Journal of Nursing
UFPE On Line
JNUOL
ISSN: 1981-8963

J Nurs UFPE on line.
2019;13:e241472
DOI: 10.5205/1981-8963.2019.241472
https://periodicos.ufpe.br/revistas/revistaenfermagem

INTEGRATIVE LITERATURE REVIEW ARTICLE

FACTORS ASSOCIATED WITH OVERLOAD IN FAMILY CAREGIVERS IN RADIOTHERAPY

FATORES ASSOCIADOS À SOBRECARGA EM CUIDADORES FAMILIARES NA RADIOTERAPIA

FACTORES ASOCIADOS CON LA SOBRECARGA EN CUIDADORES FAMILIARES DE RADIOTERAPIA

Daniel de Macêdo Rocha[1], *Aliny de Oliveira Pedrosa*[2], *Aline Costa de Oliveira*[3], *Claudia Daniella Avelino Vasconcelos Benício*[4], *Ítalo Arão Pereira Ribeiro*[5], *Lídya Tolstenko Nogueira*[6]

ABSTRACT

Objective: to analyze the factors associated with overload in family caregivers of patients undergoing radiotherapy treatment. ***Method:*** this is a bibliographic study, integrative literature review type, by searching the databases MEDLINE, CINAHL, SCOPUS, Web of ScienceTM and LILACS. The sample consisted of 15 primary studies, published until 2017, in English, Portuguese and Spanish. Critical analysis and synthesis of the results were performed descriptively, which allowed the classification by semantic similarity and the construction of two thematic categories. ***Results:*** it was found that factors associated with overload were related to both patients and caregivers, such as self-care deficit, clinical conditions, sleep disturbance and psychosocial pressures. Among the manifestations of overload, stress, fatigue, exhaustion and intensification of depressive and anxious symptoms were identified. ***Conclusion:*** it was evidenced that radiotherapy treatment generates overload for family caregivers, requiring educational interventions, care strategies and implementation of public health policies to minimize these effects. ***Descriptors***: Neoplasms; Radiotherapy; Family Caregivers; Cost of Illness; Nursing; Nursing Care.

RESUMO

Objetivo: analisar os fatores associados à sobrecarga em cuidadores familiares de pacientes em tratamento radioterápico. ***Método***: trata-se de estudo bibliográfico, tipo revisão integrativa da literatura, por meio da busca nas bases de dados MEDLINE, CINAHL, SCOPUS, *Web of Science*™ e LILACS. Compôs-se a amostra por 15 estudos primários, publicados até 2017, nos idiomas inglês, português e espanhol. Realizaram-se a análise crítica e a síntese dos resultados de forma descritiva, o que possibilitou a classificação por similaridade semântica e a construção de duas categorias temáticas. ***Resultados***: verificou-se que os fatores associados à sobrecarga se relacionaram tanto aos pacientes quanto aos cuidadores, sendo eles o *deficit* do autocuidado, as condições clínicas, a alteração do sono e as pressões psicossociais. Identificaram-se, dentre as manifestações de sobrecarga, o estresse, a fadiga, a exaustão e a intensificação de sintomas depressivos e ansiosos. ***Conclusão***: evidenciou-se que o tratamento radioterápico gera sobrecarga para os cuidadores familiares, sendo necessárias intervenções educativas, estratégias assistenciais e implementação de políticas públicas de saúde para a minimização desses efeitos. ***Descritores***: Neoplasia; Radioterapia; Cuidador Familiar; Ônus da Doneça; Enfermagem; Cuidados de Enfermagem.

RESUMEN

Objetivo: analizar los factores asociados con la sobrecarga en cuidadores familiares de pacientes sometidos a tratamiento de radioterapia. ***Método:*** este es un estudio bibliográfico, tipo de revisión de literatura integradora, mediante la búsqueda en las bases de datos MEDLINE, CINAHL, SCOPUS, Web *ofScience*™ y LILACS. La muestra consistió en 15 estudios primarios, publicados hasta 2017, en inglés, portugués y español. El análisis crítico y la síntesis de los resultados se realizaron de forma descriptiva, lo que permitió la clasificación por similitud semántica y la construcción de dos categorías temáticas. ***Resultados:*** se encontró que los factores asociados con la sobrecarga estaban relacionados tanto con los pacientes como con los cuidadores, siendo ellos el déficit de autocuidado, las condiciones clínicas, los trastornos del sueño y las presiones psicosociales. Entre las manifestaciones de sobrecarga, se identificaron estrés, fatiga, agotamiento e intensificación de síntomas depresivos y ansiosos. ***Conclusión:*** se evidenció que el tratamiento con radioterapia genera una sobrecarga para los cuidadores familiares, que requiere intervenciones educativas, estrategias de atención e implementación de políticas de salud pública para minimizar estos efectos. ***Descriptores***: Neoplasias; Radioterapia; Cuidador Familiar; Costo de Enfermedad; Enfermería; Atención de Enfermería.

[1,2,3,4,5,6] Federal University of Piauí / UFPI. Teresina (PI), Brazil. [1] https://orcid.org/0000-0003-1709-2143 [2] https://orcid.org/0000-0002-1396-9609 [6] https://orcid.org/0000-0003-1738-4808 [4] https://orcid.org/0000-0003-4638-2465 [5] https://orcid.org/0000-0003-0778-1447 [6] https://orcid.org/0000-0003-4918-6531

How to cite this article

Pedrosa AO, Rocha DM, Oliveira AC de, Benício CDAV, Ribeiro ÍAP, Nogueira LT. Factors associated with overload in family caregivers in radiotherapy. J Nurs UFPE on line. 2019;13:e241472 DOI: https://doi.org/10.5205/1981-8963.2019.241472

INTRODUCTION

Despite the technological, diagnostic and therapeutic advances, cancer is a public health problem, considering the incidence indicators and the physical, social and psychological compromises. Among its therapeutic modalities, radiotherapy stands out, characterized by the emission of ionizing radiation aiming at curing, remission or control of physical symptoms and which can lead to adverse events that negatively impact the quality of life, increasing the care demand.[1-2]

In this context, prolonged hospitalizations, interruption of treatment, clinical complications and dependence on care are common and affect both patients and family members who assume responsibilities as caregivers even without or with little technical-scientific preparation, representing a source support that seeks to promote health, prevent complications and provide rehabilitation.[3]

Within this segment, family caregivers are considered to take care that requires availability and dedication without remuneration or professional training, such as the monitoring of disabilities and the management of physical symptoms and side effects resulting from treatment.[4] The act of caring represents a stressor factor that, added to the chronic character of the disease, can affect the routine of care and generate physical, social, psychological and financial overload.[5]

Overload is understood as a complex phenomenon, easily perceived and that persists even when the patient responds positively to treatment. It is a multidimensional biophysical reaction that results from the imbalance of care demands in relation to personal time, social roles, physical, emotional and financial states, and may be potentiated by the lack of recognition as part of the ignored or neglected therapeutic strategy.[6]

Regarding the difficulties, this study is relevant in view of the need to identify the factors that predispose to family overload, as well as professional support, especially of the Nursing team, as the development of strategies that strengthen the bond between caregiver, health team and patient. It is also considered that the routine of care represents a condition that generates morbidity for the family caregiver, which can trigger clinical manifestations, negative impacts on quality of life and physical, psychological and social wellbeing.[7-8]

OBJECTIVE

- To analyze factors associated with overload in family caregivers of patients undergoing radiotherapy treatment.

METHOD

This is a bibliographic study, integrative literature review type, conducted by six research steps: definition of the theme and elaboration of the research question; sampling, literature search and delimitation for the inclusion of studies; data extraction; critical evaluation of included studies; analysis and synthesis of results and presentation of the review or synthesis of knowledge.[9]

The domains of the acronym PICo were used to elaborate the guiding question, considering P - population as family caregivers, I - phenomenon of interest to overload and Co - context to radiotherapy.10 Thus, this study was guided by the following question: : "What is the scientific evidence about the associated factors and the manifestations of overload in family caregivers of patients undergoing radiotherapy?".

A bibliographic survey was conducted in September and October 2017 on the following databases: Medical Literature Analysis and Retrieval System Online (MEDLINE, via PubMed®), Cumulative Index to Nursing and Allied Health Literature (CINAHL) , SCOPUS, Web of ScienceTM and Latin American Health Sciences Literature (LILACS), via the Virtual Health Library.

Controlled and uncontrolled descriptors (keywords) were selected after consulting the terms entered in the Health Sciences Descriptors Bank (DeCS), Medical Subject Headings (MeSH) and list CINAHL. The search terms were combined using the OR and AND boolean operators, which enabled the construction of the search strategy, which was adapted according to the specifics of each database. Figure 1 presents the descriptors, as well as the strategy performed at MEDLINE, which was structured for the other databases consulted according to their specificities.

Health Sciences Descriptors - DeCS		
P	Controlled	Caregivers.
	Not controlled	Caregiver; Family caregiver; Family caregiver; Family caregivers; Family caregivers; Caregivers Spouses; Spouses caregivers; Family Caregiver; Family Caregivers.
I	Controlled	Psychosocial Effects of the Disease.
	Not controlled	Burden of Disease; Burden of Disease; Burden of Diseases; Burden of disease; Disease Burden; Disease Costs; Disease Weight; Overload.
Co	Controlled	Radiotherapý.
	Not controlled	Implant radiotherapy; Implant Radiotherapy; Radioisotope Plate Therapy; Radioisotope Brachytherapy; Interstitial Radiotherapy; Intracavitary radiotherapy; Surface radiotherapy; Curiotherapy.
		Medical Subject Headings e list CINAHL
P	Controlled	*Caregivers.*
	Not controlled	*Caregiver; Carers; Carer; Care Givers; Care Giver; Spouse Caregivers; Spouse Caregiver; Family Caregivers; Caregivers, Family; Family Caregiver.*
I	Controlled	*Cost of Illness.*
	Not controlled	*Illness Cost; Illness Costs; Cost of Disease; Cost of Sickness; Sickness Costs; Sickness Cost; Disease Cost; Costs, Disease; Disease Costs; Economic Burden of Disease; Burden of Illness; Illness Burden; Illness Burdens; Costs of Disease; Burden.*
Co	Controlled	*Radiotherapy.*
	Not controlled	*Radiotherapies; Radiation Therapy; Radiation Therapies; Therapy, Radiation; Targeted Radiotherapies; Targeted Radiotherapy; Targeted Radiation Therapy; Targeted Radiation Therapies.*
P AND I AND Co		
(((("*Caregivers*"[*Mesh*]) *OR* ((((((((("*caregiver*") *OR* "*carers*") *OR* "*carer*") *OR* "*care givers*") *OR* "*care giver*") *OR* "*spouse caregivers*") *OR* "*spouse caregiver*") *OR* "*family caregivers*") *OR* "*caregivers, family*") *OR* "*family caregiver*"))) *AND* (("*Cost of Illness*"[*Mesh*]) *OR* ((((((((((((((("*illness cost*") *OR* "*illness costs*") *OR* "*cost of disease*") *OR* "*cost of sickness*") *OR* "*sickness costs*") *OR* "*sickness cost*") *OR* "*disease cost*") *OR* "*costs, disease*") *OR* "*disease costs*") *OR* "*economic burden of disease*") *OR* "*burden of illness*") *OR* "*illness burden*") *OR* "*illness burdens*") *OR* "*costs of disease*") *OR* "*burden*"))) *AND* (("*Radiotherapy*"[*Mesh*]) *OR* ((((((("*radiotherapies*") *OR* "*radiation therapy*") *OR* "*radiation therapies*") *OR* "*therapy, radiation*") *OR* "*targeted radiotherapies*") *OR* "*targeted radiotherapy*") *OR* "*targeted radiation therapy*") *OR* "*targeted radiation therapies*")).		

Figure 1. Controlled and uncontrolled descriptors used to construct the search strategy. Teresina (PI), Brazil, 2018.

Inclusion criteria were primary studies of different methodological designs, published in English, Portuguese or Spanish, without temporal delimitation, and which addressed aspects related to the burden of family caregivers regarding radiotherapy treatment. Productions retrieved in more than one database were excluded and considered only once.

Articles were accessed through the portal of journals of the Coordination of Improvement of Higher Level Personnel (Capes), in an area with recognized Internet Protocol (IP), and the search, selection and inclusion were performed independently by two reviewers, who proceeded to read titles and abstracts to ensure accuracy of the method and reliability of results. It is noteworthy that after the initial screening the productions were accessed in full for full text reading and in case of doubts about the inclusion a third reviewer was consulted.

145 articles were retrieved from which 23 met the inclusion criteria and were selected for the study. Eight duplicate productions were excluded from the databases, resulting in a sample of 15 publications for full reading and analysis. The selection, organization, storage of studies and deletion of duplicates were performed through the “Endnote Web” reference manager. Figure 2 describes the path taken to identify, include and exclude studies according to the basis consulted.

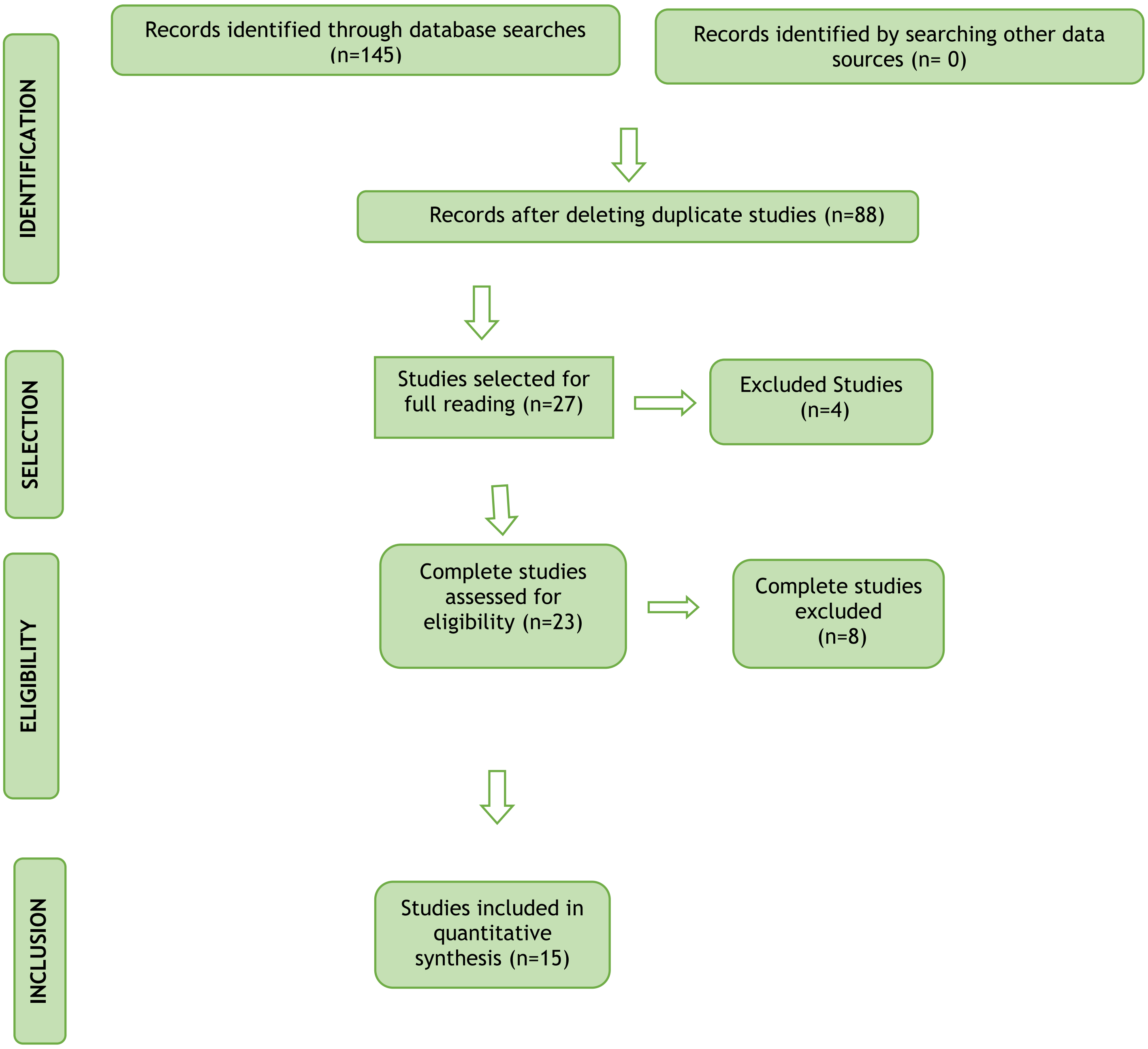

Figure 2. Study selection flowchart adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyzes (PRISMA 2009). Teresina (PI), Brazil, 2018.

The data was extracted by means of an own instrument, elaborated after identification of the variables of interest and submitted to the evaluation of three specialists for adequacy to the proposed objective, being composed by data related to the identification of the studies (authors, journal and year of publication), methodological (design and sample), main results, conclusions and level of evidence.

For the analysis of the Level of Evidence (NE), the recommendations proposed by the Oxford Center for Evidence-based Medicine were considered, which classifies the studies according to the methodological design: 1A - systematic review of randomized controlled trials; 1B - randomized controlled trial with narrow confidence interval; 1C - all or nothing therapeutic results; 2A - systematic review of cohort studies; 2B - cohort study (including lower quality randomized controlled trial); 2C - observation of therapeutic results or ecological studies; 3A - systematic review of case-control studies; 3B - case-control study; 4 - case reports (including cohort or lower quality case control); 5 - expert opinion.[11]

Critical analysis and synthesis of the results were performed descriptively, which allowed the classification by semantic similarity and the construction of two thematic categories.

RESULTS

There was a predominance of randomized clinical trials 4,[12-15] cross-sectional 4[16-9] and prospective studies 4.[20-3] The journal Cancer Nursig stood out, with three (20.0%) productions,[16,19,22] the language English, with 15 (100.0%)[12-26] and 2014, with five (33.0%).[12,15,21-22,24] It was observed, as to the level of evidence, that most of the analyzed productions 8 (53.3%) presented evaluation 2C.[16-26]

It was evidenced that the factors associated with the overload were related both to the clinical and cognitive conditions of the patients and the caregivers, being self-care deficit, care dependence, sleep alteration and psychosocial pressures prevalent. Among the manifestations of overload, stress, fatigue, exhaustion and intensification of depressive and anxious symptoms were identified.

The synthesis of knowledge was formulated into two categories: Factors associated with overload in family caregivers and Clinical manifestations and symptoms of overload presented by family caregivers of patients undergoing radiotherapy.

Figure 3 shows the distribution of the studies selected according to main author, journal, year of publication, design, sample, main results, conclusion and LE.

Category 1: Factors associated with overload in family caregivers.			
Author, journal and year	Design and sample	Main result and conclusion	LE
Johansen, Cancer Nurs, 2018[16]	Cross-sectional 281	Patient-associated conditions such as self-care deficit and sleep disorder.	2C
Nightingale, Chronic Illn, 2016[20]	Prospective 39	Psychosocial pressures faced by caregivers.	2C
Shahi, J Geriatr Oncol, 2014[12]	Randomized clinical trial 131	Patients' productive age and care dependence.	2B
Badr, Oral Oncol, 2014[21]	Prospective 49	Clinical complications and intensification of physical symptoms in patients.	2C
Bond, Cancer Nurs, 2014[22]	Prospective 23	The development of common neuropsychiatric symptoms in patients.	2C
Clark, Cancer, 2013[13]	Randomized clinical trial 117	Presence of adverse effects from treatment.	2B
Utne, Support Care Cancer, 2013[14]	Randomized clinical trial 179	Low Caregiver Hope Level.	2B
Category 2 - Clinical manifestations and symptoms of overload presented by family caregivers of patients undergoing radiotherapy treatment.			
Nightingale, Biol Res Nurs, 2017[23]	Prospective 32	Stress.	2C
Pedraza, Rev Cuid, 2015[17]	Cross-sectional 75	Exhaustion, change in eating pattern, sleep and pain.	2C
Govina, Eur J Oncol Nurs, 2015[18]	Cross-sectional 100	Depressive symptoms and suffering.	2C
Clark, Am J Hosp Palliat Med, 2014[15]	Randomized clinical trial 131	Fatigue.	2B
Stenberg, Soc Work Health Care, 2014[24]	Longitudinal 278	Depressive Symptoms and Sleep Disorders.	2C
Fletcher, Res Nurs Heal, 2009[25]	Longitudinal 82	Fatigue that intensifies at night.	2C
Mystakidou, Cancer Nurs, 2007[19]	Cross-sectional 96	Depressive symptoms.	2C
Clavarino, Aust J Rural Health, 2002[26]	Qualitative 19	Anxiety and psychological instability.	2C

Figure 3. Summary of studies included in the literature review (n = 15) on the burden on family caregivers of patients undergoing radiotherapy. Teresina (PI), Brazil, 2018.

DISCUSSION

It is observed in Brazil that care for patients undergoing radiotherapy is traditionally performed in the family, which is the primary source of support, support and strategy for coping with the disease.[31] In this review, it was found that different factors contributed to the overload of family caregivers, being predictors for greater impairment in the caregiver's physical, psychological and social health.

There is a need to look for evidence focused on humanization and qualification of care based on the effective participation of patients, families and professionals, as well as strategies that enable identifying the determining factors for overload and minimize the clinical manifestations arising from the routine care.

♦ Factors associated with overload in family caregivers

It is evident from the literature consulted that the dependence on a caregiver represents a condition that generates morbidity for the family member, due to the overload that threatens the balance and personal functioning, considering that radiotherapy treatment is performed in most cases, sometimes in an outpatient setting, requiring long-term care that can lead to adverse events, leading to the need to manage home care.[16-30]

In this segment, it is highlighted that chronic diseases such as cancer require intense action by caregivers, whether for food, leisure activities, medication administration, hygiene, follow-up consultations and clinical evaluations, requiring time and dedication of the caregiver to maintain clinical stability and the support needed for adequate rehabilitation.[31]

From this perspective, it is observed that different conditions related to the prioritization of patients' needs over those of caregivers, as well as the lack of information about the disease and treatment, were determinant to establish the degree of overload, since the routine of the treatment. Care is a frequent and complex experience, characterized by tensions, poor knowledge or technical preparation, and impairment of daily living activities, including communication, financial concerns, and emotional conflicts.[21,27]

In different studies, overload is associated with certain clinical conditions of patients who arose or worsened during treatment, such as physical symptoms, cognitive, neurodegenerative and somatic deficits, were predictive and were associated with higher levels of overload. of the family caregiver.[16,18,21-22] It is noteworthy that the presence of adverse reactions among them the development of skin lesions, the intensification of physical symptoms or sleep pattern disorders contributes to the deterioration of the patient's functional capacity and care dependence, generating a higher level of burden and requiring more attention, time and dedication from the caregiver.[13,16,21]

Functional dependence is considered a stressor and overload factor, being defined by the inability to maintain the necessary skills for self-care, independent and autonomous life. Thus, it is characterized by limitations presented by patients that threaten the balance of personal, family and social functioning in which the caregiver is inserted.[28]

Also, as a condition related to overload, is the age of the patient who, although not representing a deficit, can influence its level due to impairments in autonomy, the difficulty to recognize the condition of dependence or the need for care, mood disorders and financial impacts.[12] This result is justified by the poor acceptance of the health condition, as it is an aggressive and limiting disease, leading to the interruption of future plans and the removal of work activities.[29]

The low level of hope as a predictor for overload is also presented, as the belief in negative results was related to greater physical and social problems, such as emotional distress and weaknesses of the support network.[14] Hope and the adoption of religious practices in Oncology are one of the main strategies for the fight against cancer, being constant targets of studies in people who experience difficult situations such as the treatment of stigmatized diseases and disability.[30]

♦ Clinical manifestations and symptoms of burden presented by family caregivers of patients undergoing radiotherapy treatment

In this study, overload is described as a morbidity-generating condition in which many productions presented evidence of the influence on the mental health of this population. Thus, the psychosocial pressures resulting from the unpreparedness in dealing with the attributions of care stand out, compromising the psychological well-being, determining the manifestation of neuropsychiatric symptoms that change the priorities of life and trigger fear of the unknown, anxiety, depression. , uncertainties and low self-esteem.[22]

It is inferred, therefore, that the presence of overload in family caregivers can lead to a state of physical, psychological and social disorganization, often accompanied by negative impacts such as fear, anxiety and feelings of guilt. There are manifestations related to the high level of tension and the higher prevalence of psychosomatic symptoms such as changes in emotional state, stress, exhaustion, depression, suffering, sleep disorders, hopelessness, anxiety and fatigue.[15,17-9, 23-6]

Muscle fatigue, exhaustion, pain and changes in eating habits were also highlighted, having detrimental effects that negatively affected physical actions and led to limitations regarding the execution of activities of daily living, thus interfering with the perception in relation to their quality of life.[17] It is noteworthy that the higher the degree of dependence of the family member, the greater the intensity of symptoms generated by physical and emotional overload.[31]

Chronic stress is found to limit the performance of activities related to self-care, considering that the presence of clinical complications in patients requires greater dedication to meet the care needs, being determinant for the presence and intensity of overload symptoms.[28]

It is also considered that stress is prevalent among family caregivers, being a predictor for psychosomatic disorders, since it favors the development of psychopathological comorbidities such as mental tiredness, difficulty concentrating, memory loss and emotional indifference and influencing the type of care that the patient receives.[32]

From this perspective, it is observed that radiotherapy treatment intensified depression, anxiety, anxiety and psychological instability, which were generally associated with sleep pattern disorders, especially in caregivers who performed their function for more than three months.[18,24,26] It is noteworthy that the development of psychopathological comorbidities in family caregivers has increased in recent years, given that the caregiver cannot provide support to the patient due to lack of knowledge, insecurity in care delivery or not believing in the effect of treatment.[19]

It is identified that fatigue represents an important physical symptom described by most caregivers, being related to the hard work, the frequency in which the caregiver is asked, the specific factors of each hour, the need for excessive workload to meet the needs of the patient, care dependence and technical-scientific unpreparedness.[15,25]

Thus, it is considered that the management of care to patients undergoing radiotherapy requires preparation, dedication and demands a change in daily routine, which may be related to the process of illness of family caregivers. In this sense, the presence of symptoms resulting from overload reinforces the need for nursing interventions, considering the perceptions, difficulties and limitations arising from care, in order to provide support for the development of support networks, maintenance and health promotion.

CONCLUSION

This review shows that the physical condition of patients undergoing radiotherapy treatment represented the factor that most contributed to the burden on family caregivers, and the manifestation of physical and emotional symptoms such as fatigue, stress, exhaustion, anxiety and depression was common. This is a current and relevant theme for the development of new studies and educational actions, formation of support networks, self-care teaching and care strategies aimed at the inclusion of family caregivers as part of the therapeutic project and nursing care.

A limitation of the study is the scarcity of national productions related to the theme. It is noteworthy that the contributions of the study to the scientific field and to the care practice can give visibility to the need for physical, psychological, educational and social support to the caregivers, as well as attention within the public health policies.

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Corresponding author
Daniel de Macêdo Rocha
E-mail: daniel_m.rocha@outlook.com.br

Submission: 2019/06/28
Accepted: 2019/08/29