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## REVIEW

### Family of the elderly with cancer: living with the difficulties

Família do idoso com câncer: vivenciando as dificuldades

La familia de los ancianos con cáncer: las dificultades que experimentan

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### ABSTRACT

**Objective:** to investigate how the care for the elderly with cancer has been provided by a Brazilian family. **Method:** We opted for the method of revision of literature in the bases of Lilacs, BDNF, BDTD and MEDLINE-Brazil data, using family, elderly and cancer as descriptors, during the period of 2000 to 2009. **Results:** We analyzed four studies that emphasized the aspects related to the main caretaker of elderly patients with cancer and not to the family, and the need for partnerships with health's professionals and family members. **Conclusion:** The findings show that research in this area is not yet consolidated, and it is necessary to intensify efforts for the development of evidences on the subject. **Descriptors:** Family, Elderly, Neoplasms, Family nursing.

### RESUMO

**Objetivo:** investigar como o cuidado ao idoso com câncer tem sido vivenciado pela família brasileira. **Método:** optou-se pelo método de revisão da literatura nas bases de dados Lilacs, BDNF, BDTD e MEDLINE - Brasil, utilizando os descritores família, idoso e câncer, no período de 2000 a 2009. **Resultados:** foram analisados quatro estudos que apontaram ênfase nos aspectos relacionados ao cuidador principal do idoso com câncer e não à família, e a necessidade de parcerias entre profissionais de saúde e familiares. **Conclusão:** os resultados demonstram que a pesquisa nessa área ainda não está consolidada, entendendo-se ser necessário intensificar esforços para o desenvolvimento de evidências fortes sobre o tema. **Descritores:** Família, Idoso, Neoplasias, Enfermagem familiar.

### RESUMEN

**Objetivo:** investigar la experiencia de las familias brasileñas que cuidan a los pacientes ancianos con cáncer. **Método:** Hemos elegido el método de revisión de la literatura en las bases de datos LILACS, BDNF, y MEDLINE BDTD - Brasil, usando como palabras claves: familia, anciano e cáncer en el período 2000 a 2009. **Resultados:** Se analizaron cuatro estudios que mostraron un énfasis exclusivo en el cuidador principal de pacientes ancianos con cáncer y no de la familia. **Conclusión:** Los resultados demuestran que la investigación en esta área no son concluyentes, que requieren esfuerzos para desarrollar una fuerte evidencia sobre el tema. **Descriptor:** Familia, Anciano, Neoplasias, Enfermería de familia.

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## INTRODUCTION

The increased number of elderly in the Brazilian population is something that draws attention for its characteristics and consequences, especially those related to chronic diseases and the demand for care of this population. Although this is not exclusive to Brazil, it is a universal phenomenon; the increase in population size over 60 years comes along with some peculiarities due to the speed with which this process occurs, creating a lack of training and infrastructure.

In developed countries, aging is occurring gradually, accompanied by improvements in the coverage of the health system, housing conditions, sanitation, work, food and social security. In Brazil, it occurs rapidly and in a social inequality background, fragile economy, with poor access to specialized support services and limited financial resources, without the structural changes which corresponds to the demands of the new emerging age group.<sup>1</sup>

If, on one hand, population aging has brought the benefits of greater longevity on the other, it has brought a new profile of morbidity and mortality, characterized by a significant increase of chronic diseases.<sup>2</sup> Among the non-communicable diseases and conditions that predominate in health statistics we can highlight heart disease, cancer, cerebrovascular diseases, diabetes, hypertension, depression, panic disorder, neuroses and psychoses, alcohol and legal and illegal drugs, accidents and violence.<sup>3</sup>

Special attention may be given to neoplasms, which are the second cause of death. In the elderly, age advancing is a high risk factor for cancer, with estimates of people over 65 accounting for 60% of malignant tumors diagnosed and 70% of cancer deaths.<sup>4</sup>

In Brazil, the distribution of different types of cancer suggests an epidemiological transition in progress, and the estimated new cases for the year 2008, according to the National Cancer Institute was of 231,860 cases in men and 234,870 cases in women.<sup>5</sup>

Chronic diseases like cancer may represent a threat to life resolutions of people, especially when regarding elderly people who are organically weak, because cancer requires strict control in their lifestyle, and constant vigilance over the signs and symptoms that if not controlled, may lead to serious situations and even death.<sup>6</sup>

Assistance to cancer patients and their families is conceived as a complex and painful experience that cannot be explained only by the disease, but it often requires radical changes in personal life, changing at some level, their social and family roles, which may bring consequences to the family. The more advanced the disease, the greater the suffering of the patient and other family members. Thus, specific demands made to families may become greater, since the dependence increases as well as the need for care of patients.<sup>7</sup>

The increasing elderly population affected by chronic diseases in Brazil and the world, as well as the impact of cancer in the sick individual and his/her family represent a topic of great importance since it indicates the need for improvements in cancer care to also take the family as the object of care.

### Goal

This study aimed to investigate how the care the elderly with cancer has been experienced by the Brazilian family. Therefore, we decided to conduct a literature review, which is a method widely used to identify existing evidence, supporting the practice of health care in different specialties.<sup>8</sup>

## METHODOLOGY

The evidence-based practice (EBP) is a new paradigm in health care services that has recently emerged in the international literature in the field. The EBP easily applies to nursing classes and other health professionals because it incorporates the best evidence for clinical experts to assess the individuality of the patient and family.<sup>9</sup>

Choosing EBP as a theoretical framework, enables the search for evidence about the family of the elderly with cancer, makes gaps in knowledge show up, and synthesize the knowledge produced to plan and properly assist these patients in order to improve the quality of life.<sup>9</sup>

For this revision we covered the following steps: identification of the subject and selection of research hypothesis, establishment of inclusion/exclusion criteria of articles (sampling), definition of information to be extracted from articles (categorization of studies), evaluation and interpretation of the included studies, presentation of the integrative review (synthesis of knowledge).<sup>10</sup>

Considering all the aforementioned factors and the fact that traditionally in Brazil caregivers are the elderly's family, we came up with the following question: How cancer in the elderly has been experienced by the Brazilian family?

Regarding the selection of texts, we conducted a survey online, using the Lilacs (Latin American Literature in Health Sciences) national databases, BDEF (Bibliographic Database Specializing in the area of Nursing Brazil) and BDTD (Brazilian Digital Library of theses and Dissertations), considering that these are the main bases for Brazilian health. We also did research on MEDLINE (Medical Literature Analysis and Retrieval System), however on this basis, in addition to the subject descriptors we also used the "country of publication" - Brazil to set a limit, since it is a review of studies regarding Brazilians.

To do the research on the texts we used the following descriptors (DECs): family, elderly and cancer using the Boolean expression *and*. We included studies published in Portuguese between 2000 and 2009. The texts we did not find online were requested via Bibliographic Commuting Program (COMUT).

We excluded works that have appeared repeatedly in the four bases surveyed. Also, one of the articles did not regard the elderly with cancer, even though it was found in the research, so it was excluded.

We developed a data collection form, which was completed for each job in the study sample. The form allowed us to obtain identifying information of the text - title, category, journal name or place of defense, volume, number and year of publication, pages and identifying data of the authors - name, job category, place of work, in addition to analysis of the article - goals, design, characteristics of the study and synthesis of knowledge produced.

Para eliminar possível viés, todos os autores do presente manuscrito participaram do preenchimento do formulário, buscando um consenso de opiniões.

To eliminate possible bias, all authors of this manuscript participated in the completion of this form, seeking a consensus of opinion.

## RESULTS AND DISCUSSION

This review analyzed four studies that met the inclusion criteria previously established, and then presented an overview of these.<sup>11,12,13,14</sup>

Of the total studies reviewed, two correspond to scientific articles and two to dissertations. Among the articles, one was published in a journal of psychology and the other in a journal of health. The dissertations are from two public universities.

Regarding the design of the studies, out of the four studies found, only one used qualitative methodology<sup>12</sup>, two are literature reviews<sup>11,13</sup> and one is a quantitative research.<sup>14</sup> We can easily see that this is a little explored field, since only one study uses qualitative methodology; therefore, it focuses on relationships, representations, perceptions and opinions. This constitutes a method with theoretical foundation, usually used to reveal little-known processes related to particular groups.<sup>15</sup> Thus, we can say that it is a field that is still evolving, but it has a lot to contribute and be investigated, as we that can see from the results of the studies.

Regarding the publication period, each work has been published on a date. There was a paper published in 2002 and the other from 2004 to 2006 (one each year). This fact indicates that, although still little explored, this issue has been addressed more recently.

Tables 1 and 2 show a summary of the studies included in the integrative review.

**Table 1 - Summary of studies included in the review: Part 1. São Carlos, 2010.**

Title	Goal	Synthesis of knowledge produced
Caregivers of elderly patients with advanced cancer: a hacked actor <sup>11</sup>	To characterize, based on the literature review, the problems encountered during the work performed by family caregivers of elderly patients with advanced cancer. It also present some proposed interventions.	The studies in the review revealed that the primary caregiver of the elderly with cancer is the family which is responsible for the majority of care and the elderly was helped out with small tasks by other members. It turned out to be a great burden to caregivers, including health threats. The financial burden and the changes in the family routine were highlighted. There is a need for further studies in this area with respect to the burden of caregivers of elderly patients with advanced cancer, with the implementation of programs to protect these important social actors.
Family experience regarding the elderly with cancer <sup>12</sup>	To know the experience of low-income family groups with cancer in the elderly and describe the organization of these families regarding the care provided to this patient.	Families stressed that cancer is a disease that carries stigma and fear of death. Faith was highlighted as a source of support in difficult times. Family disorganization was observed soon after diagnosis and its reorganization over time. Regarding the difficulties, we can highlight financial problems followed by chemotherapy side effects and lack of transportation to services. It was concluded that professionals must turn to the family, with a closer approach which can minimize some reported aspects.

**Table 2 - Summary of studies included in the review: Part 2. São Carlos, 2010.**

Title	Goal	Synthesis of knowledge produced
Caregivers of elderly patients with advanced cancer: a bioethics approach <sup>13</sup>	Describe what has been described in the literature on caregivers of elderly patients with advanced cancer, their relations scenario, the negative and positive consequences of their daily work and proposed interventions related to ethics and/or bioethics.	The study provides an overview of the caregiver, characterizing him, showing what their difficulties and constraints are due to the role he voluntarily or involuntarily assumed. Being a caregiver not only brings up chores, but it also may end up giving light to the meaning of their lives. The text points to the need for measures that protect the welfare of the caregiver of the elderly with cancer; implementation of palliative care; housing support to meet either the patient and the caregiver and their possible changes, including the creation of new hospital beds if the caregiver is unable to continue his role and the creation of protection measures by health policies managers, including financial support.
Caregiver profile of elderly patients with cancer <sup>14</sup>	Bring up family caregivers profile of the elderly, analyse how they provide care and what are the difficulties.	The study reaffirms that care for elderly patients with cancer is done by the family, especially one of the members, which in most cases is a daughter or the wife of the elderly. The financial issue, the overhead functions, withdrawal from social activities and leisure and learning with practical and emotional demands of care ultimately change the caregiver health and the family welfare. The author indicates that there is change in the family routine to meet the sick member and little is offered, regarding the health teams as well as social policies to assist in this care.

As can we can see in Tables 1 and 2, according to the goals of the studies, the majority (three) seeks to find aspects related to primary caregiver of the elderly with cancer, for example, the problems they encountered in the care process, the interventions/treatment choices proposals, the profile of caregivers, performance of activities, changes in their lives, setting of care, positive and negative consequences of care, how care is provided and difficulties.<sup>11,13,14</sup>

One study tried to rescue the image of family as a whole, seeking to find the family experience to the disease and how it is organized to take care of the elderly.<sup>12</sup> We emphasize that only this study sought to interview the family, and the others only focused the point of view of the primary caregiver. The family-centered care image is considered recent in nursing care.

Literature reviews allow us to know more about the field of research, and the two review studies<sup>11,13</sup>, show research on this topic, but most are owned by international databases, which may point to a lag in production of articles related to this area in the Brazilian literature.

The reviews present studies pointing to overhead, development of multiple functions and health care threats that an elderly with cancer may bring to the primary caregiver. The financial difficulties, caused by the adverse effects of the disease, the decrease in leisure activities as well as the lack of transportation to perform the treatment and monitoring difficulties and restrictions were reported by caregivers. As a positive factor, they pointed out that the disease can strengthen ties among family members, and may even give meaning to the life of the caregivers.

Traditionally, the woman takes care of the sick family member (wife or daughter), which was confirmed in a study analysed here and in a previous study.<sup>14,16</sup> It was also pointed out that the choice to become caretaker is usually not taken arbitrarily, but depends on the economic and social situation of each family<sup>(11)</sup>. This woman may have a job, two families, be aged and despite it all, she is the one

who takes care.<sup>12</sup>

In the study which focus was on the family, it was mentioned that the disease comes along with a lot of stigma and fear and the family becomes disorganized when the diagnosis is made, however, with time, it gets back to place.<sup>12</sup>

The use of scales that assess the caregiver stress, getting to know most vulnerable caregivers and to plan more focused interventions, respecting diversity of values and experience of each family have been suggested and may help to minimize damage.<sup>11,13</sup>

The papers mention the need for partnership between health professionals and caregivers/family, creating public policies for interdisciplinary planning of health and home care and follow-up of patients and families. They also point to the need of supporting household and an ambulatory support to meet the caregiver when he/she feel unable to continue the caring process.

It is suggested that bioethical issues related to the caregiver of elderly patients with advanced cancer are included in the agenda of these policies, and that professionals take into consideration the faith and spirituality of the family as a support strategy.<sup>12,13</sup>

Some studies have identified the need for more research on caregivers of elderly patients with advanced cancer, characterizing it from the Brazilian reality in order to know the universe of conflicts and needs.<sup>11</sup>

## CONCLUSION

Given the goal of this study, we observed that the experience of the Brazilian family in relation to the elderly with cancer confined mostly to aspects related to the primary caregiver for the elderly. Only one of the studies brought back the image of the family as a whole.

We can highlight one important point regarding the relation to the care of the elderly with cancer which is the need for health professionals to establish some partnership with families so that care may be more complete. This partnership should be both domiciliary and ambulatory when needed.

Although the family may fall apart when initially facing the diagnosis, family structure may reorganize with time and may even help to bring the members closer due to the illness. This is another point that should be considered by health professionals treating elderly with cancer, in order to direct efforts to strengthen this approach and support among family members, since the disease still carries a lot of stigma and fear.

By the featuring of the reports analyzed, it is considered that there are few studies with Brazilian families of elderly with cancer due to gaps in knowledge production. Therefore, it is necessary to identify research priorities in the area for the construction of knowledge in areas lacking scientific basis, and thus prevent the development of isolated studies, which bring little contribution. Furthermore, it is necessary to intensify efforts to develop research with designs that produce strong evidence for the investigated theme, especially in the reality of practice attention to Brazilian families.

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