

**REVIEW**

## Individual, social, and programmatic vulnerabilities experienced by people with elimination stomas: a scoping review

**HIGHLIGHTS**

1. The vulnerabilities are interconnected, requiring complex approaches.
2. Ostomy implies a social phenomenon, with intersectoral interventions.
3. Social relationships are harmed in the face of the ostomy condition.
4. The study reveals a disorganization in public health programs.

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**ABSTRACT**

**Objective:** To map the scientific literature on individual, social, and programmatic vulnerabilities experienced by people with elimination stomas. **Method:** Scoping review, guided by the guidelines of the Joanna Briggs Institute and PRISMA Extension for Scoping Reviews. Original articles were included, with no time or language restrictions. Articles were excluded if they did not address the research question. **Results:** Four articles, published in English and Portuguese and conducted in China and Brazil, were included in the final sample and mapped social, individual, and programmatic vulnerabilities in health. Difficulties with hygiene, shame, family disorganization, lack of self-esteem, prejudice, difficulty working, and access to public health services were highlighted. **Conclusion:** The experience with elimination stomas exposes the individual to vulnerabilities that impact their quality of life, manifesting from the difficulty of adapting to the changes imposed by the stoma.

**DESCRIPTORS:** Ostomy; Surgical Stomas; Intestinal Elimination; Vulnerable Populations; Health Vulnerability.

**HOW TO REFERENCE THIS ARTICLE:**

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## INTRODUCTION

A stoma is a surgical procedure that exteriorizes a portion of the respiratory, digestive, or urinary tract, creating a communication with the external environment. This condition, especially regarding elimination stomas, can lead its bearers to experience social and health vulnerabilities that must be identified and addressed.

Despite the elimination of ostomies, the clinical decision to perform such a procedure is related to factors such as cancer, abdominal trauma, and clinical errors<sup>1</sup>. Its creation aims to divert intestinal or urinary content to a collecting device, due to the impossibility of elimination in a physiological manner<sup>2</sup>.

In the international context, the number of ostomized individuals increases significantly every year. A study indicates that approximately 1 million people have fecal elimination ostomies in the United States of America<sup>3</sup>. In Europe, 700,000 people live with elimination ostomies, particularly in Spain, which has about 70,000 ostomized individuals, with an estimated 16,000 new cases each year, of which 60% are temporary and 40% are permanent<sup>4</sup>. In Brazil, it is estimated that there are about 400,000 individuals with intestinal ostomies, with approximately 10,000 new cases reported each year<sup>5</sup>.

Given the need to establish an intestinal elimination stoma, patients may face a series of implications that can negatively impact their lives. A study points out that these individuals, due to a lack of fecal control and gas elimination, experience feelings that can affect their mental health, such as loss of self-esteem, altered perception of their body image, depression, distress, hatred, repulsion, and non-acceptance<sup>6</sup>. Such factors directly interfere with their social and family status, causing difficulties in relationships and making them socially vulnerable<sup>7</sup>.

Vulnerability is a broad and controversial concept, used in various fields of knowledge. In this study, the conception that vulnerability is related to the guarantee of citizenship for politically fragile populations is adopted, from the perspective of human rights<sup>8</sup>.

Based on this conception, three dimensions are considered: a) individual: corresponds to the capacity and conditions of each person to face adverse situations, such as access to information, self-knowledge, self-care, family support, and emotional support; b) social: represents the socioeconomic and cultural context, such as housing, work, income, social support, prejudice, stigma, and access to public policies; and c) programmatic: involves the presence or absence and the quality of policies, programs, services, and health actions aimed at meeting the needs of the ostomized population<sup>8</sup>.

In this sense, people with elimination ostomies can be considered vulnerable due to their physical, psychological, and social conditions, and these should be identified for confrontation. In this perspective, this study has the general objective of mapping the scientific literature on the individual, social, and programmatic vulnerabilities experienced by people with elimination stomas.

## METHOD

This is a scope review that seeks to map the scientific studies on the subject in question, to ascertain the dimension, reach, and nature of the study, synthesizing and publishing the data, as well as pointing out the gaps in existing research<sup>9</sup> on the health vulnerabilities faced by people with elimination stomas.

The choice of this type of study is justified, as it is a methodology that allows the synthesis of previously published information<sup>9</sup>. Mapping what is available in the literature on the subject broadly and systematically allows the identification of existing gaps and unexplored aspects, enabling the development of future research and public policies.

The study was guided by the Joanna Briggs Institute (JBI) guidelines and integrated in accordance with the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews* (PRISMA-ScR), ensuring methodological rigor and transparency throughout the process. In accordance, a protocol was created and published on the *Open Science Framework* (OSF) platform under DOI 10.17605/OSF.IO/YTKMG, ensuring replicability and the predefinition of the entire research pathway.

After the protocol registration, the review followed the steps described below. The research question was constructed using the mnemonic PCC, which stands for Population, Concept, and Context. Thus, P was assigned to: people using elimination stomas. Those with permanent or temporary stomas, with intestinal and/or urinary elimination, will be considered; C: individual, social, and programmatic vulnerabilities experienced by people with elimination stomas; and C: studies conducted in any health setting involving people with elimination stomas in a situation of health vulnerability. Based on this information, the following guiding question was formulated: What health vulnerabilities do people with elimination stomas experience?

The descriptors in English contained in the Health Sciences Descriptors (DECs) and the Medical Subject Headings (MeSH), and the boolean operators AND and OR, were used, adapting the strategy to the particularities of each Database, as illustrated in Chart 1.

**Chart 1.** Description of the search strategies in the databases. Maceió, AL, Brazil, 2025

Database	Search Strategy
Latin American and Caribbean Literature in Health Sciences (Lilacs)	(Ostomy) AND ((social vulnerability) OR (Health vulnerability) OR (vulnerability analysis))
MEDLINE	(Ostomy) AND ((social vulnerability) OR (Health vulnerability) OR (vulnerability analysis))
Cumulative Index to Nursing and Allied Health Literature (Cinahl)	((vulnerability AND analysis) OR (health AND vulnerability) OR (social AND vulnerability) OR (vulnerability AND study)) AND ((surgical AND stomas) OR (ostomy) OR (colostomy) OR (ileostomy))
Embase	((vulnerability AND analysis OR (health AND vulnerability) OR (social AND vulnerability) OR (vulnerability AND study)) AND (surgical AND stomas OR ostomy OR colostomy OR ileostomy))
Scopus	((vulnerability AND analysis) OR (health AND vulnerability) OR (social AND vulnerability) OR (vulnerability AND study)) AND ((surgical AND stomas) OR (ostomy) OR (colostomy) OR (ileostomy))
ScienceDirect	("Vulnerability Analysis") OR ("Health Vulnerability") OR ("Social Vulnerability") OR ("Vulnerability Study") AND ("Surgical Stomas") OR ("Ostomy") OR ("Colostomy") OR ("Ileostomy")
Web of Science	(Ostomy) AND ((social vulnerability) OR (health vulnerability) OR (vulnerability analysis))

Source: The authors (2025).

Original articles were adopted as inclusion criteria, with no restrictions on period and language. Articles whose titles and abstracts did not address the guiding question, as well as experience reports, opinion articles, editorials, reviews, and book chapters, were excluded.

Data collection was conducted between April and May 2025 via the CAPES Journal Portal, with access provided by the Federated Academic Community (CAFé) of the Federal University of Alagoas (UFAL), enabling access to a larger number of internationally published articles.

The articles were exported to the software Rayyan, which enabled the exclusion of duplicates and the reading of titles and abstracts by three independent researchers. Two researchers selected and read the articles. In cases of disagreement, a third researcher was called to resolve the discrepancies and establish the final consensus.

The process of identifying the articles was summarized in a flowchart, following the items of the report for systematic reviews and meta-analyses for scoping reviews (PRISMA -ScR). These articles were compiled into a structured table, highlighting: author(s); year of publication; country of origin; general objective; method; and the main results.

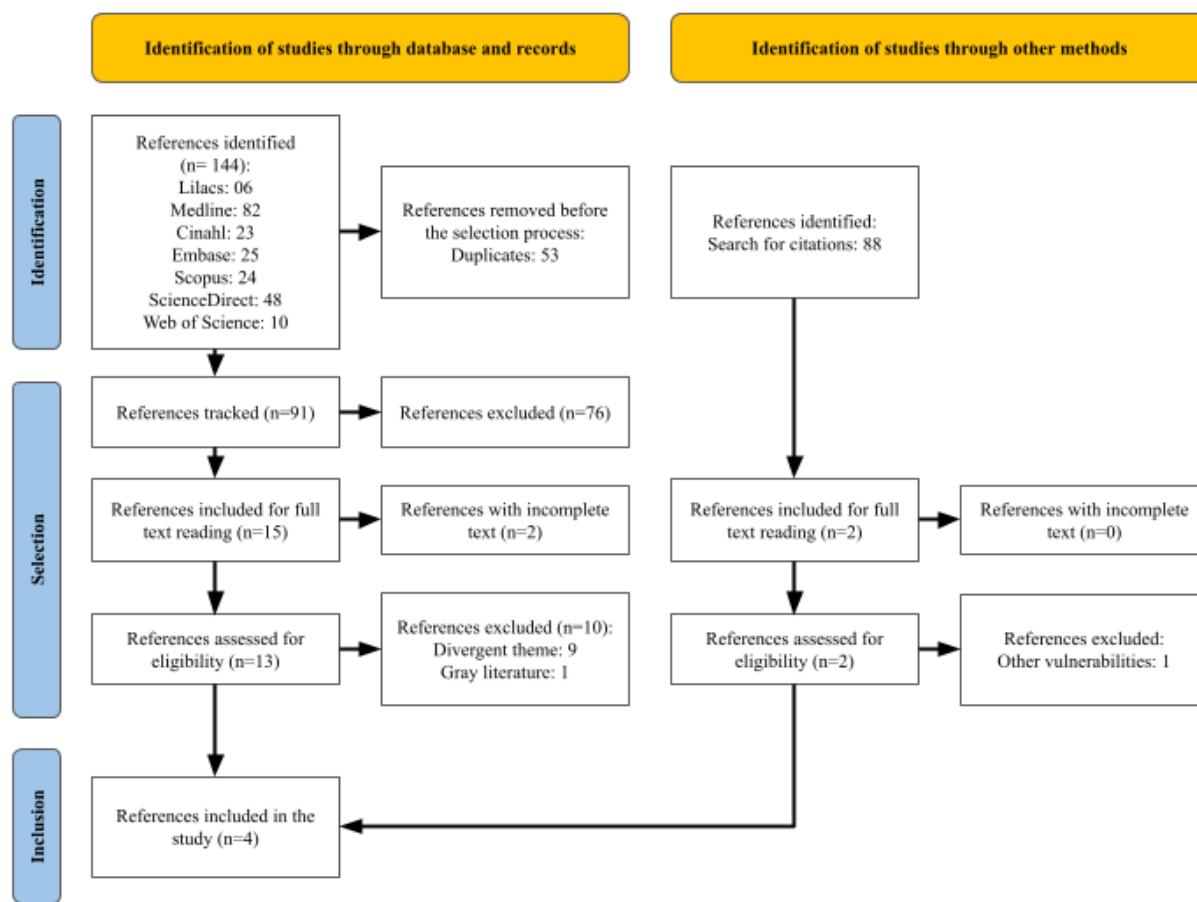
The data were analyzed in light of the theory of health vulnerabilities by Ayres et al<sup>8</sup>, which considers the vulnerability of not obtaining information, the ability to metabolize it, and the power to incorporate practical changes. Aspects that depend not only on individuals but also on factors such as access to communication means, education, availability of material resources, power to influence political decisions, ability to face cultural barriers, freedom from violent coercion, and the ability to defend oneself against them.

## RESULTS

144 publications were collected from the previously selected databases. After applying the eligibility criteria and removing duplicates, a total of 91 articles were obtained. After reading the titles and abstracts, both evaluators selected 13 studies. After a complete reading of the texts, one evaluator selected six texts and the other four. The analysis of the discrepancies, conducted by the third evaluator, yielded a sample of three articles: one in MEDLINE and two in Lilacs. Considering the low sample size, a consultation was made to the references of the included studies<sup>10</sup>, totaling a final sample of 4 articles, as shown in Figure 1.

The selected articles (Chart 1) were published in English and Portuguese and conducted in China and Brazil. There was a predominance of studies with a qualitative approach, with one adopting a phenomenological approach and one an ethnographic approach, as shown in Chart 2.

The articles presented an approach to characterizing the individual, social, and programmatic vulnerabilities present in the daily life of a person with an elimination stoma, as shown in Figure 2.



**Figure 1.** PRISMA flowchart of the identified and included articles in the scoping review. Maceió, AL, Brazil, 2025

Source: The authors (2025).

**Chart 2.** Summary of the articles included in the scope review. Maceió, AL, Brazil, 2025

(continue)

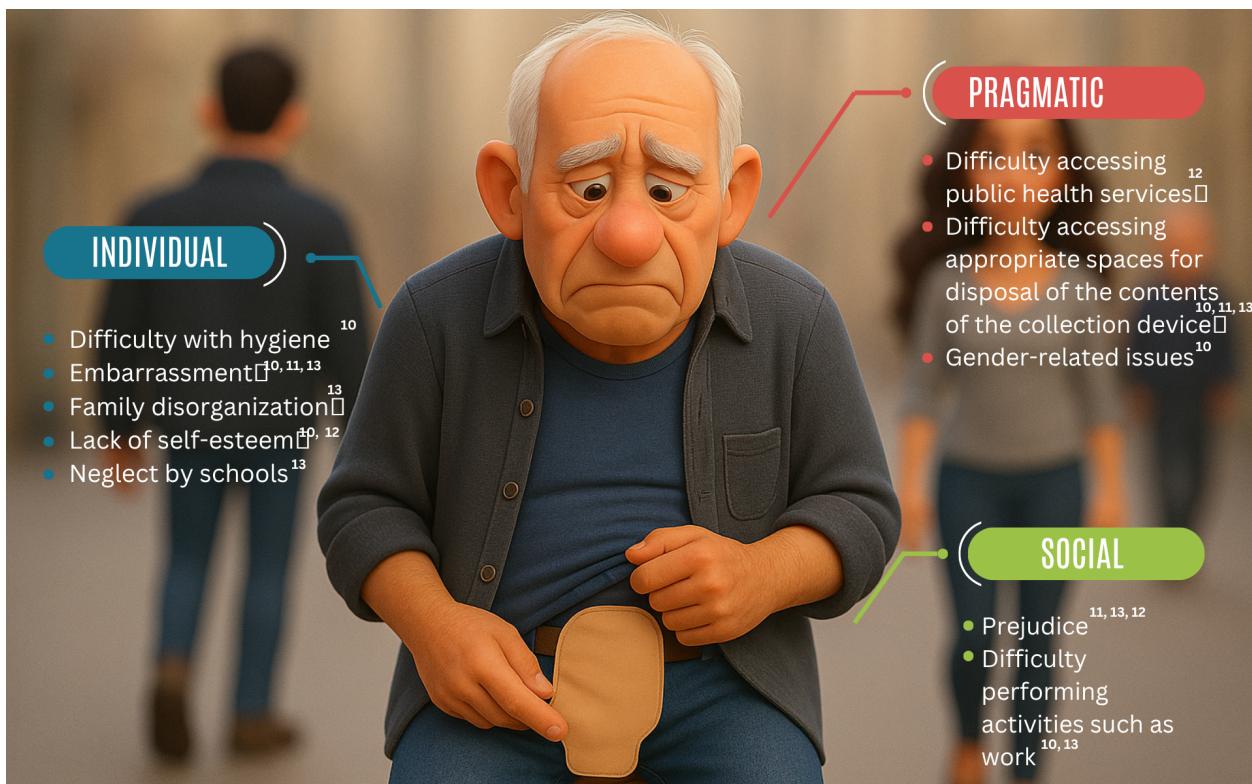
ID	Title	Author and Year	Country	Objective	Study Design	Population and Sample
E1 <sup>10</sup>	As repercussões de viver com uma colostomia temporária nos corpos: individual, social e político	Souza et al. 2011	Brazil	Analyze its repercussions on the lives of people based on bodies: individual, social, and political	Qualitative study	8
E2 <sup>11</sup>	Resilience and vulnerability of post-ostomy patients with early-onset colorectal cancer from the perspective of social-ecological theory: a qualitative study	Yang et al. 2025	China	Understand the adaptation process of EOCRC post-ostomy patients (POEOCRC)	Phenomenological qualitative study	16

**Chart 2.** Summary of the articles included in the scope review. Maceió, AL, Brazil, 2025

(conclusion)

ID	Title	Author and Year	Country	Objective	Study Design	Population and Sample
E3 <sup>12</sup>	O contexto de pessoas em situação de rua que vivem com estomias	Paczek et al. 2024	Brazil	Know the context experienced by homeless people with stomas in a municipality in Southern Brazil	Ethnographic qualitative study	4
E4 <sup>13</sup>	Vulnerabilidade da família de crianças com estomia intestinal	Zacarin et al. 2014	Brazil	Characterize the existence of vulnerability in families living with children who have intestinal stomas	Qualitative study	6

Source: The authors (2025).



**Figure 2.** Summary of the results identified in the scope review. Maceió, AL, Brazil, 2025.

Source: The authors (2025).

## DISCUSSION

Vulnerability is the likelihood of individuals' exposure to illness due to a set of individual, collective, and contextual factors. These lead to greater susceptibility to infection and illness, as well as a greater or lesser availability of resources to protect against both<sup>8</sup>.

The process of adapting to life with an elimination stoma is characterized by different vulnerabilities due to the challenges imposed on the person's routine<sup>14</sup>. The maladaptation and vulnerability faced daily culminate in issues related to mental health, difficulties in hygiene, shame, and lack of self-esteem. Children with elimination stomas present different individual vulnerabilities, such as helplessness in schools and family disintegration, due to the need for the procedure<sup>13</sup>.

In this axis, regardless of the causes that resulted in a stoma, the individual experiences changes in lifestyle habits, sleep patterns, diet, and bowel elimination, characterized by a lack of fecal control, insertion of devices in the abdominal wall, and consequently in social interactions and relationships<sup>15-18</sup>.

Social vulnerabilities, as characterized in the theory of vulnerabilities<sup>8</sup>, were mentioned<sup>10</sup> as a dimension related to the political body, in which the individual feels threatened when performing daily activities, such as working to access quality food - a fundamental human need for a person with a stoma. Engaging in work activities is an essential factor for recovering self-esteem and overcoming prejudice. Work makes a person feel useful and promotes social inclusion, in addition to being the means for financial support, indispensable for their survival and that of their family<sup>10,12</sup>. The difficulty in accessing public health services with professionals who act in a humanized manner also influences the routine of this population<sup>12</sup>.

The programmatic vulnerabilities experienced in the daily life of a person with an elimination stoma involve different aspects, including the difficulty of accessing appropriate spaces for emptying the collection device, such as in schools and health services. Moreover, the literature highlights the challenges of continuing medical treatment for people with elimination stomas who are homeless, due to the difficulty of accessing health services and the absence of public policies that ensure the continuity of care for this population<sup>11,13</sup> repercussions of living with a temporary colostomy on bodies: individual, social, and political.

Programmatic vulnerabilities are also influenced by gender variables concerning routine. A study conducted with 150 patients using intestinal stomas in a stomatherapy service observed a prevalence of male patients, highlighting the low access of this group to primary health services, the absence of public policies directed at this population, and the consequent increase in care at the more complex levels of the health system<sup>19</sup>.

## FINAL CONSIDERATIONS

The scope review allowed mapping of the fact that living with an elimination stoma exposes the individual to multiple vulnerabilities that significantly impact their quality of life.

Individual vulnerabilities manifest from the difficulty of adapting to the changes imposed by the stoma, affecting aspects such as self-esteem, hygiene, and family routine. Social vulnerabilities are reflected in exclusion from social interactions and

daily activities, such as access to the workplace, which reinforce feelings of uselessness, prejudice, and isolation. Programmatic vulnerabilities refer to the insufficiency of health services and the lack of specific public policies for the ostomized population.

Thus, the articulation of the three axes of vulnerability theory highlights that the condition of the ostomized extends beyond biological aspects, being a phenomenon that demands intersectoral interventions and effective public policy actions to promote social inclusion and access to health.

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**Role of Authors:**

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **dos Anjos CS, Melo JLL, Bastos MCS.** Drafting the work or revising it critically for important intellectual content - **dos Anjos CS, Melo JLL, Bastos MCS, Bernardo THL, Dias RBF, da Silva AF.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **dos Anjos CS, Melo JLL, Bastos MCS, dos Santos AAP, Dias RBF, da Silva AF.** All authors approved the final version of the text.

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The authors have no conflicts of interest to declare.

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The authors declare that all data are fully available within the article.

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