

The role of the nurse in the diagnosis and care of an infant with craniosynostosis

Rola pielęgniarki w diagnostyce i opiece nad niemowlęciem z kraniosynostozą

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A – Development of the concept and methodology of the study/Opracowanie koncepcji i metodologii badania; B – Query - a review and analysis of the literature/Kwerenda – przegląd i analiza literatury przedmiotu; C – Submission of the application to the appropriate Bioethics Committee/Złożenie wniosku do właściwej Komisji Biotycznej; D – Collection of research material/Gromadzenie materiału badawczego; E – Analysis of the research material/Analiza materiału badawczego; F – Preparation of draft version of manuscript/Przygotowanie roboczej wersji artykułu; G – Critical analysis of manuscript draft version/Analiza krytyczna roboczej wersji artykułu; H – Statistical analysis of the research material/Analiza statystyczna materiału badawczego; I – Interpretation of the performed statistical analysis/Interpretacja dokonanej analizy statystycznej; K – Technical preparation of manuscript in accordance with the journal regulations/Opracowanie techniczne artykułu zgodne z regulaminem czasopisma; L – Supervision of the research and preparation of the manuscript/Nadzór nad przebiegiem badań i przygotowaniem artykułu

STRESZCZENIE

ROLA PIELĘGNIARKI W DIAGNOSTYCE I OPIECIE NAD NIEMOWLĘCIEM Z KRANIOSYNOSTOZĄ

Wprowadzenie. Pielęgniarki odgrywają priorytetową rolę w diagnostyce kraniosynostozy poprzez badanie fizyczne głowy noworodka, różnicowanie deformacji oraz skierowanie na badania obrazowe. Wspierają rodzinę poprzez edukację i zapewnienie wsparcia emocjonalnego. Po operacji monitorują dolegliwości bólowe i rozwój neurologiczny dziecka oraz wspomagają proces rehabilitacji.

Cel pracy. Celem pracy była analiza roli pielęgniarki w diagnostyce i opiece nad niemowlętami z kraniosynostozą, z uwzględnieniem zaangażowania we wczesne rozpoznanie deformacji czaszki, różnicowanie z plagiocefalią ułożeniową oraz wspieranie rodziny podczas procesu leczenia i rehabilitacji.

Metoda. Przegląd został przeprowadzony zgodnie z ramami metodologicznymi zaproponowanymi przez Arksey i O'Malley, które zostały następnie zaktualizowane i rozszerzone przez Levaca, Colquhouna i O'Brien. Praca opiera się na przeglądzie zakresu (scoping review) dostępnego piśmiennictwa, uwzględniającym etapy zdefiniowane w PRISMA-ScR Checklist. Analizowano publikacje dostępne w bazach danych, takich jak PubMed, Scopus i Google Scholar, a także w polskich czasopismach naukowych. Do szczegółowej analizy zakwalifikowano 32 publikacje. Role pielęgniarek zostały przeanalizowane w oparciu o schemat chronologiczny obejmujący etapy diagnostyki, leczenia, opieki pooperacyjnej oraz rehabilitacji.

Podsumowanie. Holistyczna opieka pielęgniarska oraz współpraca interdyscyplinarna są niezbędne dla skutecznej diagnostyki i leczenia dzieci z kraniosynostozą. Pielęgniarki dysponując profesjonalnymi kompetencjami znacząco wpływają na poprawę wyników leczenia oraz jakości życia pacjentów i ich rodzin.

Słowa kluczowe: kraniosynostozą, opieka pielęgniarska, jakość życia, rozwój neurokognitywny

ABSTRACT

THE ROLE OF THE NURSE IN THE DIAGNOSIS AND CARE OF AN INFANT WITH CRANIOSYNOSTOSIS

Introduction. Nurses play a critical role in the diagnosis of craniosynostosis by performing physical examinations of the newborn's head, differentiating deformities, and referring the patient for imaging studies. Postoperatively, nurses monitor pain management, assess the child's neurological development, and facilitate the rehabilitation process.

Aim. The study aimed to analyze the nurse's role in diagnosing and caring for infants with craniosynostosis, emphasizing early detection, differentiation from positional plagiocephaly, and family support during treatment and rehabilitation.

Method. This review adhered to the framework proposed by Arksey and O'Malley, subsequently revised and expanded by Levac, Colquhoun, and O'Brien. A scoping review methodology was employed, guided by the stages outlined in the PRISMA-ScR Checklist. Literature was sourced from databases such as PubMed, Scopus, and Google Scholar, as well as Polish scientific journals. Ultimately, 32 studies were selected for in-depth analysis. The role of nurses was evaluated within a chronological framework encompassing the stages of diagnosis, treatment, postoperative care, and rehabilitation.

Summary. The holistic nursing care and interdisciplinary collaboration are essential for the effective diagnosis and treatment of children with craniosynostosis. Nurses, with their professional competencies, significantly contribute to improving treatment outcomes and enhancing the quality of life for patients and their families.

Key words:

craniosynostosis, nursing care, quality of life, neurocognitive development

INTRODUCTION

Craniosynostosis is a congenital malformation that involves premature overgrowth of one or more cranial sutures. This results in cranial deformity and can negatively affect a child's neurological development. Early diagnosis and implementation of appropriate treatment, including both surgical intervention and comprehensive medical care, are crucial to improving patient prognosis.

Nurses play an important role in the diagnostic process, as they are often the first to notice abnormalities in the shape of a newborn's head during routine physical examinations. Their role is also to educate parents and provide emotional support throughout the treatment process, from diagnosis to the postoperative period. The purpose of this article is to outline the role of the nurse in the early diagnosis of craniosynostosis, differentiating it from other cranial deformities and providing holistic care for the infant and his family. Special attention will be given to the importance of interdisciplinary collaboration and the challenges of this developmental defect.

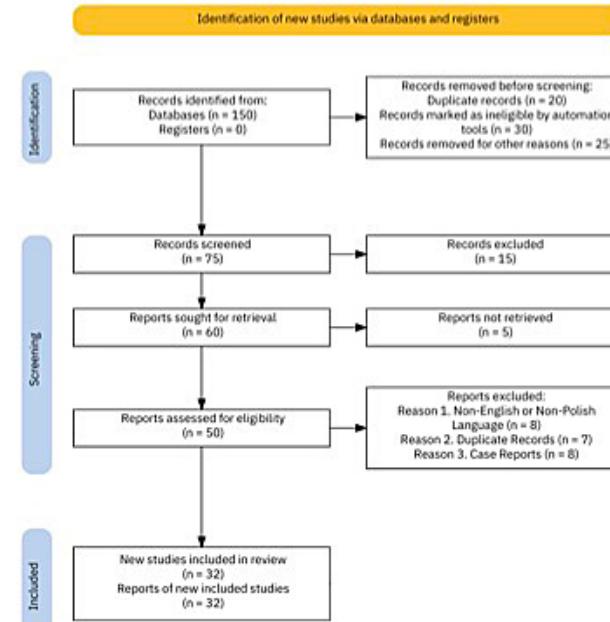
Epidemiology

Craniosynostosis occurs with a frequency of about 1 case per 2,000 births. It can be primary, caused by direct abnormalities in skull bone development, or secondary, resulting from abnormalities in brain growth. There are two main types of craniosynostosis. The first is non-syndromic craniosynostosis, also known as isolated craniosynostosis, which accounts for the majority of cases (80-85%) and most often involves premature overgrowth of a single cranial suture [1]. The second type is syndromic craniosynostosis, associated with genetic syndromes such as Crouzon, Apert and Pfeiffer syndromes. It is often accompanied by other craniofacial deformities, facial deformities and systemic defects [2]. Abnormalities resulting from craniosynostosis can lead to increased intracranial pressure, neurological abnormalities, vision and hearing problems, and breathing difficulties due to pressure on the airway [3,4]. Most cases require surgical intervention, for both aesthetic and functional reasons. The exception is a mild form of frontal suture craniosynostosis, known as metopic ridge, which is not associated with hypertelorism and usually does not require surgery [5].

MATERIAL AND METHODS

This review followed the framework proposed by Arksey and O'Malley [6], later revised and expanded by Levac, Colquhoun, and O'Brien [7]. The process included the following five stages: (1) identification of the research question, (2) identification of relevant studies, (3) selection of studies, (4) data charting, and (5) collation, summary, and reporting of results. The study employed a scoping review approach guided by the PRISMA-ScR checklist [8,9]. A comprehensive literature search was performed using the keywords: *craniosynostosis, nursing care, quality of life, neurological development, diagnosis, infants, physical examination, positional plagiocephaly, interdisciplinary collaboration,*

holistic care, postoperative care, parental education, neurocognitive difficulties, surgical intervention, and health-related quality of life (HRQoL). These terms were combined in pairs using Boolean operators [10]. The review utilized scientific databases, including PubMed, Scopus, and Google Scholar, and analyzed publications from 2010 to 2023. Inclusion criteria for the analysis were: publication in English or Polish, availability of full-text access, and a minimum quality score of 60% based on the JBI Critical Appraisal Checklists. Initially, 150 records were retrieved, from which 50 abstracts were reviewed. Ultimately, 32 articles were selected for detailed analysis (Fig. 1). The selection of articles, at the levels of titles, abstracts, and full texts, was conducted independently by two authors. Articles were included when both reviewers agreed on their relevance. In cases of disagreement, discussions were held among all authors to reach a final decision. Articles employing qualitative methodologies were not excluded at this stage, as they were considered valuable sources of information on holistic care for children with craniosynostosis. The collected data were organized and presented according to key topics, including the diagnosis, treatment, and the role of nurses in the care of patients with craniosynostosis (Tab. 1).



■ Fig. 1. Flowchart PRISMA diagram with review process

AIM

Care in this complex clinical situation is interdisciplinary in nature; however, this study specifically focuses on the scope of the nurse's role, presented in chronological order. The purpose of this study is to analyze the role of the nurse in the diagnosis and care of infants with craniosynostosis. The focus is on early recognition of the cranial deformity, differentiating it from other possible causes, such as positional plagiocephaly, and the importance of parental education and emotional support. Key elements of post-operative care and interdisciplinary cooperation to improve the quality of life for the child and his family are also presented.

Tab. 1. Summary of the studies included in the scoping review on nursing care and outcomes in craniosynostosis

Authors	Title	Date	Purpose	Methods	Population/Group	Results	Relevance to Article	Assessment of Quality
Amanda J. Osborn, Olivia Lange & Rachel M. Roberts	Attention Deficit/Hyperactivity Disorder in Individuals with Non-Syndromic Craniosynostosis: A Systematic Review and Meta-Analysis	2024	Evaluate the prevalence of ADHD	systematic review and meta-analysis	711	ADHD prevalence in NSC is 20%, significantly higher than general population	the critical role of nurses in holistic care, focusing on both physical and behavioral health outcomes for children with craniosynostosis	100%
Suleiman F. et al.	The Role of Helmet Therapy in Craniosynostosis: A Systematic Review	2024	effectiveness of helmet therapy (HT)	Systematic review	542	Cranial Morphology: Both SC with and without HT improved cranial indices, with no statistically significant differences in outcomes. Preoperative cephalic index (CI): 66.8 (HT) vs. 67.8 (non-HT). Postoperative CI: 75.0 (HT) vs. 76.2 (non-HT). Reoperation Rates: SC with HT: 3.7%; SC alone: 3.2%. Complications: low complication rate (2.9%) primarily involving skin irritation. Parental Satisfaction: High compliance and positive social impact reported. Quality of Life: HT showed benefits in head morphology but required high patient commitment for proper usage.	This review underscores the nurse's pivotal role in guiding families through helmet therapy, ensuring compliance, and optimizing patient outcomes	90.90%
Blanco-Díaz M, et al.	Effectiveness of Conservative Treatments in Positional Plagiocephaly in Infants: A Systematic Review	2023	the effectiveness of conservative treatments	Systematic review	5051	Conservative treatments significantly improved cranial asymmetry and parental perception. Physical therapy was the first-line intervention for non-syndromic asymmetries. Helmet therapy was effective for moderate-to-severe cases but raised concerns about cost-effectiveness, and side effects. Manual therapy showed superior outcomes when combined with caregiver education.	Relevance to Article: Nurses play a critical role in early diagnosis and care by: educating caregivers on repositioning and physical therapy techniques. Monitoring for improvement or need for escalation to helmet therapy. Collaborating with multidisciplinary teams to personalize interventions and optimize therapeutic outcomes.	90.90%
Park KM, et al.	Quality of life in patients with craniosynostosis and deformational plagiocephaly: A Systematic Review	2021	investigate the quality of life (QoL)	Systematic review	736	QoL metrics, such as CHQ forms, provide comprehensive insights into the emotional and social aspects of care beyond traditional surgical outcomes. Syndromic patients faced the most severe QoL challenges, necessitating multidisciplinary approaches.	Nurses play a vital role in enhancing QoL for infants and families affected by craniosynostosis and DPs	90.90%
Mortada H, et al.	The management of perioperative pain in craniosynostosis repair: a systematic literature review of the current practices and guidelines for the future	2022	review current practices and guidelines for managing perioperative pain	Systematic review	848	Pain Management Strategies: Multimodal analgesia was commonly used, involving opioids, acetaminophen, NSAIDs, and local nerve blocks. Complications: Common issues included nausea, vomiting, and a decline in hemoglobin levels. Effectiveness: Combining NSAIDs like ibuprofen with acetaminophen showed promising results in reducing hospital stays and minimizing narcotic use. Challenges: A lack of standardized perioperative pain management protocols was noted, leading to variable practices among institutions.	Nurses play a critical role in implementing and monitoring pain management protocols, ensuring patient comfort and safety	100%
Connolly JP, et al.	Progressive postnatal craniosynostosis and increased intracranial pressure	2004	examine the clinical features, diagnosis, and management	retrospective cohort study	27	Increased ICP Indicators: Papilledema, anterior fontanelle bulge, and thumbprinting were more prevalent in progressive cases. Surgical Intervention: All patients with progressive postnatal craniosynostosis required skull expansion to alleviate ICP. Genetic Findings: FGFR2 mutations in exon 7 or 9 were commonly found in patients with progressive craniosynostosis, suggesting a genetic overlap with Crouzon syndrome. Comparison to Classic Group: Progressive patients showed later onset but required similar vigilance in monitoring for ICP-related symptoms.	This study underscores the importance of vigilant nursing care in detecting progressive craniosynostosis, coordinating timely interventions, and supporting families through the diagnostic and treatment process.	54.50%

Pastor-Pons I, et al. Effectiveness of pediatric integrative manual therapy in cervical movement limitation in infants with positional plagioccephaly: a randomized controlled trial 2021 Ital J Pediatr	Cranial Suture Regeneration Mitigates Skull and Neurocognitive Defects in Craniosynostosis 2021 Yu M, et al.	effectiveness of pediatric integrative manual therapy (PIMT) randomized controlled trial	34	The PIMT group demonstrated a statistically significant improvement in total cervical AROM (29.7° vs. 6.1° in the control group, $p = 0.001$). Neuromotor development improved in both groups, with no statistically significant difference between them ($p = 0.887$). The manual therapy intervention was effective and well-tolerated, with no adverse events reported	Early Detection: Nurses can identify head shape abnormalities during routine assessments, ensuring timely referral for further evaluation. Education and Support: Providing families with guidance on positioning, motor stimulation, and therapy options. Care coordination: Acting as a liaison between multidisciplinary teams, including physical therapists and pediatricians, to ensure comprehensive care. Post-Treatment Monitoring: Overseeing the progress of infants undergoing therapy and providing continuous support to families.	81.80%
Stanton E, et al. The clinical manifestations, molecular mechanisms and treatment of craniosynostosis 2022 Dis Model Mech	The clinical manifestations, molecular mechanisms and treatment of craniosynostosis 2022 Kadiric N, et al.	innovative therapeutic strategies cranial suture regeneration using mesenchymal stem cells (MSCs) and biodegradable materials 2021 Bosn J Basic Med Sci	n/a	Regenerated cranial sutures corrected skull deformities and normalized intracranial pressure in Twist1+/- mice.	Understanding the potential of regenerative therapies, nurses can play a pivotal role in post-operative monitoring, patient education, and advocating for innovative, less invasive treatments that improve both neurocognitive outcomes and quality of life for affected infants and their families.	66.70%
Kadiric N, et al. Craniosynostosis - Recognition, clinical characteristics, and treatment 2018 J Multidiscip Healthc	Craniosynostosis - Recognition, clinical characteristics, and treatment 2017 Buchanan EP, et al.	overview of developmental biology, clinical characteristics, diagnosis, and treatment options. It emphasizes the importance of early diagnosis and intervention to prevent complications such as increased intracranial pressure, neurological dysfunction, and psychological impacts.	narrative reviews n/a	Clinical Manifestations: Craniosynostosis can result in increased intracranial pressure, neurocognitive deficits, and facial abnormalities. Molecular Mechanisms: Mutations in genes like TWIST1, FGFR, and others are implicated in premature suture fusion. Loss of mesenchymal stem cells plays a crucial role in pathogenesis. Treatments: Surgery remains the primary treatment but is associated with risks such as re-synostosis and complications. Emerging therapies include stem cell-based approaches for suture regeneration. Research insights: Animal models demonstrate the role of genetics and environment in cranial suture development.	Nurses play a pivotal role in early diagnosis and ongoing care for infants with craniosynostosis. This includes recognizing clinical signs, supporting genetic testing, preparing families for treatment options, and managing post-surgical care. Understanding the molecular basis and emerging therapies equips nurses to provide evidence-based care and educate families about the condition and its management.	40%
Duan M, et al. Neuro-Ophthalmological Manifestations of Craniosynostosis: Current Perspectives 2021 Eye Brain	Multidisciplinary care of craniosynostosis. Multidisciplinary care of craniosynostosis. 2017 J Multidiscip Healthc	highlight the importance of multidisciplinary care 2017 neuro-ophthalmological manifestations	narrative reviews n/a	Clinical Features: Classification based on sutures involved (e.g., sagittal, coronal, metopic, lambdoid) and syndromic versus nonsyndromic craniosynostosis. Diagnosis: Clinical ICUs Imaging techniques such as 3D CT and ultrasound are critical, with CT being the gold standard despite radiation concerns. Genetic testing aids in diagnosing syndromic craniosynostosis. Treatment: Surgical options include minimally invasive endoscopic procedures and open craniotomy. Timing of surgery (6-12 months) is crucial for optimizing outcomes. Postoperative care and helmet therapy are often required. Regular follow-ups are essential to monitor cranial growth and detect complications.	The necessity of a multidisciplinary approach, where nurses are pivotal in ensuring timely intervention and comprehensive care for infants with craniosynostosis	40%
				Multidisciplinary Teams: Key members included plastic surgeons, neurosurgeons, geneticists, ophthalmologists, audiologists, nurses, and therapists. Teams were coordinated by a nurse or care coordinator, ensuring streamlined communication and care delivery. Surgical Interventions: Endoscopic and open surgeries tailored to the patient's age, suture involvement, and syndrome severity. Helmet therapy and long-term monitoring were critical for nonsyndromic cases. Comprehensive Care: Syndromic cases required genetic counselling, airway management, and complex surgical planning. Regular follow-ups addressed neurodevelopmental concerns and monitored intracranial pressure. Family Support: Provided educational resources and emotional support, reducing anxiety and improving care adherence.	Integral role of nurses in fostering a collaborative environment within multidisciplinary teams, ensuring that infants with craniosynostosis receive comprehensive, patient-centered care.	40%
				Craniosynostosis affects visual pathways and requires early identification to mitigate vision loss risks. Strabismus, refractive errors, and optic neuropathy from elevated intracranial pressure (ICP) are common complications. Diagnosis relies on imaging modalities like CT and ultrasound. However, emerging non-invasive methods (e.g., optical coherence tomography) show promise. The effectiveness of early surgical interventions, including endoscopic strip craniectomy and whole-vault cranioplasty, was highlighted for improving long-term outcomes. Clinical Observations: Syndromic cases often involve more severe visual and systemic complications.	Nurses are integral to early identification and ongoing care of infants with craniosynostosis.	40%

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Russo C, et al.	Neuroimaging in Nonsyndromic Craniosynostosis: Key Concepts to Unlock Innovation	2024	To explore the applications of neuroimaging	Expert opinion	n/a	C1 imaging: Still the gold standard for evaluating bone structures but involves significant radiation exposure. MRI: Emerging as a safer alternative, particularly with black-bone MRI offering detailed cranial imaging without ionizing radiation. US: Useful for initial screening but limited in advanced diagnostic applications. Advanced techniques: Black-bone MRI and fMRI provide enhanced imaging capabilities, including brain structure visualization and vascular assessment.	Patient Advocacy: Ensuring the use of radiation-sparring imaging techniques for infants. Coordinating care: Assisting in multidisciplinary approaches that integrate neuroimaging into patient management plans. Education and Counselling: Informing families about imaging options, potential risks, and the importance of early diagnosis and follow-up. Postoperative Monitoring: Supporting the use of neuroimaging for assessing surgical outcomes and guiding further interventions.	40%
Shruthi NM, et al.	Craniosynostosis: A Pediatric Neurologist's Perspective	2022	a pediatric neurologist's perspective	Expert opinion	n/a	Neurodevelopmental Impact: Children with craniosynostosis, especially syndromic forms, are at risk for cognitive and behavioral deficits, language delays, and academic difficulties. Surgical Outcomes: Early surgical intervention improves morphological outcomes and may reduce neurocognitive risks, though some deficits persist despite surgery. Multidisciplinary Approach: Collaboration among neurologists, surgeons, geneticists, and other specialists is essential for effective management. Diagnostic Advances: Genetic testing and advanced imaging modalities enhance early detection and planning.	This study reinforces the nurse's role as a cornerstone in the early diagnosis, holistic care, and advocacy for children with craniosynostosis, ensuring optimal health and developmental outcomes.	40%
Marbatté T, et al.	Evaluation and Management of Nonsyndromic Craniosynostosis	2022	evaluate and manage nonsyndromic craniosynostosis (NSC), focusing on early diagnosis, surgical and non-surgical treatment approaches	diagnostic test accuracy study	150	Surgical Outcomes: Early interventions yielded better neurocognitive and morphological outcomes, minimizing intracranial hypertension and developmental delays. Surgical Timing: Open procedures: Optimal at 6–12 months. Endoscopic approaches: Recommended within 3–4 months followed by helmet therapy. Diagnostic Advancements: Rapid low-dose craniofacial CT reduced radiation exposure significantly. Complications: Effective perioperative management, including blood loss control and infection prevention, reduced morbidity and mortality rates..	The study highlights how nurses contribute to early interventions and comprehensive care, significantly improving patient outcomes in craniosynostosis management.	60%
Krimmel M, et al.	Value of high-resolution ultrasound in the differential diagnosis of saphenous and occipital plagiocephaly	2012	evaluate the effectiveness of cranial ultrasound	cohort studies	101	Craniosynostosis: Ultrasound diagnosed fused sutures in 5 cases. In 2 cases, ultrasound results were inconclusive. Deformational Plagiocephaly: Ultrasound demonstrated patent sutures in 45 cases. 2 cases had inconclusive results. Diagnostic Utility: Ultrasound was shown to be a reliable screening tool for differentiating fused from patent cranial sutures. It avoided the radiation exposure associated with CT.	This study reinforces the importance of nurses in integrating safer, more efficient diagnostic modalities into routine care, improving outcomes while prioritizing infant safety.	75%
Pogliani L, et al.	Cranial ultrasound is a reliable first step imaging in children with suspected craniosynostosis	2017	the diagnostic accuracy of cranial ultrasound scans (CUS)	cohort studies	196	Accuracy: CUS demonstrated high sensitivity and specificity in diagnosing craniosynostosis, with only 2 false positives in the early study phase. CT confirmed CUS results in all 30 cases diagnosed with craniosynostosis. One case of temporal suture closure, not assessed by CUS, was identified by CT. Clinical Follow-Up: 148 infants with negative CUS findings showed progressive normalization of head shape, excluding craniosynostosis. Limitations: US was inconclusive in 2 infants over 12 months due to age-related limitations. Operator dependence and a learning curve for accurate CUS application.	Early Screening and Detection: Nurses can advocate for CUS as the first imaging modality, minimizing radiation exposure for infants.	72.70%
Klaić M, et al.	Health-related quality of life of children treated for nonsyndromic craniosynostosis	2023	evaluate the health-related quality of life (HQoL)	cohort studies	73	HQoL was strongly correlated with cognitive abilities ($\rho = 0.42$) and adaptive behavior skills (ABAS: $r = 0.57$). Slightly lower scores were noted for school and psychosocial functioning, particularly in children treated for sagittal synostosis.	The study underscores the importance of nursing involvement in both clinical assessments and the broader psychosocial care of children treated for craniosynostosis.	81.80%
Kurniawan MSIC, et al.	Health-related Quality of Life in Children and Adolescents With Sagittal Synostosis	2023	to evaluate the health-related quality of life (HQoL)	cohort studies	68	HRQoL Compared to Normative Group: Patients with SS had HRQoL scores similar to the general population, except for higher "Family Cohesion" ($p = 0.02$) and lower "Mental Health" ($p = 0.05$). Frequent headaches were associated with significantly lower HRQoL scores in domains such as mental health, physical summary, and psychosocial summary.	Nurses play a pivotal role in enhancing patient outcomes and family cohesion.	60%
Ahuwalia R, et al.	Deformational brachycephaly: the clinical utility of the cranial index	2020	assess using the cranial index (CI)	cohort studies	1499	Mean CI: 82.6 across all age groups. Prevalence of Brachycephaly: 27% in infants at birth. Decreased to 6% by > 2 years of age. Age-Related Changes: Significant reductions in CI observed at 12 and 24 months of age ($F[2,1496] = 124.058, p < 0.0005$). CI decreased by 0.038 per month on average, with a significant regression equation ($F[1,1497] = 296.846, p < 0.0005; R^2 = 0.140$). Conclusions: Deformational brachycephaly is common in infancy but improves significantly through early childhood. Clinicians can use predictive regression models to anticipate natural CI improvements as children grow.	This study reinforces the importance of nurses in early detection, education, and follow-up care, ensuring that cranial abnormalities are addressed promptly and effectively.	60%

Fu Z, et al.	Association of gut microbiota composition and craniosynostosis.	2023	the association between gut microbiota composition	case-control study	60	The CS group showed significantly lower levels of bacterial family, genus, and species compared to the non-CS group (all $p < 0.05$). Enriched taxa in the CS group included <i>Staphylococales</i> (order), <i>Enterococcaceae</i> and <i>Staphylococcaceae</i> (families), and <i>Enterococcus</i> and <i>Staphylococcus</i> (genus). Key metabolic pathways, such as polyyclic aromatic hydrocarbon degradation and penicillin and cephalosporin biosynthesis, were more abundant in the CS group. Significant differences in gut microbiota diversity and function were identified between the two groups.	Nurses play a crucial role in the multidisciplinary care of infants with craniosynostosis, including early diagnosis, monitoring for associated conditions, and supporting family education.	90%
DeFreitas CA, et al.	Prenatal Diagnosis of Craniosynostosis Using Ultrasound	2022	the feasibility of ultrasound imaging	case series	44	Diagnostic Accuracy: The automatic shape classifier correctly classified 85% of cases (sensitivity: 82%; specificity: 87%). Cephalic index showed low sensitivity for sagittal synostosis (45%). Visual inspection alone was less accurate, with only 40–50% agreement and a low kappa statistic (0.09–0.23). Shape Profiles: Statistically significant differences were observed between controls and synostotic patients ($p < 0.001$). Implications: Quantitative shape analysis demonstrated strong potential for identifying craniosynostosis prenatally compared to cephalic index or visual inspection.	Prenatal Counselling: Nurses can educate parents on the implications of a prenatal craniosynostosis diagnosis, addressing concerns and guiding them through next steps. Coordination of Care: Nurses act as liaisons between radiologists, obstetricians, and pediatric specialists to ensure families receive comprehensive care and follow-up. Postnatal Support: Following prenatal identification, nurses help coordinate early surgical consultations and provide emotional support to families. Education: Nurses can advocate for integrating advanced diagnostic techniques, such as cranial shape analysis, into standard prenatal care practices.	60%
Proisy M, et al.	Ultrasongraphy for the diagnosis of craniosynostosis	2017	the effectiveness of cranial ultrasound (US)	case series	40	Diagnostic Accuracy: Ultrasound showed 100% specificity and sensitivity in diagnosing normal or closed cranial sutures. Ultrasound was also 100% sensitive in identifying complete or incomplete synostosis. Efficiency: Ultrasound is a fast, non-radiating diagnostic tool suitable for early assessment. 3D-CT remains a secondary option, reserved for pre-surgical planning or when additional details are needed.	This study highlights how nurses, as integral members of the care team, can leverage advancements in diagnostic imaging to enhance patient outcomes and family satisfaction.	60%
Simanovsky N, et al.	Effectiveness of ultrasonographic evaluation of the cranial sutures in children with suspected craniosynostosis	2009	the effectiveness of postnatal cranial ultrasound (US)	case series	24	Diagnostic Accuracy: Ultrasound provided the correct diagnosis in 23 out of 24 cases (95%). One case had equivocal ultrasound findings, later clarified by CT. Normal Sutures: Identified in 15 infants with no abnormalities at follow-up (mean: 5.8 months). CT confirmed normal sutures in 2 cases. Craniosynostosis Diagnosed: Premature closure of cranial sutures was identified in 8 infants. Four infants required 3D-CT for surgical planning. Equivocal Findings: In one case, ultrasound findings were inconclusive, but CT revealed open sutures.	Initial Assessment: Nurses can advocate for and conduct initial ultrasound imaging as part of routine evaluations for cranial abnormalities. Family Education: Nurses are instrumental in explaining imaging options, alleviating concerns about radiation exposure from CT, and guiding families through the diagnostic process. Care Coordination: Nurses serve as a bridge between radiologists, surgeons, and families, ensuring timely follow-up and pre-surgical preparation. Post-Diagnostic Support: Nurses provide ongoing care for infants with diagnosed craniosynostosis, ensuring they receive appropriate interventions and monitoring. Advocacy for Safe Practices: Promoting ultrasound over CT when possible reduces radiation exposure, aligning with best practices in pediatric care.	75%
Zavala CA, et al.	Can Craniosynostosis be Diagnosed on Physical Examination? A Retrospective Review	2023	evaluate the reliability of physical examination	case series	140	Diagnostic Accuracy: CT confirmed craniosynostosis in 109 of 117 patients with clinical diagnoses (93.2%). Eight patients (6.8%) with physical exam findings suggestive of craniosynostosis had patent sutures on CT imaging. Intracranial Abnormalities: CT identified intracranial anomalies in 7 patients (e.g., hydrocephalus, Chiari malformation). Surgical plans were adjusted accordingly. Management for Non-Surgical Cases: Patients with patent sutures were managed with molding helmets or observation alone. Conclusion: Physical examination alone was insufficient, as some patients would have undergone unnecessary surgery without CT confirmation.	This study highlights the importance of nurses as integral members of the diagnostic and care team, contributing to accurate diagnoses, effective treatment planning, and holistic family-centered care.	60%
Hersh DS, et al.	Minimally invasive strip craniectomy for metopic craniosynostosis using a lighted retractor	2021	Focus Video	J Craniofac Surg	15	The 2-month-old patient showed significant improvement in forehead contour at the 6-month follow-up. No complications, such as seizures or hydrocephalus, were reported. Hemoglobin levels post-surgery remained stable, with no need for intensive care.	Nurses contribute to the success of minimally invasive techniques, from diagnosis and preoperative preparation to postoperative recovery and long-term care, ensuring optimal outcomes for infants with craniosynostosis.	60%

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Cardim VLN, et al. Combined Dynamic Osteotomies for Craniosynostosis Surg Glob Open Plast Reconstr 2023	effectiveness of dynamic osteotomy techniques	case series 2023	108	Dynamic osteotomy techniques provided reliable cranial remodelling and brain expansion across different age groups, demonstrating versatility and efficacy.	Dynamic osteotomy techniques highlight the importance of advanced surgical care, where nurses are integral to ensuring safe, effective, and family-centered care for infants with craniosynostosis. 81.80%
Bautista G. Craniosynostosis: Neonatal Perspectives. Neoreviews. Bautista G. 2021	the clinical features, classifications, and management	case series 2021	n/a	Early Diagnosis: Critical for preventing complications such as increased intracranial pressure and neurodevelopmental delays.	This article highlights how nurses act as critical advocates and coordinators in the care pathway for infants with craniosynostosis, contributing to better outcomes through early detection, comprehensive education, and long-term monitoring. 60%
Forester-Zhang L, et al. Craniosynostosis can occur in children with nutritional ricket 2018	association between late-onset craniosynostosis and severe vitamin D deficiency (VDD)	case series 2018	5	Participants: Five children aged 16 months to 3 years. Risk Factors: Afro-Caribbean or Asian ethnic backgrounds with darker skin pigmentation. Multiple food intolerances and prolonged breastfeeding with picky eating habits. Clinical Groups: Group 1 (n=3): Presented with severe rickets after untreated VDD. Group 2 (n=2): Presented with resolving rickets and sagittal suture ridging.	Group 1: Severe VDD (serum 25OH vitamin D <20 nmol/L), elevated alkaline phosphatase and PTH, low calcium and phosphate levels. Group 2: Moderate VDD (serum 25OH vitamin D 33–44 nmol/L) with normal PTH and bone profiles. Radiological Findings: CT confirmed sagittal suture fusion in all cases, with three children also showing multiple suture fusions. Management: Group 1: Treated conservatively with vitamin D and calcium supplementation; craniosynostosis diagnosed after rickets resolution. Group 2: Presented with raised intracranial pressure requiring emergency cranial vault remodelling surgery. Outcomes: Early recognition and referral were critical for managing intracranial pressure and preventing further complications. 80%
Almeida MN, et al. Comparison of emotional and behavioral regulation between metopic and sagittal synostosis 2024	behavioral differences	Chilids Nervy Syst Archives of Disease in Childhood	91	Support Services: More children with metopic synostosis required supportive services (57.7% vs 34.7%, p = 0.02). Behavioral Outcomes: Metopic Synostosis: Higher rates of difficulties on executive function subscales: Emotion Regulation Index: 33.3% vs 17.4%, p = 0.05 Global Executive Composite: 33.3% vs 17.4%, p = 0.05. Sagittal Synostosis: Higher scores on rule-breaking and externalizing problem subscales of the CBCL. Impact of Surgery Timing: Increasing age at surgery was associated with worse executive function scores.	Nurses are integral in supporting children and families through the diagnosis, treatment, and follow-up care for craniosynostosis. 60%
Klieverik VM, et al. Cosmetic satisfaction and patient-reported outcomes following surgical treatment of single-suture craniosynostosis: a systematic review 2023	to assess cosmetic satisfaction	Chilids Nervy Syst Analytical Cross-Sectional Studies	724	Cosmetic Satisfaction: There was a general trend toward improved cosmetic outcomes after surgery. Various measures were used such as Visual Analogue Scale (VAS) scores, binary questions, and 5-point scales, showing high levels of satisfaction. However, outcome variability was noted due to the lack of uniform assessment methods.	This review highlights the importance of patient-centered care and subjective assessments in managing SSC, underlining the role of nurses in supporting families through preoperative counselling and postoperative psychosocial care. Nurses are pivotal in addressing the psychological and social implications of craniosynostosis, facilitating long-term support to optimize quality of life and promote positive patient-reported outcomes. 90.90%
Ryall JJ, et al. Assessing the quality of life in infants with deformational plagiocephaly J Craniomaxillofac Surg 2021	evaluate the quality of life (QoL)	Analytical Cross-Sectional Studies	90	Infants adapted well to helmet therapy with minimal discomfort. Caregivers found helmet therapy manageable despite the need for recurrent adjustments.	Nurses advocate for evidence-based therapies and provide clear communication about expected outcomes, improving parental confidence. 75%

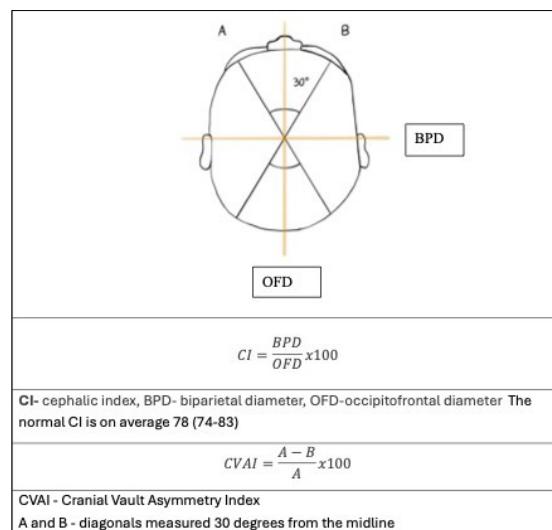
RESULTS

The role of the nurse and midwife in the diagnosis of craniosynostosis is based on physical examination. Nurses and midwives are the first professionals to assess the health of the newborn after birth. During the physical examination of the head, attention should be paid to viewing, palpation and anthropometric measurements. A thorough physical examination is necessary to examine the patient for craniosynostosis [11]. When viewing the skull, the overall shape of the head should be assessed, noting asymmetry, elongation or flattening of specific areas. It is also worth checking for the presence of visible thickening along the cranial sutures, which may indicate premature overgrowth (Fig. 2). Craniosynostosis can cause deformities of the facial part of the skull, including craniofacial dysostosis, ocular dystopia, displacement of the auricle, and flattening or bulging of the frontal or occipital region [12]. An important part of the evaluation is to analyze the proportion between the craniofacial and cerebral cranium, where the cerebrum in a newborn represents about 80% of the total cranial volume, and the craniofacial 20% [13]. During palpation, it is important to feel the rolling thickening along the cranial suture line, which may suggest premature overgrowth. It is also important to inspect the tension and size of the fontanelles (anterior and posterior fontanelles) and note any softening of the cranial bones, known as craniotabes. The presence of bone defects, known as dehiscences, may be indicative of severe forms of craniosynostosis, which result from increased intracranial pressure leading to resorption of thin bone plaques [14]. In

■ Tab. 2. Types of craniosynostosis based on the fused suture

Fused suture	Type of craniosynostosis/ skull shape	Assessment Index (CI or CVAI)	Description of the defect
Sagittal suture	Scaphocephaly	CI 55-70	Excessive elongation of the head in the anteroposterior axis; prominently protruding forehead; narrow, elongated skull with a conical shape at the posterior part; in advanced cases, a concave depression along the midline of the skull
Frontal	trigonocephaly	CI 60-80	Narrow forehead with a prominent ridge along the midline, triangular skull shape when viewed from above; underdevelopment of the lateral orbital rims, hypertelorism, and depressions in the temporal regions
Unilateral coronal suture	Anterior plagioccephaly	CVAI >20	The forehead on the side of the fused suture is flattened, and the orbit is elevated; on the opposite side, the forehead is convex, and the orbit is shifted downward. The nasal bridge may be deviated toward the fused suture, while the chin is directed toward the unfused suture
Bilateral coronal suture	brachycephaly	CI 80-100	The anteroposterior dimension of the head is small; the skull is wide and tall, with a large and flat forehead; the posterior part of the head is also flattened. The upper parts of the orbits are abnormally elevated and spaced apart
Unilateral lambdoid suture	Posterior plagioccephaly	CVAI >20	Flattened occipital region on the side of the fused suture; the ear on the same side is low-set
All sutures	Cloverleaf skull (trifolicephaly)	CI 90-100	Protrusion of the skull in the region of the anterior fontanelle and temporal fontanelles, with an extremely small anteroposterior dimension

CI: Cephalic Index, CVAI: Cranial Vault Asymmetry Index



■ Fig. 2. Diagram illustrating the calculation of the Cephalic Index and Cranial Vault Asymmetry Index to assess the degree of deformation

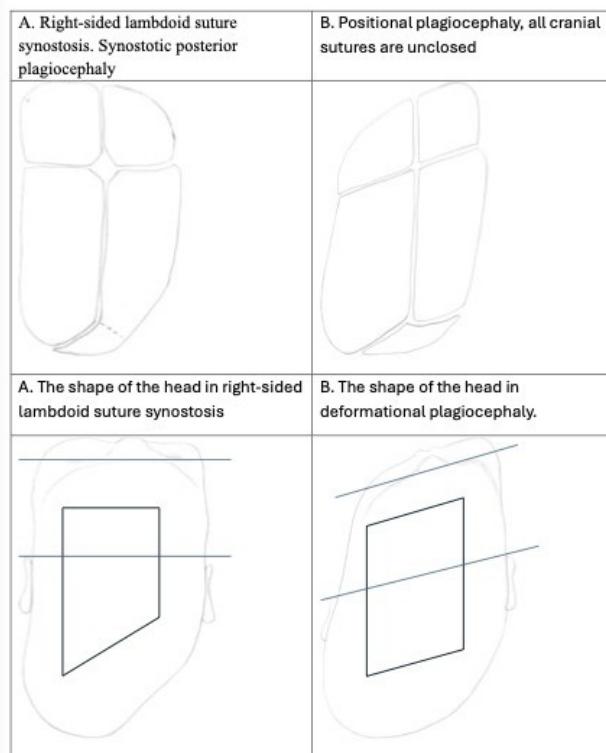
terms of anthropometric measurements, it is necessary to measure the head circumference at the widest point of the skull and compare the result with centile grids for age. It is worth remembering that newborns with craniosynostosis may have normal head circumference. If the circumference is below the 3rd percentile, a diagnosis of microcephaly should be considered. The cephalic index (CI), which is the ratio of cranial width to cranial length, should be within the normal range of 74-83 (Tab. 2, Fig. 1). The cranial vault asymmetry index (CVAI) assesses the difference between the lengths of the two cranial diagonals, which can help identify asymmetry [15] (Fig. 2). Assessing the mobility of cranial sutures involves gentle pressure testing along the sutures. Immobile sutures may suggest synostosis, requiring further diagnosis and treatment.

Differentiating craniosynostosis from plagiocephaly on physical examination

Differentiating craniosynostosis from positional plagiocephaly is an important part of diagnosis by nurses and midwives. An important step in this process is taking a detailed history of the baby's sleep position and observing the infant's behavior. Placental plagiocephaly, which is the most common cranial deformity associated with intrauterine or placental conditions, is usually caused by cranial compression in utero, such as in multiple pregnancies, small-for-gestational-onset or gut microbiota composition [15]. It is characterized by cranial asymmetry, where one side is flattened and the opposite side is convex [16]. In other deformities, such as brachycephaly, there is a shortening of the anteroposterior dimension of the skull, which is the result of uniform compression in utero. Dolichocephaly, often seen in premature infants, manifests as elongation of the skull in the anteroposterior axis

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(Fig. 3). Asymmetry of the zygomatic arches may result from prolonged pressure on one side of the fetal face, while craniotabes, or softening of the occipital bone, is associated with vitamin D deficiency or other metabolic disorders during pregnancy [17]. Frontal deformities, manifested by flattening or protrusion of the frontal region, can also result from the position of the fetus in utero. Deformities associated with positional plagiocephaly are often transient and resolve after birth, especially with the implementation of appropriate measures, such as changing the baby's position or using specialized orthopedic cushions. If the lesions persist, further diagnostics are needed to rule out pathologies such as craniosynostosis. Differentiating between the two conditions on physical examination requires experience and special attention to elements such as the mobility of the cranial sutures, the presence of shaft-like thickening, and the craniofacial-to-cerebral ratio, allowing early referral of the child to an appropriate specialist [18]. Physical examination is an effective tool for the initial diagnosis of craniosynostosis, especially in the hands of experienced clinicians. However, full diagnosis and classification of the type of craniosynostosis requires confirmation by imaging studies [19-24].

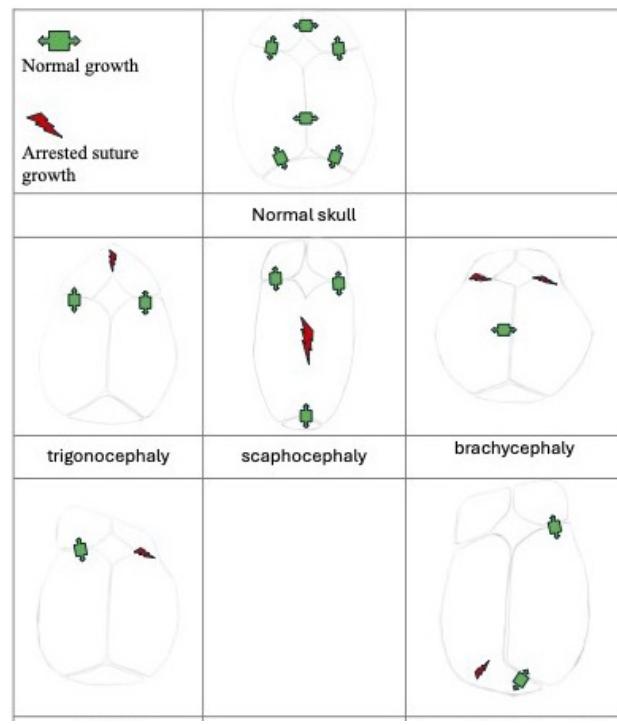


■ Fig. 3. Comparison of head shape in premature lambdoid suture synostosis (A) and positional asymmetry (B) (original illustration by the author)

Nursing collaboration with the medical team of specialists

When craniosynostosis is suspected, nurses and midwives play a vital role in referring the child for further diagnosis and ensuring coordination of interdisciplinary care. Collaboration with the medical team begins with careful clinical observation and documentation of any abnormalities noted during the physical examination. This informa-

tion is the basis for follow-up by pediatricians, neurosurgeons and radiologists [25]. Nurses and midwives support the diagnostic process by referring the child for imaging studies, such as CT scans or head ultrasound (Fig. 4). Collaboration with radiologists allows for detailed test results, which are crucial for determining the type and extent of cranial deformity. In addition, nurses take part in educating parents about diagnostic procedures, preparing them emotionally and practically for the tests [26]. Once the diagnosis is made, nurses work with surgeons and anesthesiologists to prepare the child for surgery. As part of this process, nurses monitor the patient's health, assess his or her neurological development, and coordinate a schedule for follow-up examinations and consultations [27]. After surgery, nurses continue to work with the medical team to support the child's rehabilitation process. Working with physiotherapists and neurologists, they can plan an individualized rehabilitation program to assist in optimal recovery. Nurses also stay in touch with parents, educating them about home care, monitoring potential complications and providing emotional support during the child's recovery. Effective cooperation between the nurse and the medical team of specialists is essential to provide comprehensive care for patients with craniosynostosis. Through their involvement, nurses contribute to improving treatment outcomes and quality of life for children affected by this malformation [28].



■ Fig. 4. Changes in skull shape depending on the fused suture (original illustration)

Operative treatment of craniosynostosis

Operative treatment of craniosynostosis is the primary mode of therapy. Its goal is both to correct the cranial deformity and to prevent complications such as increased intracranial pressure. Traditional open methods include cranial remodeling, known as Cranial Vault Remo-

dealing (CVR). This is a surgical procedure in which the bones of the skull are removed, reshaped and remolded to improve the shape of the skull and increase the volume of the cerebrum. This method is usually used in children over 6 months of age and provides permanent cosmetic and functional results, although it involves longer surgery time and a higher risk of blood loss [28]. Another traditional method is the Strip Craniectomy (linear craniectomy), which involves removing narrow strips of bone along a prematurely overgrown suture to allow the skull to grow naturally. This procedure is most commonly used on younger infants (up to 3-4 months of age), has a shorter surgical time, and requires the use of an orthopedic helmet after surgery for optimal cosmetic effect [29]. In recent years, minimally invasive methods such as endoscopic correction of craniosynostosis have become increasingly popular. This is a minimally invasive technique in which prematurely overgrown cranial sutures are removed using an endoscope. This method is less burdensome for the patient, has a shorter operation time, a lower risk of complications and a faster recovery. However, like linear craniectomy, it requires the use of an orthopedic helmet for several months after surgery [30]. Hybrid methods, which combine elements of traditional surgery with minimally invasive techniques, are used for more complex cases. An example is the combination of endoscopic suture removal with the subsequent use of assistive devices such as distractors. This solution reduces the risks associated with major surgeries, although it requires advanced equipment and greater precision. Another therapeutic option is osteogenic distraction, which involves gradually pulling apart bone fragments using special distractors. This method makes it possible to gain additional intracranial space and improve the shape of the skull (Fig. 5). It is particularly useful in more complex deformities or in cases of secondary surgery, although the treatment process takes longer and requires regular follow-up visits [31]. Assessing a child's development after craniosynostosis surgery and the impact of the procedure on health-related quality of life (HRQoL) requires close interdisciplinary cooperation, with nurses playing an essential role. Nursing care ranges from monitoring the child's physical and neurological condition to emotional support and family education [32,33]. Nurses play an important role in the long-term observation of a child's development, paying attention to the achievement of cognitive and motor milestones. In children without hydrocephalus or elevated intracranial pressure, neurocognitive deficits such as language, reading and writing difficulties can occur in 30-50% of patients.

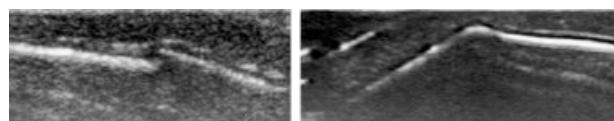


Fig. 5. Ultrasound image of overlapping bone edges, a physiological phenomenon observed after birth and in infants with features of plagiocephaly, using a 14 Hz linear probe. B. Ultrasound features of frontal suture craniosynostosis presenting as a ridge-like connection along the cranial sutures, using a 14 Hz linear probe (original material by the author MWM)

Early detection of these problems allows nurses to refer the child for specialized speech therapy or psychological evaluation. Educating parents on how to observe their child's development and use available forms of support is also an important part of their work [34]. Children's quality of life after craniosynostosis surgery is generally comparable to the general population, but nurses play an essential role in providing emotional support and facilitating social reintegration. [35]. They help families cope with anxiety and uncertainty and advise on how to support the child in establishing relationships and social acceptance. In addition, nurses can use HRQoL measurement as a tool to identify children who need more detailed psychological assessment. In long-term nursing care, it is crucial to monitor the child's developmental parameters and collaborate with neurologists, physiotherapists and psychologists. Nurses support parents in implementing therapeutic recommendations at home, which includes motor exercises and developing cognitive skills. Through their involvement, nurses contribute to improving treatment outcomes and the overall quality of life for the child and his family [36,37].



Fig. 6. Patient after sagittal suture craniosynostosis surgery using the SAS (Spring-Assisted Surgery) method. Titanium springs facilitate gradual correction of skull deformities, allowing for proper skull development following the procedure

DISCUSSION

Craniosynostosis, as a congenital malformation, poses numerous diagnostic and therapeutic challenges to medical teams that require a multidisciplinary approach. Nurses play a vital role in this process, supporting both the diagnosis and comprehensive care of the child and their family.

In the context of diagnosis, early recognition of cranial deformity is critical to improving prognosis. Nurses and midwives, as first responders, have an important role in identifying potential signs of craniosynostosis during routine physical examinations. Their ability to differentiate this defect from other deformities, such as positional plagiocephaly, and to observe physical parameters of the skull, such as asymmetry, craniofacial to cerebral ratios, and suture mobility, is crucial in referring a child for specialized diagnosis. Operative treatment of craniosynostosis, which is the therapeutic standard, requires the nursing team's involvement at every stage of the process. Nurses participate in preparing the child for surgery, educating

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parents about the procedure, its risks and expected outcomes. After surgery, nurses play an important role in monitoring vital signs, assessing the healing process and early detection of potential complications, such as increased intracranial pressure or infections. Findings indicate that despite surgical correction of cranial deformities, some children may have neurocognitive difficulties in the areas of language, reading and writing, highlighting the need for long-term monitoring of neurological development. Nurses are essential in this regard, acting as care coordinators and collaborating with neurologists, psychologists, and speech therapists. The quality of life (HRQoL) of children operated on for non-syndromic craniosynostosis is usually comparable to the general population. However, nurses can significantly improve HRQoL by emotionally supporting families and educating them about home care and coping with psychosocial challenges, such as peer group acceptance. Measuring HRQoL in clinical practice can serve as a screening tool to help identify children who require more advanced psychological support [26]. In conclusion, interdisciplinary collaboration, with nurses playing a crucial role, forms the foundation of effective care for children with craniosynostosis. Their involvement in diagnosis, post-operative care and developmental support contributes to improving the quality of life of the child and his family, as evidenced by both clinical and observational results. The introduction of an individualized approach to each case and the development of the nursing team's competence allows further improvement in the care of this demanding group of patients.

Limitations

This scoping review has several limitations. Due to the heterogeneity of the included studies, it is not possible to draw precise conclusions summarizing the analyses performed. Additionally, for the same reason, conducting a systematic review and meta-analysis was not feasible. The very broad thematic scope of the analyzed topic, combined with a relatively limited body of available literature, further hinders the ability to derive significant quantitative conclusions. However, to the best of the authors' knowledge, this is the only scoping review summarizing the involvement of nurses in the care of infants with craniosynostosis. In addition to characterizing the current literature and synthesizing the content related to the nurse's role, this paper also presents selected content in a graphical format, which, in our opinion, enhances its clarity and accessibility.

CONCLUSIONS

Nurses and midwives play a crucial role in the diagnosis of craniosynostosis, particularly through their ability to identify cranial deformities early during routine physical examinations. Their ability to differentiate craniosynostosis from positional plagiocephaly allows them to quickly refer the child for specialized diagnosis, which is essential for effective treatment. An important part of nursing work is also the education of parents, who, with the support of

nurses, better understand the treatment process and can actively participate in the care and rehabilitation of the child. Effective care of a child with craniosynostosis requires interdisciplinary cooperation, with nurses serving an essential role as care coordinators. By working closely with neurologists, neurosurgeons, physiotherapists and psychologists, it is possible to comprehensively monitor the child's condition and achieve optimal treatment results. Despite the effectiveness of surgical correction of cranial deformities, some children may have neurocognitive difficulties, especially in the areas of language, reading and writing. Therefore, long-term monitoring of neurocognitive development by nurses is crucial for early detection of these problems and referral of children for additional consultation. Children's quality of life after craniosynostosis surgery is generally comparable to the general population, confirming the effectiveness of treatment. Nurses, by providing emotional and educational support, significantly improve the quality of life for both children and their families. The holistic approach of nurses, taking into account physical, emotional and psychosocial aspects, plays a key role in the treatment and rehabilitation process, which emphasizes the need for further development of their competence and interdisciplinary cooperation.

Source of funding

The preparation and publication of the article were funded as part of a project co-financed from the state budget, granted by the Minister of Education and Science under the „Doskonała Nauka II” program. Agreement No. KONF/SP/0268/2023/01.

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