

THEORETICAL REVIEW

EVENTS THAT INTENSIFY AND REDUCE STRESS IN FAMILIES OF PATIENTS WITH CANCER: AN INTEGRATIVE REVIEW

EVENTOS INTENSIFICADORES E REDUTORES DO ESTRESSE EM FAMÍLIAS DE PACIENTES COM CÂNCER: REVISÃO INTEGRATIVA

EVENTOS INTENSIFICADORES Y REDUCTORES DE ESTRÉS EN FAMILIAS DE PACIENTES CON CÁNCER: UNA REVISIÓN INTEGRADORA

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ABSTRACT

The present study aims at identifying the events that intensify and reduce psychological stress in relatives of patients with cancer. An integrative bibliographical review of scientific articles indexed in the Virtual Health Library and the United States National Library of Medicine database was carried out. Among the 1108 studies analysed, 28 articles were selected. Data was analysed and classified in two categories according to content analysis: "intensifiers of psychological stress", and "reducers of psychological stress". Results identified the problems and needs of families that live with and care for cancer patients as well as measures that facilitate coping with it, which is vital for a more effective and systematized care to those individuals.

Keywords: Cancer; Family; Psychological Stress; Nursing.

RESUMO

O presente estudo teve por objetivo identificar os eventos intensificadores e redutores do estresse psicológico em familiares de doentes com câncer. Foi realizada revisão integrativa de literatura que incluiu artigos científicos indexados nas bases da Biblioteca Virtual de Saúde e da US National Library of Medicine. Entre os 1.108 trabalhos encontrados, foram selecionados 28 artigos. Os dados foram analisados e dispostos em duas categorias, de acordo com análise de conteúdo: intensificadores do estresse psicológico e eventos redutores do estresse psicológico. Os resultados demonstraram que identificar os problemas e necessidades das famílias que vivenciam o câncer em seus lares, bem como os eventos que facilitam seu enfrentamento, torna-se fundamental para a prestação de um cuidado mais sistematizado e efetivo a essas pessoas.

Palavras-chave: Câncer; Família; Estresse Psicológico; Enfermagem.

RESUMEN

El presente estudio tuvo por objetivo identificar los eventos intensificadores y reductores de estrés psicológico en familiares de enfermos con cáncer. Fue realizada una revisión integradora de literatura que incluye artículos científicos indexados en las bases de la Biblioteca Virtual de Salud y US National Library of Medicine. Entre los 1108 trabajos encontrados fueron seleccionados 28 artículos. Los datos fueron analizados dispuestos en dos categorías, de acuerdo con el análisis de contenido: Intensificadores del estrés psicológico y Eventos reductores del estrés psicológico. Los resultados indican que es fundamental identificar los problemas y necesidades de las familias que viven el cáncer en sus hogares, así como los eventos que facilitan su enfrentamiento, para brindar cuidados más sistematizados y efectivos a estas personas.

Palabras clave: Câncer; Família; Estrés Psicológico; Enfermería.

INTRODUCTION

The appearance of a disease within the family circle causes many changes in its structure. If the disease is cancer, the situation is intensified because of the stigma faced by patients and the suffering it causes them and their family.¹ The thought of losing a loved one to cancer produces high levels of stress. Emotionally, the family is profoundly affected maybe because it is the first time they experience death in their midst.²

The diagnosis of the disease triggers changes in the whole family group and all members, to a greater or lesser degree, are affected by a novel situation.³ The family's daily routine is affected since the time that was once available for different activities⁴ is now spent in taking care of someone with cancer.

Caring for a cancer patient is, according to the families, an exhausting and stressful task given the emotional involvement it implies. The relationship that was once based on previous reciprocity turns into one based on dependency.⁵

Many studies identified depression, sleep disorders, fear, significant use of psychotropic drugs, breaking up of relationships, isolation, loneliness, reduced social participation and less satisfaction with life⁶ within the family. This context highlights the importance and need for an appropriate psychosocial support in order to prepare and empower family members to act in the process.⁷

Given the emotional impact caused by cancer, it is extremely important to identify the situations that affect family life and the supportive measures that might protect these individuals, in order to minimize their stress.

Therefore, the aim of this study is to identify events that intensify and those that reduce psychological stress in relatives of patients with cancer. Such events are described in national and international scientific journals.

Researchers believe that knowledge gained from the present study may contribute to broadening the understanding of health professionals about the difficulties faced by families experiencing cancer and to become aware of supportive measures to alleviate their suffering.

METHODOLOGY

This study is an integrative literature review, a research method which is characterized by a systematic search, critical evaluation and synthesis of published studies on a specific topic. Integrative reviews reveal knowledge gaps that need to be filled with new studies.⁸

The following steps were considered: selection of thematic issues; data collection via search in electronic databases (inclusion and exclusion criteria were established for selecting the sample); development of a data collection instrument with information of interest to be extracted from the studies; critical analysis of the sample, data interpretation and presentation of results.⁸

The following guiding questions were applied: "According to the studies, which are the events that intensify psychological stress in relatives of patients with cancer?" and "According to the studies, which are the events that reduce psychological stress in relatives of patients with cancer?"

Selection of thematic issues was carried out from March to May 2012 and included articles published up to December 2011. Searches were conducted through the *Virtual Health Library* (VHL) and the *United States National Library of Medicine* (PubMed). *Latin American and Caribbean Health Sciences* (LILACS) and *Medical Literature Analysis Retrieval System Online* (MEDLINE) were accessed through an integrated vocabulary method from descriptors standardized by the *Descritores em Ciências da Saúde* (DeCS) "Família", "Câncer", "Estresse Psicológico"; and by the corresponding ones in the *Medical Subject Headings* (MeSH): "Family", "Neoplasms" and "Psychological Stress".

Selection criteria prioritized full texts available in Portuguese, English or Spanish. In order to ensure the inclusion of articles that corresponded to the subject investigated, the texts were selected after reading their title or abstract. In case of doubt, the article was read in its entirety.

The development of the data collection instrument was based on a validated instrument for integrative reviews adapted to this study.⁹ It includes data such as the database in which the article was indexed, the article title, authors' names, the journal where it was published, year of publication, the design methods employed by the authors and the main results. Each article was classified on a Microsoft® Excel 2010 spread sheet to organize the identified information.

The VHL provided 336 studies and PubMed, 772; only 180 presented full-text articles. These publications were selected after careful reading of titles and abstracts to confirm whether they were in accordance with the guiding questions. A total of 37 articles were pre-selected and read in their entirety; 27 were selected (Figure 1). After definition of the final sample, each selected study received a code with an alphanumeric sequencing (A1, A2... A27) to facilitate their subsequent identification.

The current study uses public domain information available in Internet databases; it does not, therefore, require confidentiality.

RESULTS

The analysis of the texts demonstrated that 23 (82.1%) articles were indexed in MEDLINE and only five (17.9%) in LILACS. The sources of articles included 22 different publications. Among them, there were eight psychology and psychiatry magazines (36.3%) and five nursing journals (22.7%).

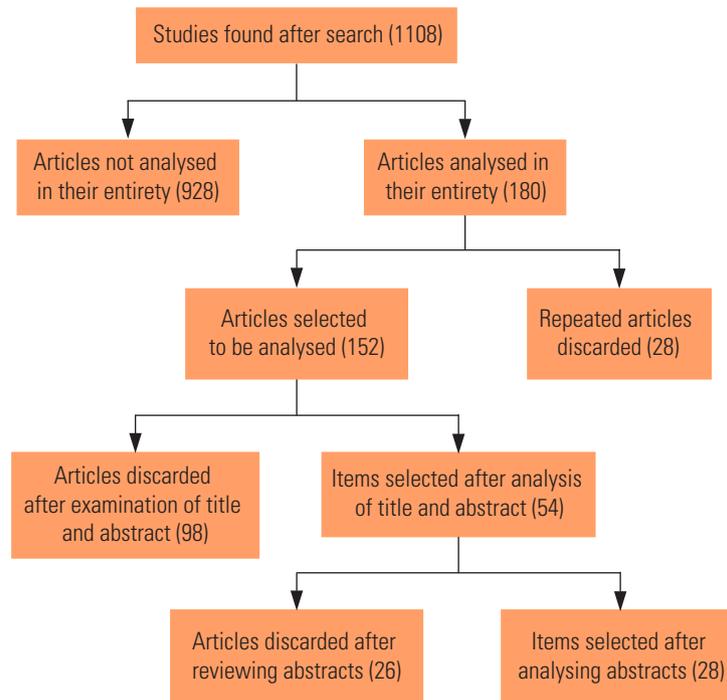


Figure 1 - Selection process of articles to be analysed. Source: study's data.

As for the year of publication, nine articles were published in 2010 and 2011 (57.1%); two in 2005, 2006, 2008 and 2009 each (28.6%); 2005 and 2007, one in each (7.1%). Nine articles (32.1%) were published in the United States; Canada and Brazil presented four each (14.3%); Australia, three (11.1%); and other countries, (28.6%) eight (Table 1).

Among the selected articles 23 were written in English (82.1%), four (14.3%) in Portuguese and one (3.6%) in Spanish (Table 2).

Results described in the analysed articles were grouped into two categories: "events that intensify psychological stress in families of patients with cancer" (Table 3) and "events that reduce psychological stress in families of cancer patients" (Table 4).

Table 1 - Distribution of articles on psychological stress in families of cancer patients, 2002-2011 – Maringá – PR, 2012

Nº	Authors	Journal	Country	Year
A1	Hughes <i>et al.</i> ¹⁰	BMC Cancer	Australia	2011
A2	Silva <i>et al.</i> ¹¹	Ciênc. saúdecoletiva	Brazil	2011
A3	Klassen <i>et al.</i> ¹²	Int J Cancer	Canada	2011
A4	Dempster <i>et al.</i> ¹³	Psychooncology	Ireland	2011
A5	Zwahlen <i>et al.</i> ¹⁴	Psychooncology	Switzerland	2011
A6	Ezer <i>et al.</i> ¹⁵	Psychooncology	Canada	2011
A7	Madsen <i>et al.</i> ¹⁶	Eur J Cancer Care (Engl)	Denmark	2011
A8	Power <i>et al.</i> ¹⁷	J Genet Couns	Canada	2011
A9	Ge <i>et al.</i> ¹⁸	Psychiatry ClinNeurosci	China	2011
A10	Hawkes <i>et al.</i> ¹⁹	BMC Cancer	Australia	2010
A11	Witt <i>et al.</i> ²⁰	Qual Life Res	USA	2010
A12	Segrin <i>et al.</i> ²¹	Res Nurs Health	USA	2010
A13	Silva <i>et al.</i> ²²	Rev Lat Am Enfermagem	Brazil	2010
A14	Fitzell <i>et al.</i> ²³	Psychooncology	Australia	2010
A15	Hasson-Ohayon <i>et al.</i> ²⁴	Psychooncology	Israel	2010

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Table 1 - Distribution of articles on psychological stress in families of cancer patients, 2002-2011 – Maringá – PR, 2012

Nº	Authors	Journal	Country	Year
A16	Faria <i>et al.</i> ²⁵	Estud Psicol (Campinas)	Brazil	2010
A17	Garlo <i>et al.</i> ²⁶	J Am GeriatrSoc	USA	2010
A18	Krikorian <i>et al.</i> ²⁷	Av Enferm	Colombia	2010
A19	Jobe-Shields <i>et al.</i> ²⁸	J DevBehavPediatr	USA	2009
A20	Bruera <i>et al.</i> ²⁹	Cancer	USA	2009
A21	Stehl <i>et al.</i> ³⁰	Neuro Immune Modulation	USA	2008
A22	Pai <i>et al.</i> ³¹	J PediatrPsychol	USA	2008
A23	Beck <i>et al.</i> ³²	Rev Bras Enferm	Brazil	2007
A24	Grossi <i>et al.</i> ³³	Health Qual Life Outcomes	Italy	2006
A25	Daneault <i>et al.</i> ³⁴	Can Fam Physician	Canada	2006
A26	Ko <i>et al.</i> ³⁵	Support Care Cancer	USA	2005
A27	Eton <i>et al.</i> ³⁶	Cancer	USA	2005
A28	Valdimarsdóttir <i>et al.</i> ³⁷	British Journal of Cancer	Sweden	2002

Table 2 - Distribution of articles according to methodological design, 2002-2011 – Maringá – PR, 2012

Methodological Design	Nº	%
Quantitative research	22	78,6
Qualitative research	4	14,3
Quantitative and qualitative research	1	3,6
Literature review	1	3,6
Total	28	100

Table 3 - Events that intensify psychological stress in families of cancer patients, 2002-2011 – Maringá – PR, 2012

Events	Articles
Fear of losing a loved one	A16; A23.
Changes in daily family routine	A3; A4; A7; A11; A16; A22; A23.
Witnessing the suffering of a sick relative	A17; A18; A19; A20; A26; A27; A28.
Lack of technical knowledge	A1; A7; A10; A16.
Family income affected	A13; A16; A25.
Burden of being the main caregiver	A7; A9; A25.
Being a female caregiver	A6; A7; A12; A15; A17; A21; A22.

Table 4 - Events that reduce psychological stress in families of cancer patients, 2002-2011 – Maringá – PR, 2012

Events	Articles
Support network	A3; A8; A9; A14; A15; A16; A17; A27; A28.
Feeling confident about caregiving	A2; A7; A17; A23; A26.
Spirituality	A1; A2; A16.
Early-detection of stress using assessment tools	A1; A5; A16; A17; A22; A24.

DISCUSSION

EVENTS THAT INTENSIFY PSYCHOLOGICAL STRESS IN FAMILIES OF PATIENTS WITH CANCER

Cancer is a negative event in people’s lives and poses a psychological strain to patients and their families.^{38,39} There are several changes in the family structure when one of its members is diagnosed with the disease. Such events intensify the emotional stress of those involved.

Literature review shows that, at first, the chance of losing a loved one impacts considerably on family members; cancer diagnosis is seen as predestination to death.^{25,32} The fear of a member’s death is, possibly, the main cause of stress within the family. Relatives become anxious and emotionally dysfunctional, since death represents the person’s eternal absence.

As the disease worsens, the family members witness the patient’s physical and emotional discomforts and are psychologically affected by the suffering of someone so dear and now so vulnerable. The distress of witnessing such suffering raises in them the feeling of helplessness and exacerbates the emotional overload.^{26-29,35,38}

In this context of anxiety, other stressors come into play when relatives realize that the family routine has changed. The need to adjust family’s arrangements to demands of patient care influences the emotional health of its members.^{16,25} As a result anxiety and conflicts can easily appear,²⁸ added to the difficulties of a demanding patient care¹³ and the family’s economic situation.^{25,34}

Lack of technical knowledge to care for the patient was one of the mentioned stressors.^{16,25} The family realizes that taking care of a cancer patient requires specific skills and knowledge about

the disease. Consequently, they experience anxiety, fear, hopelessness and lack of enthusiasm besides other negative feelings.⁴⁰

Cancer is also responsible for the financial decline of many families. Treatment is very expensive and often one of its contributing members needs to be absent from work.⁴ Regardless of the financial situation, the disease leads to changes in the family income which is one of the elements that intensify psychological stress.^{22,25,34} Furthermore, a recent study demonstrates that ever wealthier people are emotionally affected. A questioning attitude and unrelenting search for care show their difficulty in accepting the disease triggering further emotional distress.

In cases in which only one family member is responsible for direct care of the patient, with no support from other members, overload becomes even greater. Sometimes the family is forced to appoint a relative to be responsible for the care – the choosing criteria being kinship, empathic relationship, geographical proximity, lack of other people to perform the task or, in some cases, by self-appointment.³⁸ The studies^{16,18,26} revealed that the role of taking responsibility for a patient entails a major physical and emotional tension.

Finally, literature emphasizes gender as a factor that possibly influences the intensification of psychological stress. Some articles demonstrate that female caregivers express more suffering and have a higher level of depression than males performing the same task.^{14,16,21,31} This might be explained by the fact that, in the case of women, the caregiver's role is added up to other responsibilities (mother, wife, professional, and housewife) and, as they find it difficult to delegate, they are arguably buried by their multiple obligations.

Such marked distress among women may occur because they show their feelings differently than men. Women usually display more emotional attachment in the execution of their duties as caregivers. On the other hand, men usually show low levels of affectivity.⁴¹ Women's commitment and emotional attachment might explain this intensification of stress.

EVENTS THAT REDUCE PSYCHOLOGICAL STRESS IN FAMILIES OF PATIENTS WITH CANCER

Given the emotional burden caused by transformations inherent to the disease, the selected articles revealed that some events may act as psychological stress reducers. Patients as well as their families need support to cope with the process of the disease because they may also become ill, although trying to look strong.⁴²

Establishing a network of support for the affected families and caregivers can minimize suffering and facilitate the task^{23,25}. This may reflect positively on the health and quality of life of patients, families and caregivers⁴³. Such support may come

from other family members as well as from friends²⁴ and encompass social, economic, functional and/or emotional areas.

The research revealed that support groups are an important resource for family caregivers since they enable the creation of new links and provide distraction¹⁸. In this sense, group interventions may diminish the emotional burden to families and caregivers, providing more satisfaction and feelings of well-being.

Health care and psychosocial support is an important service for relatives of people undergoing cancer treatment^{12, 17}. Professionals providing support to caregivers should give them advice respecting their context, enabling them to be confident in attending to the patient's needs.⁴⁴ Self confidence in one's ability to provide care reduces the family's psychological stress.

Being able to identify signs and symptoms of clinical worsening and to properly handle devices and equipment reassures the family caregiver and facilitates the task⁴⁵. Information about the disease, the treatment and the required technical skills is essential since it supports the decision making process. Such guidelines may reduce the insecurity that leads to the usual anxiety common to the role of caregiver.³²

Meanwhile, health professionals should establish an effective communication with the family members, based on dialogue and sensitive listening in order to understand their feelings, actions and reactions.⁴² Studies highlight that conversations with families of cancer patients during medical visits can relieve caregivers' psychological stress. Listening to their concerns may not necessarily solve the problems but may act as a reliever from fear and tension.

Some articles suggest that spirituality reduces the family's emotional burden.^{9-11,25} Faith in a higher being could work as a supportive measure in the process against cancer. Caregivers' faith in God becomes a coping strategy, sometimes blaming Him, others turning the outcome over Him.²⁵ Nevertheless, the meanings attributed to cancer seem to be related to spiritual support as well as the acceptance of the disease. Spiritual faith helps to overcome obstacles, keep hopes up and promote wellness.⁴⁶

Finally, the study highlights that early identification of those emotionally distressed is a psychological stress reducer. The systematic use of validated assessment tools may facilitate intervention of health teams²⁵ anticipating future complications and subsidizing appropriate psychosocial referral.¹⁴

Some authors mentioned the *Distress Thermometer* (DT) as a tool used in the screening of symptoms of depression and anxiety in family members of cancer patients. It helps to meet the families' needs and to include them in programs for cancer treatment.^{10,14} The *Psychosocial Assessment Tool* (PAT), which assesses the psychosocial risk of relatives of children newly diagnosed with cancer, was also mentioned. The PAT is self-ad-

ministered. It comprises 15 questions with dichotomous categorical responses (Likert scale), it can be filled in approximately 10 minutes and has proven to be an effective screening tool.³¹

FINAL CONSIDERATIONS

The articles showed that cancer diagnosis in someone from the family causes emotional distress in the rest of the group and that several facts intensify such condition.

Although the articles deal with people from different backgrounds, the circumstances that lead to an increase in nervous tension are very similar. Consequently, categorization of events that intensify psychological stress enable identification of those that impair these individuals' quality of life.

The current study emphasizes that the fear of losing a loved one due to the disease is the main stress intensifier among family members. Witnessing physical and emotional suffering of a sick family member, changes in daily family routine, lack of technical knowledge to provide care, household income jeopardized by cost of treatment, overload of being the primary caregiver and being a female caregiver are also facts related to high emotional distress.

The study also suggests some measures to reduce stress such as a family caregiver support network, self confidence in providing safe and effective care to the patient, spirituality and early detection of stress by means of assessment tools.

Knowledge generated by the present study reinforces the need of developing patient and family-focused services. Identification of the families' key problems and needs as well as recognition of actions that facilitate coping with the disease are essential to provide more systematic and effective care.

It is of the utmost importance to understand and identify the changes in the lives of these individuals so that this information can contribute to teams, institutions and health professionals to ensure the delivery of high quality care.

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