

## Review Article

## Strategies to support the caregiver of people with cancer: integrative review

*Estratégias de apoio ao cuidador de pessoas com câncer: revisão integrativa*

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**ABSTRACT:** *Objective:* conduct an integrative literature review about which care and support strategies are offered to the caregiver of people with cancer, in the hospital, outpatient and or home environment. *Method:* integrative literature review in the electronic databases BDENF, LILACS, MEDLINE, Portal CAPES, PubMed and SciELO, through the descriptors “Family Therapy”, “Family Nursing”, “Caregivers”, “Neoplasms”, “Integral Health Care” in Portuguese, English and Spanish. The Boolean operators “OR” and “AND” were used to cross the descriptors. *Results:* after careful review, 7 articles met the inclusion criteria. Strategies such as training for physical care and symptom management, stimulating the development of self-efficacy, coping and self-care skills through the provision of information and psychoeducational interventions, physical activities, use of complementary integrative practices and also the approximation of family ties as promoters of reducing overload and feelings of incapacity. *Conclusion:* the studies emphasized several support strategies that promote the reduction of overload and feelings of incapacity. Further studies are needed to validate some of the results that have not been proven to have a significant impact on caregivers’ quality of life.

**Descriptors:** Health strategies; Social support; Caregivers; Nursing; Neoplasms.

**RESUMO:** *Objetivo:* realizar uma revisão integrativa da literatura acerca de quais estratégias de cuidado e apoio são ofertadas ao cuidador de pessoas com câncer, no âmbito hospitalar, ambulatorial e/ou domiciliar. *Método:* revisão integrativa da literatura nas bases de dados BDENF, LILACS, MEDLINE, Portal CAPES, PubMed e SciELO, por meio dos descritores “Terapia Familiar”, “Enfermagem Familiar”, “Cuidadores”, “Neoplasias”, “Atenção Integral à Saúde” nos idiomas português, inglês e espanhol. Utilizou-se para o cruzamento dos descritores os operadores booleanos “OR” e “AND”. *Resultados:* após análise criteriosa, 7 artigos atenderam aos critérios de inclusão. Estratégias como a capacitação para cuidados físicos e manejo de sintomas, estímulo ao desenvolvimento de habilidades de auto eficácia, *coping* e autocuidado por meio do fornecimento de informações e intervenções psicoeducacionais, atividades físicas, uso de práticas integrativas complementares e também o estreitamento dos laços familiares, foram citadas como promotoras da diminuição da sobrecarga e sentimento de incapacidade. *Conclusão:* os estudos enfatizaram diversas estratégias de apoio como promotoras da diminuição da sobrecarga e sentimento de incapacidade. São necessários mais estudos para validar alguns dos resultados que não obtiveram comprovação de impacto significativo na qualidade de vida dos cuidadores.

**Descritores:** Estratégias de saúde; Apoio social; Cuidadores; Enfermagem; Neoplasias.

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## INTRODUCTION

Cancer is one of the main public health problems in developed and developing countries, and according to estimates presented by the Global Cancer Observatory, there were 18.1 million new cancer cases and 9.6 million cancer deaths in 2018<sup>1</sup>. It is estimated, for the triennium 2020-2022 in Brazil, the occurrence of 625 thousand new cases, with the neoplasms are one of the major causes of death in the country<sup>2</sup>.

However, despite the achievements in methods of early detection and cancer screening, there is still a high percentage of cases in which the diagnosis is late, which affects patient survival, configuring a worse prognosis of the disease, as well as interfering with family dynamics, since it entails a greater need for home care on the part of family members<sup>3-5</sup>.

In this context, in order to meet the needs of their ill loved one, the family mobilizes itself, seeking strategies to produce and manage daily care, modifying its structure and adapting to the vulnerability to which it is exposed, and finds the power to play this role in the best way possible<sup>3,5</sup>. However, it is noteworthy that family caregivers, similarly to sick individuals, suffer, presenting feelings of fear and uncertainty about the cure, in face of the situation experienced<sup>6</sup>.

Thus, the experience of caring for a family member with cancer often represents a great physical, emotional, and financial burden to the family nucleus<sup>7</sup>, since it demands availability, time, and dedication, which can cause the caregiver to become ill, leading to depression, anxiety, and mental and physical fatigue<sup>6-7</sup>. Such repercussions were verified in a Brazilian study<sup>3</sup>, which aimed to know the experiences of family caregivers of people with cancer, and an unbalance in the maintenance of basic human needs of the family members interviewed was evidenced, with changes in the physical, spiritual, and also social dimensions, and negative feelings since the moment of diagnosis and through all the stages of illness and treatment, such as fear, shock, sadness, and suffering.

In this context, the need for professional support to family members and/or caregivers arises, in order to mitigate the wear and tear suffered by these individuals during the process of the family member's illness, offering care strategies that help them in the management of cancer and daily care, thus minimizing impacts on their own self-care<sup>3,5,8</sup>. In this scope, it is possible to highlight the strategic role of Nursing professionals with the caregivers of people with cancer, since they are in direct contact with the ill family nucleus, becoming essential actors to enable measures to mitigate the caregiver's overload<sup>9</sup>.

Thus, the objective of the present research was to carry out an integrative review of the literature about which care and support strategies are offered to the caregiver of

people with cancer in the hospital, outpatient and/or home environment.

## METHODS

This is an integrative literature review, conceptualized as a method that allows the summary of evidence from several studies on a given topic through a fragmented process in stages, with the definition of the guiding question, search and selection of studies, observation of the main data, evaluation of these studies, synthesis of the results and presentation of the review<sup>10</sup>.

The Protocol was registered in Figshare, under the Digital Object Identifier <https://doi.org/10.6084/m9.figshare.19424027>, in accordance with international recommendations on the principle of open data.

The question used to motivate the deepening of the theme of the review was: What is the production of knowledge about the care and support strategies that are being offered to caregivers of people with cancer in the hospital, outpatient and/or home environment? The PICOT<sup>10</sup> strategy was used to delimit the integrative review. It is an acronym, representing in the present study: P) Population (caregivers of cancer patients); I) Intervention (care and support strategies offered in hospital, outpatient and/or home environments); C) Comparison (not applicable); T) Time (studies published in the last five years).

The search was carried out from January to March 2021, interdependently by two researchers, using the controlled descriptors available in the Health Sciences Descriptors (*DeCS*).

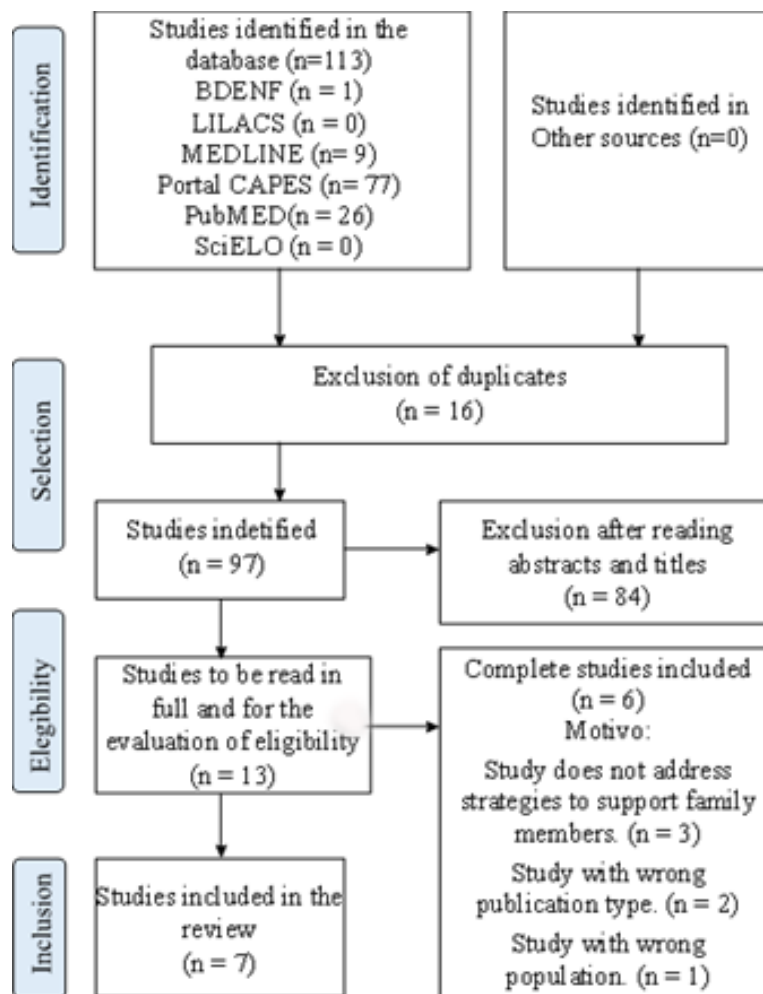
The databases where the search strategy was used were: BDNF (Nursing Database), LILACS (Latin American and Caribbean Literature on Health Sciences), MEDLINE (Medical Literature Analysis and Retrieval System Online), CAPES Portal (Portal of Periodicals of the Coordination for the Improvement of Higher Education Personnel), PubMed (US National Library of Medicine National Institute of Health) and SciELO (Scientific Electronic Library Online).

To locate the articles that made up the review, the *DeCS* in Portuguese, Spanish and English were used in the search strategy, namely: "Terapia Familiar", "Family Therapy", "Enfermagem Familiar", "Enfermería de la Familia", "Family Nursing", "Cuidadores", "Caregivers", "Neoplasias", "Neoplasms", "Atenção Integral à Saúde", "Atención Integral de Salud", "Comprehensive Health Care". The Boolean operators OR (for synonymous words) and AND (for different words) were used in all databases. Thus, the search strategy used was: ("Family Therapy" OR "Family Therapy") AND ("Family Nursing" OR "Enfermería de la Familia" OR "Family Nursing") AND ("Caregivers" OR "Caregivers") AND ("Neoplasms")

In the third stage of the review, the technology

platform called Rayyan® was used, which allows the selection of studies. For this, two reviewers made the choice of studies, and in controversial cases, a third reviewer indicated whether the study met the inclusion criteria<sup>11</sup>. The studies were selected by carefully reading the titles, abstracts and later the full articles. The inclusion criteria defined were scientific articles similar to the theme of this study, productions available in full, in Portuguese, English

and Spanish and that detailed the subject: strategies or tools to support caregivers of people with cancer in the hospital, outpatient and /or household, regardless of the research method used, published between the years 2015 to 2020. In addition, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)<sup>12</sup> guide was adapted for the reporting of this review, presented in Figure 1.



**Figure 1** -Flowchart of the primary study selection process adapted from the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA)<sup>12</sup>

Data analysis was performed through translation and reading of the articles and the extracted information was described in tables prepared in Microsoft Word® 2016, in the order of citation throughout the text.

The results were shown in a descriptive way, through a synthesis of the findings. For the characterization of the selected studies, an adapted data recording instrument was used, aiming at systematization and organization, and the selected articles were evaluated regarding the level of evidence<sup>13</sup>.

## RESULTS

Of the seven primary studies, four were derived from a well-designed randomized controlled clinical trial (level II)<sup>14-17</sup>. One study was defined as a well-designed cohort study (level IV)<sup>18</sup> and two studies were classified as descriptive or qualitative (level VI)<sup>6,19</sup>.

Chart 1 presents the description of the seven articles selected for analysis, regarding author, year of publication, country of study, population, objective, level of evidence, and caregiver support strategies.

**Chart 1** - Identification data of articles included in this review, 2020

Author / Year	Objective	Population / Country	Support strategies / Level of evidence
Aubin et al. <sup>14</sup> [2017]	To Implement and to evaluate the effectiveness of an intervention integrating community-based primary care with cancer care to improve supportive care for family caregivers of lung cancer patients.	Family caregivers (n:120) divided into a control group (n:60) and an intervention group (n:60) with an estimated life expectancy of at least 4 months) as their primary caregiver. Canada	Supply to the family caregivers of resources, information and support that propitiate the maintenance of their health and care. Information about the process of the illness, about the necessary behaviors in the care and about the flow of the process of care in cases of cancer, guaranteeing welcoming, aiming at solving doubts about the process of the illness, mitigation of anguish, anxiety, depression and other needs. Level II
Mazanec et al. <sup>15</sup> 2017	To assess the feasibility, acceptability, safety, and fidelity of an intervention that took a psychoeducational approach and included a low-impact, home-based walking activity.	15 adult patients and their family caregivers were randomized into an intervention group and a control group. USA	Psychoeducational approach with educational and supportive resources, and guidance to low-impact walking at home, with the goal of promoting well-being. The dyad (patient-caregiver) were oriented to act as “partners in responsibility”, and both should perform the walking activity. The caregivers were satisfied, with a mean score of 8.8/10. Level II
Hendrix et al. <sup>16</sup> 2017	To examine the effects of an improved informal caregiver training protocol (Enhanced-CT) on cancer symptoms and stress management in caregivers of hospitalized cancer patients.	Caregiver-cancer patient dyads (n:138). UK	Symptom areas included infection prevention, fatigue control, pain control, and maintaining proper nutrition and elimination. Providing training to assist in caregiver stress management by performing breathing and muscle relaxation exercises.
Hudson et al. <sup>17</sup> 2015	To evaluate an individual psychoeducational intervention aimed at alleviating the suffering of caregivers of patients with advanced cancer who receive palliative care at home.	Family caregivers (n:298), being in the control group (n:148) and in the intervention group (n:150). Australia	Enhancing information and promoting well-being through personalized psychoeducational intervention, providing information and stimulating communication and problem solving. Level II
O’Neil et al. <sup>18</sup> 2019	To better understand the challenges of informal end-of-life caregivers in South Africa, both at home and in inpatient facilities.	Cancer patients over 18 years of age with no prospect of curative therapy, with their informal caregivers (n:174). South Africa	An educational strategy related to the physical care and symptom management (e.g. pain management) of the cancer patient in order to decrease the caregiver’s stress, insecurity, and tension. Level IV
Fjose et al. <sup>6</sup> 2016	To explore what older cancer patients and their families experienced as important and difficult in close family relationships during the palliative phase, and how they interacted and communicated about these challenges.	26 family groups, including 26 patients, 14 spouses, 37 children, 7 sons-in-law, 1 grandson and 1 sister (for a total of 86 individuals in all families). Norway	To stimulate conversations in the family to define roles, to expose the individual needs of each member, to promote meaningful time with the family member in palliative care, through activities that are pleasant for the family member, and to strengthen and strengthen the family unit, stimulating mutual support. Level V]
Cloyes et al. <sup>19</sup> 2018	To identify the unique needs of lesbian, gay, bisexual and transgender (LGBT) cancer patients and caregivers, and to review recommendations that support more effective and inclusive palliative and end-of-life care.	Caregivers and cancer patients in Lesbian, Bisexual, Gay and Transgender (LGBT) palliative care. USA	Providing information on palliative and affirmative care. Requesting care goals so that the patient or caregiver reflects on what their needs are at that moment of care.[Level VI

Three studies approached educational strategies related to physical care and symptom management of patients, with the realization of training formulated by oncology health professionals<sup>14,16,18</sup>, since it was detected the decrease in the quality of patient care and in the quality of life of the caregiver, due to the increase of the stress load when the caregiver did not feel able or did not have the skills to perform physical care<sup>18</sup>. The study by Hendrix et al.<sup>16</sup> brought training in physical care and

symptom management to the caregiver as strategies that brought confidence and self-efficacy, decreasing tension and promoting well-being.

The research by Cloyes et al.<sup>19</sup> mentioned, as a care or support strategy for the caregiver, the request of care goals, so that the caregiver could think and reflect on what their needs were at the time of assistance. This study also showed that the promotion of a judgment-free environment combined with the creation of space for exchanges is a

facilitator in the promotion of patient and caregiver care.

Only in the study by Fjose et al.<sup>6</sup> a support strategy is presented considering the family unit, through the division of roles among family members and individual exposure of each one's needs. The authors propose the promotion of pleasant activities for the patient and that provide a significant time of life with the family, such as: important conversations and access to photos and memories, providing resistance and unity to the family unit<sup>6</sup>.

In two studies, self-care strategies were cited, such as performing breathing exercises and muscle relaxation<sup>16</sup>, and performing low-impact walks to promote well-being<sup>15</sup>.

The psychoeducational interventions demarcated in the studies<sup>14-15,17,19</sup> involved providing information about the clinical course of the disease, communication strategies to assist in the dialogue with the person being cared for, ways of dealing with stress and recognition of the indispensability of this type of care, so that, in this perspective, the caregiver was able to identify the impact of the changes in your life and the importance of leisure activities and self-care for your health.

## DISCUSSION

The results showed that the care and support actions used with caregivers of people with cancer presented by most of the articles were psychoeducational approach strategies, through the provision of information, educational resources on topics such as general care, palliative care, affirmative and self-management, in addition to promoting communication.

A Spanish study<sup>20</sup> reinforces the findings, indicating that personalized psychoeducational interventions are important factors for reducing the burden of stress, anxiety, somatic symptoms and insomnia, promoting the development of self-management in informal caregivers. A Polish study<sup>21</sup> reaffirms the psychoeducational strategies discussed so far, evidencing the reduction of depression and stress burden in informal caregivers of individuals with Alzheimer's, through training in financial matters and in subjects related to pathology, since weaknesses are identified economic and knowledge gaps on the part of caregivers. Financial difficulties related to the need to perform care were similar findings in a North American study<sup>22</sup>, where the authors emphasize the importance of paying attention to affirmative information, which will help caregivers to develop their activities in order to reduce weaknesses, especially social and economic ones.

It is also worth remembering that the improvement of diagnostic methods and advances in therapeutic regimens has brought greater longevity and quality of life to cancer patients<sup>1</sup>. Along with this, there was an increase in home care performed mostly by informal family caregivers. Such care is based on monitoring the patient's daily activities, taking psychosocial measures, taking medications,

monitoring side effects, managing symptoms such as pain and shortness of breath, among others<sup>23-24</sup>.

However, a North American study<sup>23</sup> and a Colombian study<sup>25</sup> indicate that much is discussed about the benefits of psychosocial intervention on the caregiver, addressing, for example, coping, communication and problem solving strategies. But just a little is said about the absence in the literature of strategies that help caregivers in these aspects, or about the lack of training of the health team to act in the face of illness processes that mobilize an entire family nucleus<sup>26-27</sup>, main aspects taken into account in the elaboration of this research.

The hypothesis is still raised that it would be necessary to offer both interventions mentioned above to the caregiver, which would improve their effectiveness and confidence in patient monitoring. This evidence was found in the articles selected in the present review, as they point out that many of the strategies adopted with caregivers go towards technical support and support for care actions<sup>15-18</sup>.

This measure becomes very necessary, especially if we take into consideration what was explained in a North American study<sup>28</sup>, where the authors point out that the cancer patients perceive how their care is being provided, and this perception is directly influenced by the quality of life, health, and well-being of their caregiver(s). Moreover, the caregiver is not a mere passive observer of the disease and, therefore, the degree of mental or physical health of the caregiver can have a negative reflex in the coordination of care<sup>29</sup>, in listening and understanding information about treatments given by health professionals and in helping the patient make decisions. These factors corroborate the findings of Hendrix et al.<sup>16</sup> and O'Neil et al.<sup>18</sup>, which reinforce the positive role that caregiver empowerment brings. There is solid evidence that the family caregiver is a central part in the monitoring and treatment of a person with cancer, as seen in a North American study<sup>31</sup>, where it was explained that anxiety, depression, anguish, fear and uncertainty are feelings present in both the parts and that manifest from the initial diagnosis to the end of life. These symptoms were cited in most of the studies addressed in this debate; therefore, it is valid to consider that the stage of the disease affects the intensity and amount of support needed by the caregiver, and therefore, their preparation to perform their task, as well as the emphasis on self-care, are challenges of Oncology<sup>9,31</sup>.

Regarding the results obtained from the study by Cloyes et al.<sup>19</sup>, who indicated the request for care goals as a form of support for caregivers, their main objective is to stimulate the caregiver's reflection about their needs. Other studies also demonstrate that requiring the caregiver's demands provides benefits for reducing the burden, in addition to being a factor that guides care planning with this public<sup>3,5,25</sup>.

Thus, an Australian study<sup>32</sup> demonstrated that by providing personalized information over the phone, it is

possible to address the possible unmet needs of caregivers of people with cancer, by raising questions for discussion, that is, the caregiver is encouraged to think about their unmet needs. It is noteworthy that during the phone calls, topics such as family support and financial and practical issues were still addressed<sup>32</sup>.

In the results already evidenced previously by Fjose et al.<sup>6</sup>, the division of roles, identification of the needs of each family member and the promotion of significant time had a stress-reducing effect in the family group of people with cancer. In a Polish study<sup>33</sup>, which addressed the needs of parents of children suffering from cancer, the author states that the greatest need of family members is for information. Therefore, dialogue with the family, whether individually or in a family unit, in addition to being essential, is the main strategy for including family members in the treatment and care of the individual<sup>33</sup>. Thus, studies are needed to better explain the approach to family dynamics as a form of support for caregivers, especially in relation to cancer.

Regarding self-care, an agenda that is progressively gaining ground in today's society, it is necessary to discuss the impact it has on the lives of caregivers and cancer patients<sup>34</sup>. The time of care spent by the family caregiver varies according to the degree of incapacity and need of the sick person, with no, low, medium or high degree of dependence in the literature<sup>24,35</sup>. It is noteworthy that this time contributes to reducing adherence to activities that involve self-care by the family member responsible for home care.

Furthermore, the person who provides the care may neglect some potentially beneficial activities, or even not perform them due to a feeling of guilt of leaving, even momentarily, the family member under the care of other individuals<sup>36</sup>. The authors define self-care as a series of attitudes and behaviors that aim at maintaining mental and physical health and well-being, such as: having a healthy diet, practicing physical exercises, getting adequate and restful rest, dedicating time to oneself in a balanced way, connecting with the spiritual side, that is, performing activities that reduce stress<sup>36</sup>.

However, a counterpoint to the self-care practice of family caregivers is the fact that not all of them have the possibility of sharing the care with someone else<sup>3,5</sup>, since the caregiver is usually someone imposed by the family, who, instead of having to care, starts living for the patient<sup>3,5,24</sup>. It is also pointed out that, because they are informal caregivers, they do not have a salary and can still be exposed to criticism from family members. Therefore, it can be noticed that it is not only a choice or the feeling of guilt that lead someone to assume the role of caregiver<sup>3,5-6</sup>.

There are still few studies that analyze how the degree of engagement of the caregiver in such activities impact on his own well-being and on his capacity and ability to offer support to his family member; however,

by the studies and discussions presented by Hendrix et al.<sup>16</sup> and O'Neil et al.<sup>18</sup> in this integrative review, it can be inferred that the family member's quality of life interferes significantly in the effectiveness of care.

A literature review<sup>37</sup> pointed out the integrative complementary therapies as a way to stimulate the self-care in caregivers of people with cancer, promoting potentially positive impacts in the reinforcement of these caregivers' quality of life. In the study evidenced by Mazanec et al.<sup>15</sup>, other types of activities to stimulate self-care, such as low-impact walking and some breathing exercises, were addressed as promoters of self-efficacy.

It is noteworthy that, according to the literature, complementary integrative therapies, such as yoga exercises, massage therapy, reflexology, meditation, music therapy, animal therapies, among others, performed in a comfortable environment, whether this home or places where the practices are developed, provide caregivers' self-care<sup>37</sup>. It is pointed out that the review did not demonstrate which are the most indicated practices, which could be chosen if the caregiver is consulted about their wishes<sup>37</sup>. Furthermore, studies on these practices, regarding effectiveness, number of sessions and benefits, are scarce.

A North American study<sup>38</sup> demonstrated an online mindfulness meditation program, offered electronically (phone, web, etc.) for a period of eight weeks, which works as a self-care tool for caregivers participating in support groups, without specifying which practices these are in the habit of performing. This personal care strategy includes topics such as self-reflection, self-care focused on self-compassion, mindfulness meditation and care, helping to reduce burden<sup>39</sup>.

It should be noted that the caregiver care strategies found in this review were mostly focused on individual actions, aimed at caregivers or the family unit. However, it is worth noting the importance that support groups represent as support strategies for caregivers of people with cancer<sup>40</sup>, despite not being reported in the analyzed studies. A Turkish study<sup>41</sup> with an exclusively female audience (daughters and wives of people with dementia), which sought to understand the effects of interventions in a support group for caregivers of people with dementia, showed that interventions carried out during the groups, with health education regarding pathology, discussion of topics and sharing of experiences promoted an improvement in the ability to cope with situations related to care,

Evidence about support groups is very relevant and can be used as family support, as well as in the suggestions by Fjose et al.<sup>6</sup>, who emphasize the importance of moments of family unity through dialogue and performing simple tasks.

It is noteworthy that despite the systematization in the search and selection of articles, the impossibility of exhausting the available literature on this topic is recognized. Therefore, among the limitations of the method,

the search limited to six databases, the limitation of five years regarding the search period, as well as the limitation of the authors' domain languages (Portuguese, English and Spanish) stand out.

Despite these limitations, the present study synthesized evidence from seven studies, most of which were clinical trials. It was clearly demonstrated that support strategies collaborate to reduce the burden and provide opportunities for caregivers to take care of themselves, assuming that the absence of these strategies can compromise the care process for individuals with cancer. Therefore, this study contributed to the advancement of scientific knowledge and confirmed the importance of policies and practices in Oncology services, aiming at strategies to support family caregivers in hospital, outpatient and/or home environments, both nationally and worldwide.

## CONCLUSION

The data obtained in this study showed that the care and support strategies for caregivers of people with cancer in the hospital, outpatient and/or home environment turned to individual practices and together with the family unit,

which were presented as promoters of reducing the burden and feeling of incapacity and insecurity in care.

The analyzed studies brought as evidence the training for physical care and symptom management, stimulus for the development of self-efficacy skills, coping and self-care, through the provision of information and psychoeducational interventions, physical activities, use of complementary integrative practices and also the strengthening family ties as important support strategies for caregivers of people with cancer.

It is noteworthy that studies outside the review addressed the importance of support groups for family members and caregivers as another important tool in reducing caregiver burden. Thus, given the current situation of scientific production on the subject, this work highlights the lack of research on forms of care and support in the collective sphere for caregivers, especially with regard to educational support groups.

Finally, more studies are needed to validate some of the results that did not have evidence of a significant impact on the quality of life of caregivers, to deepen the theme and improve strategies to support caregivers, as they play a fundamental role in maintaining well-being and dignity of the person cared for.

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