]. This shows that care should be focused on the family [8, 11], integrating it in the child's treatment.

DISCUSSION

In this study, social support proved to be a relevant and significant element in coping with the context of the family living the experience of having a child with cancer. The selected studies showed family members, parents of other children experiencing a similar problem, co-workers, as well as teachers and colleagues of other children as important sources of support. The health network was also an essential

source of support, in the assistance, information, instruction, emotional and mediation dimensions of the community resource network.

We consider here that other sources of support such as neighbors, friends and spiritual supporters can still be encouraged.

This family moment may involve anxiety and emotional pain when facing the child's suffering, as well as the difficulty of reconciling the care of the sick child with meeting the demands of the parents' other children, performing daily activities such as household chores and fulfilling duties and professional obligations, in addition to the possible financial difficulties that may arise due to the costs related to the treatment and care of the child, or the reduction of time devoted to work activities.

The impact of this chronic illness on a family member is permeated by emotions such as insecurity, sadness, helplessness and fear, intensifying the love for the child, encouraging the family to seek and develop coping strategies. Support within the family is essential at this moment within the family nucleus itself, as well as the instructional/informative support of health professionals. Such support, when left unaddressed, is filled on the subjects' own initiative, when the family needs to gather forces to seek information, guidance and assistance on their own [18] at a moment of greater emotional vulnerability when receiving support becomes essential, making it an ethical imperative for professionals to offer this support in the most qualified, committed and humanized way possible.

At different times in the family's life cycle as well as in situations of vulnerability, the social support network directly influences the quality of family functioning and its ability to adapt to situations experienced [19].

The quality and amount of social support to the family experiencing this moment tends to also have a quantitative impact on the care that the child receives from the family, since a more supportive family will have better emotional conditions as well as more time, tranquility and willingness not only to care for the child, but also seek to improve in doing so.

Satisfactory social support and socioeconomic status are aspects that positively affect the quality of life of caregivers [20], so the health teams that assist the child and family also have the role of facilitating these factors, as found in the present study.

For such, health professionals and managers recognize the importance of these elements in the humanization of family coping with cancer cases and successful treatment, acknowledging the need to take on the role of co-responsible for encouraging the family in the search for support and for identifying, pointing and mediating resources available in the community, actively building and daily improving an interprofessional and intersectoral care network.

Thus, health professionals should incorporate into their actions the consideration and approach of the microsocial and macrosocial context of families as determinants of health and child care conditions, including the mapping of the social network and the opinion of the family about the established and potential bonds which can be created, identifying issues in support and the vulnerability of relevant resources for adequate adaptation and family functionality, in addition to consequent increase in the quality potential of child health care actions [21].

People-centered care is based on the assumption of health professionals who value social aspects among community members and families, strengthening health-related values related to the appreciation and encouragement of a social culture that provides support through bonding and partnerships between professionals, services, communities and families [22].

It is thus necessary to expand care-related conceptions and actions, including the appreciation and understanding of the social support network; the appropriation of tools that explore these elements, such as the genogram and the ecomap; and interventions aimed at consolidating effective networks that enable families to receive the support they need in order to take care of the child and to go through this phase in a functional and humane manner [21], given the vulnerability associated with the child, a situation which becomes particularly impactful in cases of pediatric cancer, turning into an ethical duty for society and health professionals to act in all possible dimensions to support these children and their families.

Child health care requires responsibility and protection through health practices that promote child protection [23]. There is a need for dialogue with parents, caregivers and family, making caring for children with cancer a participatory and democratic process.

It is worth noting that the lack of a support network sensitive to family needs at this stage of their life cycle

can reduce the diversity, amount and quality of sources of support, parental care, interpersonal care interactions, as well as stimuli and child care, intensifying stress factors and the physical and emotional overload of caregivers and family members [21], as well as that of children themselves.

As such, the approach and encouragement of social support networks as a foundation of protection and care for others and their context is taken into account as a confrontational element that favors resilience processes in times of crisis and post-crisis, which becomes facilitated if acknowledgement of values such as solidarity, cooperation and partnership are also present [24]. This was corroborated by a study that demonstrated the relevance of attributing value to such an element in child health care practices by analyzing the social network in child care [21].

A certain study identified potential weaknesses in the health care of children with chronic disease, namely the fragmented and non-continuous care between services as well as failure to provide information, indicating a need to improve communication strategies in the child care network and the articulation of services related to caring for this group, taking into account that children with chronic diseases have specific needs during each stage of the disease, demanding sensibility of professionals and qualification to welcome these children, mediated by supportive, extended, continuous, proactive and resolute care, constituting essential aspects of comprehensive care that takes into account the vulnerability of children with chronic diseases [25].

Based on the assumption of co-responsibility and comprehensive care, we emphasize primary health care as a validated space as well as support and care center focused on the family and community, and therefore the Family Health Team must work under the guidance of social support [18], becoming part of it, in addition to identifying, expanding, creating, encouraging, enabling and monitoring the constitution of new support bonds, thus contemplating a continuous and qualified flow of communication and cooperation with the secondary and/or tertiary care team assisting the child.

FINAL CONSIDERATIONS

This integrative review demonstrates the importance of social support in the fight against this diagnosis and in the treatment of pediatric cancer for both caregivers and their families. This support occurs

in many ways, both material and immaterial, and comes from people who occupy the most diverse social roles. There is an exchange of roles regarding who is offering support and who is receiving it, and this relationship can contribute to the strengthening of caregivers and family in handling the child's situation.

The relevance of health professionals concerning social support for caregivers and family members of children diagnosed with cancer should be emphasized, not only directly through sensitive listening, compassion and respect, but also indirectly, for instance, by exercising patient advocacy, thus contributing to in-hospital classes for hospitalized children with cancer.

Lastly, it is observed that health professionals need to know the social support network of caregivers and families of children with cancer, be part of this network and work to strengthen it.

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