

## Overview of scientific production on self-care for people with ostomy: a bibliometric review

### Panorama da produção científica sobre autocuidado de pessoas com estomia: revisão bibliométrica

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#### ABSTRACT

**Objective:** to map the scientific production on self-care among people with ostomy. **Methods:** a bibliometric review was conducted, encompassing publications from 2009 to 2024 related to self-care in individuals with ostomy. Data were collected from the BDENF, LILACS, MEDLINE, SCOPUS, Web of Science, Embase, and CINAHL databases. Indexed articles linked to Brazil were included. Analyses were performed using the VOSviewer software. **Results:** a total of 241 articles were included, with the main descriptors being nursing care, quality of life, stomatherapy, women, children, validation studies, and distance education. Two authors stood out for their volume of production, one from the Southeast region and another from the Northeast region. Scientific output is concentrated among research groups affiliated with universities, but without the establishment of a collaborative network. **Conclusion:** there has been an increase in scientific production, although it remains concentrated in groups that do not establish collaborative networks. Self-care in individuals with ostomy is associated with a variety of themes, indicating researchers' intention to address this phenomenon in its entirety. **Contributions to practice:** the findings reveal gaps and underexplored topics, highlighting the need to develop joint research agendas to enhance evidence on self-care for people with ostomy.

**Descriptors:** Self Care; Bibliometrics; Ostomy; Scientific Publication Indicator.

#### RESUMO

**Objetivo:** mapear a produção científica sobre o autocuidado em pessoas com estomia. **Métodos:** revisão bibliométrica que contemplou a produção publicada no período de 2009 a 2024 sobre autocuidado de pessoas com estomia. Os dados foram coletados nas bases BDENF, LILACS, MEDLINE, SCOPUS, *Web of Science*, Embase e CINAHL. Foram incluídos artigos indexados e vinculados ao Brasil. As análises foram realizadas por meio do software *VOSviewer*. **Resultados:** foram incluídos 241 artigos, tendo como principais indexadores: cuidado de enfermagem, qualidade de vida, estomaterapia, mulheres, crianças, estudos de validação e educação à distância. Dois autores destacaram-se em volume de produção, um da região Sudeste e outro do Nordeste. A produção científica está concentrada em grupos de pesquisadores vinculados a universidades, mas sem a formação de uma rede de colaboração. **Conclusão:** houve aumento da produção científica, apesar de sua concentração em grupos que não estabelecem rede de colaboração. O autocuidado na pessoa com estomia está relacionado a diversos temas, indicando a intenção dos pesquisadores de abordar esse fenômeno em sua totalidade. **Contribuições para a prática:** os resultados revelam lacunas e temas pouco explorados e a necessidade de desenvolvimento de agendas de pesquisa conjunta para aprimorar evidências sobre o autocuidado de pessoas com estomia.

**Descritores:** Autocuidado; Bibliometria; Estomia; Indicadores de Produção Científica.

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## Introduction

Scientific production in the field of Health Sciences has shown consistent growth over recent years<sup>(1)</sup>. Nursing stands out as one of the disciplines contributing most significantly to scientific output, particularly by addressing gaps in care, management, and education. These contributions are reflected in Brazilian research, positioning the country as the fourth-largest publisher of nursing articles indexed in the Web of Science in 2021<sup>(2)</sup>.

Given the specificity and thematic breadth of nursing research, which enables the identification of issues critical to health, the development of innovative solutions becomes essential. In this context, scientific production plays a pivotal role in overcoming challenges faced both in clinical practice and health management<sup>(3)</sup>.

Nursing research is crucial for understanding and addressing shifts in population epidemiological profiles, which have signaled a significant rise in the burden of non-communicable chronic diseases, with a particular emphasis on cancers. Although cancer mortality has decreased in recent years, its incidence has increased<sup>(4)</sup>. The rising number of colorectal cancer cases, coupled with declining mortality rates, often results in a growing population of individuals living with ostomy<sup>(5)</sup>.

From this perspective, self-care emerges as a central theme in health research due to its importance in promoting patient autonomy and reducing costs associated with ostomy and peristomal skin complications<sup>(6-7)</sup>. Ostomy represent a group of surgical alternatives that create an opening in an organ of the digestive, respiratory, or urinary system to establish communication between the organ and the external environment. This compensates for impaired function caused by dysfunction, obstruction, or injury<sup>(8)</sup>, significantly impacting the quality of life of individuals with ostomy<sup>(9-10)</sup>.

In this regard, the literature highlights recurring themes, such as the implications of living with

a ostomy and the challenges related to self-care<sup>(10-12)</sup>. Despite this, no studies were found in the literature that systematically mapped national scientific production on the topic. This gap hinders the identification of priority research areas and limits knowledge about evidence-producing sources and trends in this field over time. Therefore, by identifying thematic gaps, collaboration networks, institutional hubs, and temporal trends, this investigation aims to guide research agendas, enhance the implementation of the National Policy for Care of People with Ostomy, and support care management, education, and training in health.

Considering the above, this study seeks to address the following guiding question: What is the landscape of Brazilian scientific production on self-care among people with ostomy? Accordingly, the objective was to map the scientific production on self-care among people with ostomy.

## Methods

This study is a bibliometric review, a method used to measure scientific and technological progress. This type of study enables the identification of patterns, trends, and gaps in the scientific literature, providing a comprehensive overview of research dynamics on specific topics through graphical representations. It followed four main steps: defining the scope, selecting the techniques, collecting and processing the data, and conducting the analysis with the support of specialized software<sup>(13)</sup>.

Data collection took place in July 2024, covering the period from January 2009 to June 2024. This time-frame was chosen based on two significant regulatory milestones in Brazil in 2009: one from the Ministry of Health<sup>(14)</sup> and another from the *Conselho Federal de Enfermagem* (COFEN)<sup>(15)</sup>. The Ministry of Health established national guidelines for the healthcare of individuals with ostomy, emphasizing self-care as a key focus for healthcare professionals. Meanwhile, COFEN formalized the Nursing Process in the country, promo-

ting the standardization of care and the adoption of evidence-based practices<sup>(6)</sup>.

Data were extracted from articles indexed in major health sciences databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (Embase), Latin American and Caribbean Health Sciences Literature (LILACS), Nursing Database (BDENF), Medical Literature Analysis and Retrieval System Online (MEDLINE), SCOPUS, and Web of Science (WoS). Access to these databases was facilitated through the Coordination for the Improvement of Higher Education Personnel (CAPES) journal portal via the Federated Academic Network (CAFe).

The search terms were mapped in English using the Medical Subject Headings (MeSH), specifically "Self Care" and "Ostomy," and in Portuguese using the Health Sciences Descriptors (DeCS), namely "*Autocuidado*" and "*Estomia*." The Boolean operator AND was used to combine the descriptors, with the following search strategy applied: ("Self Care" AND "Ostomy") in MEDLINE, Web of Science, Scopus, Embase, and CINAHL; and ("*Autocuidado*" AND "*Estomia*") in LILACS and BDENF. Additional terms such as "Colostomy," "Ileostomy," "Surgical Stomas," "*Colostomia*," "*Ileostomia*," and "*Estomas Cirúrgicos*" were tested in various combinations but did not yield an increase in retrieved records, leading to the retention of the core descriptors.

Inclusion criteria were as follows: publications from the defined period (2009–2024) featuring the descriptors "*autocuidado*" and "*estomia*" in the title, abstract, or keywords, available in full text and accessible in Portuguese, English, or Spanish. Letters, editorials, opinion pieces, and conference abstracts were excluded. During the selection process, a filter was applied to include only studies linked to Brazil, defined as those conducted within the national territory, to contextualize the findings and align them with the national scope of this research.

The identified articles were imported into

Mendeley software, where duplicates were removed. Titles and abstracts were independently screened by two researchers, with discrepancies resolved through consensus.

Extracted data included titles, authors, affiliations, keywords, publication year, and citation counts, which were organized into Microsoft Excel spreadsheets. Data analysis was performed using VOSviewer (version 1.6.20) to construct network maps and analyze term co-occurrence. Specific thesauri were developed to normalize keywords and author names, ensuring consistency and clarity in the visualizations. The analysis encompassed the most frequent themes in the scientific literature, derived from the keywords used to index articles in the databases, the authors with the highest publication volumes, and the temporal evolution of publications, represented by heatmaps.

The temporal distribution of publications was visualized using the "overlay visualization" map. This feature enables the analysis of data networks by adding an extra layer of information to the network nodes (elements). Such visualization is particularly valuable for understanding variations over time or other specific characteristics of the represented data.

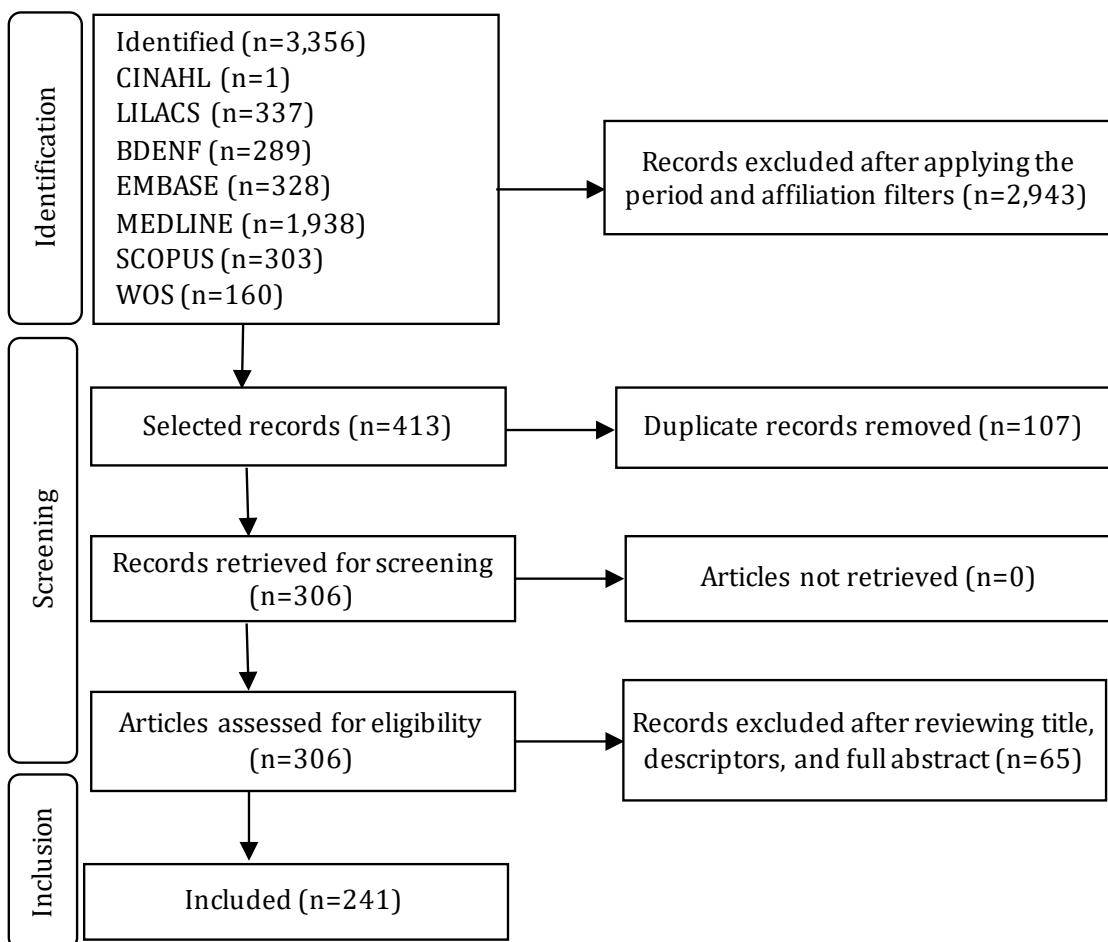
Colors indicate the publication periods of the documents, ranging from cooler tones (blue) for older works to warmer tones (green and yellow) for more recent ones. A bibliometric map was also created to illustrate the collaboration network among authors with the highest frequency of publications on the studied topic. The different clusters, represented by various colors, identify groups of researchers who share themes, co-authorships, or scientific approaches.

All ethical aspects related to research using open-access data were addressed, considering that the study exclusively utilized publicly available information. Submission to an Ethics Committee was not required, in accordance with prevailing ethical guidelines.

## Results

The final sample consisted of 241 articles distributed across the following databases: BDENF, 122

(50.6%); LILACS, 61 (25.3%); MEDLINE, 29 (12.0%); Web of Science (WOS), 15 (6.2%); SCOPUS, 9 (3.7%); EMBASE, 5 (2.1%); and CINAHL, with no records retrieved (Figure 1).



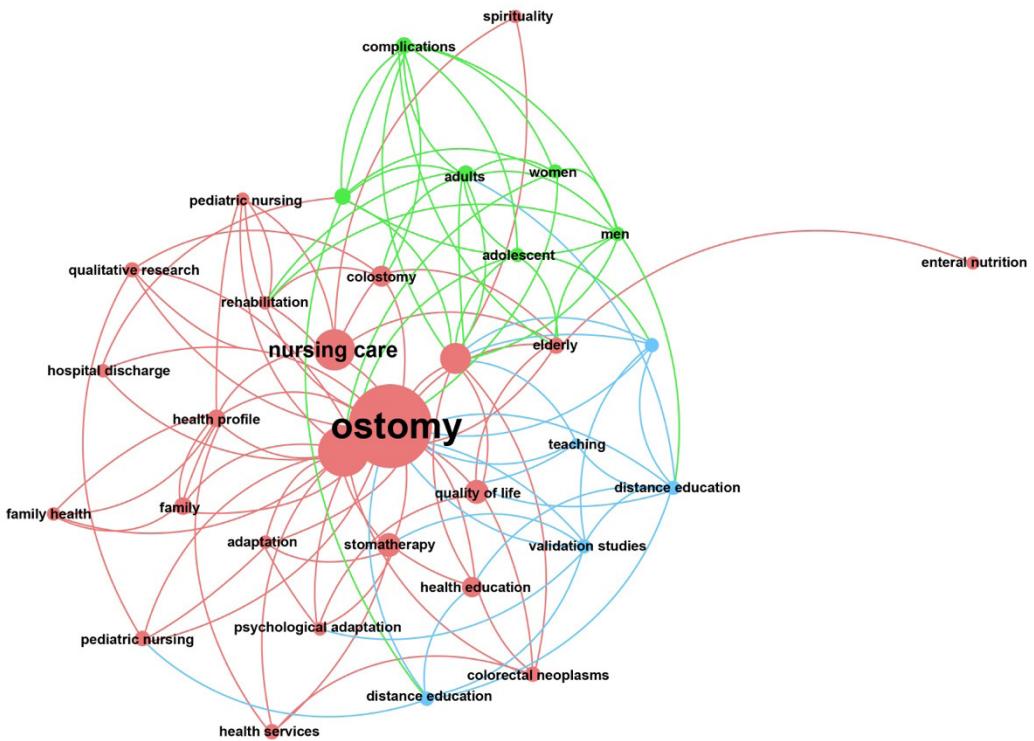
**Figure 1** – Flowchart of the article selection process. Belo Horizonte, MG, Brazil, 2024

As predetermined, the studies were published between 2009 and 2024, with the following distribution: 7 (2.9%) in 2009, 9 (3.7%) in 2010, 7 (2.9%) in 2011, 13 (5.4%) in 2012, 17 (7.1%) in 2013, 21 (8.7%) in 2014, 13 (5.4%) in 2015, 21 (8.7%) in 2016, 18 (7.5%) in 2017, 11 (4.6%) in 2018, 21 (8.7%) in 2019, 25 (10.4%) in 2020, 17 (7.1%) in 2021, 15 (6.2%) in 2022, 20 (8.3%) in 2023, and 6 (2.5%) in 2024.

It is worth noting that the terms “self-care” and “ostomy” exhibited the highest frequency in the

co-occurrence map, which was expected since all included articles contained these descriptors in the title, abstract, or keywords. However, given that these terms were predefined criteria in the search strategy, they hold no interpretative value for the analysis of the results.

Thus, the main themes identified were grouped into three clusters (red, blue, and green), highlighting different approaches related to the central topic (Figure 2).



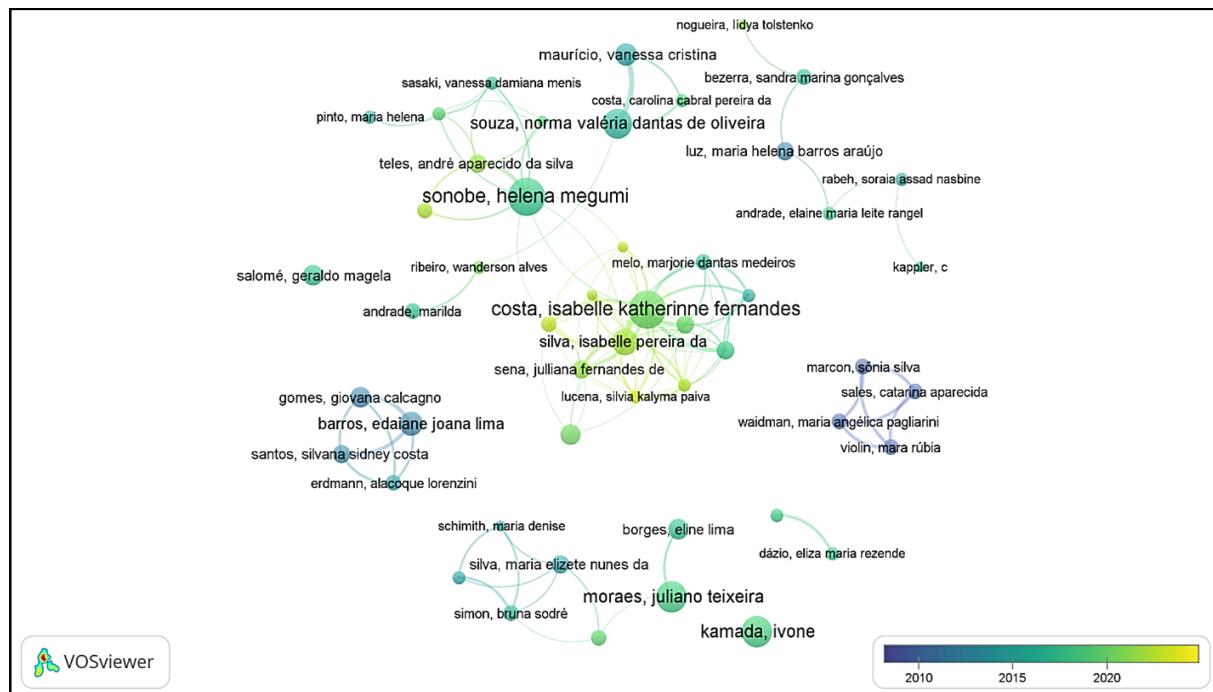
**Figure 2** – Bibliometric map of the most frequent terms. Belo Horizonte, MG, Brazil, 2024

The red cluster focused on the central theme “ostomy,” encompassing 158 studies. The main terms in this group were “nursing care” (48), “self-care” (29), “quality of life” (20), and “stomatherapy” (18). Additionally, “colostomy” (16), “health education” (13), “health profile” (13), “family” (11), “elderly” (10), and “colorectal neoplasms” (9) were identified. Other recurring concepts included “rehabilitation” (8), “adaptation” (8), “perioperative nursing” (7), “psychological adaptation” (6), “qualitative research” (6), “health services” (6), “spirituality” (4), “family health” (4), “pediatric nursing” (4), “hospital discharge” (5), and “enteral nutrition” (3).

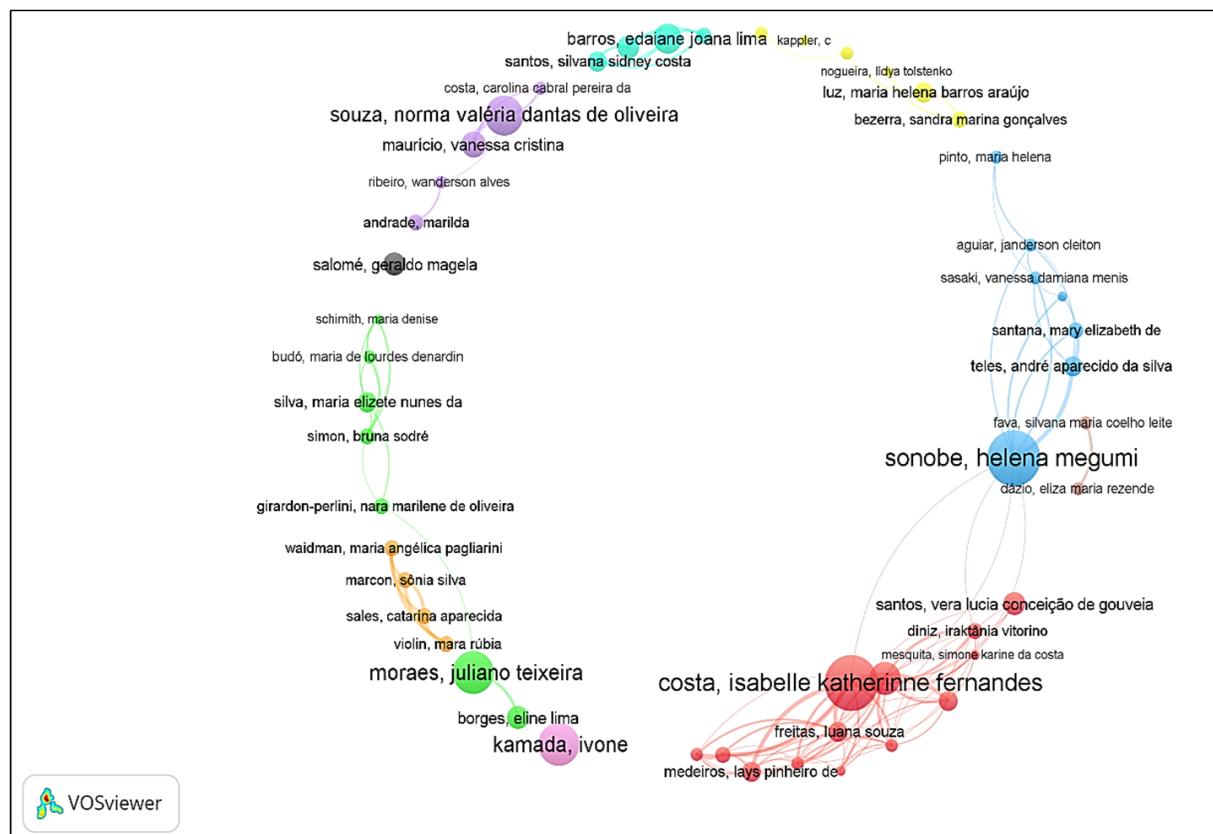
The blue cluster centered on the theme “women,” with 7 related studies. Among the most frequently used terms were “children” (6), “adolescents” (5), “adults” (5), and “men” (5), along with the term “complications” (3). The green cluster addressed “validation studies,” with 8 studies. Related terms included

“nursing education” (6), “teaching” (5), and “distance education” (3).

The majority of the articles were published from 2015 onward. Among the authors with the highest number of articles indexed with the terms “self-care and ostomy,” Helena Megumi Sonobe, a professor at the *Universidade de São Paulo*/Ribeirão Preto, and Isabelle Katherinne Fernandes Costa, a professor at the *Universidade Federal do Rio Grande do Norte*, stood out. Both researchers had the same number of publications during the 2009–2024 period. However, the most productive period on this topic occurred predominantly between 2015 and 2020, with contributions from professors at other public teaching institutions, such as Norma Valéria Dantas de Oliveira Souza (*Universidade do Estado do Rio de Janeiro*), Juliano Teixeira Moraes (*Universidade Federal de São João del-Rei*), Eline Lima Borges (*Universidade Federal de Minas Gerais*) and Ivone Kamada (*Universidade de Brasília*) (Figure 3).



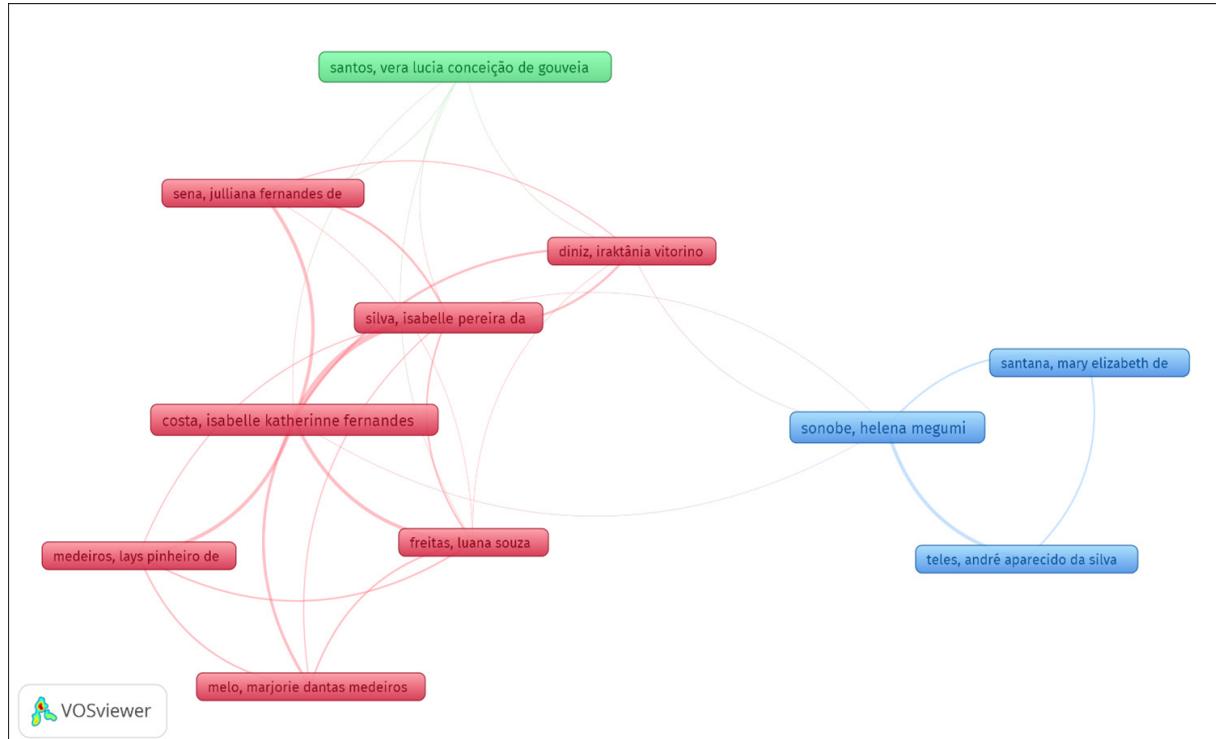
**Figure 3 – Bibliometric map of authors with the highest publication frequency and temporal distribution. Belo Horizonte, MG, Brazil, 2024**



**Figure 4 – Bibliometric map of the collaboration network among authors. Belo Horizonte, MG, Brazil, 2024**

In the context of connections between authors, there was limited interaction between the clusters (Figure 4). A more in-depth analysis of the relationships established between the red and blue clusters highlights

the significance of the researcher Santos, given her connections with other authors, such as Silva, Costa, Sena, Diniz and Freitas (Figure 5).



**Figure 5** – Bibliometric map of the connections established among authors. Belo Horizonte, MG, Brazil, 2024

## Discussion

The analysis of the results enabled the identification not only of the volume of publications over time but also of the most frequent related themes, the most productive authors on the topic of self-care for individuals with ostomy, and the collaboration networks. The pattern, trends, and, consequently, gaps in the scientific production of Brazilian researchers were revealed.

Despite the growing number of publications, a concentration of studies in specific areas and the predominance of particular groups of authors or institutions were observed, indicating that scientific production is still in the process of development and consolidation. This fact underscores the need to promote knowledge dissemination, as this process facilitates

the sharing of information, ideas, concepts, and technologies with a broader audience, including among researchers themselves<sup>(16)</sup>.

Such dissemination fosters knowledge transfer, particularly through networked studies, which tend to expand the number of professionals dedicated to the same topic. Furthermore, it seeks to make knowledge more accessible and applicable in less time by a larger contingent of individuals or institutions, generating positive impacts on clinical practice<sup>(17)</sup>.

The analysis reveals that, although the topic is widely recognized as relevant to nursing and there are studies linking self-care to nursing care, these investigations have yet to explore fundamental dimensions of the phenomenon in depth. Notably, gaps remain regarding the assessment of the reach of self-care and its classification as an indicator of nursing

intervention outcomes. Thus, there is a clear need for more analytical approaches capable of transcending immediate care and broadening the understanding of the effects of self-care on the quality of care provided.

From this perspective, the main self-care requirements for individuals with ostomy can be organized into three categories: universal requirements, with an emphasis on nutritional needs; developmental requirements, which encompass ostomy and peristomal skin care; and health deviation requirements, related to the proper use of collecting devices and adjuvant products<sup>(11)</sup>.

The same study highlighted the scarcity of research on topics beyond ostomy and effluent management, such as physical activity, sexuality, and social aspects, underscoring the need for investigations that broaden the understanding of self-care for individuals with ostomy<sup>(11)</sup>. These findings corroborate the results of another review study, which concluded that self-care is a multifaceted concept and that, in most approaches, this phenomenon is reduced to the execution of care actions, translated into procedures<sup>(18)</sup>.

Regarding the most recurrent themes in this study, they were organized into three clusters. In the first, terms such as nursing care, quality of life, and stomatherapy stood out. For this discussion, it is essential to revisit the assumptions of Orem's General Self-Care Theory, which reaffirms nursing as a compensatory system that, through care, can promote health recovery and the autonomy of individuals with health deficits<sup>(19)</sup>.

In the context of individuals with ostomy, there are various possibilities for care, which translate into nursing interventions aimed at promoting self-care and improving quality of life<sup>(19-20)</sup>. The main interventions to promote self-care in individuals with ostomy have already been mapped in an international scoping review<sup>(21)</sup>. Broadly, these interventions fall into three groups: direct care, training, and psychological support<sup>(20)</sup>.

Recommendations for promoting self-care in individuals with ostomy include the implementation

of planned educational actions, conducted systematically during the perioperative period and preferably led by ostomy care nurses. These actions should be individualized, considering the specific needs of each person, and utilize various technological resources<sup>(8)</sup>.

Such care should go beyond the assistive aspect and include education, involving family members and caregivers. In this context, it is crucial to address topics such as stoma and peristomal skin assessment, appliance changes, and the identification of potential postoperative complications, such as dehydration, intestinal obstruction, and peristomal dermatitis. They should also include guidance on the impact of the ostomy on body image, self-esteem, sexuality, social and professional life, as well as provide strategies for the prevention and management of complications and social reintegration to promote greater autonomy in self-care<sup>(8)</sup>.

Nursing stands out as a profession with the skills to teach and promote self-care in individuals with ostomy<sup>(6,11)</sup> and, over the years, has made efforts toward training and specialization, culminating in the emergence of a specialty. Stoma care, recognized worldwide, was officially established in Brazil in 1990 with the creation of the first specialization course at the University of São Paulo School of Nursing. Since then, the specialty has occupied a prestigious position in the care of individuals with wounds, ostomy, and incontinence, playing a crucial role in fostering self-care, with involvement not only in care but also in research<sup>(22)</sup>.

Another key point is that self-care, stimulated by nursing care, is a predictor of the quality of life for individuals with ostomy. Studies indicate that individuals who engage in self-care behaviors exhibit maintenance and monitoring behaviors directly linked to improvements in health-related quality of life<sup>(10,22-23)</sup>.

In the second cluster, the diversity of age groups (children, adolescents, adults, and older adults) highlights the breadth of the topic. Self-care presents specificities that vary according to age group and gender. Women with ostomy tend to experience more psycho-

logical distress, complex social functioning, and less sexual distress, and they choose more positive coping strategies than men<sup>(9)</sup>.

The publication of studies involving different age groups demonstrates that self-care represents a cross-cutting challenge common to all populations<sup>(10,23)</sup>. In the case of children, this particularity is accentuated, as they depend on a caregiver, who often face uncertainties and require support for home care. Notably, in the pediatric context, parents, together with nurses, act as total or partial compensatory systems<sup>(12)</sup>.

In this regard, the main challenges faced by caregivers include overcoming the fear of dealing with ostomy, as well as progressively learning to change the appliance<sup>(12)</sup>. Professionals need to employ strategies to overcome existing barriers, such as the lack of guidance. It is essential to ensure access to appropriate educational materials for ostomy care<sup>(6)</sup>.

Considering that self-care requires a specific set of knowledge and skills, it is crucial to understand that factors exacerbating this condition represent challenges to its maintenance. Thus, complications related to the ostomy and peristomal skin emerge as significant obstacles and were among the most frequent themes in this bibliometric mapping.

It is known that the prevalence of these complications is high, and, despite the lack of consensus, it may exceed 80%<sup>(24)</sup>, with complications classified as early or late<sup>(8)</sup>. Such complications lead to various problems that, collectively, hinder self-care, adaptation to the new condition, and reduce the perception of quality of life for individuals with ostomy<sup>(10)</sup>.

Evidence shows that patients with ostomy experience significant alterations in quality of life, particularly in the domains of physical and emotional well-being<sup>(25)</sup>. Therefore, the presence of complications can impact these domains. They are often related to pain, loss of adhesion of collecting devices, and difficulties in performing self-care. Mitigating this situation requires support from compensatory systems represented by family members, caregivers, and healthcare professionals<sup>(26)</sup>.

The third cluster highlighted the centrality of validation studies, which are essential for obtaining evidence regarding the adequacy and reliability of measurement instruments and applied technologies. In the context of self-care for individuals with ostomy, these investigations stand out in the bibliometric mapping, given the need for validated instruments to support accurate assessments and guide effective interventions. The literature identified validations of instruments aimed at assessing individuals with ostomy<sup>(27)</sup>, measuring self-care<sup>(28)</sup>, as well as developing technologies and educational materials to promote it<sup>(29-30)</sup>.

Over the past few years, a significant expansion in scientific production related to self-care and ostomy has been observed, marked by fluctuations in publication volume. Starting in 2015, this increase became more pronounced, reflecting a broader trend of intensification in publications on self-care in general, with a peak in production recorded during the same period<sup>(31)</sup>. The analysis of publication distribution also revealed a significant concentration in the BDENF and LILACS databases, which together accounted for more than 75% of the identified works.

It is known that BDENF is a bibliographic database specialized in nursing. It was created to facilitate access to and dissemination of publications in the field, which are often absent from national and international bibliographies. This predominance suggests strong regional and national scientific production, reflecting the topic's relevance to public health in Brazil, particularly in the context of nursing. Additionally, the authors chose to evaluate articles whose research setting was located in Brazil.

Furthermore, it is important to note that a significant portion of journals indexed in these databases are part of the open science movement, providing full-text articles free of charge. Unlike other databases, such as SCOPUS and Web of Science, which also include commercial journals. Another relevant point pertains to article submission and processing fees. In international journals indexed in SCOPUS and Web of Science, these fees are quoted in U.S. dollars, requiring

substantial investment and representing an obstacle for Brazilian researchers<sup>(32)</sup>.

The dynamic behavior of publications over the years highlights the impact of different historical moments and research funding. The initial increase in the number of studies can be attributed to the expansion of resources allocated to science and technology in Brazil, as well as the growth in the number of master's and doctoral degree holders. Conversely, periods of declining production may be related to reduced investment in science, technology, and innovation due to the government's adoption of fiscal austerity programs<sup>(33)</sup>.

In this context, it is worth noting that the budget of Brazil's Ministry of Science, Technology, and Innovation suffered successive cuts between 2015 and 2016, with a temporary recovery in 2017 and 2018, followed by another decline starting in 2019, with 2021 being the year of greatest loss. The *Conselho Nacional de Desenvolvimento Científico e Tecnológico* (CNPq) has also faced cuts since 2014, with an attempted increase in 2019 that, however, did not reach previous levels, followed by an even more severe reduction in 2020 and 2021. The contraction of the Science, Technology, and Innovation Program follows this trend, accumulating a reduction of over 75% between 2013 and 2021, with the pandemic years (2020 and 2021) recording the lowest investments in the historical series<sup>(33)</sup>.

Regarding the main authors, it was found that Senior Lecturers from Public Universities in the country stood out, such as Helena Megumi Sonobe (*Universidade de São Paulo*) and Isabelle Katherinne Fernandes (*Universidade Federal do Rio Grande do Norte*). Relationships were present between the supervising professor and students from other educational or healthcare institutions. Therefore, it was observed that collaboration networks were extremely limited, with no international participation. This fact diverges from the general context, given the intense collaboration among researchers from different states across Brazil, demonstrating significant collaboration among

researchers from states with less weight in the Brazilian scientific system<sup>(1)</sup>.

The lack of scientific collaboration limits productivity, excellence, and innovation in academia. The absence of partnerships between countries, states, and institutions restricts the exchange of knowledge and the circulation of ideas, essential elements for scientific advancement. This limitation reduces the capacity to solve problems and adapt to global demands<sup>(34)</sup>.

## Study limitations

The main limitation of this study lies in the scope of the bibliometric mapping, which was restricted to articles linked to Brazil and utilized descriptors present in the title, abstract, or keywords. Consequently, it is possible that relevant studies on the topic were not included in the sample due to inadequate indexing.

Furthermore, inconsistencies in the indexing of author names were identified. In an attempt to mitigate this issue, a thesaurus was created to standardize terms. However, this procedure was applied only after the article selection process, potentially reducing its effectiveness during the initial mapping phase. Another limitation pertains to the graphical visualization of the data, which considered only the top 50 terms and authors. This decision influenced the configuration of the bibliometric maps and the number of clusters identified, possibly omitting terms and authors with lower publication and citation frequencies.

## Contributions to practice

This study provides significant contributions to nursing practice by identifying trends and gaps in the scientific literature, highlighting the need for research that moves beyond operational aspects to explore the underlying factors influencing the development of self-care. The findings can guide researchers toward underexplored topics, such as barriers to the adop-

tion of self-care practices, while also supporting the development of research agendas aimed at strengthening and refining the evidence base on self-care for individuals with ostomy. Enhancing the “research dimension” of nursing care in this manner translates into direct benefits for clinical practice, promoting evidence-based interventions and ultimately improving patient outcomes.

## Conclusion

There has been an increase in scientific production regarding the self-care of individuals with ostomy, despite fluctuations in certain years and the concentration of research within specific groups, which lack collaborative networks. Self-care in individuals with ostomy is associated with a wide range of themes, reflecting researchers' efforts to address this phenomenon in its entirety.

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## Authors' contributions

Conception and design or analysis and interpretation of data; Drafting of the manuscript, critical revision of the intellectual content; Final approval of the version to be published; Responsibility for all aspects of the text in ensuring the accuracy and integrity of any part of the manuscript: Alonso CS, Borges EL.

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