

INTEGRATIVE REVIEW ARTICLE

FAMILY CAREGIVER WORKLOAD WITH THE ONCOLOGIC PATIENT AND NURSING

SOBRECARGA DO CUIDADOR FAMILIAR DE PACIENTE ONCOLÓGICO E A ENFERMAGEM LA SOBRECARGA DEL CUIDADOR FAMILIAR DEL PACIENTE ONCOLÓGICO Y LA ENFERMERÍA Aline Isabella Saraiva Costa de Souza Abreu¹, Áderson Luiz Costa Júnior²

ABSTRACT

Objective: to identify the impact of caring cancer patients under palliative care and the importance of nursing in support for family caregivers. **Method:** the integrative review LILACS, Medline and PsycInfo, in articles in English, Spanish and Portuguese, in the period from 2012 to 2017, selected 14 articles by means of exploratory and critical reading of titles, summaries and results in the studies. **Results:** there were found repercussions of care: low quality of life, increasing the time aloof to the tasks and bureaucratic, forced reduction of the working day, financial problems, lack of technical knowledge, increased anxiety and depression, concern with the fall of the condition of the patient and yearning to know about the future of the patient. **Conclusion:** nursing professionals have a basic participation in the encouragement of family caregivers and identification and mitigation of stressing factors. Results of this study can contribute to the knowledge of the burden of family caregivers, allowing being directed a look on the potentiation of capacities and coursework of the same. **Descriptors:** Palliative Care; Neoplasms; Caregivers; Burden; Nursing; Patient Care Team.

RESUMO

Objetivo: identificar as repercussões do cuidar de um paciente oncológico em Cuidados Paliativos e a importância da atuação da enfermagem no suporte aos cuidadores familiares. *Método*: revisão integrativa nas bases de dados LILACS, *Medline* e PsycInfo; em artigos nos idiomas inglês, espanhol e português, no período de 2012 a 2017, selecionando-se 14 artigos por meio da leitura exploratória e crítica dos títulos, resumos e resultados alcançados nos estudos. *Resultados*: foram identificadas as repercussões do cuidar: baixa qualidade de vida, aumento do tempo desprendido para as tarefas domésticas e burocráticas, diminuição forçada da jornada de trabalho, problemas financeiros, falta de conhecimento técnico, aumento da ansiedade e depressão, preocupação com a queda do estado geral do paciente e anseio por saber sobre o futuro do paciente. *Conclusão*: os profissionais de enfermagem têm participação fundamental no encorajamento dos cuidadores familiares e na identificação e minoração dos fatores estressores. Os resultados deste estudo podem contribuir com o conhecimento da sobrecarga dos cuidadores familiares, permitindo que seja direcionado um olhar sobre a potencialização das capacidades e atribuições dos mesmos. *Descritores*: Cuidados Paliativos; Neoplasias; Cuidadores; Sobrecarga; Enfermagem; Equipe de Assistência ao Paciente.

RESIIMEN

Objetivo: identificar el cuidado a los pacientes con cáncer bajo cuidados paliativos y la importancia de la labor de enfermería a los cuidadores familiares. Método: es un examen integrador en LILACS, Medline y PsycInfo, artículos en inglés, español y portugués, período de 2012 a 2017, seleccionados 14 artículos de trabajos exploratorios y lectura crítica de los títulos, los resúmenes y los resultados obtenidos en los estudios. Resultados: fueron identificadas los efectos de la atención: baja calidad de vida, aumentado el tiempo apartado de los quehaceres y burocrática, forzada reducción de la jornada de trabajo, problemas financieros, falta de conocimiento técnico, aumento de la ansiedad y depresión, preocupación con la caída de la condición del paciente y el anhelo de conocer su futuro. Conclusión: los profesionales de enfermería tienen participación básica reforzar los cuidadores familiares e identificar y mitigar los factores de estrés. Estos resultados contribuyen al conocimiento de la carga de los cuidadores familiares, lo que les permite ser dirigida una mirada en la potenciación de las capacidades y las cesiones de los mismos. Descriptores: Cuidados Paliativos; Neoplasias; Cuidadores; Sobrecarga; Enfermería; Grupo de Atención al Paciente.

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INTRODUCTION

Cancer is a public health problem whose guess of new cases for the biennium 2016-2017 was of 600 in Brazil¹ and of 1,688,780 in the United States.² Directly related to an increase in the incidence of chronic nontransmissible disease, it has been the increase in life expectancy of the population, which, currently, it is of 75.5 years old in Brazil.3 The progression of cancer causes impact on the life of the patient to present as prevalent symptoms: pain, fatigue, anorexia, weakness, dyspnea, constipation, irritability, depression and physical deterioration.4

Considered the most prevalent symptoms and as a way to promote quality of life in patients who cope diseases causing threat to life (like cancer) and their families, we have the approach of Palliative Care (PC). PC can get as much at the beginning of the diagnosis as in the absence of treatment modifier of the disease and have to relieve symptoms and treat pain and other disorders of physical, psychosocial and spiritual order.5

The approach of PC, the person qualified to assist the patient in his needs and daily activities, regardless of having or not any level of kinship, is the family caregiver (FC).6

Family caregivers help patients in the management of treatment⁷, aiming their wellbeing. For this reason, they have as assignments: physical support for housework, bureaucratic work, maintenance transport, emotional support, social and financial assistance, among others.

Due to the energy spent in the monitoring of the patient and the responsibilities in providing their well-being, family caregivers have been affected indirectly by the disease⁸⁻ 9, with the involvement of their emotional and physical health and, as a result, with the decrease in their quality of life. characterizes workload of the caregiver, concept described in the literature since the decade of the 50's¹⁰.

OBJECTIVE

• To identify the impact of caring for a cancer patients under palliative care and the importance of the work of nursing in support for family caregivers.

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METHOD

The integrative review, using the strategy PICO (in Portuguese), acronym for Patient, Intervention, Comparison and Outcomes, which is based on the construction of a question to guide the search for evidence. 11 The guestion set was: "What are the implications of caring for cancer patients under palliative care in the FC?"

Along these lines, the strategy PICO was employed giving: to P, the family caregivers of patients with cancer under PC; to the I, the assessment of dimensions affected; to C, the comparison with the results obtained in the studies; and to the O, the result expected in research.

That's why we conducted a search in the following databases: Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE, PsycInfo, using the descriptors indexed: "caregiver, workload, neoplasia, cancer, palliative care" associated with the Boolean operators AND and OR.

It is of note the delimitation in the last five years, from 2012, to the search strategy. The inclusion criteria were: studies in which the population was composed of caregivers of cancer patients under PC and/or patients under palliative care; studies published in Portuguese, English or Spanish; and studies recorded in the databases until October 2017. There were excluded from the studies minors than 18 years of age, which is not beheld the triad theme "cancer, palliative care and relatives", as well as those who addressed "mourning", "psychological interventions" "pediatric oncology" (due to specificity of the population), Masters' dissertations, Doctoral theses, editorials, annals of congress, guidelines and studies in languages not present in the inclusion criteria.

There were found 280 articles to be consistent with the theme, of which 60 were repeated on the basis of data recorded and 203 were excluded for being aligned with the exclusion criteria. Of the 17 articles, it was not possible to have full access to the three Capes institutional stages, as shown in Figure 1.

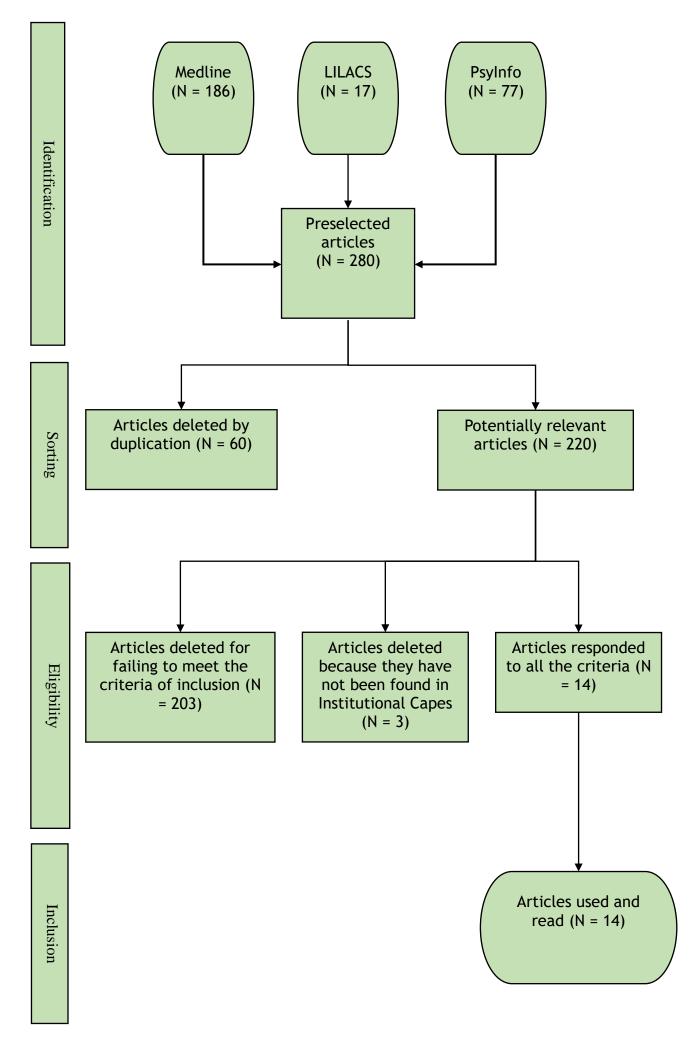


Figure 1. Flowchart PRISMA of the process of search and selection of the included studies in the Integrative Review. Brasília (DF), Brazil, 2017.

There were selected for reading 14 articles, because it met all of the inclusion criteria. The selected studies were carried out in 10 countries, being South Korea (3) and Germany (3) those showed the highest number of publications. Thirteen were published in English and only one in Portuguese.

The studies used diverse methodologies and primary data with the following search types: quantitative and transverse (7), randomized (2), prospective cohort study (2), longitudinal quantitative (2) and qualitative phenomenological (1).

The articles were selected after reading the title and summary, excluded the duplicates, those which did not meet the inclusion criteria and those which were aligned with those of exclusion. The reading was done in its entirety of the articles selected and the data were organized by means of categorizing containing data base, magazine's name, and the name of the authors, type of study, country of origin, goals, population, results and the level of evidence. Basic statistics was used for quantification of the study population.

The levels of evidence were classified according to the hierarchy of the studies, being: Level I - Evidence from a systematic review or meta-analysis of randomized clinical trials (RCTS); Level II - Evidence from welldesigned RCTS; Level III - Evidence got from well-designed clinical trials without randomization; Level IV - Evidence from casecontrol studies and cohort as well delineated; Level V - Evidence from systematic review or descriptive and qualitative studies; Level VI -Evidence derived from a single descriptive or qualitative survey; and Level VII - Evidence from opinion of authorities and/or report from committees of experts.¹²

The process of analysis of the articles was made by means of exploratory and descriptive reading of the titles, summaries and results found about the workload of FC. The interpretation and discussion were carried out in a descriptive way, depending on the purpose of the survey, which is responsible for reading the qualitative perspective of the findings.

RESULTS

The selected studies were conducted with pairs of caregivers and patients, except in three articles ¹³⁻⁵ those addressed only the caregivers. The total number of participants in the studies was of 2117 caregivers.

Several instruments were used to assess the burden of the caregiver. From these, only the Family caregiver workload with the...

Hospital Anxiety and Depression (HADS) and the Caregiver Reaction Assessment (CRA) have been cited more than once. The range of tools may be due to the diversity of countries involved in this study.

In relation to demographic features, the percentage of females who played the role of caregiver was above 50%. In relation to the level of kinship, the caregivers were divided into "wife" and "children", in greater proportion, followed by "cousins", "uncles" and "friends".

The findings show several indicative of the caregiver's workload, as the increase in anxiety and depression 13,16-9,20, increasing the distress ^{14,17,21-2}, emotionally burdened ^{9,14,17,21-} ³, low quality of life of the caregiver ^{13,15,17,19-} ²², negative thinking about the fall of the general state of the patient 16,18,20-3, negative reports: effects arising from the development of symptoms by patients 16-20,22,24,25, time spent for the chores and bureaucratic tasks $^{\rm 13-8,21,25},$ forced reduction of the working day and the consequent financial problems 8,13-6,21,23,25, longing to recognize about the future of the patient 16,18,20,23,24 and the direct relationship between greater workload of the caregiver and the low level of instruction, the (low) age 14-6,22,25 and the lack of knowledge about the subject 15,21, both on the part of the patient as the caregiver.

In the literature, we can find positive aspects of care of cancer patients in advanced stage, from the point of view of caregivers. As factors that favor the adaptation to the function of caregiver, there were described the social and emotional support ^{8,14,16,21,25}, religion ²⁵, satisfaction of caring for a person ¹⁴⁻⁵, changes of priorities in life ^{15,25}, increase in the affective bond with the patient ²⁵, sense of accomplishment and hope. ^{13,16,25}

The articles were characterized as the population, tools used, results obtained and level of evidence, as shown in Figure 2.

Author/Year/Country	Aim	Population	Applied tools	Summary of results	NE
Choi, Hwang, Hwang, Lee, Kim, Kim et al. (2016) ⁸ Korea	Investigate determinants of QOL and subdomains among family caregivers Koreans at the end of life.	299 pairs of patients and caregivers	CQOLC; HADS; Family APGAR; The Medical Outcome Study Social Support Survey.	*Caregivers of new patients are more burdened; * Emotional Overload worsens the QOL; *Positive adaptation: frequent visits, religion, social support, satisfaction with care provided;	\
Utne, Miaskowski, Paul, Rustøen et al. (2013) ¹⁶ Norway	Describe the level of workload of family caregivers.	112 pairs of caregivers and patients	HHI; HADS; CRA; EORTC QLQ 30	*Moderate level of anxiety and depression; *Workload: lack of family support and impact on daily schedule; *Hope as predictor for selfesteem and lack of family support. * Anxiety associated with pain and depression of patients; *Impact on finances linked to educational level and Comorbidities of patients.	=
Lee, Shin, Cho, Yang, Kim, Yoo et al. (2015) ²³ Korea	To assess the association between caregiver workload and self-perceived workload.	326 pairs of patients and caregivers	Caregiver Burden Inventory	*The likelihood of caregiver prefers PC increases with worsening of the patient. *Patients prefer the PC due to overload auto vision referred to the caregiversfinancial expenses, physical and emotional workload.	VI
Chua, Wu, Wong, Qu Tan, Neo et al. (2016) ¹³ Singapore	Describe the quality of life, economic aspects, mental health and factors that contribute to the workload.	16 informal caregivers	ZBI; Caregiver Quality of Life Index; Studies Depression Scale; Work Productivity and Activity Impairment Questionnaire.	*Zarit points out the impact stress in the relationship. *Depression in caregivers, poor quality of life, commitment of more than 50% of the capacity for work.	VI
Krug, Miksch, Peters- Klimm, Engeser, Szecsenyi (2016) ²⁴ Germany	Identify the correlations between the change of patient QOL and changing the workload of family caregivers.	55 pairs of caregivers and patients	Burden Scale for Family Caregivers	*Workload influenced by: dyspnea, insomnia and emotional functioning of patients. *Study failed association between reducing the quality of life of patients and increased caregiver workload.	IV
Leroy, Fournier, Penel, Christophe (2016) ¹⁷ France	Establish association between caregiver workload and self- perceived workload and effect on emotional distress between the caregiver and the patient.	60 pairs of caregivers-patients	CRA; HADS; Family Relationship Index.	*Patients underestimate the dimensions of esteem and time of caregivers; *The deteriorating health of the patient increases distress of the caregiver; *Perception of lack of caregiver's time related to depression of the patient; *Overrated anxiety/depression of patients. * Caregivers tend to hide their feelings when makes the patient.	VI
Park, Shin, Choi, Kang, Baek, Mo et al. (2012) ²⁵ Korea	Investigate determinants of workload and positivity of family caregivers of patients with	136 pairs of caregivers and patients	CRA	*The workload was on the agenda, health problems, financial problems and lack of support. *Positive: 'change of priorities', improves the bond and	VI

	terminal cancer in Korea.			sense of accomplishment. *Men accuse lower burden of "agenda"; caregivers married men have greater support; caregivers with religion have greater exchange of priorities. Increases the burden of the caregiver-advanced age, low monthly income and education, marital status unmarried, lack of support.	
Jacobs, Shaffer, Nipp, Fishbein, MacDonald, El-Jawahri et al. (2017) ¹⁸ United States	Understand the prevalence of psychological symptoms in patients newly diagnosed with no cure and their main caregiver.	350 patients and 275 caregivers	HADS		II
Schrank, Ebert-Vogel, Amering, Masel, Neubauer, Watzke et al. (2016) ¹⁴ Austria	Examine the influence of psychosocial workload on gender difference in caregivers of patients in terminal stage.	308 caregivers	ZBI; FIN; IHS; The Coping Inventory for Stressful Situations.	*Significant workload between men and women due to the tension; *Level of hope, dealing with coping and emotion-driven need for self-realization were associated with decreased workload; *Hope was a predictor for both genders. * For men, hope is correlated negatively as dealing with emotions and positively related to need for achievement.	VI
Seekatz, Lukasczik, Löhr, Ehrmann, Schuler, Keßler et al. (2017) ²¹ Germany	Trace the symptoms of overload and need support on patients and caregivers regarding the use of PC.	46 caregivers and 79 patients in the first phase	Adapted Canadian Problem Checklist; Hornheider Questionnaire for Caregiver; Distress Thermometer	* Caregivers reported high level of distress in the rating scales. * Expressed need for support and information about existing resources; * 60% changed their lifestyle; * Caregivers in CP had increased overhead and high need for support; * There was a reduction in levels of distress with caregivers in CP.	VI
Marchi, Paula, Girardon-Perlini, Sales (2016) ¹⁵ Brazil	Understand the meaning of being a family caregiver with cancer and with high dependency for daily activities.	17 caregivers	Guiding question - "How's you care (family name with cancer)?"	* The fear of discovery; * Lack of knowledge about the disease; * Carry out the daily activities of care generates permanent attention and exhausting; *The caregiver referred to be busy in the execution of tasks and lack time for you; *For humanization of care, the support, the help, the concern for feelings that the disease brings to the patient.	VI

Guerriere, Husain, Zagorski, Marshall, Seow, Brazil et al. (2016) ²² Canada	Identify the caregiver overload factors of patients in palliative care.	327 pairs of caregivers and patients	Caregiver burden scale in end of life care	*Workload increases non- linearly until the death of the patient. * Associated with the genre of the overload caregiver, caregiver education and degree of patient, male patient, level of General State, while detached to care, the costs of a caregiver, emergency department visits. * The increase in days in the hospice care was associated with fall in workload.
Mystakidou, Parpa, Panagiotou, Tsilika, Galanos, Gouliamos (2013) ¹⁹ Greece	Examine the relationship between levels of anxiety, self-efficacy and defined to be sociodemographic of the caregiver of patients with advanced cancer.	107 pairs of caregivers and patients	STAI, General Perceived Self Efficacy Scale	*Differences of anxiety VI were significant for female gender, cohabitation, relationship with the patient/partner and self-efficiency of caregivers. *Caregivers with low self-efficacy are more susceptible to high levels of anxiety.
Oechsle, Goerth, Bokemeyer, Mehnert (2013) ²⁰ Germany	To evaluate the prevalence of anxiety and depression in caregivers of cancer patients in terminal stage and investigate factors that may influence anxiety and depression.	33 pairs of caregivers and patients	Memorial Symptom Assessment Scale Short Form, GAD-7 e PHQ-9 (DSM- IV)	*55% of men and 36% of Women were classified eager of moderate to severe intensity; *Men showed levels of moderate to severe depression. *Anxiety was correlated with depression. *There was no significance relation to indexes of anxiety/depression.*There was found association between anxiety/depression of caregivers with the patient's anxiety levels and the development of symptoms from the treatment.

Caption: Caregiver QOL Index-Cancer (CQOLC), the European Organization for Research and Treatment of Cancer (EORTC), Herth Hope Index (HHI), level of evidence (NE), Reaction Assessment (CRA), State-Trait Anxiety Inventory (STAI), The Family Inventory of Needs (FIN), The Family APGAR Adaptation, Partnership, Growth, Affection and Resolve), The Integrative Hope Scale (IHS); The Caregiver's Burden Scale in End-of-Life Care (CBS-EOLC), The Zarit Burden Interview (ZBI).

Figure 2. Characteristics of articles found. Brasilia (DF), Brazil, 2017. Source: LILACS, Medline/Pubmed, PsycInfo, Jan. 2012 /Oct. 2017.

DISCUSSION

The selected studies were heterogeneous regarding objectives, methodological design and tools used to assess the workload of the FC and his quality of life (QOL), which does not allow generalizations due to the complexity of the task of caring for a family member in the imminence of death. The caregiver's burden is a theme that is under study since the decade of the 50's, having been published research in various countries,

showing a considerable concern with the subject. 10

In almost all articles surveyed in this study, except one ¹⁵, family caregivers were female. Historically, women play the role of a caregiver, resulting from the traditional task of gender and family structure inflexible. The function employed requires intimacy and care for the family in the palliative care can feel good and welcomed by the family. It is suggested that caregivers may not refuse the paper, regardless of the reason, may receive social stigmatization. ²⁶

The average age of caregivers (50 years old) was related to the degree of kinship with patients with bond of marriage, followed by direct descent. The caregiver is chosen within the family so that there are feelings of empathy and compassion in care.¹⁵

The caregivers, aiming at the promotion of well-being, the relief of suffering and the healing of patients end up being affected by physical and psychological suffering, reduce their working day and alter their routines. The difficulty encountered, the renunciation of the self, the adequacy to the new reality in favor of another and the responsibility for the organization of the patient regarding food, transportation and medication, cause stress to which the family tries to resist daily. However, as the stressor continues and burden is not managed, the body tends to adapt to the psychological and physical exhaustion, resulting in the reduction of its level of quality of life.27

The resizing of the routine care and the fear of losing loved one carries the exclusive adoption of the actions of caring, generating a loss of energy, fatigue, physical exhaustion and, consequently, the decline in the quality of care provided.²⁸

How to revert this framework is to provide support to caregivers. There is a possibility to minimize the impact generated by the lack of information about the functions to be performed and by wear of caring. This would be possible through the involvement of the family with a multidisciplinary team, which can be formed by art-therapists, social caregivers, workers, spiritual nurses, pharmacists, physical therapists, physicians, nutritionists, educationalists, psychologists, psychiatrists, tanatologists and volunteers, and the consequent establishment of a relationship of trust between the parties.²⁸

Care, in general, is the intrinsic value of a job well done, the competence and transparency of intentions.²⁹ The nursing professionals have, by primary mission, the act of caring. Especially in palliative care, nurses are directly responsible for the increase in the autonomy of the patient, listening to him and to his family and employing the maximum of apanagios of his career, such as empathy, understanding, respect and altruism, to provide well-being and transmit safety and confidence.³⁰

The family caregivers need strengthening spiritual, physical and emotional, as well as information for that feel safe to play its role. This support can be provided, in large part, by nursing professionals from members of the multidisciplinary team, whose characteristics

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of the function provide a natural bond established with patients and families, allowing the identification of weaknesses and support with attitudes, gestures and technical knowledge, and even with the engagement of other members of the team to deal with a specific problem.³¹

To take care requires a bond that provides understanding the individual's of dimensions, in order to provide relief and comfort³². It is, the multidisciplinary team provides Family Caregivers, constantly, information about the health status of the patient, to engage them in decision-making, facilitating the resolution emotional, of and social pending spiritual patient/family, respecting the wishes of belief, opinions, personal history and be open to the existential lessons of this journey.³³

The feeling of satisfaction of the caregiver brings well-being to the patient. The act of caring reveals the hidden potential and skills to multiple demands, having, as a positive factor, the normality of the routine for the family and the patient, both.³⁴

CONCLUSION

Nursing professionals, members of the multidisciplinary team, have contact with patients, relatives and FC. Thus, they have fundamental participation in the the encouragement of FC and the identification and mitigation of stress factors, in order to maximize the results to be obtained in the PC through the strengthening of FC.

Moreover, the results found in this integrative review will contribute about the knowledge of workload of FC, which would allow him to be directed a look on the potentiation of skills and assignments of FC, so that they can contribute greatly to reach better quality of life for patients and family.

Equally, it becomes necessary, for example in the countries where there were produced the articles presented in this research, the implementation of new qualitative studies, mainly, due to the low number exists about the workload of the FC and the impact on the quality of life of whole family in the context of the Brazilian reality, providing the nurse an increment in his skills and the opening of new questions about the theme.

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