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Review Article

Instruments and dimensions for assessing care quality for people living with an ostomy: a scoping review

Instrumentos e dimensões para avaliação da qualidade do cuidado à pessoa com estomia: revisão de escopo

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ABSTRACT
Objective: to map the instruments — and their underlying dimensions — used to evaluate the quality of care for people living with an ostomy. **Methods:** scoping review. We searched nine national and international databases and three thesis/dissertation catalogs, with no date limits. **Results:** of 5,178 records, 16 studies met the inclusion criteria. Five instruments were identified: Quality of Care and Support; Service Quality; Quality from Patients' Perspective; The Quality of Care Support; and Quality of Care Scale. The most frequently reported dimensions included access to services, comprehensiveness of care, continuing education, and patient satisfaction. **Conclusion:** care quality is multifaceted, with patient perception as a central indicator. Using standardized instruments and understanding the dimensions that shape care help teams incorporate users' needs and expectations, fostering humane, individualized care. **Contributions to practice:** applying these instruments supports the identification of gaps in care and the adoption of integrated, patient-centered practices, strengthening quality and aligning services with real-world demands.

Descriptores: Quality of Health Care; Health Care Quality, Access, and Evaluation; Persons with Disabilities; Ostomy.

RESUMO
Objetivo: mapear os instrumentos e suas dimensões utilizados na avaliação da qualidade do atendimento à pessoa com estomia. **Métodos:** trata-se de uma revisão de escopo. A pesquisa foi realizada em nove bases de dados, nacionais e internacionais, e em três catálogos de teses e dissertações, sem limite temporal. **Resultados:** identificaram-se 5.178 estudos, sendo que 16 compuseram a amostra final. Foram mapeados cinco instrumentos: *Quality of Care and Support*, *Service Quality*, *Quality of Care from the Patient's Perspective*, *The Quality of Care Support* e *Quality of Care Scale*. Já em relação às dimensões identificadas, destacam-se a acessibilidade aos serviços, integralidade no atendimento, educação continuada e satisfação do paciente. **Conclusão:** a qualidade do cuidado é um conceito multifacetado, tendo a percepção do paciente como indicador central. A aplicação de instrumentos e o conhecimento das dimensões que podem influenciar o cuidado prestado permitem incorporar necessidades e expectativas dos usuários, promovendo cuidado humanizado e individualizado. **Contribuições para a prática:** o uso desses instrumentos favorece a identificação de lacunas na assistência e adoção de práticas integradas e centradas no paciente, assegurando qualidade e alinhamento às demandas reais.

Descritores: Qualidade da Assistência à Saúde; Qualidade, Acesso e Avaliação da Assistência à Saúde; Pessoas com Deficiência; Estomia.

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Introduction

Creating an ostomy places a person in a condition of disability that affects multiple dimensions of life, shaping physical, emotional, and social aspects. These individuals are often uninformed and underserved, which undermines adaptation, rehabilitation, and quality of life. In this context, qualified health care is essential to promote well-being and autonomy(1-3).

In Brazil's Unified Health System (SUS), care for people with an ostomy is guided by the Brazilian National Guidelines for the Health Care of People with Ostomies and integrated into the Brazilian Health Care Network(4).This structure is intended to ensure access to services across different levels of complexity, promote self-care, support continuity of care, and provide essential supplies. In practice, however, fragmentation within the health system makes it hard for patients to navigate services, creating gaps and delays that undermine quality of care(4-5).

Because of these challenges, assessing health care quality through three dimensions — structure (resources and organization), process (actions delivered), and outcomes (health impacts and patient satisfaction) — is crucial. Within this framework, studies indicate that health care services for people with ostomies perform better in supplying devices than in providing clinical and educational support. There is also a shortage of evaluations that capture users' perspectives on the care received, limiting understanding of their real needs(6-8).

Perceptions of quality differ between professionals and patients and are influenced by factors such as team preparedness, informational support, the care relationship, family support, and access to specific guidance, including sexuality and mental health(9). Proper documentation of patient conditions and the work of multidisciplinary teams are also key to personalizing care. Yet communication failures and social stigma remain significant barriers(10).

Continuous evaluation of care quality is therefore necessary, especially for groups with specific needs, such as people with an ostomy(11–12). Validated assessment instruments help identify gaps, improve processes, and foster more effective, humane, patient-centered care. Accordingly, this study aimed to map the instruments — and their underlying dimensions — used to evaluate the quality of care for people living with an ostomy.

Methods

This scoping review followed JBI methodology and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)(13). The review protocol was registered on the Open Science Framework (OSF) under DOI: 10.17605/OSF.IO/2D9UK.

The process comprised nine stages: (1) defining the study objective and the review question; (2) establishing and aligning inclusion criteria; (3) identifying evidence, selecting records, extracting data, and planning presentation; (4) conducting the search; (5) selecting studies; (6) extracting evidence; (7) analyzing evidence; (8) presenting and interpreting results; and (9) summarizing the evidence, conclusions, and implications(14).

We used the PCC framework to build the review question: P (participants) = people with an ostomy; C (concept) = quality of care; C (context) = ostomy care. Based on these elements, the guiding review question was: Which instruments and dimensions are used to evaluate the quality of care as perceived by people with an ostomy?

Search terms were identified in Medical Subject Headings and Health Sciences Descriptors, combined with the Boolean operators AND and OR. Informed by a preliminary search, we also incorporated text words from titles and abstracts of relevant articles and the subject terms used to index them, to develop a comprehensive strategy. The core search string was: ("Quality of Health Care" OR "Health Evaluation" OR "Health Research Evaluation" OR "Quality Assurance Health Care") AND ("Disabled Persons" OR Ostomy OR Colostomy). The strategy was adapted for each database while preserving equivalent descriptor combinations.

The initial search was run in July 2024 and finalized in January 2025 across the following sources: MEDLINE (via PubMed), Web of Science, Scopus, Embase, LILACS and BDENF (via the Virtual Health Library), LISA, Cochrane Library, and CINAHL. Grey literature sources included the *Repositório Latino-Americano*, the Brazilian Digital Library of Theses and Dissertations, and Open Access Theses and Dissertations. All databases were accessed through the *Coordenação de Aperfeiçoamento de Pessoal do Nível Superior* (CAPES) Journals Portal via the Federal University of São João del-Rei.

We included online studies in any language and without date limits, retrieved from electronic databases or obtained directly from authors. Grey literature encompassed institutional documents, dissertations, theses, materials from governmental and nongovernmental organizations, opinion articles, and scientific conference records that addressed instruments for assessing the quality of care for people with an ostomy. All included materials met eligibility criteria and were relevant to the review objective. Data appraisal was conducted carefully, with emphasis on synthesizing the most impactful studies. Narrative and integrative reviews were excluded.

Records were then exported to the Rayyan software(15). In phase one, three review authors independently and blindly screened titles and abstracts. Disagreements were resolved through discussion, and a fourth review author was consulted when needed. In phase two, studies meeting inclusion criteria were assessed in full to extract information on instruments and dimensions related to the quality of care received by people with an ostomy.

Three review authors performed data extraction independently and organized it in Microsoft Excel® spreadsheets. We collected publication characteristics (year, source, authors, title, study type, method, language, country, and descriptors/keywords). Levels of evidence and grades of recommendation were assigned according to JBI guidance(14), with levels of evidence I–V and grades of recommendation A–E.

From each included study, we extracted key elements regarding the hypothesis, context, methodology, discussion, and conclusions. When necessary, full texts of articles, dissertations, and these were consulted to ensure analytical fidelity. Because this is a scoping review, ethics approval was not required.

Results

Database searches retrieved 5,178 records: 1,448 from CINAHL, 1,206 from LISA, 833 from MEDLINE, 660 from SCOPUS, 558 from LILACS, 406 from BDENF, 36 from Embase, 19 from Web of Science, and 12 from Cochrane. After primary screening, 2,002 duplicates were removed.

Of the 3,176 titles and abstracts screened, 26 studies were selected for full-text review, of which 10 did not meet the study objective. A total of 16 studies were included in the review (Figure 1).

Among the 16 included articles, publications ranged from 2005 to 2022. Four (25%) were conducted in Brazil, four (25%) in the United States, two (12.5%) in Sweden, and one (6.25%) each in Ireland, China, Korea, Portugal, New Zealand, and England. All included studies were descriptive, cross-sectional designs, corresponding to a low level of evidence (16/16; 100%). Study details are presented in a structured chart (Figure 2).

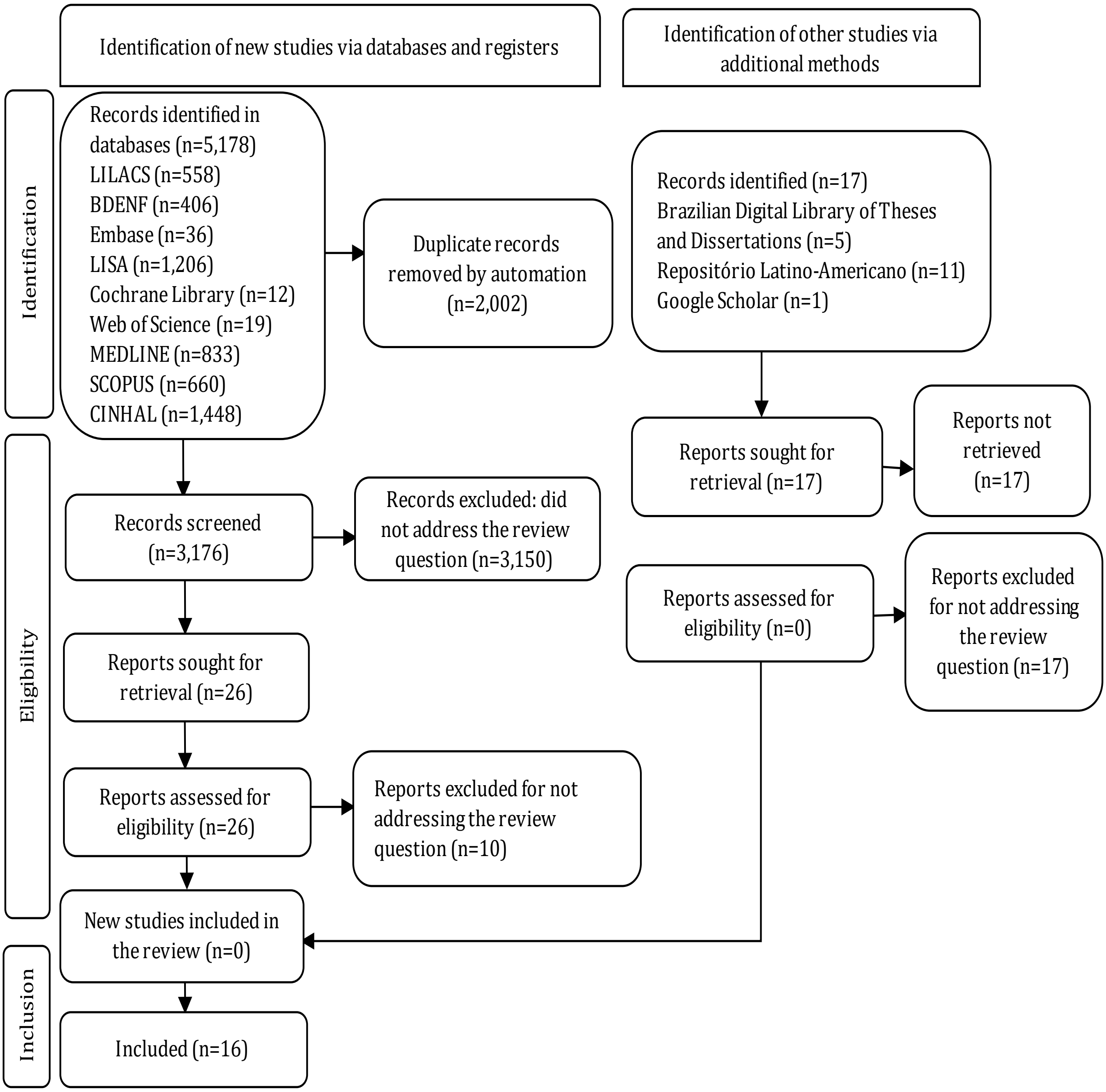


Figure 1 – Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of study selection for the scoping review. Divinópolis, Minas Gerais, Brazil, 2025

Authors	Year	Country	Instruments for assessing care quality	LE
Bowles et al(16)	2022	England	Study-specific instrument	4b
Houston et al(17)	2021	New Zealand	Study-specific questionnaire	4b
Dias et al(18)	2020	Brazil	Quality of Care Scale	4b
Romão et al(19)	2020	Portugal	Confidential self-report, study-specific instrument	4b
Swords et al(20)	2019	USA	Semi-structured interviews with a study-specific questionnaire	4b
Dias et al(21)	2019	Brazil	Interview guide and Quality of Care Scale	4b
Morris et al(22)	2017	USA	Semi-structured interviews and study-specific questionnaires	4b
Vries et al(23)	2016	USA	Study-specific instrument used in in-person and virtual focus groups	4b
Zheng et al(24)	2014	China	The Quality of Care Support	4b
Bredemeier et al(25)	2014	Brazil	Participants completed World Health Organization Disability Assessment Schedule II, sociodemographic questionnaire, QOCS-D, QOCS-ID, Satisfaction with Life Scale, and Beck Depression Inventory–II	4b
Mattevi et al(26)	2012	Brazil	Quality of Care and Support	4b
Lucas et al(27)	2010	Spain	Quality of Care and Support	4b
Shin et al(28)	2008	Korea	Study-specific instrument	4b
O'Reilly et al(29)	2007	Ireland	Service Quality	4b
Persson et al(30)	2005	Sweden	Quality of Care from the Patient's Perspective	4b
Persson et al(31)	2005	Sweden	Study-specific instrument	4b

LE: Level of evidence; QOCS-D: Quality of Care and Support - Physical Disabilities; QOCS-ID: Quality of Care and Support - Intellectual Disability

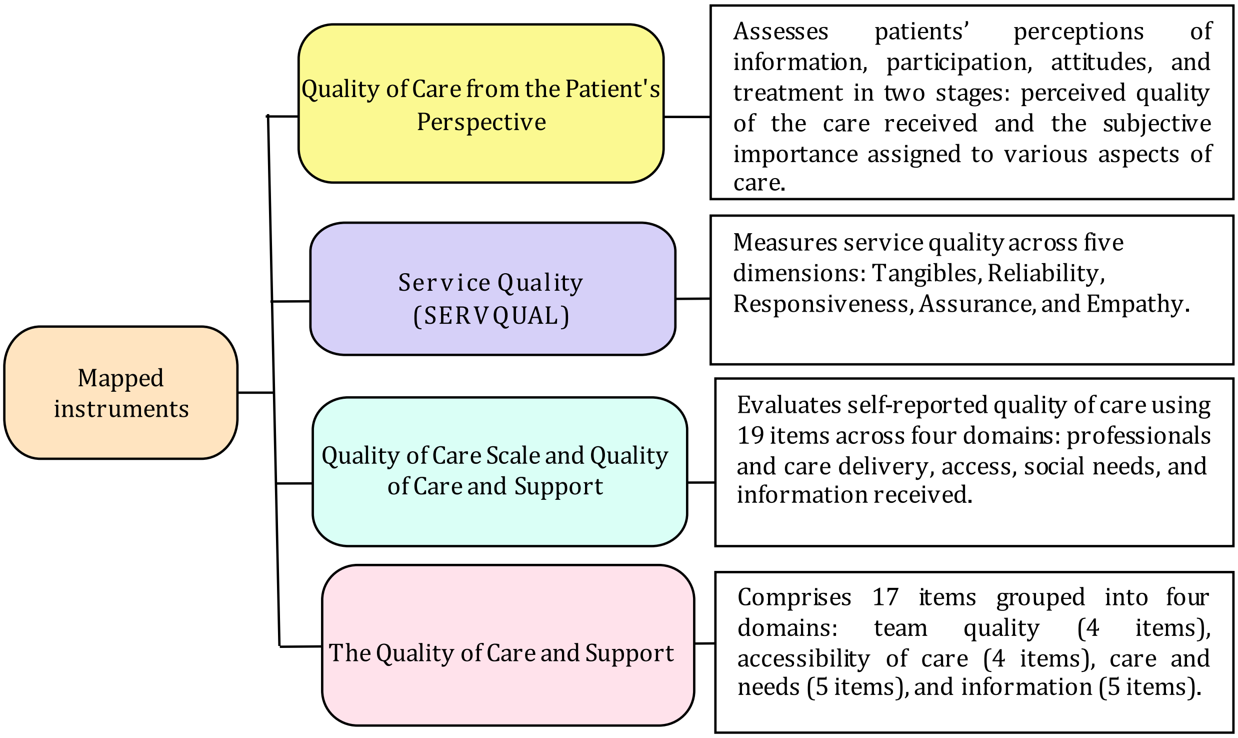
Figure 2 – Study characteristics (authors, year of publication, country, and instruments for assessing quality care; n=16). Divinópolis, Minas Gerais, Brazil, 2025

To examine care quality in light of the methodologies initially identified, we first synthesized the findings and then ran a word-frequency analysis in R using the *wordcloud2* package (Figure 3).

Figure 3 – Word frequency extracted from the articles' objectives (n=16). Divinópolis, Minas Gerais, Brazil, 2025

The studies identified in this review used a range of methodologies to evaluate instruments, most commonly questionnaires, focus groups, and interviews. These approaches were applied to explore perceptions of care quality, access to services, and sociodemographic, clinical, and care-related factors, and were consistently cited as strategies that yield positive impacts on this type of assessment. Five distinct instruments were mapped: Quality of Care and Support (QOCS), Service Quality (SERVQUAL), Quality from Patients' Perspective (QPP), The Quality of Care Support (TQCS) and the Quality of Care Scale (QCS) (Figure 4).

Across the included studies, several dimensions shaping the evaluation of care quality for people with an ostomy — and, more broadly, for people with disabilities — were examined. The dimensions most frequently considered were access to services, comprehensiveness of care, continuing education, and patient satisfaction, along with the key factors reported to negatively affect care quality (Figure 5).



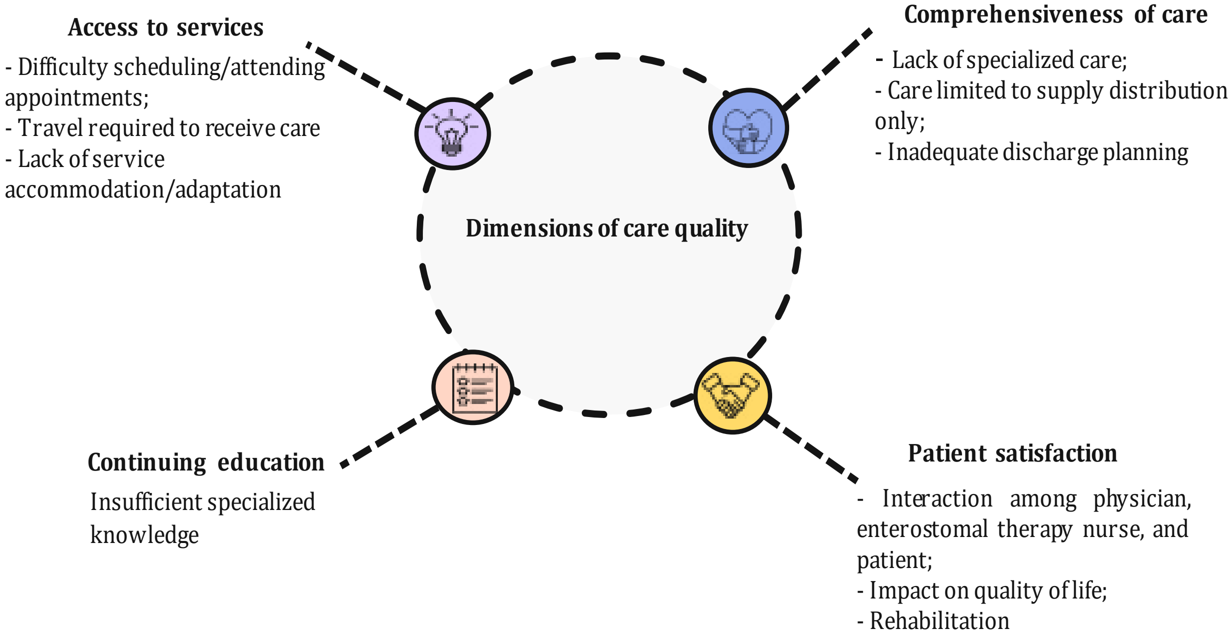
Assesses patients' perceptions of information, participation, attitudes, and treatment in two stages: perceived quality of the care received and the subjective importance assigned to various aspects of care.

Measures service quality across five dimensions: Tangibles, Reliability, Responsiveness, Assurance, and Empathy.

Evaluates self-reported quality of care using 19 items across four domains: professionals and care delivery, access, social needs, and information received.

Comprises 17 items grouped into four domains: team quality (4 items), accessibility of care (4 items), care and needs (5 items), and information (5 items).

Figure 4 – Instruments mapped for assessing care quality (n=16). Divinópolis, Minas Gerais, Brazil, 2025



Access to services
- Difficulty scheduling/attending appointments;
- Travel required to receive care
- Lack of service accommodation/adaptation

Comprehensiveness of care
- Lack of specialized care;
- Care limited to supply distribution only;
- Inadequate discharge planning

Continuing education
Insufficient specialized knowledge

Patient satisfaction
- Interaction among physician, enterostomal therapy nurse, and patient;
- Impact on quality of life;
- Rehabilitation

Figure 5 – Dimensions and key factors influencing care quality (n=16). Divinópolis, Minas Gerais, Brazil, 2025

Discussion

This scoping review mapped scientific evidence on instruments that assess satisfaction among people with an ostomy and disabilities regarding the quality of health care received as well as the dimensions that shape this perception. Because specific tools for evaluating care for people with an ostomy are scarce, we also included instruments used in the broader disability context.

Across the studies, multiple instruments were used to assess quality. They allowed investigators to estimate patient satisfaction, perceptions of professional skill and knowledge, and access to services(24,26-27). Some questionnaires, in addition to addressing care and access, also captured demographic variables (age, sex, socioeconomic status), physical and mental health, and quality of life(20,25,32). Interviews and focus groups were notable for enabling a detailed exploration of individual patient experiences(19,25-26).

The QPP instrument, developed in Sweden and validated in Brazil, focuses on the patient perspective and includes both objective and subjective aspects of care(31). SERVQUAL, developed in the United States and validated in Brazil, is flexible and can be applied across hospital and outpatient settings, as illustrated by an Asian meta-analysis(30,32-33).

The QCS, created in the United States and validated in Brazil in 2014, captures quality in several critical areas, including the patient perspective; however, without adaptation to a specific population, it may not encompass all needs(18,21,25). Finally, the QOCS, of unknown origin, is multidimensional and covers multiple technical and interpersonal attributes, but its lack of validation in Brazil limits applicability(25).

Using these instruments together with varied data-collection methods provided a comprehensive appraisal of care quality and the factors that influence patient perception and satisfaction, helping to identify gaps and improve care delivery based on patients' own accounts(17,28,31). The included articles therefore supported an in-depth analysis of quality-of-care dimensions.

Quality of care is shaped by interrelated factors such as professional preparedness, the caliber of service delivery, informational support, and respect for patient needs. Family members often play a central role in caring for people with specific conditions such as ostomy, acting not only as primary caregivers but also as intermediaries between patients and professionals to report needs and help ensure appropriate care(6,21,32,34). This underscores the importance of clear, consistent guidance for families and caregivers, particularly at hospital discharge and during critical recovery periods(17-18,31).

Accurate documentation of patient status — especially mobility, communication, and health literacy — is also essential for patient-centered care. Such records give health services a clearer, more accessible understanding of patient needs, improving continuity and personalization. Yet studies indicate these data are not always easily accessible and are often inconsistent, making it difficult to tailor care to individual needs(35-36).

Other issues include lack of privacy during care and insufficient information in hospital settings, particularly emergency departments(37). Hospital care quality can be improved with more comprehensive guidance, from mobility and exercise to the prevention of complications such as hernias(17,35). Consistent, detailed information helps patients better prepare for recovery and adopt safer self-care(19,30,37).

An integrated multidisciplinary team is crucial for sharing information and providing more assertive, safer care. Although trust in health professionals, a stable care relationship, and specialist support are fundamental, many patients still need more guidance on sexual health and psychological support — areas that remain neglected(10,17,37).

Attitudes toward people with disabilities directly affect perceived care quality. Respectful, accepting attitudes facilitate treatment and foster a more positive view of the health system(33). Social beliefs and stigma can create barriers to equitable, humane care, harming patients' functionality and quality of life. Social inclusion and family support, in contrast, aid recovery and create a more welcoming, supportive environment(22,28).

Ongoing professional education is essential to ensure care is appropriate and adaptive. Specialist nurses, such as enterostomal therapists, play a key role in preparing patients for physical and emotional changes after invasive surgeries, including ostomy creation. Their expertise is critical for providing the guidance patients need to manage their condition, supporting self-management and better quality of life(14-15,27).

The broader discussion of care quality and patient experience highlights persistent challenges and inequities that influence both perception and effectiveness of care. Valuing patients' experiences and understanding their needs are essential for high-quality care. Still, there is a gap in implementing improvement initiatives that truly incorporate patients' lived experiences and expectations. This becomes even more apparent given that many patients — with or without disabilities — navigate a complex, fragmented health system, which leads to frustration and feelings of devaluation(37). Critical issues include a lack of workplace adaptations, long wait times, and transportation costs(17).

Reports indicate that many patients feel health professionals rarely have sufficient time to discuss health concerns, impairing communication during brief appointments — especially for those needing additional support, as is often the case for people with disabilities(25). The situation is compounded by the fact that many participants with disabilities had lower educational levels, were unemployed, and lived in disadvantaged socioeconomic conditions(36). Women with disabilities faced even greater barriers to adequate care, reflecting disparities in health conditions and access to services(37).

Within the SUS, limitations in access to services and medications were reported, indicating challenges to continuity and comprehensiveness. Although not all interviewees experienced long waits or excessive bureaucracy, a significant share did(22). Access to high-quality care also varied markedly by location. Peripheral hospitals struggled to provide safe, effective care, while the main hospital experienced delays due to workload, resulting in different care experiences depending on local infrastructure and resources(17).

In short, inequitable access compromised care quality — a pattern also seen in Brazil. Larger, better-equipped hospitals were able to offer more comprehensive care thanks to resources and specialists, whereas smaller hospitals faced significant constraints. These disparities mirror structural and socioeconomic inequalities that must be addressed to make the health system more inclusive, fair, and equitable(18).

Patient satisfaction is increasingly used as an indicator of quality of care, defined as the cognitive and emotional evaluation of how well patients' expectations regarding ideal nursing care match their perceptions of the care they received. This is apparent as patients adapt to life with an ostomy. Detailed pre- and postoperative information — both verbal and written — on living with an ostomy (leisure activities, diet, ostomy appliances, sexual life) is essential, yet such high-quality guidance is often lacking(28,33,35-37).

Service quality can be measured from the consumer's perspective, and a recurring debate concerns the distinction between client satisfaction and service quality. A broad consensus has emerged: satisfaction is a transaction-specific evaluation, whereas service quality is an overall judgment or attitude about the service(31).

This distinction has implications for measurement. Health services involve intensive interaction and surrounding services that must meet individual user needs, requiring a high degree of customization. Defining quality solely as "excellence" risks a provider-centric view, leading organizations to neglect the client's definition of quality and, in turn, to miss their needs(31,36-37).

Study limitations

This review is limited by the predominance of studies with low levels of evidence, the scarcity of randomized clinical trials, and the few systematic reviews with meta-analysis — factors that weaken the robustness of current recommendations on the topic.

In addition, there is a lack of studies conducted in the Brazilian context and a possibility that relevant research indexed in other databases was not captured.

Contributions to practice

The findings offer practical guidance for health professionals who care for people with an ostomy. Identifying validated instruments to assess care quality supports the adoption of evidence-based tools and strengthens services' ability to measure the effectiveness of care in a systematic way.

Prioritizing instruments that center the patient perspective promotes more humane, individualized care aligned with the real needs of people with an ostomy, reinforcing both quality and comprehensiveness.

Conclusion

This scoping review mapped several international instruments used to assess care quality, including Quality of Care and Support, Service Quality, Quality of Care from the Patient's Perspective, The Quality of Care Support, and Quality of Care Scale. Together, these tools underscore that quality in health care is a complex construct that encompasses not only technical excellence but also the patient's perception.

Regarding the dimensions analyzed, the studies show that incorporating users' satisfaction and expectations into the evaluation process is essential to ensuring patient-centered care that meets individual needs.

Authors' contributions

Conception and design or data analysis and interpretation: Castro LC, Moraes JT. Drafting of the manuscript or critical revision for important intellectual content, and responsibility for all aspects of the text to ensure the accuracy and integrity of any part of the manuscript: Castro LC, Custodio LB, Silva LO, Nunes VC, Castro JC, Moraes JT. Final approval of the version to be published: Moraes JT.

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