

Clinical Nursing Care for Pediatric Patients with Myelomeningocele: A Scoping Review Protocol

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Abstract

Introduction. Myelomeningocele (MMC) is an open spinal dysraphism characterized by a neural tube defect in which the spinal cord, nerves and meninges protrude through a skin defect, predominantly in the lumbosacral region. Nursing care is essential in the early management of affected newborns, encompassing monitoring, prevention of complications, family support, and interdisciplinary coordination to ensure continuous care.

Objective. This scoping review aims to systematically map the available literature on hospital-based nursing care for pediatric patients with MMC and identify knowledge gaps in order to provide an up-to-date overview of the state of the art and to suggest areas for future research.

Methods and Analysis. This protocol follows the PRISMA-ScR guidelines. The review will include primary research studies, clinical guidelines, and expert opinions published in English and Italian, without time restrictions. We will search PubMed/MEDLINE, CINAHL, Web of Science, Scopus, Cochrane Library, OpenGrey, and Google Scholar. Two independent reviewers will conduct screening and data extraction using Rayyan. Data will be synthesized thematically and presented in tabular and narrative formats.

Expected Results. Preliminary evidence highlights three

main pillars in the management of myelomeningocele: prevention of complications, optimization of functionality, and enhancement of patient well-being. A multidisciplinary approach is essential to address the complex needs of neonates with MMC, with nurses playing a key role in coordinating care, ensuring continuity, and monitoring clinical status. Current recommendations emphasize specific nursing interventions for early care, including protective positioning, sterile dressing techniques, and allergen avoidance. However, despite the presence of some guidance, perioperative nursing practices remain underexplored in the literature. This review aims to identify, map, and summarize existing evidence to support and improve clinical nursing care for pediatric patients with MMC.

Ethics and Dissemination. Ethical approval is not required for this review. Findings will be submitted for publication in a peer-reviewed journal and disseminated through academic conferences and institutional training.

Protocol Registration. osf.io/rnc9u

Keyword: Myelomeningocele, Spina Bifida, Pediatric Nursing, Nursing Care, Patient Care Management, Open Spinal Dysraphism, Open Spina Bifida, Pediatric Care

Introduction

Myelomeningocele (MMC) is the most severe form of spina bifida, an open spinal dysraphism characterized by the failure to close the spinal column during embryonic development in which the spinal cord, nerves and meninges protrude through a skin defect, predominantly in the lumbosacral region.

The prognosis depends on the site and extent of the lesion, as well as the presence of comorbidities such as hydrocephalus and Chiari malformation II. The main clinical complications include paralysis, urinary and faecal incontinence, and cognitive disorders. (Cartwright & Wallace, 2017; Chellathurai et al., 2022)

Since the 1960s, the approach to myelomeningocele has undergone a significant transformation with the introduction of neonatal surgery and, later, fetal surgery. The latter emerged as a result of the “two-hit” theory, according to which prolonged exposure of the spinal cord to amniotic fluid during gestation contributes to further neurological damage. Although many children are born with significant neurological deficits, a significant percentage have normal intelligence and good

prospects for independent life. Functional and cognitive outcomes are influenced by the level of the lesion, the presence of hydrocephalus, central nervous system infections, and the ability to ambulate and control sphincter functions. In particular, mobility and continence are central to autonomy and social inclusion. (Zerah & Kulkarni, 2013; Bowman & McLone, 2010)

The clinical management of myelomeningocele is complex and requires a multidisciplinary approach. In this context, nursing care plays a key role throughout the care pathway from birth to adulthood, including aspects of health education, management of complications, family support and promotion of autonomy. However, the available literature on the specific contribution of the nurse in the care of the patient with myelomeningocele appears fragmented and not systematically mapped. (Bowman & McLone, 2010; Brand, 2006; Rosen & Angert, 2018)

Objectives

This scoping review aims to map the existing literature on hospital nursing care for pediatric patients with MMC, identify research gaps, and inform clinical practice and future studies.

Primary Research Questions:

1. What nursing interventions are reported in the hospital care of pediatric patients with MMC?
2. What are the main goals and outcomes associated with nursing care in this population?
3. What are the gaps in the literature regarding hospital nursing care for MMC?

Secondary Question:

- What is the role of the nurse within the multidisciplinary team in the management of MMC in hospital settings?

Eligibility Criteria**Inclusion Criteria:**

- Population: Pediatric patients (0–18 years) diagnosed with MMC.
- Concept: Hospital-based nursing care (e.g., wound care, positioning, monitoring, family support, interdisciplinary collaboration).
- Context: Inpatient care settings (e.g., PICU, NICU, pediatric surgical units).
- Types of evidence sources: Primary research (qualitative, quantitative, and mixed-methods studies), clinical guidelines, and expert opinions will be included. Secondary studies will be considered to explore how existing evidence has been synthesized and applied, to describe the available evidence base, and to better identify knowledge gaps and priorities for future research. Data extraction, however, will be restricted to primary data from original studies.
- Language: English or Italian.
- Time restrictions: None.

Exclusion Criteria:

- Studies focused exclusively on surgical techniques or outpatient care
- Non-nursing interventions or adult populations
- Studies not available in full text or conference abstracts with insufficient data
- Studies focused on community-based or

Methods and Analysis

This scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews and reported following PRISMA-ScR. (Aromataris et al., 2024; Tricco et al., 2018). The study protocol was registered and is available at the following link: osf.io/rnc9u.

Search Strategy

The following databases will be searched: PubMed/MEDLINE (via PubMed), CINAHL (via EBSCO), Scopus, Web of Science, Cochrane Library, OpenGrey and Google Scholar for grey literature

Search string (PubMed):

((Meningomyelocele[mh] OR Spina Bifida Cystica[mh] OR meningomyelocele*[tiab] OR myelomeningocele*[tiab] OR myelocele*[tiab] OR "spina bifida aperta"[tiab] OR "open spina bifida"[tiab] OR Spina Bifida Cystica[tiab])) AND ((Nursing care[mh] OR patient care management[mh] OR pediatric nursing[mh] OR ((pediatric[tiab]) AND (care[tiab] OR nursing[tiab] OR management[tiab])))

The search string will be adapted for the additional databases to be consulted.

The search strategy has been validated with the support of a medical librarian. Additionally, reference and citation tracking will be performed using Zotero.

Study Selection

All references will be imported into Rayyan. Duplicates will be removed. Two reviewers will independently screen titles and abstracts against the inclusion criteria. Full texts will then be reviewed for eligibility. A third reviewer will resolve disagreements.

Data Extraction

A data charting form will be developed and piloted. Data items to be extracted include:

- Author(s), year
- Country of study

- Study design
- Population characteristics
- Nursing interventions
- Outcomes reported (clinical, educational, family-related, and professional training outcomes, where applicable)
- Role of the nurse
- Main findings and conclusions

Data will be extracted independently by two reviewers and discussed for consistency.

Outcomes will be extracted as reported in the included studies and may include clinical outcomes (such as pre-operative management, infection prevention, post-operative wound care, prevention of pressure injuries, and maintenance of stable vital parameters), as well as educational and family-related outcomes, including family involvement throughout the care process. Where available, outcomes related to the training and preparation of healthcare professionals involved in the care of this patient population will also be considered.

The extraction of outcomes will support the mapping of how nursing interventions and roles have been described in relation to patient, family, and professional-related outcomes, in line with the exploratory aims of this scoping review.

Data Synthesis

Extracted data will be synthesized using a descriptive and thematic approach. Results will be presented in tables, with categories such as:

- Preoperative and postoperative nursing care
- Monitoring and complication prevention
- Family education and support
- Role in multidisciplinary teams

A PRISMA-ScR flow diagram will illustrate the selection process.

Ethics and Dissemination

Ethics approval is not required for this review as it involves only published and publicly available data. Results will be disseminated through peer-reviewed publication, presentations at pediatric or nursing conferences, internal workshops for nursing staff.

Limitations

Potential limitations include the exclusion of non-English/Italian studies, possible publication bias, and heterogeneity in study designs that may affect data synthesis. Due to the exploratory nature of this review, critical appraisal of study quality and risk of bias will not be conducted.

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