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Ostomy Assessment Systematic Integration of Studies (OASIS): Maternal, Child, and Youth Assessment Scoping Review

ABSTRACT

Background

Unique physical and psychosocial challenges are present in the maternal, child, and youth population. Despite the complexities of living with or caring for individuals living with an ostomy in this population, few studies focus specifically on this population. This study seeks to better understand the specific challenges, outcomes, and care strategies for this population, highlighting the unique considerations and educational needs for the assessment of the individual living with an ostomy, as well as their families and caregivers.

Methods

As part of the Ostomy Assessment Systematic Integration of Studies (OASIS) study, this scoping review explores evidence related to ostomy assessment in maternal, child, and youth populations. A systematic search of MEDLINE and CINAHL was conducted in January 2021 using the Joanna Briggs Institute and the PRISMA-ScR framework to guide the study. Data were extracted, analyzed using content analysis, and organized using the PAGER framework.

Results

Of the 42,059 results obtained from the search, 26 included studies focused on the maternal, child, and youth populations. Three themes emerged from the data, including pregnancy, family dynamics, and management and complications in newborns. Results revealed opportunities to improve ostomy assessment practices to support the maternal, child, and youth populations.

Conclusions

Ostomy assessment in the maternal, child, and youth population requires evidence-informed approaches that consider factors unique to this population. Further research is needed to guide best practice.

Key Words: Ostomy, nursing, nursing assessment, surgical stomas, maternal-child nursing, scoping review

Intégration systématique des études sur l'évaluation des stomies (OASIS) : examen de la portée de l'évaluation auprès des mères, des enfants et des jeunes

RÉSUMÉ

Contexte

Les populations maternelle, infantile et jeunesse font face à des défis physiques et psychosociaux particuliers. Malgré la complexité associée au fait de vivre avec une stomie ou de prendre soin d'une personne vivant avec une stomie au sein de ces populations, peu d'études portent spécifiquement sur celles-ci. Cette étude vise à mieux comprendre les défis particuliers, les résultats et les stratégies de soins propres à ces populations, en mettant en évidence les considérations particulières et les besoins éducatifs liés à l'évaluation des personnes vivant avec une stomie, ainsi que de leurs familles et de leurs proches aidants.

Méthodes

Dans le cadre de l'étude Ostomy Assessment Systematic Integration of Studies (OASIS), cet examen de la portée explore les données probantes relatives à l'évaluation des stomies auprès des populations maternelle, infantile et jeunesse. Une recherche systématique dans les bases de données MEDLINE et CINAHL a été effectuée en janvier 2021. Les cadres méthodologiques du Joanna Briggs Institute et PRISMA-ScR ont été utilisés pour orienter l'étude. Les données ont été extraites, analysées au moyen d'une analyse de contenu et organisées selon le cadre PAGER.

Résultats

Parmi les 42 059 résultats obtenus lors de la recherche, 26 études incluses portaient sur les populations maternelle, infantile et jeunesse. Trois thèmes se sont dégagés des données : la grossesse, la dynamique familiale ainsi que la prise en charge et les complications chez les nouveau-nés. Les résultats ont révélé des possibilités d'améliorer les pratiques d'évaluation des stomies afin de mieux soutenir les populations maternelle, infantile et jeunesse.

Conclusions

L'évaluation des stomies auprès des populations maternelle, infantile et jeunesse nécessite des approches fondées sur des données probantes qui tiennent compte des facteurs propres à ces populations. Des recherches supplémentaires sont nécessaires afin d'orienter les pratiques exemplaires.

Mots-clés : stomie, soins infirmiers, évaluation infirmière, stomies chirurgicales, soins infirmiers maternels et infantiles, examen de la portée

Conflicts of Interest

No authors note any competing interests as it relates to this study.

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Availability of Data and Materials

Data supporting the findings of this study are available within the article. A structured dataset is available from the corresponding author upon reasonable request.

Contribution Statement According to CRediT Roles

CH - Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, validation, visualization, writing – original draft, writing - review and editing
BB - Conceptualization, data curation, formal analysis, methodology, validation, visualization, writing - review and editing

DF - Formal analysis, writing - original draft
GH - Data curation
EM - Data curation
KM - Data curation, formal analysis, visualization, writing - original draft
AL - Data curation, formal analysis, visualization
EC - Writing - original draft
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INTRODUCTION

A fecal or urinary diversion, commonly referred to as an ostomy, is a surgical procedure used to manage a range of conditions, including cancer, congenital disabilities, inflammatory bowel disease, and various digestive and urinary diseases.¹ While the procedure provides numerous benefits, it also presents significant challenges that profoundly affect both the physical and psychosocial aspects of a patient's life, particularly in vulnerable populations, such as pregnant women, infants, children, and adolescents. The assessment and management of an ostomy in maternal, child, and youth populations present unique challenges and considerations for healthcare providers, patients, and their caregivers. Around 90,000 individuals in Canada live with an ostomy, with an estimated 13,000 individuals obtaining an ostomy annually.² Special consideration of ostomy surgeries, outcomes, and complications is required to capture the complete picture in pediatric, adolescent, and maternal populations.

In the context of pregnancy, an ostomy can complicate both the gestation and delivery process. The physiological changes during pregnancy, coupled with the presence of an ostomy, necessitate specialized prenatal and perinatal care. The PAPooSE Study Group highlights the experience and outcome of pregnancy after stoma surgery, indicating the levels of fear and anxiety surrounding pregnancy and its impact on stoma function.³ The literature highlights that individuals living with an ostomy have a poor understanding about conception, stomal complications, the experience of pregnancy, the obstetric mode of delivery, and maternal and fetal outcomes, resulting in lower birth rates for these patients.³⁻⁵ Healthcare providers must carefully monitor maternal and fetal health, adjusting medical assessment to accommodate the ostomy. The delivery process itself may also require adaptations to ensure the safety and health of both mother and child.³ Pregnant patients with a stoma for inflammatory bowel disease have a higher rate of cesarean sections and stoma complications. Therefore, more studies

that investigate comprehensive care strategies, tailored pre-natal management plans, and specific delivery protocols for pregnant women with ostomies are needed to improve maternal and fetal outcomes.³

For neonates and infants, ostomies may be required shortly after birth, often because of congenital anomalies or conditions, such as necrotizing enterocolitis. Forest-Lalande discusses the different specialized approaches needed for ostomy surgery and care in neonatal and youth populations, noting the scarcity of evidence for ostomy care in these populations.⁶ Additionally, the role of caregivers is significant in these populations, where support, ostomy education, and coping mechanisms are crucial for effective care.⁷ Stoma-related morbidity in pediatric populations is approximately 30%, highlighting the significant challenges and complications associated with ostomy care in this vulnerable group.⁸ Factors, such as the delivery method, caregiver education, weight and body mass index, and management of complications, such as prolapse, are recurrent themes in the literature, emphasizing their importance in this population.

Living with an ostomy can profoundly affect child and adolescent quality of life, impacting physical, emotional, and social well-being. Issues, such as body image, self-esteem, and adaptation, can pose significant challenges as children grow and develop.^{9,10} These challenges can be particularly pronounced during adolescence, a critical period for social development and identity formation.⁹ Addressing these psychosocial aspects is essential for promoting well-being in young individuals living with an ostomy.⁹ Families and caregivers play a pivotal role in managing ostomies, yet they often face substantial educational and emotional burdens.¹¹ The level of education and support provided to families and caregivers is crucial in ensuring effective ostomy care, reducing anxiety, and improving the overall quality of life for both the patient and their support network.^{11,12} Financial constraints may also impact families of those living with an ostomy, with different provinces across Canada providing different levels of financial aid for those caring for children living with an ostomy.² Proper education and resources can empower families, enabling them to manage the ostomy with confidence and competence. Ostomies, essential for managing various medical conditions, present significant physical and psychosocial challenges, particularly for vulnerable populations such as pregnant women, infants, children, and adolescents who need specialized care and increased awareness to optimize health outcomes and quality of life.

Aim

The Ostomy Assessment Systematic Integration of Studies (OASIS) scoping review aims to determine the evidence base related to the assessment of individuals living with an ostomy. The OASIS scoping review findings are presented in 5 articles. This publication aims to discuss the specific factors related to the assessment of challenges, outcomes, and care strategies for populations, including maternal, child, and youth groups, highlighting the unique considerations and educational needs for patients, families, and caregivers.

Identification of Research Questions

The primary research question for this study was: What is the evidence base related to the assessment of the individual living with an ostomy? This question is written in accordance with the PCC Framework, which stands for population, concept, and context,¹³ where the population is individuals living with an ostomy, the concept is the assessment of the individual living with an ostomy, and the context is the evidence base related to the assessment of the individual living with an ostomy.

METHODS

A comprehensive methodology was included in a previous manuscript (Assessment Tools) of the OASIS study.¹⁴ The current scoping review was not preregistered and followed the Joanna Briggs Institute (JBI) framework as well as the Preferred Reporting Items for Systematic Review and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).

The search was completed using the MEDLINE and CINAHL databases in January 2021. When conducting the search, no limitations or filters were used in order to collect as much data as possible.

Covidence® software for systematic reviews was used, and 7 independent researchers double-screened and used the article titles and abstracts for selection based on the inclusion and exclusion criteria outlined in the descriptive methods section of the Assessment Tools manuscript. A nurse specialized in wound, ostomy, and continence (NSWOC) reviewed any conflicts regarding selection and made the final determination. Two NSWOCs reviewed the full texts and made further selections based on their findings. The reviewers discussed disagreements regarding the selection process until consensus was reached.

Data from the articles, including the author and year, country of origin, purpose and aim of the study, research design, sample and setting, data analysis, results, and any accessory comments, for instance whether ethics approval was obtained, were extracted and made into tables. The tables were then used to create a searchable database of the articles' findings, following the Elo and Kyngas content analysis approach.¹⁵ The findings were summarized and presented in accordance with Bradbury-Jones et al.'s PAGER Framework, which outlines the patterns in the data, the advancements made to knowledge, gaps in the literature, evidence for practice, and recommendations for follow-up research.¹⁶ Table 1 includes the PAGER Framework for the maternal, child, and youth manuscript.

RESULTS

The OASIS scoping review located 42,059 articles across the CINAHL and MEDLINE databases. Of these articles, 12,023 duplicates were removed, leaving 30,035 articles that were double-screened by title and abstract. After 29,294 additional records were removed post-screening for inclusion and exclusion criteria, 741 articles remained for full-text screening. Two

Table 1: PAGER Framework

PATTERN	ADVANCES	GAPS	EVIDENCE FOR PRACTICE	RESEARCH RECOMMENDATIONS
Pregnancy With an Ostomy	Improving maternal and fetal outcomes compared to historical outcomes and demonstrated feasibility	A lack of recent prospective research studies and literature related to assessing and monitoring those individuals who are pregnant and living with an ostomy	Pregnant individuals living with an ostomy should have regular stoma assessment with monitoring for intestinal obstruction	Develop and validate pregnancy-specific monitoring tools and conduct prospective studies related to living with an ostomy during pregnancy
Family and Caregiver Needs	Evidence demonstrating education improves stoma management competence and recognition of needs related to psychosocial and body image in youth living with an ostomy	More longitudinal research is needed related to adaptation to living with an ostomy over time	Provide family-centered education, assess knowledge of caregivers, and assess for and provide support for psychosocial and body image issues	Study long-term psychosocial outcomes of living with an ostomy as a child or youth
Newborn and Pediatric Complications	Common risks were identified, such as skin breakdown, and high output and complication predictors identified, such as low birth weight and gestational age	Remains unclear whether there are increased risks for complications if a case is emergency as opposed to elective; further guidance is needed regarding postoperative monitoring and assessment	Screening for complication risk and early assessment for complications should be considered	Create postoperative assessment and monitoring strategies for pediatric and newborns living with an ostomy and conduct studies to determine if there is an increased risk between elective and emergency procedures

nurses specialized in wound, ostomy, and continence screened these articles, after which it was determined that 383 studies were appropriate to include in the OASIS scoping review. Figure 1 presents this process as a PRISMA flow diagram.

Content analysis of the 383 studies identified 5 major themes across findings, including: (1) assessment tools (n=29); (2) maternal, child, and youth assessment (n=26); (3) physical assessment (n=74); (4) psychosocial assessment (n=114), and (5) complication assessment (n=140). Due to the number of articles and findings in each of these core themes, each theme has been presented in its own report. These following pages focus on the 26 articles included in the maternal, child, and youth assessment theme. For more on the study methodology, please refer to the OASIS article on assessment tools.¹⁴

Characteristics of Sources of Evidence

The author, year, and country of the study, along with the study's aim, methodology, participants, data analysis technique, results, and ethical considerations of the evidence, will be summarized to aid in contextualizing the findings. Of the 26 articles included in this review, the majority were conducted in the United States (n=10).¹⁷⁻²⁶ The remaining studies were conducted in the United Kingdom (n=6),²⁷⁻³² Brazil (n=2),^{33,34} Canada (n=2),^{10,35} Australia (n=1),⁵ Austria (n=1),³⁶ Ireland

(n=1),³⁷ Nigeria (n=1),³⁸ Poland (n=1),³⁹ and the Netherlands (n=1).⁴⁰ Most of the studies were conducted after the year 2000 (n=17).^{5,10,17,18,21,22,26,31-40}

The studies aimed to provide insights into complications and risk factors,^{17,24,26,31,35,36,40} patient and caregiver experiences and perspectives,^{33,34,38,39} surgical outcomes and techniques,^{18,21,23,29,30,32} quality of life and psychological impact,^{10,22} and specific conditions and demographics,^{5,19,20,25,27,28,37} all within maternal, pediatric, and family domains.

The methodologies employed across the studies varied widely, incorporating quantitative, qualitative, and mixed methods approaches. Research designs included retrospective studies (n=14),^{17,18,21,23,24,26,28,29,31,32,35-37,40} surveys (n=2),^{19,38} cross-sectional studies (n=2),^{33,39} grounded theory design (n=1),²² prospective observational studies (n=1),²⁰ case studies and series (n=3),^{25,27,30} ethnographic research (n=1),¹⁰ hermeneutic phenomenology (n=1),⁵ and qualitative studies (n=1).³⁴ Common data analysis techniques included descriptive statistics, thematic analysis, Fisher's exact tests, T-tests, chi-square analyses, Mann-Whitney U tests, and Kaplan-Meier curves.

The participant demographics in these studies span a wide range, from preadolescents and adolescents to neonates

with an average gestational age of 28 weeks.¹⁷ Many studies also examine the involvement of family members and caregivers in ostomy management, including parents, relatives, and caregivers of children with ostomies. Additionally, maternal outcomes are a key focus in some studies, featuring pregnant women undergoing ostomy procedures or those who become pregnant after having an ostomy.

Ethical considerations are crucial when studying vulnerable populations, such as neonates, infants, preadolescents, adolescents, and pregnant individuals. Therefore, ethical compliance was analyzed across all studies. All studies conducted before 2000 lacked discussions on ethical compliance, approval, and informed consent, with Schwarz et al.²⁵ being the only exception. In contrast, most studies conducted after 2000 included discussions on ethical compliance. Overall, 10 studies addressed ethics, 9 of which were conducted after 2000.^{5,10,17,18,21,26,32-34}

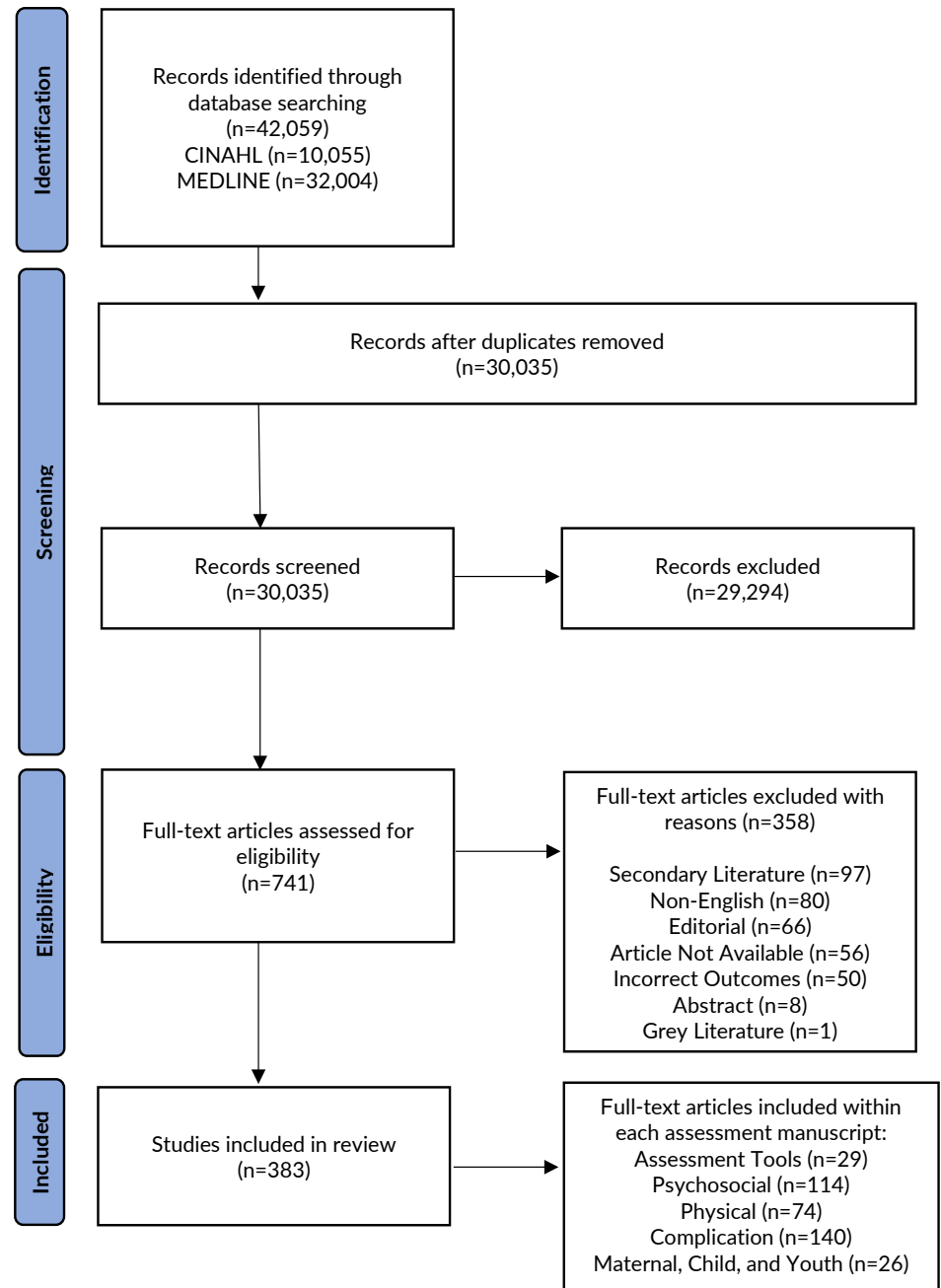
Results of Individual Sources of Evidence

Following our inductive content analysis approach, the findings from this portion of the OASIS review were grouped into 3 categories: (1) pregnancy, (2) family, and (3) management and complications in newborns.

Pregnancy

Four articles in this study examined the implications of having an ostomy on pregnancy. Hudson found that a pregnant individual's medical team should monitor their patient closely as intestinal obstruction is a common complication that labour pains can mask.²⁸ Whiteley and Gullick found that the level of concern of pregnant people was much lower than anticipated.⁵ The participants described their stoma as a "lifeline." Pregnancy with a stoma was found to be feasible and often successful.¹⁹ Maternal and fetal outcomes today are significantly better than historical reports and can likely be explained by early surgical intervention and improved perioperative care.¹⁸ Although pregnancy outcomes are significantly

Figure 1: PRISMA Flow Diagram



Adapted from: PRISMA 2020 flow diagram, PRISMA Statement / PRISMA Executive. Licensed under CC BY 4.0.

better than historical records, regular stomal assessment is needed to prevent complications.

Family

Several articles included in this study investigated the impact that stoma management has on the parents of a child with a stoma. A few studies found that parents expressed the need for more

support. Support needs identified included improved stoma management education, easier access to collection appliances, and access to social supports.^{34,38,39} A lack of parental knowledge can lead to issues with management. For example, Bezerra and Assis noted an instance where the lack of parental knowledge was shown to result in stomal complications.³³

Adolescents were observed to have difficulties with body image which frequent health assessments and negative social changes exacerbated.^{10,22} It was also noted that parents had difficulty relinquishing care when the patient was competent enough to care for their own stoma. Merenda et al. found that youth that underwent the Mitrofanoff procedure were very satisfied with their continent catheterizable urinary stoma as it resulted in increased independence.²¹ The findings of the included studies suggest the need for assessing parental ostomy knowledge and implementing education programs for parents and youth.

Management and Complications in Newborns

Complications were a common theme across the articles included in this study. A significant predictor of complications included gestational age and preoperative weight.¹⁷ High stoma output was a common complication associated with poor weight gain.^{37,40} Other complications included dermatitis, fungal infections, stomal obstruction, skin excoriation, and abscess formation.^{19,20,27,30,31,33} Schwarz et al. found that infants and children tend to excrete more sodium with an ileostomy and should be assessed to determine if sodium supplementation is needed.²⁵ Rees found that the most common reasons for colostomy creation included Hirschsprung's disease, anorectal abnormalities, and the need to address postoperative concerns.²⁹ It was found that elective and emergent stoma surgeries had similar complication rates among infants.²⁴ Umbilical ostomies were found to have an increase in prolapse/peristomal hernias.²⁶ A study Kargl et al. conducted found that although complication rates in infants are high, mortality is low, and morbidity is manageable.³⁶ Mollitt et al. found that sigmoid colostomies have lower complication rates and are therefore preferred.²³ Additionally, Singh et al. found that primary resection and anastomosis is a safe and viable alternative to stoma formation in preterm neonates with necrotizing enterocolitis and/or isolated intestinal perforation.³² Given the range of complications discussed, it is essential to conduct a systematic and comprehensive evaluation.

DISCUSSION

Summary of Evidence

This section of the OASIS scoping review focuses on the 26 studies we identified that analyzed maternal, child, and youth assessment. Studies were grouped into 3 themes. Four studies focused on pregnancy with an ostomy, and 7 focused on the impact of a child with an ostomy on family members, such as their mother. Finally, 16 articles focused on management and ostomy complications in the newborn population.

Pregnancy was a theme among the articles included in this review. Overall, pregnancy with a stoma is feasible and often successful,¹⁹ and both maternal and fetal outcomes are significantly better today than they have been historically.¹⁸ Authors discussed how pregnant individuals should be closely monitored as intestinal obstruction is a common complication of

having a stoma while pregnant, which labour pains can mask.²⁸ Recent literature by Bouwknecht et al., who evaluated stoma complications peri- and postpartum, also found that although pregnancy with a stoma is feasible and manageable, the most common complication is intestinal obstruction.⁴¹

Several articles examined the impact of stoma management on the family dynamic. Parents of a child with a stoma often expressed the need for additional education and social support when caring for a stoma.^{34,38,39} It was found that a lack of parental knowledge often resulted in stomal complications.³³ A recent literature review conducted by Mulyani and Anggraeni explored the influence of education on parents' ability to care for their child with a stoma.⁴² The authors found that education improved parents' knowledge and skills, demonstrating congruence with the findings of this review.

Having a stoma was also noted to negatively impact a child's body image, which frequent health assessments can exacerbate.^{10,22} A recent review Uzsen et al. conducted of nursing studies exploring children living with an ostomy also discussed findings related to body image.⁴³ It was recommended that children be able to share their body-image-related concerns along with their fears and anxieties to obtain support, further demonstrating the need for the assessment of perceived body image in this population.⁴³

Both individual characteristics and surgical factors appear to influence complication rates in children living with an ostomy. Predictors of adverse outcomes found within the literature included gestational age and preoperative weight.¹⁷ These were also found to be relevant factors in a recent literature review by Cho et al., who examined 61 infants with low birth weights who underwent enterostomy surgery.⁴⁴ High output ostomies, which have been associated with poor weight gain, were also found to be a postoperative complication in the literature.^{37,40} Other postoperative complications included skin-related complications (i.e., dermatitis, fungal infections, excoriation), abscess formation, and mechanical problems such as stomal obstruction.^{19,20,27,30,31,33}

Physiological changes in how sodium is managed in children can also add complexity as children tend to excrete more sodium than adults, therefore requiring closer assessment and the potential for sodium supplementation.²⁵ Furthermore, the current scoping review found similar complication rates between elective and emergency ostomy formation.²⁴ In contrast, more recent studies, such as that conducted by Alghamdi et al., compared complication rates in infants that underwent emergency versus elective ostomy surgery and found emergency cases had longer hospital stays than elective cases.⁴⁵ Ostomy-type sigmoid colostomies were found to have lower complication rates, making them the preferred method of stoma creation.²³

While there are a number of postoperative complications in the pediatric population, mortality was discussed in the litera-

ture as low and morbidity as manageable.³⁶ This demonstrates the importance of early complication identification through risk identification and assessment.

Limitations

There are several limitations to consider in this scoping review. Given the review's extensive findings, themes found within the overarching OASIS study were published across multiple articles. While this separation improves the ability to locate and synthesize findings, included results were limited to the thematic article for which they were selected. This may have led to some secondary findings of research studies being excluded from the overall review.

Due to the scope of the review, the search was limited to 2 databases and to studies published in English. There may be further literature that could contribute to an understanding of the topic, but it was not collected because of the exclusion criteria. The exclusion of grey literature, editorials, abstracts, and secondary literature may have also led to the exclusion of new data in the literature. However, focusing only on peer-reviewed literature enhances the methodological rigor of the findings.

Finally, no formal appraisal of studies included in this review was conducted. While this aligns with the scoping review methodology, study outcomes should be considered with caution. Findings provide insight into the current status of research and gaps and limitations in knowledge on the subject matter.

CONCLUSION

This scoping review provides an overview of the current evidence related to the assessment of individuals living with or caring for an individual living with an ostomy in the maternal, child, and youth populations. Findings addressed physical, psychosocial, and caregiver-related considerations for assessment in these populations when caring for individuals living with an ostomy. This review noted that the evidence related to the child population living with an ostomy is growing. However, further research is needed to address gaps, such as pregnancy and living with an ostomy. Assessment related to those living with an ostomy in the maternal, child, and youth population should consider potential complications, caregiver education and support, quality of life, and adjustment over time for those living with an ostomy long-term. The findings of this study underscore the importance of considering family-centered approaches to assessment in view of the unique factors associated with these vulnerable populations.

Implications of the Findings for Research

The scoping review findings reveal several important areas for future research. The review yielded limited results for several subgroups in the study. Few studies addressed pregnant individuals living with an ostomy. Many of the studies focusing

on living with an ostomy while pregnant were over 20 years old and/or were retrospective in design, highlighting the need for further research in this area.

Further research is needed on the long-term psychosocial effects of living with an ostomy and to understand the long-term development of an individual's identity, changes to mental health, and effects on social function for those individuals living with an ostomy. Furthermore, assessment to determine educational needs in the maternal, child, and youth populations may be beneficial in improving ostomy knowledge and self-efficacy in family units.

Implications of the Findings for Practice

The findings of this study demonstrate the importance of considering the unique needs of the maternal, child, and youth populations when assessing an individual living with an ostomy. For clinicians, this study identifies the need for individual monitoring for stoma-related complications during pregnancy and early infancy. Findings also stress the importance of considering the individual's adaptation and developmental and physiological changes when living with an ostomy over time. This study also identifies the importance of assessing the educational and psychosocial needs of caregivers and family and the need for education and psychosocial support access for parents and families given its correlation with patient outcomes. Integrating the findings of this study and the impact of assessment may help improve health outcomes and the overall well-being of this vulnerable population. ●

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