

REHABILITATION NURSE INTERVENTION IN CAREGIVERS OF PEOPLE WITH DEMENTIA: INTEGRATIVE LITERATURE REVIEW

INTERVENÇÃO DO ENFERMEIRO DE REABILITAÇÃO NOS CUIDADORES DE PESSOAS COM DEMÊNCIA: REVISÃO INTEGRATIVA DA LITERATURA

INTERVENCIÓN DEL ENFERMERO DE REHABILITACIÓN EN LOS CUIDADORES DE PERSONAS CON DEMENCIA: REVISIÓN INTEGRATIVA DE LA LITERATURA

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How to cite this article: Antunes CBR, Soares JAP, Silva CPR, Rocha IARS. Rehabilitation nurse intervention in caregivers of people with dementia: integrative literature review. *Rev baiana enferm.* 2024;38:e56329.

Objective: to map and analyze the existing evidence on the role of the specialist nurse in rehabilitation nursing in the therapeutic education of the family caregiver of the person with dementia to promote the management of the therapeutic regime. **Method:** integrative literature review, in which data collection was performed in January 2023, in the EBSCO Host aggregator. **Results:** the final sample consisted of eight articles and allowed the verification that family caregivers provide better care, consequently reducing the burden of caregiver and better quality of life. **Final considerations:** in view of the specific skills of the nurse specialist in rehabilitation nursing, this can play a crucial role in the training of the caregiver, through therapeutic education, in order to promote self-care and care for the person with dementia.

Descriptors: Nursing. Dementia. Caregivers. Health Education. Rehabilitation.

Objetivo: mapear e analisar a evidência existente sobre o papel do enfermeiro especialista em enfermagem de reabilitação na educação terapêutica do familiar cuidador da pessoa com demência para a promoção da gestão do regime terapêutico. *Método:* revisão integrativa da literatura, em que a colheita de dados foi realizada em janeiro de 2023, no agregador EBSCO Host. *Resultados:* a amostra final foi composta por oito artigos e permitiu constatar que familiares cuidadores capacitados prestam melhores cuidados, havendo consequentemente diminuição da sobrecarga do cuidador e melhor qualidade de vida. *Considerações finais:* face às competências específicas do

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enfermeiro especialista em enfermagem de reabilitação, compreende-se que este poderá desempenhar um papel crucial na capacitação do cuidador, por meio da educação terapêutica, de modo a promover o seu autocuidado e o cuidado prestado à pessoa com demência.

Descritores: Enfermagem. Demência. Cuidadores. Educação em Saúde. Reabilitação.

Objetivo: mapear y analizar la evidencia existente sobre el papel del enfermero especialista en enfermería de rehabilitación en la educación terapéutica del familiar cuidador de la persona con demencia para la promoción de la gestión del régimen terapéutico. Método: revisión integrativa de la literatura, en que la recolección de datos fue realizada en enero de 2023, en el agregador EBSCO Host. Resultados: la muestra final fue compuesta por ocho artículos y permitió constatar que familiares cuidadores capacitados prestan mejores cuidados, habiendo consecuentemente disminución de la sobrecarga del cuidador y mejor calidad de vida. Consideraciones finales: teniendo en cuenta las competencias específicas del enfermero especialista en enfermería de rehabilitación, se comprende que éste podrá desempeñar un papel crucial en la capacitación del cuidador, por medio de la educación terapéutica, para promover su autocuidado y el cuidado de la persona con demencia.

Descriptores: Enfermería. Demencia. Cuidadores. Educación en Salud. Rehabilitación.

Introduction

According to the World Health Organization, there are more than 55 million people worldwide with dementia and more than 10 million new cases are diagnosed per year, being this pathology considered one of the causes that most collaborates with dependency and disability in the elderly population⁽¹⁾.

In Portugal, data indicate a growing increase in people with dementia: in 2018, there were 193,516 cases of dementia, and estimates show that by 2050, there will be about 346,905 cases, being one of the European countries that exceeds the European trend. This increase is due to the population aging⁽²⁾.

Dementia affects various cognitive functions such as memory, thinking, mentoring, understanding, calculus, learning ability, language, and judgment. With the deterioration of these skills, other losses arise, such as changes in the control of emotions, behavior and motivation⁽¹⁾.

With the loss of these functional capacities, it becomes essential the presence of a caregiver who provides support and contributes to the functional rehabilitation of this public, in order to promote the autonomy of the person with dementia. Thus, it is important to train informal caregivers and to implement recommendations that help them in their new role⁽³⁾.

In people with dementia, loss of mobility leads to loss of autonomy, namely in carrying

out activities of daily living, such as walking, dressing/undressing, going up and down stairs, among others. Functional rehabilitation promotes improvement in the activities of daily living and functional capacity of these people⁽⁴⁾.

Thus, there are seven domains to be covered in the rehabilitation of the user, one of which is the support and education of family caregivers⁽⁵⁾.

In fact, people with dementia are often left out of rehabilitation because there is a belief that they will not progress due to cognitive impairment and progress cannot be demonstrated. However, the need for functional rehabilitation in people with dementia is a current reality for the promotion of autonomy⁽⁵⁾.

The role of the Specialist Nurse in Rehabilitation Nursing (SNRN) becomes important in the deconstruction of this belief, since the rehabilitation of the person with dementia and his/her family caregiver provides quality of life, reduces the number of hospitalizations and brings benefits to both⁽⁵⁾.

In the case of rehabilitation focused on the person with dementia, there are two strands of action: cognitive stimulation and the approach of relational/emotional aspects. The SNRN must intervene in the capabilities that the person still maintains, in order to provide greater autonomy and empower the family caregiver for their maintenance. These interventions aim

to stimulate cognitive, functional, relational and behavioral capacities⁽⁶⁾.

In the case of the family caregiver, it is relevant to transmit knowledge about the disease, its management and the importance of functional rehabilitation⁽⁵⁾. In fact, the main objectives of the nurse's intervention focused on the family caregiver are: to prevent institutionalization, once the person with dementia has a better quality of life at home; to prevent caregiver overload; and improve the provision of care to the person with dementia⁽⁶⁾.

This review aims to map and analyze the existing evidence on the role of SNRN in the therapeutic education of the family caregiver of the person with dementia to promote the management of the therapeutic regime. These data are important for the future development of a protocol of action of the SNRN in the training of the family caregiver.

Method

This work was developed through an integrative literature review (ILR), which is a

research method that consists of a vast analysis of a certain topic of interest to the researcher. This approach allows broad research, since it uses empirical and theoretical studies. Thus, ILR synthesizes the investigation and draws conclusions from several sources on the same topic, which allows the researcher to have the ability to provide a more holistic understanding of a specific topic⁽⁷⁾. Because it is an ILR, it was not necessary to ask for authorization from the Health Ethics Committee, since no data will be collected from people.

ILR focuses on the topic of SNRN in the therapeutic education of the family caregiver of the person with dementia to promote the management of the therapeutic regimen, and the following research question has been developed: *What is the SNRN intervention in the therapeutic education of family caregivers of people with dementia to promote the management of the therapeutic regime?*

The inclusion criteria for articles are described in Chart 1 and were defined according to population, context, concept, type of study, language and date of publication.

Chart 1 – Inclusion criteria of the studies

Population	Context	Concept	Types of study	Language	Date of publication
Informal caregivers and family caregivers	Home	Studies that identify and describe educational strategies	All studies with full text	Studies published in Portuguese, English and Spanish	Studies published between 2018 and 2023

Source: created by the authors.

The selection of the articles that constitute the ILR was elaborated through a rigorous and systematic process. First, exploratory searches were performed in databases using indexed terms such as “caregivers”, “aged”, “dementia”, “home Nursing”, “education”, “nursing” and “rehabilitation”, to frame the theme addressed. After reading and analyzing the most pertinent articles, MeSH Terms were selected in order to build the Boolean expression for the research.

The search was carried out on the EBSCO Host aggregator, which aggregates the following databases: CINAHL Complete, MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science & Technology Abstracts, MedicLatina, Cochrane Clinical Answers.

The following Boolean expression was used: (“caregivers” OR “family members” OR “relatives” OR “informal caregivers”) AND (“dementia” OR “Alzheimer” OR “cognitive impairment”) AND (“strategy*” OR “method*” OR “training*” OR “learning*” OR “education*”) AND (“management” OR “self-care” OR “self-management”) AND (“behavior*” OR “psychologi*” OR “symptom “).

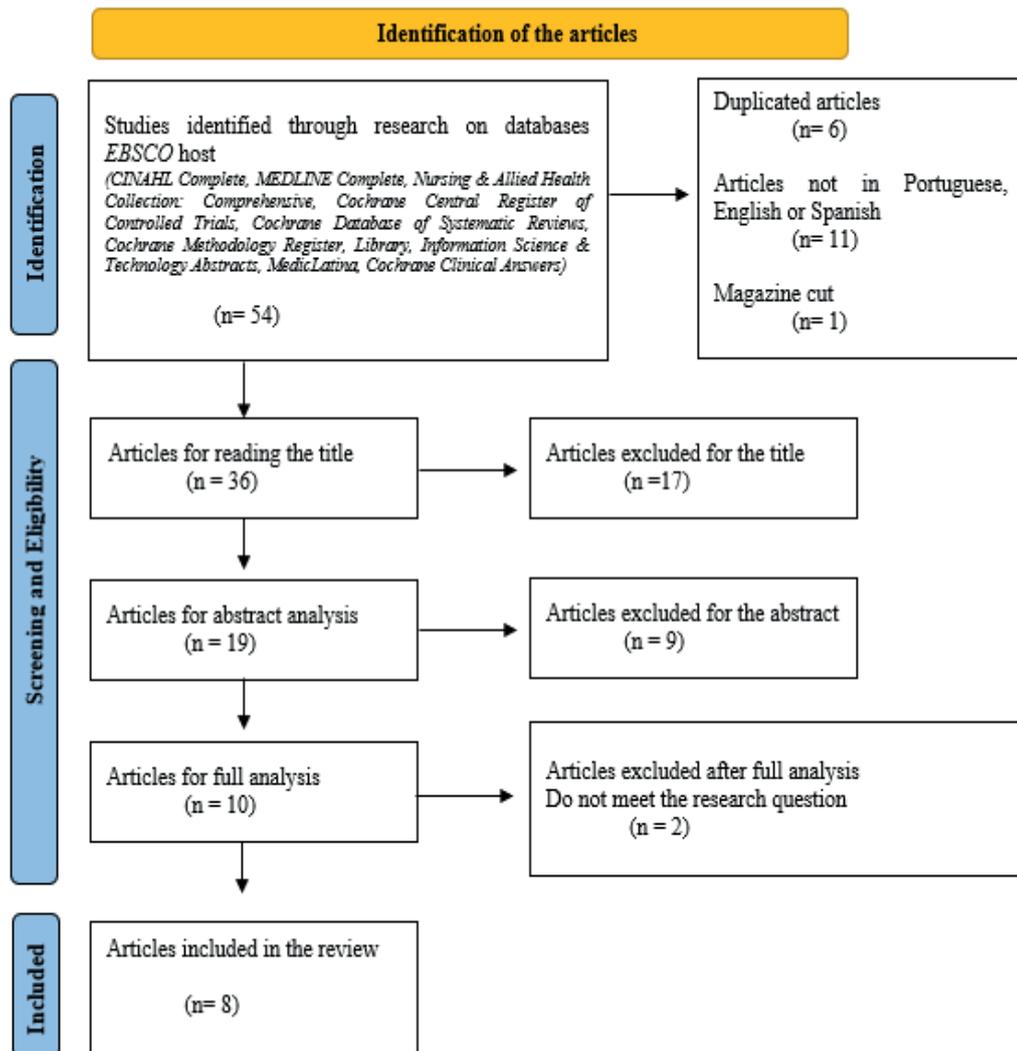
Results

The aforementioned method applied resulted in 749 evidences. By applying the temporal refiner and full text, a total of 54 articles were

obtained. Subsequently, the selection process of articles was started, excluding 6 articles that were duplicated, 11 articles that were in other languages and 1 was excluded because it is a magazine cut.

36 articles were obtained, of which 17 were excluded by reading the title. Thus, of the remaining 19 articles, 9 were excluded by reading the abstract. In the end, 10 articles were obtained that were read in full, and 2 were excluded because they did not answer the research question. This whole process is represented in the PRISMA flow diagram (Figure 1).

Figure 1 – Process of Identification of Studies – PRISMA Diagram flow



Source: created by the authors.

Chart 2 describes the characterization of the studies included in the ILR, including the name of the authors, title, journal and year of publication of the selected articles, the objectives and main results of each one. Of the selected articles, we have articles dated from 2018 to 2021, one from 2018 and 2019, and three from 2020 and 2021.

As can be seen in Chart 2, there is a large discrepancy in the objectives and main results

found. In the objectives of the articles, four of them (50%) address the topic of online training, either by applications, by e-mail or by teleconference⁽⁸⁻¹¹⁾; two articles (25%) address quality of life and burden of informal caregivers⁽¹²⁻¹³⁾; one article (12.5%) addresses the training of caregivers through thematic workshops⁽¹⁴⁾ and the other (12.5%) addresses the management of behavioral and psychological changes⁽¹⁵⁾.

Chart 2: – Characterization of the studies included in the Integrative Literature Review, according to author, year, name of the journal, objectives and main results. (continued)

N.	Authors, year, title, journal	Objectives	Main results
S1	Ramirez M, Duran MC, Pabiniak CJ, Hansen KE, Kelley A, Ralston JD, et al ⁽⁸⁾ . 2021. Family caregiver needs and preferences for virtual training to manage behavioral and psychological symptoms of dementia: Interview study. JMIR Aging	To understand the needs of family caregivers to improve the management of behavioral and psychological symptoms of dementia, and understand the extent to which caregivers perceive that STAR-Caregivers Virtual Training and Follow-up (STAR-VTF) can meet these needs.	Caregivers believe they benefit from education about behavioral and psychological changes early. Healthcare professionals do not provide enough information about the personality and behavioral changes that people with dementia may experience. Informal caregivers would likely welcome a program, such as STAR-VTF, focused on managing behavioral and psychological changes that is offered entirely virtually.
S2	Sitges-Maciá E, Bonete-López B, Sánchez-Cabaco A, Oltra-Cucarella J ⁽⁹⁾ . 2021. Effects of e-health training and social support interventions for informal caregivers of people with dementia: a narrative review. International Journal of Environmental Research and Public Health	To analyze the effectiveness of e-health programs for informal caregivers.	E-health programs increase caregivers' knowledge about dementia, leading to improvements in mental health and quality of life. Surveillance systems and telephone interventions do not appear to be useful in improving caregivers' competence in managing medication management or behavioral changes in people with dementia. As for training platforms, they have a positive impact on caregivers, increasing knowledge about dementia, reducing depression, anxiety and burden, and improving their quality of life. However, these benefits do not translate into the quality of care provided.

Chart 2: – Characterization of the studies included in the Integrative Literature Review, according to author, year, name of the journal, objectives and main results. (continued)

N.	Authors, year, title, journal	Objectives	Main results
S3	<p>Huis in het Veld JG, van Asch IFM, Willemse BM, Verkade PJ, Pot AM, Blom MM, et al⁽¹⁰⁾. 2019.</p> <p>Process evaluation of nurse-led online self-management support for family caregivers to deal with behavior changes of a relative with dementia (Part 1): Mixed methods study.</p> <p>Journal of Medical Internet Research</p>	<p>To understand the importance that family caregivers attribute to various elements of online self-management support; evaluate the satisfaction of family caregivers with the various elements; nurses' use and evaluations of online support through personalized email contacts.</p>	<p>Caregivers valued e-mail contacts with the specialist nurse and felt that these contacts were more advantageous than videos and electronic newsletters. Caregivers who received the videos and e-newsletters mentioned difficulties in translating the information and advice to their own situations. The process evaluation showed variation in the extent to which caregivers made use of the various elements of online self-management support: only 37% of caregivers selected the "electronic newsletters" option. This can be explained by the fact that not everything that is offered is used. It can also be illustrated by the low rates of use of e-newsletters by caregivers who also had email contact with a nurse and access to online videos. This indicates that caregivers do not anticipate intervention, but decide for themselves the necessary care and appropriate to their specific situation.</p>
S4	<p>Huis in het Veld JG, Willemse BM, van Asch IF, Groot Zwaartink RB, Verkade PJ, Twisk JW, et al⁽¹¹⁾. (2020).</p> <p>Online Self-Management Support for Family Caregivers Dealing With Behavior Changes in Relatives With Dementia (Part 2): Randomized Controlled Trial.</p> <p>Journal of Medical Internet Research</p>	<p>To study the effects of an online self-management support intervention to help family caregivers deal with changes in the behavior of a family member with dementia.</p>	<p>The online self-management support intervention involving email contacts did not lead to positive effects compared to online interventions without personal email contacts. Furthermore, the average intervention involving online videos and e-newsletters did not show statistical improvements compared to the smaller intervention involving only e newsletters.</p>
S5	<p>Zwingmann I, Hoffmann W, Michalowsky B, Dreier-Wolfgramm A, Hertel J, Wucherer D⁽¹²⁾. 2018.</p> <p>Supporting family dementia caregivers: testing the efficacy of dementia care management on multifaceted caregivers' burden.</p> <p>Aging and Mental Health</p>	<p>To investigate the impact of care provided to people with dementia on the multifaceted dimensions of caregiver burden, differentiating between objective and subjective burden.</p>	<p>Caregivers in the "DCM" intervention group showed decreased caregiver burden, especially in objective caregiver burden due to caregiving (i.e., emotional support), subjective caregiver burden due to behavioral change (cognition, aggression and resistance, depression , late symptoms) and subjective caregiver burden due to perceived conflicts between caregiving needs and responsibilities (financial losses) compared to caregivers in the "care as usual" control group, who showed significantly increased caregiver burden after 12 months.</p>

Chart 2: – Characterization of the studies included in the Integrative Literature Review, according to author, year, name of the journal, objectives and main results. (conclusion)

N.	Authors, year, title, journal	Objectives	Main results
S6	Söylemez BA, Küçükgüçlü Ö, Akyol MA, Işık AT ⁽¹³⁾ . 2020. Quality of life and factors affecting it in patients with Alzheimer's disease: A cross-sectional study. Health and Quality of Life Outcomes	To determine the quality of life of people with Alzheimer's disease and investigate the factors that affect the quality of life score of patients and caregivers.	There is a discrepancy between the Quality of Life (QoL) reported by the patient and the caregiver. Determined low self-assessed and surrogate QoL ratings were observed with low caregiver education and patients with functional impairment. Proxy-assessed QoL was also classified as low if the patient had advanced dementia and behavioral problems, as well as if caregivers had experienced distress-related behavioral problems.
S7	Santos MI, Leite CD, Barbosa VFB, Alves ANO, Silva Filho MC, Oliveira SSS, et al ⁽¹⁴⁾ . 2021. <i>Gerontotecnologia cuidativo-educacional: oficinas temáticas com cuidadores familiares de idosos com demência de Alzheimer.</i> Enfermagem Brasil	To promote health education in caring for elderly people with Alzheimer's disease, through thematic workshops for family caregivers.	The research contributed positively to training family caregivers of elderly people and promoting their health. Sharing the problems experienced and the support of the operating group allowed the adoption of measures related to self-care and reflection on necessary changes in the provision of self-care to people with dementia.
S8	Sperling SA, Brown DS, Jensen C, Inker J, Mittelman MS, Manning CA ⁽¹⁵⁾ . 2020. FAMILIES: an effective healthcare intervention for caregivers of community dwelling people living with dementia. Aging and Mental Health	To evaluate the effectiveness of a modified New York University (NYUC) caregiver intervention, called FAMILIES, applied to caregivers of people with dementia of various etiologies in a reduced number of sessions.	There were significant improvements in caregiver burden, symptoms of depression and their ability to respond effectively to the behavioral symptoms of the person with dementia. Different demographic factors were associated with different outcomes.

Source: created by the authors.

Discussion

The studies found showed that there is a big bet on online interventions, which allows the caregiver to remain close to the person with dementia. In studies S1, S2, S3, S4 and S8, intervention strategies are remote, but allow the family caregiver to acquire important knowledge for the management of the therapeutic regime. Family caregivers report that it is important to receive information about the management of behavioral and psychological changes caused by dementia and that access to this information with virtual training is an asset⁽⁸⁾.

Although family caregivers find it important to use online interventions, they still experience great difficulty due to their lack of knowledge about their use. First, caregivers need to have more in-depth knowledge about the technology to be able to take advantage of all online interventions⁽⁹⁾.

However, when online interventions vary in elements, not all study relatives use and benefit from this intervention. Although in the S3 there is no strong statistic for online self-management interventions, it is possible to perceive that electronic newsletters were used and valued, as well as contact by email with a specialist nurse⁽¹⁰⁾.

The validation of the acquired information and the confirmation that the management of the therapeutic regimen is being performed correctly by a specialized professional transmits confidence to the family caregiver. All the interventions of the S3 would be more valued and apprehended if the advice and online interventions were personalized for the personal situations of each caregiver⁽¹⁰⁾.

In studies S3 and S4, the caregiver attaches great importance to the presence of a specialized professional who supports and follows the entire evolution from the diagnostic phase. The nurse case manager should teach and support the caregiver throughout the process, with personalized care that meets the needs of the person with dementia and his/her caregiver⁽¹⁰⁻¹¹⁾.

According to the Regulation of Specific Skills of the Specialist Nurse in Rehabilitation Nursing, it is the competence of the SNRN to teach, demonstrate and train techniques within the established programs with the objective of promoting self-care and continuity of care in different contexts⁽¹⁶⁾.

Other studies prove that the presence of a professional who accompanies them throughout this process is facilitating, however, it is still necessary to conduct more research in order to demonstrate the effectiveness of the interventions performed by the reference professional⁽¹⁷⁾.

S5 reports that *ideal care* is based on three pillars: drug management, care and treatment management, and caregiver support and education. In this last pillar, there are four important focuses: social integration, mental health, physical health, and the social, legal and financial issue. It should be noted that each focus has specific associated interventions. The effectiveness of these interventions is reflected in the reduction of caregiver burden⁽¹²⁾.

These results are corroborated by other studies, in which the More at Home with Dementia program was implemented, which recommends 14 educational sessions to the informal caregiver, and in each one a different theme was addressed, with the aim to care for the person with dementia at home⁽¹⁸⁻¹⁹⁾. In the various

sessions, the following themes were addressed: combating social isolation; information about dementia; planning for the future; responsibility and changing roles; reminiscence techniques and guidance; communication; affirmation strategies (knowing how to deal with criticism, assertiveness); therapeutic use of activities; work organization and home security; nursing skills (incontinence, personal care, medication and mobility); physical fitness; food; self-care and use of social services. With these sessions and follow-up throughout the period defined for this program, it was found that, from the point of view of the person with dementia, there was a lower number of institutionalizations in homes, and family caregivers resorted less to other health care⁽¹⁸⁻¹⁹⁾.

On the other hand, S6 evaluates the quality of life of the caregiver and the person with dementia, stating that these should be evaluated whenever possible. The nurse should focus on the management of behavioral problems and support in functionality and cognitive functions, as these can interfere with the quality of life of the dyad person with dementia/family caregiver. Thus, programs that promote the education and training of caregivers should be implemented and, consequently, evaluated the quality of life of both actors⁽¹³⁾.

The programs applied in the articles analyzed, both online and in-person, demonstrate that there are benefits in the therapeutic education of the informal caregiver, in the promotion of the management of the therapeutic regime and in the health of the caregiver him/herself. Workshops that promote coexistence and sharing of the experiences of informal caregivers are also beneficial for the caregiver, who thus realizes that he/she is not the only one going through the same situation; several people report that they experienced feelings of support and sharing, that were central to understanding the situations experienced⁽¹⁴⁾.

All studies corroborate the importance of training the family caregiver, both for an improvement in care delivery and for reducing their burden. Based on the studies analyzed, the

importance of performing therapeutic education to the caregiver is perceived, in order to promote the management of the therapeutic regime. This education involves the teaching related to the various self-care, as well as the management of behavioral changes^(8,14-15).

These results are corroborated by another study, which states that caregivers feel the need to receive training on pathology, symptomatology management and the management of family and social relations⁽²⁰⁾.

Studies related to dementia are more framed in the pathology of mental health and cognitive rehabilitation performed by colleagues in this specialty, and may be one of the reasons why it is not explored by the SNRN.

In short, family caregivers who have the capacity to manage the therapeutic regimen of the person with dementia provide better care and have a decrease in the caregiver's burden⁽¹²⁻¹⁴⁾.

Throughout the integrative literature review, some limitations were detected, namely that the articles do not address rehabilitation in the broad sense of the word. This theme is little explored by the SNRN, especially because there is no great evolution of these users. However, we must look at the caregiver and work the dyad in its entirety.

Regarding the contributions of the study, for being an integrative literature review, it summarizes the scientific evidence produced in the area of SNRN intervention in caregivers of people with dementia. This fact is relevant as role of this health professional is clearly crucial, while there is still lack of knowledge of this subject, thus requiring more research.

Final Considerations

The analysis of the articles found allowed the conclusion that studies on rehabilitation in people with dementia are important, especially when it covers their family caregiver. The training of the caregiver for therapeutic management is extremely important for the dyad person with dementia/family caregiver.

Therefore, the SNRN should invest in the training of the family caregiver, in order to

promote his/her self-care and the care provided to the person with dementia, because the caregiver is present 24 hours a day in the care of the person with dementia and needs the knowledge, support and backup that the SNRN can provide.

It is relevant to invest in studies related to the role of SNRN in the training of family caregivers, in order to produce new knowledge for an evidence-based practice.

Collaborations:

1 – conception and planning of the project: Carolina Beatriz Ramos Antunes, José Alexandre Pinto Soares and Inês Alves da Rocha e Silva Rocha;

2 – analysis and interpretation of data: Carolina Beatriz Ramos Antunes;

3 – writing and/or critical review: Carolina Beatriz Ramos Antunes, Cristiane Pavanello Rodrigues Silva and Inês Alves da Rocha e Silva Rocha;

4 – approval of the final version: Carolina Beatriz Ramos Antunes and Inês Alves da Rocha e Silva Rocha.

Competing interests

There are no competing interests.

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- Received: September 05, 2023
Approved: June 29, 2024
Published: September 02, 2024



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