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Scientific knowledge of the nursing process for older adults living with dementia and their caregivers

Conhecimento científico sobre processo de enfermagem à pessoa idosa que vive com demência e seu cuidador

Conocimiento científico sobre el proceso de enfermería para las personas mayores que viven con demencia y su cuidador

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ABSTRACT

Objective: to map the scientific knowledge of the nursing process applied to older adults living with dementia and their caregivers. **Method:** this scoping review was conducted in three databases following the Joanna Briggs Institute. **Results:** of the 23 studies included, 11 grounded the nursing process on theoretical bases, particularly the General Self-Care Deficit Theory. Data collection instruments were found to assess psychological and behavioral symptoms, functionality and cognition/indicators of dementia. Most did not specify use of standardized language; and when they did, the North American Nursing Diagnosis Association taxonomy was the most used, predominantly in the perception/cognition, safety/protection and activity/rest domains. **Conclusion:** the findings inform the clinical practice of nursing based on current scientific knowledge and point to gaps in the use of theoretical bases and taxonomies to support the nursing process.
Descriptors: Aged; Caregivers; Dementia; Standardized Nursing Terminology; Nursing Process.

RESUMO

Objetivo: mapear o conhecimento científico sobre o processo de enfermagem aplicado à pessoa idosa que vive com demência e seu cuidador. **Método:** revisão de escopo conforme o *Instituto Joanna Briggs* desenvolvido em três bases de dados. **Resultados:** dos 23 estudos incluídos, 11 fundamentaram o processo de enfermagem em bases teóricas, com ênfase na Teoria Geral do Déficit de Autocuidado. Para a coleta de dados, evidenciou-se instrumentos de avaliação de sintomas psicológicos e comportamentais, funcionalidade e avaliação da cognição/indicativos de demência. A maioria não especificou o uso de linguagem padronizada; e quando presente, a taxonomia *North American Nursing Diagnosis Association* foi a mais utilizada, com predominância de diagnósticos nos domínios percepção/cognição, segurança/proteção e atividade/repouso. **Conclusão:** os achados subsidiam a prática clínica do enfermeiro baseado em conhecimento científico atualizado e apontam para lacunas do uso de base teóricas e taxonomias para sustentar o processo de enfermagem.
Descritores: Idoso; Cuidadores; Demência; Terminologia Padronizada em Enfermagem; Processo de Enfermagem.

RESUMEN

Objetivo: mapear el conocimiento científico sobre el proceso de enfermería aplicado a los ancianos que viven con demencia y a su cuidador. **Método:** revisión de alcance según el Instituto Joanna Briggs desarrollada en tres bases de datos. **Resultados:** de los 23 estudios incluidos, 11 fundamentaron el proceso de enfermería en bases teóricas, con énfasis en la Teoría General del Déficit de Autocuidado. Para la recolección de datos, se utilizaron instrumentos de evaluación de síntomas psicológicos y conductuales, funcionalidad y evaluación de la cognición/indicios de demencia. La mayoría no especificó el uso de lenguaje estandarizado; y, cuando presente la taxonomía de la *North American Nursing Diagnosis Association* ha sido la más utilizada, con predominio de diagnósticos en los dominios de percepción/cognición, seguridad/protección y actividad/repudio. **Conclusión:** Los hallazgos subsidian la práctica clínica del enfermero con base en el conocimiento científico actualizado y apuntan hacia las lagunas del uso de base teórica y taxonomias para sustentar el proceso de enfermería.
Descriptores: Anciano; Cuidadores; Demencia; Terminología normalizada de Enfermería; Proceso de Enfermería.

INTRODUCTION

Dementia is a clinical syndrome characterized by cognitive decline of a permanent, progressive or transient nature, which impairs individuals' autonomy and independence[1]. In 2019, it was estimated that nearly 50 million people had some type of dementia, of which 60% lived in middle- or low-income countries, such as Brazil[2]. It is noted that this condition affects around 6.5% of the world's aged population[3].

The impacts generated by dementia on older adults' life are gradual. They start with mild cognitive impairment, where everyday life tasks are still performed independently, although demanding certain effort[1]. As they progress, there is greater harm in functional capacity and in maintenance of the person's own safety, requiring the help of others to perform the activities of daily living[4].

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Family members are usually the main caregivers of aged people living with dementia; however, they are often not prepared to assume this function due to lack of knowledge, as well as to the repercussions on life[5,6]. In addition to the financial cost, comprehensive care targeted at dependent older adults can cause physical and psychological wear out[6,7]. In this perspective, family caregivers need, in a continuous and integrated way, social support, relevant information about the particularities of dementia in older adults and, above all, guidelines to improve their quality of life.

Thus, the importance of Nursing assistance in the care provided to older adults with dementia and their caregiver is evidenced. To be efficient and effective, this assistance must be systematized through the Nursing Process (NP), which represents the main methodological instrument for the performance of nurses' professional practice[7-9].

In this scenario, it becomes necessary to conduct studies that support Nursing care targeted at the health of this population segment and which, at the same time, direct actions and guidelines for the family members involved in care. This scientific basis can ground the Nursing team's work in order to devise interventions that favor health management and care in these individuals and their caregivers.

Thus, a scoping review is considered to be a useful tool for the identification and synthesis of scientific knowledge, enabling the planning of care actions for aged people living with dementia and their caregivers based on evidence-based practice[10]. In addition to that, evaluation of the studies can target priority areas that need to advance in terms of the knowledge about the theme.

The objective of this study was to map the scientific knowledge about the NP applied to older adults with dementia and their caregivers.

METHOD

The current study is based on a scoping literature review, following the Joanna Briggs Institute protocol[10].

The *Population, Concept and Context* (PCC) strategy was used to formulate the research question, where P corresponds to older adults/caregivers, C to the NP and C to dementia. The guiding question was the following: "Which is the scientific knowledge about the NP applied to older adults with dementia and their caregivers?".

The following inclusion criteria were adopted: original articles, case reports, case series, and opinion and reflection articles. Review studies and letters to the editor were excluded.

The following databases were selected for this mapping: *National Institutes of Health* (NIH/PubMed), *Cumulative Index to Nursing and Allied Health Literature* (CINAHL) and *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS). The controlled and uncontrolled descriptors from each of these databases were defined and an advanced search was performed, which ended on July 22nd, 2022, using the "*AND*" and "*OR*" Boolean operators, without introducing filters regarding year or language limits. It is noted that the controlled descriptors (*Medical Subject Headings*, MESH) were used as references for the other databases, namely: "*aged*"; "*caregivers*"; "*dementia*"; "*nursing process*"; and "*standardized nursing terminology*".

The studies found in the databases were imported into the *Clarivate Analytics EndNote* program (https://access.clarivate.com/login?app=endnote), in order to identify and exclude duplicate articles. After exclusion, the *Rayyan* program (https://rayyan.qcri.org/welcome) from the *Qatar Computing Research Institute* was used to manage and select the final sample.

The studies were first evaluated based on their titles and abstracts. Those that met the inclusion criteria were analyzed in full to select the final sample and, subsequently, to extract the data from the studies included in this scoping review.

To this end, a spreadsheet was prepared with the variables of interest of this research: author; title of the article; year of publication; journal; country of origin; research objectives; type of study; scenario; population/sample/participants; theoretical bases used for the NP; use of a taxonomy/standardized language and main results/conclusion. Theoretical bases in general and not only Nursing theories were considered for the purposes of this study[11].

These stages were in charge of two independent reviewers and, subsequently, any and all disagreements were resolved by a third reviewer.

Data synthesis was performed descriptively, according to the main results evidenced about the NP applied to older adults with dementia and their caregivers.

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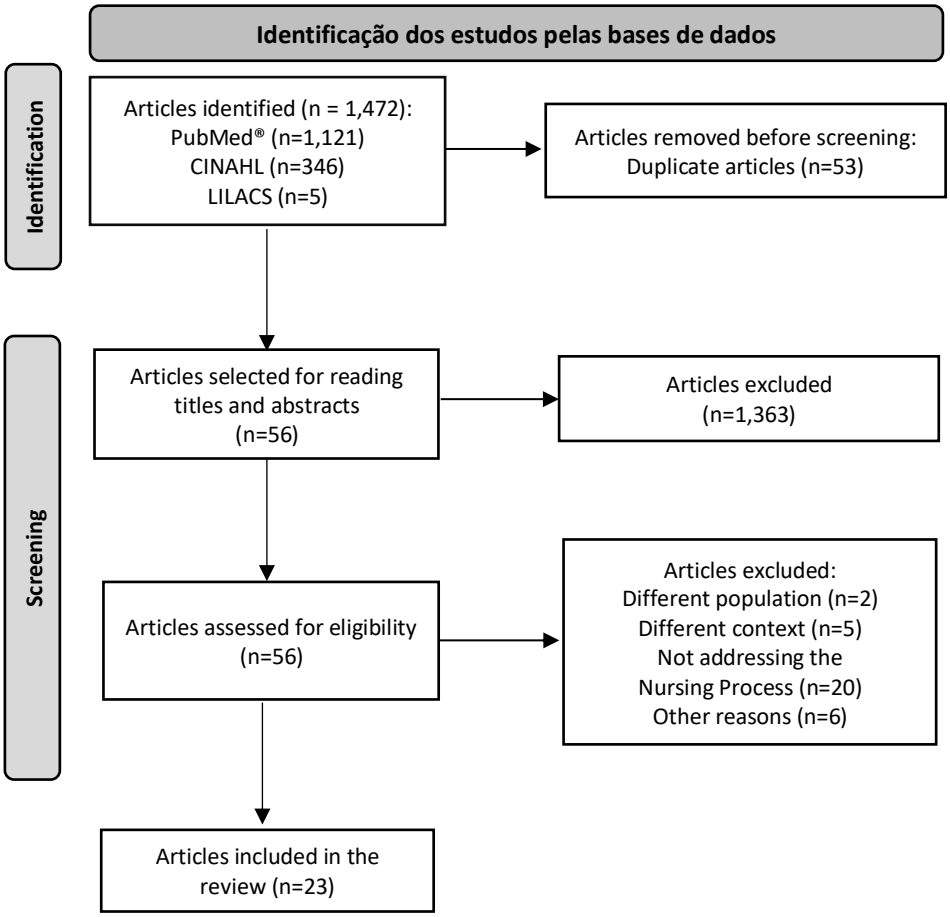
RESULTS

Eligibility and inclusion of the studies

The search in the databases selected yielded 1,472 potentially suitable studies, with 53 duplicates. After reading their titles and abstracts, 56 were included for full-reading. Of these, 33 were excluded for the following reasons: different population or context from those proposed by this research (n=7), not addressing the NP (n=20), or others (n=6). Therefore, 23 articles were included in this mapping.

The *Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews* (PRISMA-ScR) flowchart was used to select the studies of this scoping review, as shown in Figure 1[10].



CINAHL: Cumulative Index to Nursing and Allied Health Literature; LILACS: *Literatura Latino-Americana e do Caribe em Ciências da Saúde*.
Figure 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flowchart to select the articles. Brasília, DF, Brazil, 2022.

Characteristics of the studies included

Figure 2 below presents a synthesis of the characteristics of the articles selected in terms of author, title of the article, year and country of origin.

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Author	Title	Year	Country
Sandman P et al.[12]	Morning care of patients with Alzheimer-type dementia. A theoretical model based on direct observations	1986	Sweden*
Bleathman C.[13]	The practical management of the Alzheimer's disease patient in the hospital setting	1987	England*
Fruehwirth SES.[14]	An Application of Johnson's Behavioral Model: A Case Study	1989	Canada*
Adams T.[15]	A descriptive study of the work of community psychiatric nurses with elderly demented people	1996	England
Dijkstra A et al.[16]	Construct validity of the Nursing Care Dependency Scale	1999	Netherlands*
Biercewicz M, et al.[17]	Nursing Problems of Patients with Parkinson's Disease	2016	Poland*
Edberg A, Hallberg IR.[18]	Actions seen as demanding in patients with severe dementia during one year of intervention. Comparison with controls	2001	Sweden
Carradice A,; Shankland MC, Beail N.[19]	A qualitative study of the theoretical models used by UK mental health nurses to guide their assessments with family caregivers of people with dementia	2002	England
Park M, et al.[20]	Using a Nursing Minimum Data Set with older patients with dementia in an acute care setting	2004	United States
Neary SR, Mahoney DF.[21]	Dementia Caregiving: The Experiences of Hispanic/Latino Caregivers	2005	United States
Santana RF, Santos I, Caldas CP.[8]	Cuidando de idosos com Demência: um estudo a partir da prática ambulatorial de enfermagem	2005	Brazil
Penrod J, et al.[22]	Reframing Person-Centered Nursing Care for Persons With Dementia	2007	United States
De Jesus IS, et al.[23]	Cuidado sistematizado a idosos com afecção demencial residentes em instituição de longa permanência	2010	Brazil
Flanagan NM, Fick CDM.[24]	Delirium Superimposed on Dementia: Assessment and Intervention	2010	United States
Mirc, A, Cuk V.[25]	Ohranjanje življenjskih aktivnosti varovanca z demenco s pomočjo teoretičnih modelov zdravstvene nege	2010	Slovenia
Pierce ME.[26]	Case Management Considerations of Progressive Dementia in a Home Setting	2010	United States
Valente GSC, et al.[27]	Nursing diagnoses for caregivers of elderly with dementia.	2011	Brazil
Laukivik LB, Molstad K,; Fossum M.[28]	The construction of a subset of ICNP for patients with dementia: a Delphi consensus and a group interview study	2015	Norway
Emiliano MS, et al.[29]	A percepção da consulta de enfermagem por idosos e seus cuidadores	2017	Brazil*
Lee, SJ et al[30]	Concept Development of Identification of Discomfort for Nursing Home Patients With Advanced Dementia	2020	Korea
Passarelles, DMS et al.[31]	Diagnóstico de enfermagem síndrome de terminalidade em idosos com demência avançada: mapeamento cruzado	2020	Brazil
Rey S, et al.[32]	Finding the fundamental needs behind resistance to care: Using the Fundamentals of Care Practice Process	2020	Canada*
Vas MD, et al.[33]	Alternativas a la sujeción ratamen en un paciente con ratamen vascular avanzada em tratamiento de hemodiálisis	2020	Spain

FIGURE 2: Characteristics of the articles included according to author, title, year and country (n=21). Brasília, DF, Brazil, 2022.
Source: Information extracted by the authors from the scientific articles included in this review, 2022.
*In case it is not specified in the article's description, the country of origin considered was the corresponding author's.

A total of 11 countries of origin were identified in the characterization of the studies selected (23; 100%), with the United States (5; 21.7%) and Brazil (5; 21.7%) as the most frequent, followed by England (n=3; 14.3%). Regarding the publication period, articles published between 1986 and 2020 were found; with 2010 (4; 17.4%) and 2020 (4; 17.4%) as the most frequent.

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Mapping of the studies related to the Nursing Process applied to older adults with dementia and their caregivers

Only 11 articles (43.5%) cited use of a theoretical basis to ground the NP. Dorothea Orem's General Theory of Self-Care Deficit was the most used in the NP applied to older adults with dementia and their caregivers (n=3), in the following settings: Long-Term Institutions for Older Adults (*Instituições de Longa Permanência para Idosos*, ILPI) and Psychogeriatric ILPIs[12,25,29]. Subsequently, Virgínia Henderson's theory was evidenced when addressing the concept of independence (n=2), which was also used in ILPIs[16,25]. Other theories also evidenced in this mapping were the following: a variation of the Nancy Roper Model of Life Activities, suggested by Thomas in 198815; Johnson Behavioral Systems Model14; Leininger's Ethno-Nursing approach[21]; the need-driven dementia-compromised behaviour (NDB) model[22]; Fundamentals of Care (point-of-care Nursing theory)[32] and the theoretical model developed in the study by Carradice et al.[19].

Figure 3 presents the description of the data collection instruments used in the articles selected for this review, according to the evaluation domains.

Evaluation domain	Instruments
Psychological and behavioral symptoms	*Demanding Behaviour Assessment Scale*[18]
	Multi-Dimensional Dementia Assessment Scale[18]
	Confusion Assessment Method[24]
	NEECHAM Confusion Tool[24]
	Geriatric Depression Scale[8,23]
Functional assessment	*Lawton Instrumental Activities of Daily Living Scale*[8]
	Katz Instrumental Activities of Daily Living Scale[8,33]
	Barthel Scale[33]
	Nursing Care Dependency Scale[16]
	Pfeiffer's Testt[33]
Cognitive assessment/ indicative of dementia	*Mini-Cog*[24]
	Mini Mental State Examination[24]
	Clock Drawing Test[26]
	Neuropsychiatric Battery Test[26]
	Modified Blessed Dementia Scale[24]
Others	*Mini Nutritional Assessment*[17]
	Charlson's Comorbidity Index[33]
	Assessment of Discomfort in Dementia[30]

FIGURE 3: Description of the instruments according to the evaluation domains. Brasília, DF, Brazil, 2022.

The assessment instruments for older adults and/or caregivers included the following domains: psychological and behavioral symptoms, functional assessment, cognitive/indicative assessment of dementia and others (nutritional, clinical staging and discomfort).

Regarding the use of a Nursing standardized language, NANDA-I® Taxonomy II was the most employed (7; 30.4%), with identification of 33 Nursing Diagnoses in these studies. The most prevalent Nursing Diagnoses were in the following domains: perception/cognition (n=9), safety/protection (n=8), activity/rest (n=10), comfort (n=5), coping/stress tolerance (n=5) and other domains (n=4)[20,23,25,27,30,33]. A study in which high prevalence of the terminality syndrome was identified in end-of-life care among aged people with advanced dementia stands out, which, according to the authors, supports inclusion of the Nursing Diagnosis in NANDA-I® Taxonomy II, considering that nurses already identify and record it in their clinical practice[31].

Use of the International Classification for Nursing Practice (ICNP®) was mentioned in a study (4.3%), whose result identified a subset of 301 concepts – 77 Nursing Diagnoses, 78 Outcomes and 146 Nursing Inventions – predominantly related to physical needs to the detriment of psychosocial ones[28]. In addition, use of the Nursing Interventions Classification (NIC) taxonomy (2; 8.6%) was evidenced, as well as of the Nursing Outcomes Classification (NOC) (1; 4.3%), with interventions and/or outcomes related to Nursing Diagnoses[20,33].

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It is also noted that most studies (n=12; 52.2.6%) did not specify use of any standardized Nursing language in the NP applied to older adults living with dementia and their caregivers; as for the others (2, 8.7%), this analysis did not apply, considering the research objective.

DISCUSSION

Nursing theories are part of the very knowledge of the profession and contribute to fostering nurses' autonomy and independence[34]. In Brazil, the Federal Nursing Council (*Conselho Federal de Enfermagem*, COFEN) emphasizes that use of theoretical models should support the entire NP[9]; however, part of the studies found in this review did not mention the theoretical grounds that supported the NP applied to older adults living with dementia and to their caregivers, which is presented as a gap found in this scoping review[13,17,18,20,23,24,26-28].

When present, the mention of Dorothea Orem's General Theory of Self-Care Deficit was predominantly evident, which can be related to nurses' role in guiding the self-care practices[12,25,29]. This theory has been identified as beneficial in the performance or practice of actions that older adults and caregivers perform to maintain health and well-being and is capable of supporting nurses in interventions that help them to achieve greater autonomy in health care[25,29]. However, It is worth mentioning the relevance of the intercession of other theoretical bases to strengthen the professional Nursing practice, as the dementia syndrome exerts impacts on several dimensions in the life of older adults and their caregivers, demanding a holistic approach to meet the health needs of this population segment.

In this reasoning sphere and during the data collection stage, nurses must also perform a multidimensional evaluation of older adults with dementia in terms of their caregivers. As evidenced in this scoping review, there are validated instruments available in the scientific literature, which can be incorporated into nurses' clinical practice, which include an evaluation of psychological and behavioral symptoms, functional assessment, cognitive assessment/indicative of dementia and others (nutrition and clinical staging).

Also, in relation to the NP stages, it is known that standardized language systems offer a formal structure to support clinical reasoning and organize Nursing knowledge and experience, in addition to increasing the reliability, validity and usability of Nursing documentation. However, as identified in this study, they are still little used, and this can be related to the fragility of nurses' training and to the need to change their attitude towards the technical-scientific domain required by the profession[35].

Among the standardized language systems evidenced in this study, the predominance of NANDA-I Taxonomy II stands out, which converges with the literature that refers to it as one of the most used and consolidated taxonomies for years through revisions and adaptations by scholars, submitting Nursing Diagnoses that assist in clinical control and risk reduction[30,36,37]. On the other hand, there is the fact that some of the studies were only limited to the NP stage, which can result in care fragmentation.

The most prevalent domains of Nursing diagnoses were perception/cognition and safety/protection, which can be related to the fact that memory impairment is the main challenge for older adults living with dementia and, consequently, increase the risks to their safety and protection. Thus, assessing the perils associated with the Nursing Diagnoses can contribute to implementing preventive interventions[37,38].

The activity/rest domain was also prevalent and was possibly associated with the clinical condition of older adults living with dementia, such as impaired physical mobility, for example, while overload and impaired mental health were prevalent in the caregivers due to the high care demand[5,7,8,30].

The comfort domain is also noted as important, due to the difficulty of older adults with dementia to verbally report pain, for example[39]. It is possible that the presence of the coping/stress tolerance domain is due to problems that are intensified when caregivers lack a support network, which generates negative subjective interpretations about care and, consequently, can produce and worsen psychological distress. This idea reinforces the need for nurses to promote a holistic look and provide the necessary guidance and supervision to successfully achieve the patient's and the family's objectives established through the individualized and specific care plan[32].

As for the lower percentage of articles that cite the NIC and the NOC, the need to improve the notes is reiterated, as this is a challenge for the Nursing team and studies involving interventions can assist in individualized care plans[40]. These data indicate the need for research studies aimed at integrating all three standardized languages in the NP for older adults living with dementia and their caregivers, in order to operationalize the NP in its entirety.

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Finally, it is worth mentioning the potential of the NP applied to older adults with dementia and their caregivers. Some authors assert that consultations can relieve tensions and improve health in the older adult/caregiver dyad. Consequently, in these cases, frequent application of the NP can modify the individual's perspective, as it is there that the client perceives the care capacity and differential[8].

Study limitations

A potential limitation of this study is the fact that no searches were performed in the Gray Literature. Nevertheless, it is inferred that this scoping review can support the NP-related development protocols applied to older adults living with dementia and their caregivers based on updated scientific knowledge.

In addition, the findings revealed gaps for the advancement of the Nursing science, in particular the need for studies that report and analyze the implementation of all the NP stages, using theoretical bases and standardized taxonomies.

CONCLUSION

The review evidenced that 11 articles mentioned the use of theoretical bases to support the Nursing Process applied to older adults living with dementia and their caregivers, with predominance for the use of Dorothea Orem's General Theory of Self-Care Deficit.

For evaluating the older adult/caregiver during the data collection stage, validated instruments are available in the scientific literature that can be incorporated into nurses' clinical practice, which include an evaluation of psychological and behavioral symptoms, functional assessment and cognitive/indicative of dementia and others (nutritional, clinical staging and discomfort).

It is also noted that most of the studies did not specify the use of any standardized Nursing language in the Nursing Process applied to older adults living with dementia and their caregivers and, when they did, NANDA-I® Taxonomy II was the most used, with predominance of Nursing Diagnoses in the perception/cognition, safety/protection and activity/rest domains.

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