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# A Systematic Review & Quality Assessment of Clinical Practice Nursing Guidelines for Ostomy Care

## Abstract

### Background

People living with an intestinal stoma require specialized interdisciplinary care throughout their surgical journey and beyond. As part of the Endpoint Development for Ostomy Clinical Trial (EndO-trial) Consortium for patients with Crohn's disease and permanent ileostomies, we evaluated nursing guidelines focused on the clinical management of people living with intestinal ostomies, identified knowledge and system gaps, and supported the development of evidence-based patient care pathways.

### Methods

We conducted a systematic literature search across Medline, EMBASE, CINAHL, and major nursing organization websites up to March 25, 2024, to identify evidence-based guidelines nursing organizations developed for caring for patients with intestinal stomas post-ostomy formation. The authors summarized the evidence and critically appraised it using the AGREE II Instrument.

### Results

Fourteen nursing guidelines from Australia, Canada, Italy, the United Kingdom (UK), the United States of America (USA), and 3 international working groups, ranging from 2013 to 2023, met the inclusion criteria. These guidelines offer extensive coverage of ostomy care topics and provide valuable first-line care experience and consensus statements, particularly for postoperative stoma and peristomal care. In the AGREE II assessment, most guidelines were rated as moderate quality (scores <6), with recommended modifications primarily in the rigor of development and applicability.

### Conclusion

Critical appraisal of clinical practice nursing guidelines for ostomy care highlights both strengths and areas for improvement and expansion within existing guidelines. These insights are essential for non-nursing health care providers and contribute to the development of patient care pathways for individuals with Crohn's disease and permanent ileostomies.

**Key Words:** Nursing, guidelines, ostomy, ileostomy, stoma

## Revue systématique et évaluation de la qualité des lignes directrices en soins infirmiers pour les soins de stomie

### Résumé

#### Contexte

Les personnes vivant avec une stomie intestinale nécessitent des soins interdisciplinaires spécialisés tout au long de leur parcours chirurgical et au-delà. Dans le cadre du consortium de développement de critères d'évaluation pour les essais cliniques (EndO-trial) auprès de patients atteints de la maladie de Crohn et ayant une iléostomie permanente, nous avons évalué les lignes directrices infirmières portant sur la prise en charge clinique des personnes vivant avec une stomie intestinale,

identifié les lacunes de connaissances et organisationnelles, et appuyé le développement de parcours de soins fondés sur des données probantes.

### Méthodes

Nous avons réalisé une recherche systématique de la littérature dans Medline, EMBASE, CINAHL et sur les principaux sites internet d'organisations infirmières jusqu'au 25 mars 2024 afin d'identifier les lignes directrices fondées sur des données probantes élaborées par des organisations infirmières pour le suivi des patients avec une stomie intestinale après la chirurgie. Les auteurs ont résumé les données probantes et procédé à une évaluation critique à l'aide de l'outil AGREE II.

### Résultats

Quatorze lignes directrices infirmières provenant d'Australie, du Canada, d'Italie, du Royaume-Uni, des États-Unis et de trois groupes de travail internationaux, publiées entre 2013 et 2023, répondaient aux critères d'inclusion. Ces lignes directrices couvrent de façon étendue les sujets liés aux soins de stomie et fournissent des indications précieuses de soins de première ligne ainsi que des énoncés consensuels, en particulier pour les soins postopératoires de la stomie et de la peau péristomiale. Dans l'évaluation avec AGREE II, la majorité des lignes directrices ont été classées comme étant de qualité modérée (résultats < 6) les modifications recommandées portant principalement sur la rigueur de l'élaboration et l'applicabilité.

### Conclusion

L'évaluation critique des lignes directrices en soins infirmiers pour les soins de stomie met en évidence à la fois les forces et les aspects à améliorer et à développer dans les lignes directrices existantes. Ces constats sont essentiels pour les fournisseurs de soins de santé non infirmiers et contribuent à l'élaboration de parcours de soins pour les personnes atteintes de la maladie de Crohn et ayant une iléostomie permanente.

**Mots-clés :** soins infirmiers, lignes directrices, stomie, iléostomie

### Conflicts of Interest:

- MH, HP, SR, SA have none to disclose.
- YY: consulting fees from Alimentiv.
- VS: speaker's fees from Pfizer.
- SV: consulting fees from Alimentiv.
- FR is consultant to Agomab. Allergan, AbbVie, Boehringer Ingelheim, Celgene, Cowen, Falk Pharma, Genentech, Gilead, Gossamer, Guidepoint, Helmsley, Index Pharma, Janssen, Koutif, Mestag, Metacrine, Morphic, Origo, Pfizer, Pliant, Prometheus, Receptos, RedX, Roche, Samsung, Takeda, Techlab, Theravance, Thetis, UCB and received funding from the National Institute of Health, Helmsley Charitable Trust, Crohn's and Colitis Foundation, Rainin Foundation, UCB, Boehringer-Ingelheim, Pliant, Morphic, BMS, 89Bio.
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### Availability of Data and Materials:

This systematic review did not involve the collection of primary data. The data supporting the findings are available in the supplemental files or can be accessed through the published references cited in the manuscript.

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## INTRODUCTION

An ostomy is a surgical procedure that creates an intestinal opening on the abdomen's surface, allowing luminal content to exit the body by bypassing the usual pathways. The most common ostomies are a colostomy and ileostomy (temporary or permanent) for diversion of the fecal stream.<sup>1</sup> They are performed in people with conditions such as colorectal cancer, inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), and following trauma. Approximately 50% of individuals diagnosed with CD require surgical intervention within 10 years of diagnosis, and more than 10% may ultimately need a permanent ileostomy (PI).<sup>2</sup> Nevertheless, an ileostomy is seldom curative, and small bowel clinical recurrence of CD occurs in roughly 27% of patients following total colectomy with permanent ileostomy.<sup>3</sup>

Complications after an ostomy vary and can include skin irritation, granulomas, parastomal psoriasis and parastomal hernia, pyoderma gangrenosum, and others such as stomal or peristomal bleeding, stoma prolapse, and retraction. Many factors are associated with peristomal skin complications.<sup>4</sup> The presence of a stoma also significantly impacts persons' health-related quality of life (HRQoL). The global prevalence of anxiety (48%) and depression (39%) in people living with an ostomy is high.<sup>5</sup> Each type of ostomy and the associated

complications require careful and holistic management to ensure that the person living with an ostomy has a good quality of life and to prevent further health issues.

People living with an intestinal stoma require specialized care throughout their surgical journey and beyond. The standard care for prevention and treatment of stoma complications can be inconsistent.<sup>6</sup> Stoma nurse specialists play a crucial role in caring for and supporting patients with intestinal stomas by utilizing evidence-based practices and specialized expertise.<sup>7</sup> Nursing interventions can improve self-efficacy, enhance self-care and self-management, lead to a reduction in adverse outcomes and ostomy complications, and increase patient satisfaction.<sup>8</sup>

To aid in the delivery of effective ostomy care, many organizations, including nursing organizations, have developed clinical practice guidelines. The standards of wound, ostomy, and continence (WOC) nursing practice include several components of the nursing process, including assessment, diagnosis, outcomes identification, planning, implementation, coordination of care, health teaching and health promotion, and evaluation.<sup>9</sup> These guidelines provide valuable insights not only for nurses but also for other clinicians. To date, only 2 systematic reviews have evaluated clinical practice guidelines for ostomy care. One included 5 guidelines,<sup>10</sup> the other included 10 guidelines.<sup>11</sup> Both targeted health care professionals without focusing on nursing guidelines.

The Endpoint Development for Ostomy Clinical Trial (EndO-trial) Consortium, funded by the Helmsley Charitable Trust (USA), is dedicated to addressing the gaps in care provision for people living with an ostomy, including developing structured clinical care pathways for patients with CD and PI through several interconnected workstreams. As part of the consortium, we aim to systematically review and evaluate the nursing guidelines that focus on the management of patients with intestinal ostomies, identify the knowledge gaps from the perspective of nursing care, and provide evidence to support the development of evidence-based patient care pathways and guidelines for patients with CD and PI.

## METHODS

We conducted a systematic review focusing on the nursing guidelines intended for nurses caring for people with intestinal stomas before and after surgery, specifically focusing on ileostomies. We followed the PRISMA-2020 Checklist for reporting systematic reviews (Table 1 is available online: <https://cjwoc.ca/index.php/cjwoc/article/view/14197>).<sup>12</sup>

### Literature Search

We searched the following databases for nursing guidelines from inception to March 25, 2024: Medline (Ovid, from 1946-); EMBASE (Ovid, from 1974-), using a validated guideline filter. We searched MeSH or Emtree terms as well as free text words related to ostomy, ileostomy, and stoma in combination with

terms related to nurse or nursing, with validated design filters for guidelines and recommendations applied. We limited the search to English language studies and excluded conference abstracts (Figure 1). We also searched the Cumulative Index to Nursing and Allied Health Literature (CINAHL) via EBSCOhost from 2010, the Guidelines International Network (GIN), and the 10 large nursing organizations' and ostomy associations' websites in Australia, Canada, New Zealand, the UK and the USA (Figure 1).

We imported references into Covidence (<https://www.covidence.org/>), and at least 2 authors (MH, HP, YY) who Covidence randomly assigned screened each record independently. Consensus was discussed with conflict resolved. We conducted a recursive manual search of the bibliography of eligible guidelines to retrieve eligible nursing guidelines. To reflect current practice guidance, we only included guidelines published since 2010.

### Selection Criteria

We used a definitive list of inclusion and exclusion criteria.

#### Inclusion Criteria

- Guidelines developed by nursing organizations and aimed at nurses as major users.
- Guidelines aimed at nurses caring for patients with abdominal stomas following ostomy, including ileostomy.
- Guidelines included recommendations for preoperative, perioperative, postoperative, and post-discharge nursing interventions, which could include but are not limited to preoperative stoma site marking, preoperative counselling, postoperative skin care, postoperative education, post-discharge support, and complications prevention and management.
- Guidelines developed based on evidence-based approaches, including literature search, systematic reviews, and level of certainty of evidence assessment; or guidelines declared they were evidence-based. If the evidence was limited or there was no evidence, consensus was reached via rigorous methodology (e.g., Delphi approaches).
- Guidelines published after 2010.

#### Exclusion Criteria

- Guidelines developed by other professional organizations that are not aimed at nurses as major users (e.g., those aimed at surgeons or intended for all health care professionals as general management guidelines), even if they invited nurses to participate in their development or mentioned the role or value of ostomy nurses.
- Guidelines focused solely on urostomy.
- Guidelines focused on patients with cancer.
- Guidelines specific to nursing practice discipline or scope and standards of Nurses Specialized in Wound, Ostomy and Continence (NSWOC) practice.

Figure 1: Search Strategy

**DATABASE: EMBASE <1974 TO 2024 MARCH 22>, OVID MEDLINE(R) ALL <1946 TO MARCH 22, 2024>**

1 (guideline or practice guideline or consensus development conference or consensus development conference, NIH).pt. (48151)  
 2 (guideline\* or standards or consensus\* or recommendat\*).ti. (454407)  
 3 (practice parameter\* or position statement\* or policy statement\* or CPG or CPGs or best practice\*).ti. (42728)  
 4 (care adj2 (path or paths or pathway or pathways or map or maps or plan or plans or standard)).ti. (22968)  
 5 ((critical or clinical or practice) adj2 (path or paths or pathway or pathways or protocol)).ti. (11649)  
 6 (algorithm\* and (pharmacotherap\* or chemotherap\* or chemotreatment\* or therap\* or treatment\* or intervention\*)).ti. (9861)  
 7 (algorithm\* and (screening or examination or test or tested or testing or assessment\* or diagnosis or diagnoses or diagnosed or diagnosing)).ti. (11217)  
 8 (guideline\* or standards or consensus\* or recommendat\*).au. (36)  
 9 (guideline\* or standards or consensus\* or recommendat\*).co. (2295)  
 10 (guideline\* or standards or consensus\* or recommendat\*).ca. (1969)  
 11 systematic review.ti,pt,kf,sh. and (practice guideline\* or treatment guideline\* or clinical guideline\* or guideline recommendation\*).ti,ab,kf. (14083)  
 12 or/1-11 (574309) [guideline filter]  
 13 exp nursing/ or exp nursing care/ (686774)  
 14 (nurse or nurses or nursing or telenursing).ti,ab,kw,kf. (1154629)  
 15 (nurse or nurses or nursing).so. (126256)  
 16 (nurse or nurses or nursing).in. (806066)  
 17 (nurse or nurses or nursing).jn. (22540)  
 18 (nurse or nurses or nursing).jw. (1089239)  
 19 (nurse or nurses or nursing).go. (9315)  
 20 nu.fs. (137473)  
 21 (nurse or nurses or nursing).af. (2388212)  
 22 or/13-21 (2507794) [nursing terms]  
 23 12 and 22 (46849)  
 24 Ileostomy/ (25419)  
 25 (Ileostomy or ileostomies or colostom\*).ti,ab,kw,kf. (41063)  
 26 ((stoma or stomas or parastoma\*) adj5 (entero\* or instetinal\* or ileo\* or ileum or bowel or gut or abdom\* or colo\*)).ti,ab,kw,kf. (5981)  
 27 ((ostomy or ostomies) adj5 (entero\* or instetinal\* or ileo\* or ileum or bowel or gut or abdom\* or colo\*)).ti,ab,kw,kf. (1330)  
 28 (stoma or stomas or parastom\* or ostomy or ostomies or ileostomy or ileostomies).ti. (16783)  
 29 or/24-28 (60979) [ostomy terms]  
 30 23 and 29 (185)  
 31 remove duplicates from 30 (107)  
 32 limit 31 to english language (104)  
 33 conference abstract.pt. (5088203)  
 34 32 not 33 (97)

Note: lines 1-12. Guidelines filter - Standard - MEDLINE, Embase, PsycInfo. In: CADTH Search Filters Database. Ottawa: CADTH; 2024: <https://searchfilters.cadth.ca/link/25>. Accessed 2024-03-22.

**DATABASE: CINAHL (VIA EBSCOHOST)**

S1 TX (ostom\* or colostom\* or ileostom\* or stoma\*)  
 S2 TX (nurse or nurses or nursing)  
 S3 S1 AND S2  
 S4 S3. Limiters - Publication Date: 20100101-20251231; English Language; Exclude MEDLINE records; Any Author is Nurse; Publication Type: Practice Guidelines; Language: English  
 We also searched the Guidelines International Network (<https://guidelines.ebmportal.com/>) and 10 large nursing organizations' and Ostomy associations' websites in Australia, Canada, New Zealand, the UK, and the USA, including:  
 The Australian Association of Stoma Therapy Nurses (AASN) (<https://stomalthrapy.au/>);  
 The Association of Coloproctology of Great Britian & Ireland (ACPGBI) (<https://www.acpgbi.org.uk/default.aspx>);  
 The Association of Stoma Care Nurses UK (ASCNUK) (<https://ascnuk.com/>);  
 The Global Paediatric Stoma Nurses Advisory Board (GPSNAB) (<https://www.coloplastprofessional.co.uk/stoma/clinical-evidence>);  
 Nurses Specialized in Wound, Ostomy and Continence Canada (NSWOCC) (<https://www.nswoc.ca/bpr>);  
 The New Zealand Nurses Organisation College of Stomal Therapy (NZNOCSTN) (<https://www.nzno.org.nz/>);  
 The Ostomy Canada Society (OCS) (<https://www.ostomycanada.ca/>);  
 The Registered Nurses' Association of Ontario (RNAO) (<https://rnao.ca/bpg/guidelines/ostomy>);  
 The United Ostomy Association of America (UOAA) (<https://www.ostomy.org/>); Wound, Ostomy and Continence Nurses Society (WOCN) (<https://www.wocn.org/>);  
 The World Council of Enterostomal Therapists (WCET) (<https://wocetn.org/>).

- Nursing guidelines not related to stoma management and care (e.g., focusing on debridement).
- Nursing guidelines or position statements with no indication of an evidence-based approach (e.g., no literature search, systematic review, or assessment of the level of evidence).
- Primary studies or educational materials that involve the implementation of guidelines, surveys, or development of algorithms, etc.
- Consensus studies or results of a consensus meeting on definitions, terminology of complications, outcome criteria, and roles of nurse specialists in ostomy care.
- Experts' recommendations without evidence-based or consensus-based approaches.
- Commentary or review of published guideline(s), systematic review, or scoping review performed by nurses for evidence-based recommendations.
- Protocol or background information for an upcoming guideline.
- Not published in the full paper or not posted as a full guideline on the nursing organization website.
- Guidelines that have been updated and replaced by a newer version.
- Guidelines published in a language other than English.
- Duplicates.
- Guidelines published before 2010.

### Data Extraction

Two reviewers acting independently extracted the following data from each guideline: Author, publication year, nursing guideline organization, country, number of recommendations or statements, and key topics covered by the recommendations. We also checked whether a literature search and a systematic review were conducted within the included sources, and if so, we noted the search databases and search dates. Additionally, we assessed whether the certainty or level of evidence was evaluated, and if so, we noted the methods used.

### Evidence Synthesis

We reviewed each included guideline's recommendations or statements, summarizing the key topics into different categories, including preoperative, perioperative, postoperative, and post-discharge nursing interventions. We summarized the information descriptively and used a mapping table to present it. No statistical analysis was required.

To provide evidence to support the development of evidence-based patient care pathways, we focused on the recommendations related to the prevention, assessment, diagnosis, and management of parastomal (peristomal) hernias.

### Quality Assessment

We assessed the quality of the evidence-based guidelines using the AGREE II tool,<sup>13</sup> with 3 reviewers (MH, YY, SR) independently evaluating each guideline. The tool includes 23 different items across 6 domains, each item rated on a

7-point scale (1: strongly disagree to 7: strongly agree), with each domain representing a distinct aspect of guideline quality. The AGREE II protocol does not include an overall score to recommend for or against using a specific guideline. Each domain score is calculated as the average score among the assessors, scaled to the total score of that domain (<https://www.agreetrust.org>). In general, guidelines are considered high quality if 5-6 domains score above 60%, average quality if 3-4 domains score above 60%, and poor quality if 1-2 domains score above 60%. Two supplementary items evaluate the global impression of each assessor: the overall quality assessment and whether the guideline would be recommended for use in clinical practice.

### RESULTS

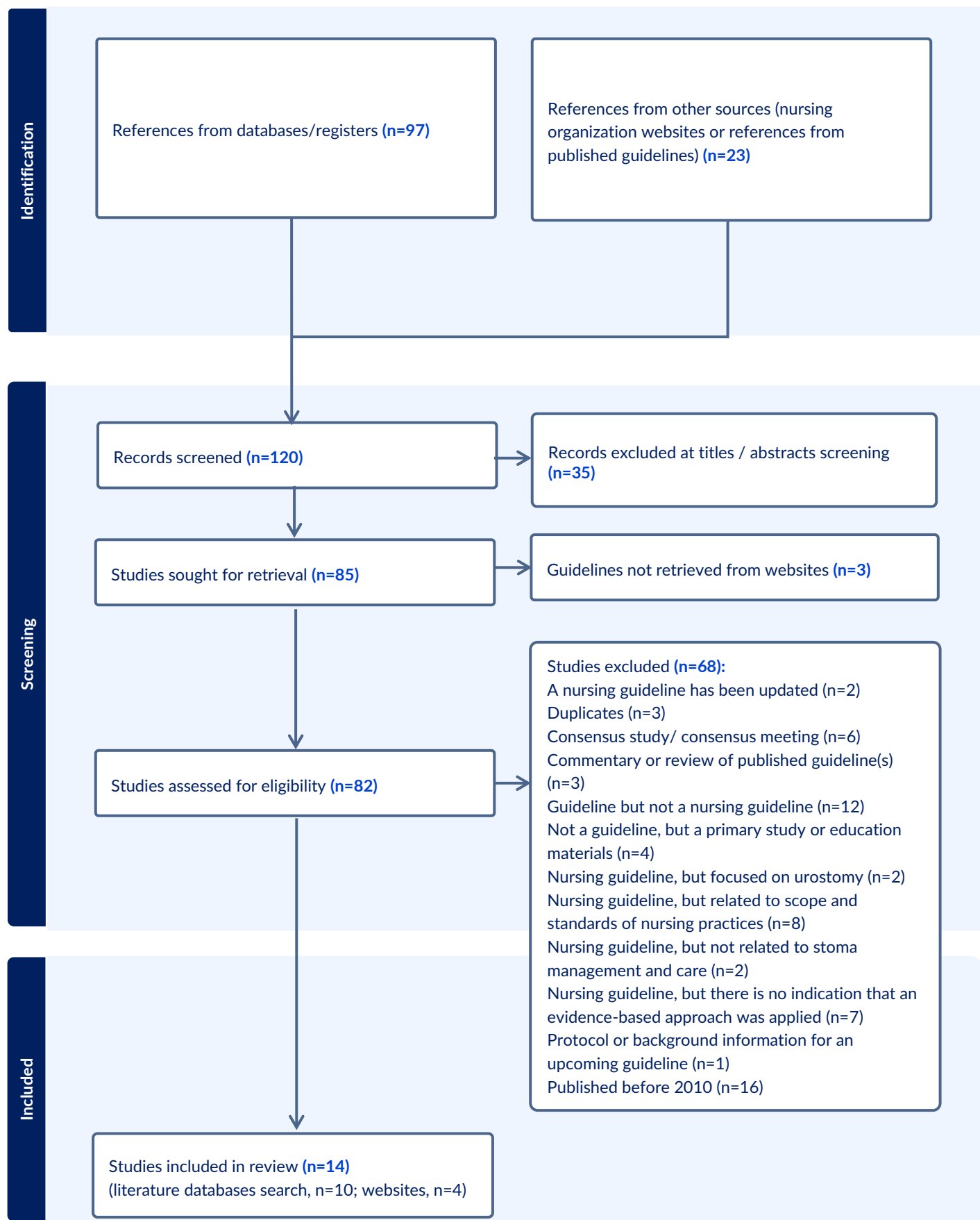
The database search yielded 97 references, while we identified an additional 23 documents on major nursing organization websites. We excluded 35 references at the titles and abstracts screening stage. Among 85 recorded, full texts of 3 documents were not retrieved from 2 nursing organization websites (World Council of Enterostomal Therapists 2020, 2014; Association of Coloproctology of Great Britain and Ireland 2017) and were excluded. We reviewed a total of 82 full-text documents and excluded 68 of them because they did not meet the inclusion criteria (Figure 2).

In total, 14 nursing guidelines met the inclusion criteria. Among these, we identified 10 guidelines from the literature search,<sup>14-23</sup> and 4 full guidelines<sup>24-27</sup> from the search of nursing organization websites (NSWOCC, RNAO, ASCN UK, AASTN). The 14 guidelines originated from Australia, Canada, Italy, the UK, the USA, and 3 international working groups, with publication dates ranging from 2013 to 2023 (Table 2).

The guidelines vary in scope; some focus on specific topics such as ostomy care in neonates, children, and adolescents; preoperative stoma site marking; use of convexity; peristomal skin health; parastomal hernia care; and enhanced recovery after surgery. Others provide comprehensive coverage of general ostomy care for patients anticipating or living with an ostomy. These guidelines offer recommendations for all stages of care, including preoperative, peri-operative, postoperative, and post-discharge phases (Table 2).

Key topics include referrals and access to ostomy care and other professionals; preoperative assessment and preparation; preoperative education and counselling; stoma site marking; postoperative assessment and evaluation; selection, teaching, use, and care of pouching products and accessories; ongoing education; documentation; discharge planning; post-discharge follow-up, assessment, and support; prevention, assessment, diagnosis, and management of parastomal (peristomal) hernias and other stomal and peristomal complications; ostomy care programs; daily living activities, exercises, and physiotherapy considerations; dietary and lifestyle guidance; sexual health; and quality

Figure 2: Study Flow Diagram



of life and psychological support (Table 2). There are no guidelines specific to patients with Crohn's disease and permanent ileostomies.

These guidelines vary in their terminology for recommendations, including "guidelines," "statements," "recommendations;" evidence-based "statements;" consensus-based "statements;" "consensus-based practice guidelines;" "steps" for marking; "assessment" tables, with the number ranging from 3 "assessment tables"<sup>19</sup> to 36 "statements" covering 17 questions in 9 categories.<sup>22</sup>

### Quality Assessment

Three guidelines do not specify whether a literature search and review were conducted,<sup>19,24,25</sup> and the other 3 guidelines do not specify the search strategy or details of the searches.<sup>15,26</sup> Other guidelines report they searched varied databases with varied search dates. Three guidelines do not assess the level of certainty or quality of the evidence.<sup>16,19,25</sup> Six guidelines apply organization-specific evidence scales or numerical grading systems (e.g., Level 1-4, A-C), while only 3 use the GRADE approach.<sup>18,21,27</sup> Most recommendations are based on a low level of evidence, often relying on retrospective or observational studies and expert opinion. Two guidelines claim they are consensus-based due to a lack of supporting evidence.<sup>15,17</sup> (Table 3)

In the AGREE II assessment, only 2 guidelines were considered high quality<sup>23,27</sup> (mean overall scores >5). Most guidelines (n=8) were rated as average quality (mean overall scores ranging from 3.0 to 5.7). Four guidelines were assessed as poor quality (mean overall score ranged from 2.7 to 4.0), all published before 2020.<sup>15,17,18,24</sup> Finally, the assessors gave recommendation "yes" to the 2 high quality guidelines, "yes with modifications" to 7 average quality guidelines and 1 poor quality guideline, while a "no recommendations" was given to 1 overall average and 3 overall poor quality guidelines. All 14 guidelines obtained > 60% scores in Domain 1 (Scope and Purpose). Low percentage scores (< 60%) suggest that modifications are recommended. In particular, Domain 2 (Stakeholder Involvement) had 9 guidelines scoring below 60%, Domain 3 (Rigour of Development) had 8 guidelines scoring below 60%, and Domain 5 (Applicability) had 11 guidelines scoring below 60% (Table 4).

## DISCUSSION

Nursing guidelines offer extensive coverage of ostomy care topics and provide valuable first-line care experience and consensus statements. Even though nursing ostomy guidelines are intended for nurses and stoma care nurses, they can aid other health care professionals as well, as all play a role in patient education. Although we reviewed guidelines generated by different organizations globally, we acknowledge that international standardization of ostomy care is not realistic due to significant differences in culture,

access to care and products, reimbursement models, and other factors. Instead, increasing access to high quality guidelines can enhance the availability of evidence-based information in a format that is accessible to health care professionals. Our systematic review of nursing ostomy guidelines further confirms that stoma care nurses play a crucial role in the quality of ostomy care and patient outcomes. These nursing guidelines cover various topics. These first-hand recommendations are valuable for clinical practice and establish clinical care pathways for patients undergoing ostomy surgery. Although no guideline was specifically tailored to patients with CD and a PI, recommendations on preoperative, perioperative, postoperative, and post-discharge interventions remain relevant and can inform patient care pathways. We also assessed the quality of the nursing guidelines using the rigour of the AGREE II tool, with 2 guidelines<sup>23,27</sup> considered to be high quality, while the majority of the guidelines were considered to be average quality with valuable information.

After reviewing the published nursing guidelines, some gaps were identified that could be considered in future guidelines. When developing clinical pathways for those with PI because of CD, consideration along the continuum of life stages should be examined. Although not common, including those with a PI as the result of CD in the paediatric population<sup>28</sup> could be addressed. The paediatric person with an ostomy will eventually transition to the adult health care setting and understanding their past experiences and psychosocial development and adjustment to an ileostomy could assist in guiding needs and care.

Having a stoma has a major impact on daily life. As patients progress through various life stages, events, such as pregnancy, changes in relationships, or just changes in body contours and body image, can impact the physical, emotional, and psychological well-being of a person with an ostomy. Another area where patients face challenges is sexual health. This topic is discussed in guidelines, such as the RNAO 2019 guideline during preoperative and postoperative care.<sup>27</sup> Health care professionals are encouraged to address sexual health openly throughout follow-up care.

Incidence of a parastomal hernia with an end ileostomy is 1.8-28.3%.<sup>26</sup> This can have significant physical, psychological, and financial implications that affect overall quality of life.<sup>26</sup> A person with a PI may have initial care with a stoma care nurse and physiotherapist, but as the patient ages, they need on going support, both for prevention and care, if a parastomal hernia is present. As noted in the ASCN UK EXPASS recommendations, health care professionals do not feel confident or even educated enough to provide information on physical activity.<sup>29</sup> This is a gap in care, particularly for those with a permanent stoma. Those with CD are less likely to be active, especially with an ileostomy, which may increase the risk of a flare. Therefore, we hope to see this important topic included in more nursing guidelines.

**Table 2:** Characteristics of the 14 Included Nursing Guidelines

AUTHORS/ ORGANIZATION, YEAR	COUNTRY	NUMBER OF RECOMMENDATIONS/ STATEMENTS/ GUIDELINES	REFERRAL/ ACCESS TO OSTOMY NURSE OR OSTOMY EDUCATED HEALTH CARE PROFESSIONALS	PREOPERATIVE ASSESSMENT, EDUCATION/ COUNSELLING	PREOPERATIVE STOMA SITE MARKING	POSTOPERATIVE ASSESSMENT/ EDUCATION/ON GOING EDUCATION	POUCHING PRODUCTS & ACCESSORIES SELECTION/ TEACHING/ USE, & CARE
NSWOCC 2023 <sup>26</sup>	Canada	15 recommendations	✓	✓	✓	✓	
Forest-Lalande 2023 /GPSNAB 2018 <sup>16</sup>	International	13 guidelines for 24 topics		✓	✓	✓	✓
Zwiep 2022/CSCRS and NSWOCC 2020 <sup>23</sup>	Canada	17 steps for stoma site marking	✓	✓	✓		
Perrin 2021/ASCN UK 2021 <sup>19</sup>	UK	3 assessment tables		✓		✓	✓
Ratliff 2021/WOCN 2021 <sup>20</sup>	USA	6 evidence-based statements and 19 consensus statements with content validation index					✓
Roveron 2021/ MISSTO 2021 <sup>21</sup>	Italy	19 statements for preoperative preparation (n=2) and nursing care of stoma complications (n=17)		✓	✓		✓
Chabal 2021/WCET 2021 <sup>14</sup>	International	15 recommendations covering the 4 key arenas of education, holistic aspects, and pre- and postoperative care	✓	✓	✓	✓	✓
RNAO 2019 <sup>27</sup>	Canada	4 priority recommendation questions but covered multiple recommendations and PICO's	✓	✓	✓	✓	✓
Colwell 2019/ WOCN 2019 <sup>15</sup>	International	7 consensus-based practice guidelines covered 3 major topics	✓	✓		✓	✓
WOCN 2018 <sup>22</sup>	USA	36 statements covered 17 questions in 9 categories	✓	✓	✓	✓	✓
Miller 2017/The Ontario Provincial ERAS ETN 2017 <sup>18</sup>	Canada	11 recommendations: preoperative care (n=2), post-operative care (n=5), post-discharge care (n=4)	✓	✓	✓	✓	
ASCN UK 2016 <sup>25</sup>	UK	14 statements	✓		✓		✓
AASTN 2013 <sup>24</sup>	Australia	8 guidelines	✓	✓			✓
Gray 2013/WOCN <sup>17</sup>	USA	9 consensus-based statements				✓	✓

Abbreviations: ASCN—Association of Stoma Care Nurses UK; AASTN—Australian Association of Stomal Therapy Nurses; CSCRS—Canadian Society of Colon and Rectal Surgeons; ERAS—Enhanced Recovery After Surgery; ETN—Enterostomal Therapy Network; GPSNAB—Global Paediatric Stoma Nurses Advisory Board; MISSTO—Multidisciplinary Italian Study Group for STOMAs; NSWOCC—Nurses Specialized in Wound, Ostomy and Continence Canada; RNAO—Registered Nurses' Association of Ontario; WCET—World Council of Enterostomal Therapists; WOCN—Wound, Ostomy, and Continence Nurses Society

DOCUMENTATION/ VALIDATED ASSESSMENT TOOL USAGE	OSTOMY CARE PROGRAM (AN ORGANIZATION -LEVEL APPROACH)	DISCHARGE PLANNING	POST-DISCHARGE FOLLOW-UP / ONGOING ASSESSMENT/ SUPPORT	PARASTOMAL (PERISTOMAL) HERNIA (PH) PREVENTION, ASSESSMENT, DIAGNOSIS & MANAGEMENT	DIAGNOSIS, PREVENTION & MANAGEMENT OF OTHER (NOT PH) STOMAL & PERISTOMAL COMPLICATIONS	ACTIVITIES OF DAILY LIVING/ EXERCISES/ PHYSIOTHERAPIST CONSIDERATIONS	DIET/ REGISTERED DIETITIAN/ LIFESTYLE CONSIDERATIONS	QUALITY OF LIFE/ PSYCHOLOGIC CONSIDERATIONS/SOCIAL DETERMINANTS OF HEALTH/ SEXUAL HEALTH
✓			✓	✓		✓		✓
	✓		✓	✓	✓	✓		✓
✓	✓		✓					
			✓					
					✓	✓	✓	✓
				✓	✓			
				✓	✓			
✓	✓	✓	✓	✓	✓	✓	✓	✓
✓			✓		✓			✓
			✓	✓	✓			✓
	✓	✓	✓					
		✓		✓		✓		
				✓	✓			
✓			✓		✓	✓	✓	✓

**Table 3:** Other Covered Content, Literature Searches, and Level of Certainty Assessment of the Included Nursing Guidelines

AUTHORS/ ORGANIZATION, YEAR	COUNTRY	OTHER COVERED CONTENT
NSWOCC 2023 <sup>26</sup>	Canada	Further research is required to gain a greater understanding of the risk factors associated with, prevention of, and management strategies for parastomal hernias.
Forest-Lalande 2023/ GPSNAB 2018 <sup>16</sup>	International	1. Common pathologies and indications for a stoma in neonates and children. 2. How to develop a therapeutic relationship with the child and family according to age and developmental phase. 3. Types of ostomies observed in paediatrics 4. Premature neonates, neonates, and children's skin characteristics.
Zwiep 2022/ CSCRS and NSWOCC 2020 <sup>23</sup>	Canada	Describes ERAS program that includes postoperative recommendations. Mentions but does not go into possible stoma complications and QoL considerations.
Perrin 2021/ASCN UK 2021 <sup>19</sup>	UK	NA
Ratliff 2021/ WOCN 2021 <sup>20</sup>	USA	Consensus statements included: nonmodifiable and modifiable associated factors, fluid/ diet/ lifestyle; discusses skin health which is part of assessment, however, does not specify when (would have to assume with any assessment postoperatively; either in hospital or on going). Showering/bathing considered a part of ADLs.
Roveron 2021/ MISSTO 2021 <sup>21</sup>	Italy	Describes ERAS program that includes postoperative recommendations. Mentions but does not go into possible stoma complications and QoL considerations.
Chabal 2021/ WCET 2021 <sup>14</sup>	International	Holistic approach to care (a holistic assessment of the person/family to guide co-participatory care). "Education and scope of practice" statements (specialised training, maintain knowledge, skill, and competency, practice parameters according to legal framework).
RNAO 2019 <sup>27</sup>	Canada	Other RNAO guidelines and resources mentioned (Appendix B): "client centred learning, culturally sensitive care, implementation science, implementation frameworks, interprofessional collaboration, person- and family-centred care, self-management of chronic conditions, therapeutic relationships."
Colwell 2019/ WOCN 2019 <sup>15</sup>	International	NA
WOCN 2018 <sup>22</sup>	USA	NA
Miller 2017/The Ontario Provincial ERAS ETN 2017 <sup>18</sup>	Canada	Supporting rods are usually unnecessary. If used, timing for removal of the supporting rod should be decided in collaboration with the surgeon. Families and caregivers should be encouraged to participate in the care and management of the patient's ostomy
ASCN UK 2016 <sup>25</sup>	UK	NA
AASTN 2013 <sup>24</sup>	Australia	Ileal Conduit/Urostomy: urine specimen from conduit; removal of ureteric stents from a urostomy; nephrostomy tube care; percutaneous endoscopic gastrostomy (PEG).
Gray 2013/ WOCN <sup>17</sup>	USA	NA

Abbreviations: ASCN—UK Association of Stoma Care Nurses United Kingdom; AASTN—Australian Association of Stomal Therapy Nursing; CSCRS—Canadian Society of Colon and Rectal Surgeons; ERAS—Enhanced Recovery After Surgery; ETN—Enterostomal Therapy Network; GPSNAB—Global Paediatric Stoma Nurses Advisory Board; MISSTO—Multidisciplinary Italian Study Group for STOMAs; NSWOCC—Nurses Specialized in Wound, Ostomy and Continence Canada; RNAO—Registered Nurses' Association of Ontario; WCET—World Council of Enterostomal Therapists; WOCN—Wound, Ostomy, and Continence Nurses Society Note In column "Literature search and systematic reviews were performed/search databases and date":

LITERATURE SEARCH AND SYSTEMATIC REVIEWS WERE PERFORMED/SEARCH DATABASES AND DATE	LEVEL OF CERTAINTY/QUALITY OF CERTAINTY/LEVEL OF EVIDENCE
"Parastomal Hernia Reviews in the Cochrane Database of Systematic Reviews"	Used RNAO's Level of Interpretation of Evidence (2017 Ref). Ia-V
"Comprehensive of PubMed and CINAHL electronic databases and the Google Scholar" until August 2018	"based on clinical evidence when available and on consensus-based best practices when evidence supporting care was not available"
January 2009 to April 2019: MEDLINE, Embase, Cochrane, PubMed, CINAHL and Google Scholar	Limited: "the quality of evidence used to guide the steps involved in stoma site selection. Much of the literature on stoma site marking is retrospective, observational or based on expert opinion", "Given that little high quality evidence exists on the individual steps for stoma site marking or placement, most guidelines, including the present document, are based on expert opinion."
No mentioned literature search	Mentioned "evidence-based guideline", "As previously stated, there is a paucity of research on convexity, so it is not possible to provide robust research-based evidence for the assessment and decision-making processes necessary to help decide whether or not a convex appliance is appropriate for a patient." The guideline does not compensate for the lack of research-based evidence required to support its ongoing use. The ASCN UK acknowledges the need for further work and hopes to undertake more detailed work in future
Performed a scoping review. Searched CINAHL, PubMed, and Embase to find literature related to peristomal skin health, from Jan 1980 to "current year." (2020?)	6 evidence-based statements, with level of evidence as A, B, C, using a 3-point ordinal scale adapted from a taxonomy for statements for recommendations for treatment statements disseminated by the American Academy of Family Physicians and regularly used by the WOCN Society to generate similar scholarly documents. 19 consensus statements with content validation index.
Based on "a scoping review of the literature," updated search on March 31, 2018, performed in PubMed, national guideline clearing house, CINAHL, and the international and national databases: Cochrane CDSR, SIGN, NICE, JBI, RNAO, WOCN, BSG, AASTN, ACGBI, ASCRS, CAET, ERAS, EAUN, and WCET.	"All the studies were evaluated according to the GRADE system and AGREE II tool" (should assess evidence not studies).
A search of the literature published in English from May 2013 to December 2019 by the authors of this article, who comprise the guideline development panel. More than 340 articles were reviewed.	The strength of recommendations was rated using an alphabetical system (A+, A, A-, etc.), SOE (strength of evidence) provided for each statement.
Guideline search + gap analysis, + scoping review for pediatric population- Figure 4, 6 guidelines were reviewed by searching "through website" (no details), 3 excluded and 3 scored <3 using AGREE II.	Used GRADE for quantitative research, used GRADE-CERQual methods for qualitative research.
Literature review, list of keywords searched, 77 articles were included. No databases or search date.	Modified Delphi research methodology to reach international consensus on assessment of peristomal body profiles.
Literature search utilized EBSCO Discovery Service, published from 2009 to 2015, 126 papers were included.	Level of evidence, Level I to VI, level-of-evidence rating for strength of guideline recommendations: A, B, C, and task force consensus. Assessment of benefit/ effectiveness versus harm of recommendations: Class I-IV, from WOCN 2017.
Literature search conducted using MEDLINE and CINAHL databases encompassing the years 2004-2014, performed SRs for statements 1.1 and 2.2.	GRADE assessment: Level of evidence, very low, low, moderate, and high.
Only mentioned "these evidence-based clinical guidelines" and "peer-reviewed"; mentioned "based on current evidence", but not many details.	"Each guideline has been written utilising the same format as the Stoma Care Standards, the National Institute of Clinical Evidence (NICE) structure, process and outcome framework, to describe a level of excellence in care delivery and a measure against which practice may be audited."
Did not mention literature search.	Level of evidence: 1a, 1b, 11a, 11b, 111, 1V. Mentioned "Research into stomal therapy nursing practice to-date is limited. Current practices are primarily guided by case series or expert opinion (Level 1V) resulting in little documented evidence of best practice from the higher research levels generally accepted as evidence," did not assign a level of evidence to any guideline statements.
MEDLINE and CINAHL electronic databases after 1990-2012; 239 articles included 35 original research reports and 204 integrative or systematic review articles, individual case studies, and multiple case series	"Consensus-based statements outlining best practices for the assessment, prevention, and management of peristomal moisture-associated dermatitis among patients with fecal ostomies." No studies were identified that specifically evaluated treatment or prevention of peristomal MASD.

Green indicates that these guidelines performed a proper literature search and systematic review. Blue indicates that these guidelines did not specify the search strategy or details of the searches. Grey indicates that these guidelines did not specify whether a literature search and review were conducted. In column "Level of certainty/quality of certainty/level of evidence": Green indicates that the GRADE approach was used to assess the level of certainty of evidence. Blue indicates that these guidelines applied organization-specific evidence, scales or numerical grading systems. Grey indicates that no level of certainty was assessed. White indicates these guidelines were consensus-based due to a lack of supporting evidence.

**Table 4:** AGREE II Assessment of Included Guidelines

AGREE II DOMAINS	NSWOC 2023 <sup>26</sup>	FOREST-LALANDE 2023/GPSNAB 2018 <sup>16</sup>	ZWIEP 2022/ CSCRS AND NSWOC 202 <sup>22,3</sup>	PERRIN 2021/ASCN UK 2021 <sup>19</sup>	RATLIFF 2021/ WOCN 2021 <sup>20</sup>	ROVERON 2021/ MISSTO 2021 <sup>21</sup>
Domain 1	91%	95%	83%	94%	83%	93%
Domain 2	54%	61%	80%	43%	46%	80%
Domain 3	65%	51%	80%	31%	63%	48%
Domain 4	85%	70%	85%	74%	72%	82%
Domain 5	29%	18%	72%	15%	29%	40%
Domain 6	64%	82%	78%	85%	78%	56%
Overall based on the number of domains >60%	Average	Average	High	Average	Average	Average
Overall, by assessors (range from 1 to 7)	5.0	4.3	5.7	4.0	4.7	4.3
Recommendation by assessors	Yes, with modifications	Yes, with modifications	Yes	Yes, with modifications	Yes, with modifications	Yes, with modifications

Domain 1—Scope and Purpose; Domain 2—Stakeholder Involvement; Domain 3—Rigour of Development; Domain 4—Clarity of Presentation; Domain 5 – Applicability; Domain 6—Editorial Independence. Overall Guideline Assessment included 2 questions: 1. Rate the overall quality of this guideline. Scoring: 1(Lowest Quality) - 7(Highest Quality). 2. I would recommend this guideline for use. Scoring: "Yes", "Yes, with modifications", "No". Abbreviations: ASCN—UK Association of Stoma Care Nurses United Kingdom; AAS-TN—Australian Association of Stomal Therapy Nursing; CSCRS—Canadian Society of Colon and Rectal Surgeons; ERAS—Enhanced Recovery After Surgery; ETN—Enterostomal

As stated in the RNAO 2019 guideline, "Persons living with an ostomy have the right to comprehensive, personalized, and accessible care"<sup>27</sup> as stated in the Charter of Ostomates Rights. When considering pathways and guidelines moving forward, accessing care can take different forms, including in-person clinic-based care and telehealth. Ostomy care is an intimate form of health care; therefore, the in-person therapeutic relationships built between health care professionals and patients are very important. Web-based technology can have advantages,<sup>14</sup> such as assisting those requiring faster consultations when complications with pouching systems or peristomal skin concerns occur or for those who do not have access to a stoma care nurse in their geographical area. Regular, yearly follow-up by a stoma care nurse is suggested.<sup>27</sup> This can be a challenge if organizations do not support ongoing follow-up; therefore, telehealth could potentially make this more feasible.<sup>30</sup>

This systematic review has several strengths. First, our knowledgeable review team included nurses, an experienced ostomy nurse, IBD specialists, and researchers. We not only summarized what was reported; we also proposed possible knowledge gaps. We searched not only published guidelines but also websites of nursing organizations and included and assessed 14 international nursing guidelines related to ostomy. The 2 previously published systematic reviews on this topic included only 5 ostomy clinical practice guidelines<sup>10</sup> and 10 ostomy clinical practice guidelines.<sup>11</sup> These did not focus

on nursing, with only 3 (published from 2017-2019) and 5 (published from 2017 to 2021) nursing guidelines. These identified ostomy nursing guidelines were included in our review. They also included procedural or surgical ostomy interventions and enterocutaneous fistula recommendations. All 3 systematic reviews showed the RNAO 2019 guideline receiving the highest AGREE II score.

We acknowledge that this review also has some limitations. The search was limited to the English language. Three documents were not retrievable from the organizations' websites; therefore, we were not able to assess their eligibility, although we included newer guidelines from the same organization (WCET) or the same country (UK). Most published guidelines do not present all the information due to the space limits of the journals. Therefore, AGREE II scoring might not be accurate when based on the publication summaries for these guidelines. Some of the guidelines reviewed were not necessarily intended to be clinical practice guidelines but were based on consensus statements, practice standards, or best practice recommendations. We could only summarize what was reported, as terminology varied from "guidelines, practice guidelines, good practice guidelines, recommendations, statements, steps, topics, assessments, etc." All are intended to improve patient care, but standardizing terminology and the methodological approach can only enhance patient care, improve international collaboration, and enhance the rep-

CHABAL 2021/ WCET 2021 <sup>14</sup>	RNAO 2019 <sup>27</sup>	COLWELL 2019/ WOCN 2019 <sup>15</sup>	WOCN 2018 <sup>22</sup>	MILLER 2017/THE ONTARIO PROVINCIAL ERAS ETN 2017 <sup>18</sup>	ASCN UK 2016 <sup>25</sup>	AASTN 2013 <sup>24</sup>	GRAY 2013/ WOCN <sup>17</sup>
67%	100%	82%	94%	70%	80%	80%	74%
50%	96%	57%	56%	56%	57%	35%	43%
49%	93%	42%	65%	35%	27%	13%	65%
74%	96%	70%	78%	43%	72%	65%	57%
65%	85%	26%	17%	10%	22%	29%	29%
83%	89%	29%	69%	50%	0%	14%	19%
Average	High	Poor	Average	Poor	Average	Poor	Poor
4.7	6.0	4.0	5.0	3.3	3.0	2.7	3.0
Yes, with modifications	Yes	Yes, with modifications	Yes, with modifications	No	No	No	No

Therapy Network; GPSNAB—Global Paediatric Stoma Nurses Advisory Board; MISSTO Multidisciplinary Italian Study Group for STOMas; NSWOCC—Nurses Specialized in Wound, Ostomy and Continence Canada; RNAO—Registered Nurses’ Association of Ontario; WCET World Council of Enterostomal Therapists; WOCN Wound, Ostomy, and Continence Nurses Society Note Green indicates these domains obtained >60% scores. Blue indicates these guidelines were assessed as overall high quality and were recommended by assessors.

utation and credibility of the collaborating organizations.<sup>31</sup> As such, only 2 of the 14 guidelines reviewed achieved a high overall quality of assessment.<sup>23,27</sup> However, as the first systematic review focusing on ostomy nursing guidelines, we believe our review provides insights on this topic. Finally, we did not review data related to the urostomy. We suggest that a similar review focused on the urostomy would be valuable for future research.

## CONCLUSION

This first systematic review and quality assessment of clinical practice nursing guidelines for ostomy care highlights both strengths and areas to improve and expand within current guidelines.

Nursing guidelines offer extensive coverage of ostomy care topics and provide valuable first-line care experience and consensus statements, particularly for postoperative stoma and peristomal care. These insights are essential for non-nursing health care providers and contribute to the development of patient care pathways for individuals with Crohn’s disease and permanent ileostomies. However, the limited availability of high quality evidence underscores the need for further research in ostomy care. Involving ostomy nurses in clinical research design and execution is crucial for both advancing the quality of evidence and enhancing future guideline updates in ostomy care. ●



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