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Quality care for children and young people with complex and integrated care needs: A discussion on nursing-sensitive indicators

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ABSTRACT

This paper highlights the need for nursing-sensitive indicators tailored to children and young people with complex and integrated care needs. While nursing plays a pivotal role in influencing care quality for this population, current measures predominantly focus on adult populations, creating gaps that hinder the evaluation of nursing contributions across diverse settings such as acute, community, and home care. We examine the importance of quality care measurement for children and young people with complex and integrated care needs and highlight deficiencies in international measurement systems. The discussion highlights the multidimensional care needs of this vulnerable population and advocates for nursing-sensitive indicators that capture broader outcomes including physical health, functional outcomes, family experience, and family well-being. Also highlighted is, the weak evidence linking process indicators to improved patient outcomes, a focus on negative outcomes, such as mortality, and the lack of theoretical foundations for nursing-sensitive indicators. There is a lack of consensus on what components to measure, definitions of indicators, and appropriate methodologies for the development of nursing sensitive indicators. Donabedian's (1988) structures, processes, and outcomes framework is discussed as well as an overview of adaptations used to improve the quality of indicator sets in a variety of settings. By situating the discussion within the context of children's and young people's nursing, this paper aims to direct future research towards the development of comprehensive indicators that capture the full contribution of nursing to the care of children and young people with complex and integrated care needs. Ultimately, this paper advocates for a standardised, holistic approach to nursing-sensitive indicators for this vulnerable population to improve care quality and overall health and wellbeing for children, young people, and their families.

What is already known

- Rapid medical advances have extended the lives of children and young people with complex care needs, but this can result in poor quality of life for some due to frequent hospital admissions, developmental delays, and preventable harm, while also increasing demands on healthcare systems through higher costs and resource use.
- Donabedian's (1988) widely recognised framework for evaluating healthcare quality is underutilised in Ireland, as Quality Care Metrics primarily emphasise process metrics over outcomes and structural aspects of care, thereby limiting nursing's ability to fully demonstrate its contributions to patient care.

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- The absence of a universally accepted definition or framework for nursing-sensitive indicators along with the interchangeable use of terms like "nursing-sensitive outcomes," creates confusion and results in inconsistencies in their application across diverse methodologies

What this paper adds

- This paper offers a timely scholarly discussion on the importance of nursing-sensitive indicators in accurately measuring the full contribution of nursing care for children and young people with complex and integrated care needs.
- It contributes to a global dialogue on achieving meaningful outcomes for children and young people with complex and integrated care needs, emphasising their right to quality healthcare as well as the interdependence between their well-being and that of their families, highlighting nursing's dual role in holistic patient care.
- We highlight that existing nursing lexicons, measurement systems, models and frameworks in scholarly discourse fail to adequately capture the sensitivity and unique knowledge and skills required to care for children, young people, and their families.

1. Introduction

Nursing has recognised the importance of quality care and its impact on patient outcomes since Florence Nightingale's era (Nightingale, 1860). For children and young people with complex and integrated care needs, quality care goes beyond physical health to enhance overall well-being, helping both them and their families live more fulfilling lives (Houlihan et al., 2024). However, significant issues in the quality of care for this population have been identified, including challenges related to access to care, parental readiness to provide care, and the lack of integrated care systems (Brenner et al., 2018a). These issues can result in preventable harm, frequent hospital admissions, developmental delays, and diminished quality of life, while also increasing family stress and burnout (Cohen et al., 2023; Page et al., 2020; Brenner et al., 2018a). Nurses are central to providing comprehensive holistic care to this population in hospital, community, and home settings. They address not only patients' physical needs but also coordinate services, provide emotional support, and manage clinical technologies. Despite nursing's integral role, there is limited evidence on how its contribution to quality care for children and young people with complex and integrated care needs is measured (Nageswaran and Golden, 2017). Nursing-sensitive indicators are essential for evaluating the quality, effectiveness, and impact of nursing on patient outcomes, yet a valid and reliable suite of nursing-sensitive indicators for this population remains underdeveloped (Oner et al., 2021; Heslop and Liu, 2014). Without these indicators, the impact of nursing on this population is unclear and difficult to quantify.

2. Children and young people with complex and integrated care needs

Advancements in medical technology have contributed to a growing population of children and young people with complex and integrated care needs, who are living significantly longer lives. This has placed considerable demands on health services. For example, in the United States of America this population accounts for up to one-quarter of paediatric inpatient hospital bed days, nearly forty percent of hospital deaths and a third of overall child health spending (Cohen et al., 2018). This population is diverse, experience a range of functional limitations, chronic conditions, and medical fragility, often without a unifying diagnosis (Brenner et al., 2018a). Efforts to create consistent definitions for children and young people with complex and integrated care needs have been difficult, both in Europe and North America. Terms like "children with medical complexity," "children with complex care needs," and "children with special healthcare needs" are often used interchangeably (Azar et al., 2020; Brenner et al., 2021a; Cohen et al., 2018). In this paper, we adopt the terminology "complex and integrated care needs," proposed by the European Academy of Paediatrics, which reflects that a complex care need is inherently an integrated care need. (Brenner et al., 2021a). Given the diversity of this population, establishing clear care goals and outcomes is challenging, and defining effective care models is complex. A key issue is that the conventional biomedical model is inadequate for addressing the needs of children and young people with complex and integrated care needs (Schneberk et al., 2022). It overlooks the complex interactions among multiple medical conditions or the broader contextual factors impacting this population and their families. Instead, children and young people with overlapping comorbidities and functional limitations require a holistic multifaceted approach to care that extends beyond traditional models.

Integrated care is advocated for this population given their needs are dynamic and span multiple health and social care settings (Brenner et al., 2018). To provide integrated care an interdisciplinary approach is required to ensure continuous, coordinated support, including home care (Cohen et al., 2023; Brenner et al., 2018). However, integrating services across different levels and types of care, primary, secondary, and tertiary, remains a challenge. Research shows significant variation in the governance and accessibility of care for these children and young people (Cassidy et al., 2023; Brenner et al., 2018b). Integrated care, as described by Baxter et al. (2018), involves collaboration across health, social, and community services, with contributions from both public and private sectors. For children and young people with complex and integrated care needs, integrated care is further described by Cassidy et al. (2023) as highly specialised, involving interdisciplinary teams, families, and children and young people, supported by digital health technologies. This holistic approach includes bridging gaps between care services, disciplines, and domains of care (e.g., physical, mental, and social well-being). Despite this, nursing role within these integrated systems are not always clearly defined (Notarnicola et al., 2017). Longstanding challenges in recognising and articulating the diverse aspects of nursing have made it difficult to measure nursing

activities and evaluate their unique impact on care outcomes, distinct from other healthcare disciplines (Amatt et al., 2023; Jackson, Anderson, and Maben, 2021). Some efforts, such as Brenner et al. (2018b), multidisciplinary, child-centric principles and standards for the care of children and young people with complex and integrated care needs offer a foundational framework for defining nursing-specific activities and developing relevant indicators. These principles include access to care, co-creation of care, and integrated governance. For example, continuity of care by the multidisciplinary team has been linked to reduced emergency department admissions for this population (Arthur et al., 2018). Moving forward, it is crucial to build on these broad multidisciplinary principles by identifying nursing-specific contributions to care outcomes for children and young people with complex and integrated care needs.

2.1. Nursing care needs

There is limited evidence and few tools available to capture the full scope of nursing care needs for children with complex and integrated care needs across various settings (Nageswaran and Golden, 2017). Navarra et al. (2016) attempted to quantify the nursing care needs from a physical perspective for children and young people in long-term institutional care settings by piloting the Nursing-Kids Intensity of Care Survey. The survey identified several key nursing interventions routinely performed for this population, including infection control, medication administration, nutritional and respiratory support, tracheostomy care, seizure management, and monitoring via pulse oximetry (Navarra et al., 2016). Nurses with specialised skills are critical to delivering safe quality care to this population, as their expertise directly influences patient outcomes (Brenner et al., 2021b). However, there is a significant gap in the training and preparation of general nurses for this role (Clancy et al., 2021). Across Europe, children's and young people's care is often overlooked or left to nursing schools' discretion, resulting in inconsistent coverage and underrepresentation in standard curricula (Clancy et al., 2021). This inconsistency leads to disparities in general nurses' knowledge and skills, leaving some nurses inadequately prepared to care for children and young people regardless of care setting or condition (Clancy et al., 2021). These deficiencies can lead to serious consequences. Nageswaran and Golden (2017) documented evidence from family caregivers, where inadequate nursing care, often due to a lack of skills, resulted in emergency department visits, hospitalisations, or additional medical procedures. In Ireland, parents of children and young people receiving respite care are often hesitant to use these services unless they are confident in the nurses' abilities and skills to provide safe, quality care (Murphy et al., 2022). Additionally, families often navigate multiple services throughout the care continuum and frequently encounter substantial gaps due to poor coordination. An ideal care model involves a clinician who understands the child, young person, and family, leading a coordinated, team-based approach (Cohen et al., 2023). This model addresses the comprehensive needs of both the child and family, fostering proactive care plans and ensuring timely responses to urgent health issues through multidisciplinary shared decision-making. Effective coordination is crucial to preventing fragmented care, medical errors, and unnecessary hospitalisations, (Cohen et al., 2023). Furthermore, coordination supports continuity during transitional care to adult services, a complex process that needs to address psychosocial, medical, educational, vocational, and recreational needs (Doucet et al., 2022). Nurses can significantly improve outcomes for this vulnerable population through effective coordination across various care settings. They also play a central role in managing and coordinating interdisciplinary teams, acting as the linchpin among interdisciplinary teams, families, across various care settings. Measuring the effectiveness of nurses in coordinating care, especially during transitions between hospital, home, and community settings, is essential for evaluating overall care quality (Haspels et al., 2023). The unique and comprehensive nursing care required for children and young people with complex and integrated care needs is further complicated by the interdependence of their health and wellbeing and that of their families (Boss et al., 2020). This highlights the essential role of nursing in providing holistic support to both patients and their families.

2.2. Family needs

Families of children and young people with complex and integrated care needs often take on significant caregiving responsibilities, supported by nursing care at home (Page et al., 2020). Parent-led quality home care has been shown to keep these children and young people out of the hospital, allowing them to live longer and fuller lives (Boss et al., 2020). However, parents of children with complex and integrated care needs often find themselves assuming the roles of healthcare providers (Page et al., 2020). This includes mastering technical, nursing, and medical procedures, for instance bowel washouts, and managing emergencies, all while coordinating care across multiple systems. Collaborative relationships between nurses and families are essential for effective care coordination, decision-making, and ensuring that care plans align with the family's goals (LeGrow, Cohen, and Epsin, 2022). A human-centred approach, which emphasises the dignity and individuality of the child or young person, is strongly advocated by families (Houlihan et al., 2024). This perspective helps prevent these children and young people from being solely defined by their illness or diagnosis, a view supported by children and young people with life-limiting illnesses in the United Kingdom (Coombes et al., 2022). In North America, families have expressed concerns that traditional quality care measures, which often focus on typical developmental milestones, fail to capture the complex realities of their child's or young person's life (Randolph et al., 2024). Furthermore, siblings of these children and young people experience a range of challenges and struggle with, being overwhelmed, coping, communication within the family, and having time away from home for recreation (Grant and McNeilly, 2021). Meeting the care needs of these children and young people requires a holistic approach, focusing not only on health and functional outcomes but also on family well-being and overall family quality of life. Given the interconnectedness of patient and family well-being, evaluating nursing's contribution to both becomes essential for understanding the quality of care provided. When developing nursing-sensitive indicators for this population collaboration with nurses, children and young people, families, and multidisciplinary teams will be essential to ensure that indicators are comprehensive and aligned with lived experiences. Furthermore, it is essential that nursing-sensitive indicators capture not only clinical outcomes but also the extent to which nurses support families, coordinate care across services, and

promote psychological, physical and developmental health and wellbeing.

3. Quality care measurement

Quality healthcare is defined as safe, effective, person-centred, and continuously improving (Health Service Executive, 2016). The goal is to enhance patient experiences and outcomes by adhering to best practices and fostering ongoing improvement at all levels of care. However, children's health services have often failed to consistently meet these standards. This is evidenced by multiple high-profile inquiries into adverse incidents and deaths within children's services, including those involving children and young people with complex and integrated care needs (Health Service Executive, 2023; Courts and Tribunals Judiciary 2014; Department of Health and Children, 2005; Carille, 2002).

3.1. The need for comprehensive nursing metrics

Historically, children and young people have been underrepresented in national quality frameworks, often aggregating children's data with adults, reducing its relevance (Hargreaves, *et al.*, 2019). As a result for example, in the United Kingdom there is no unified approach or framework to measuring quality in children's and young people's services, leading to inconsistencies across care standards. This inconsistency hampers efforts to establish standardised quality indicators that are validated and appropriate for children and young people. Nursing metrics are standardised measures used to assess the quality of nursing and midwifery care (Health Service Executive, 2018). These metrics allow for the assessment and review of care practices in comparison to established benchmarks and standards (Foulkes, 2011). Several countries have introduced national nursing measurement systems, such as the National Database of Nursing Quality Indicators in the United States, Ireland's Quality Care Metrics, and Canada's Health Outcomes for Better Information. However, these systems predominantly focus on adult care, negative outcomes such as falls, pressure injuries, mortality and adverse events, which limits understanding of the full contribution of nursing (Steel *et al.*, 2021; Sim *et al.*, 2018). There is a notable lack of universally agreed nursing measures for children and young people (Amatt *et al.*, 2023). Notably, Ireland's Quality Care Metrics is one of the few systems to include children's and young people's care, however these metrics are limited to acute care settings (Health Services Executive, 2018). As a result, there is a lack of national data in Ireland reflecting the quality of nursing care for children with complex and integrated care needs and significant gaps in understanding and addressing their specific healthcare needs. Ireland's Quality Care Metrics, primarily targets nursing processes. Process metrics are the most direct way to assess the quality of care by examining the care process itself. Moreover, process metrics can highlight problems like missed care, which can undermine patient safety. Missed care has been insufficiently addressed in children's and young people's healthcare (Lake *et al.*, 2017). To gain a holistic view of the impact of nursing there is a need to measure and link nursing structural inputs and processes with patient outcomes (Mainz *et al.*, 2023). Moreover, these metrics also need to link to patient reported outcomes and experiences such as, dignity, respect, and involvement in decision-making (Mainz *et al.*, 2023; Maben *et al.*, 2012).

3.2. Barriers to quality care measurement

Alternative measures like health-related quality of life status pose challenges due to feasibility and sensitivity to change, often requiring large-scale surveys that are difficult to implement. For example, the eight care coordination measures developed and endorsed by the National Quality Forum (2004) in the United States have seen limited implementation because they rely on parent-reported surveys, which can be resource-intensive to administer, and this data is not readily available in electronic databases. (Mangione-Smith, 2017). Developing age-appropriate quality measures is also critical, as children's and young people's experiences and perceptions of care vary widely across developmental stages. Additionally, capturing children's perceptions of quality nursing care is challenging, and few studies have explored their views (Comparcini *et al.*, 2018). Research demonstrates they have better experiences when healthcare professionals build trust, involve them in care, and use child-friendly language, which makes them more comfortable and willing to confide (Davison *et al.*, 2021). Furthermore, trust between children and nurses contributes to patient safety, feeling safe, quality care and positive interactions with the nurses (Sheehan and Fealy, 2020). Conversely, poor communication or exclusion, can make children and young people lose trust, feel fearful and disconnected. Parents have a significant influence in the care experience, either facilitating or hindering communication (Davison *et al.*, 2021). Effective communication in interactions with nurses is especially important, as children and young people often struggle with medical terminology and may feel distressed when their voices are not heard (Coynne and Kirwan, 2012). Studies highlight that nurses' ability to build relationships significantly shapes children's perceptions of care, with factors such as communication style, competence, kindness, safety, and empathy playing vital roles (Comparcini *et al.*, 2018; Brady, 2009). This demonstrates the importance of relationship-building as a core competency in caring for children and young people and the need to consider when developing indicators for this population (Lambert *et al.*, 2021). Despite these insights, children's and young people's experiences are largely absent from Ireland's National Patient Care Experience Programme, revealing a significant gap in understanding the quality of care from their perspective.

3.3. Outcomes of care

A robust evidence base is essential for developing meaningful quality measures, yet significant gaps exist in evidence-based nursing practices focused on outcomes for children and young people (Connor *et al.*, 2023). Mangione-Smith (2017) suggested in paediatric medicine, a reliance on process measures that often lack validation as indicators of long-term outcomes. This reliance may be due the

health outcomes typically measured by doctors, such as hospital readmissions, emergency department visits, and child mortality, occur relatively infrequently and may not provide a comprehensive view of care quality. Health outcomes are the measurable changes in health status, physical, mental, and social well-being, resulting from healthcare interventions (World Health Organization, 2020). Developing reliable outcome measures for children and young people with complex and integrated care needs poses distinct challenges. The wide variation in developmental stages, medical conditions, and the significant role families play in care introduces complexities that make it difficult to create standardised, universally applicable measures (Schnerberk *et al.*, 2022). These factors complicate the ability to accurately measure nursing impact and patient progress, demonstrating the need for more nuanced, age-appropriate, and family-inclusive outcome measures. There has been some progress in developing broad outcome domains for children and young peoples with complex and integrated care needs. For example, Barnert *et al.* (2019), identified broad population outcome domains for children and young people with medical complexity, including child health and well-being, adaptive functioning, family well-being, healthcare use, and healthcare quality. Another example, Algurén *et al.* (2021), developed a consensus-based standard set of paediatric patient-centred outcome measures, incorporated into the International Consortium for Health Outcomes Measurement dataset. These measures, applicable to all children and young people from birth to age twenty-four, irrespective of health condition, include physical ability, sleep, pain, mental health, coping, quality of life, and school attendance. This foundational work provides a starting point for identifying how nursing can impact these outcomes and support the development of nursing-sensitive indicators specifically tailored to children and young people with complex and integrated care needs

4. Nursing-sensitive indicators

Nursing-sensitive indicators are specific cues or data used to evaluate the quality of nursing care, reflecting the structures, processes, and outcomes influenced by nursing (Sullivan *et al.*, 2023; Oner *et al.*, 2021). These indicators measure changes in health status directly affected by nursing care, although their impact may also be influenced by other factors within the healthcare system (Oner *et al.*, 2021). Establishing robust nursing-sensitive indicators for children and young people with complex and integrated care needs will enhance care delivery and demonstrate the vital role that nursing plays in supporting their health and well-being. Furthermore, they support benchmarking, cost-effectiveness analysis, and quality improvement initiatives (Kieft *et al.*, 2018; Dubois *et al.*, 2017; Burston *et al.*, 2014). Standardised nursing-sensitive indicators also support external accountability, optimise resource use, and evaluate healthcare reforms like Ireland's Sláintecare initiative (Government of Ireland, 2023; Kieft *et al.*, 2018). Once developed, these indicators should be seamlessly integrated into clinical practice, quality improvement initiatives, and healthcare policy. This requires clear guidelines and support mechanisms to assist nurses and healthcare professionals in their effective use. However, the development of nursing-sensitive indicators for children and young people with complex and integrated care is challenging and requires careful consideration.

4.1. Challenges in the concept of nursing-sensitive indicators

Despite numerous efforts to clarify the concept of nursing-sensitive indicators since the 1990s, a universally accepted definition remains elusive (Afaneh, Abu-Moghli, and Ahmad, 2021; Kieft *et al.*, 2018; Heslop and Liu, 2014; Maas *et al.*, 1996). This lack of consensus exists even with extensive international research, with the nursing community still debating what components should be measured and how these indicators should be defined (Amatt *et al.*, 2023; Afaneh, Abu-Moghli, and Ahmad, 2021; Oner *et al.*, 2021; Steel *et al.*, 2021). Despite the evident need, progress in measuring nursing has been limited, as there is no universally accepted set of indicators, and the use of nursing-sensitive indicators in practice is inconsistent (Gormley, Connolly, and Ryder, 2024). To advance effective measurement systems Kieft *et al.* (2018) stress that consistent and clear terminology is essential for effective monitoring systems. Without it, the validity of conclusions drawn from indicator sets can be compromised, leading to inaccurate assessments. Another complication in defining nursing-sensitive indicators is the interchangeable use of various terms. For instance, the terms "nurse-sensitive" and "nursing-sensitive" are often used interchangeably, but they have subtle differences (Gormley, Connolly, and Ryder, 2024). "Nurse-sensitive" focuses on outcomes directly influenced by individual nurses' actions, highlighting the impact of nursing care on patient outcomes. In contrast, "nursing-sensitive" includes all aspects of nursing care, including practices and systems that affect patient outcomes, demonstrating the broader influence of nursing as a profession. The term "nursing-sensitive outcome" is also often used interchangeably with "indicator" in the literature (e.g., Amatt *et al.*, 2023). Doran (2003) defines these as outcomes influenced by nursing scope and practice, with evidence linking nursing inputs to patient outcomes. Afaneh, Abu-Moghli, and Ahmad, (2021) advocate for the broader term, nursing-sensitive indicators, to include all aspects of nursing contributions and is adopted in this paper. Several authors have highlighted the absence of definitions across studies documenting the development of nursing-sensitive indicators (Gormely, Connolly and Ryder, 2024; Heslop and Liu 2014). The methodological quality of nursing-sensitive indicators has been questioned (Kieft *et al.*, 2018). Furthermore, a disconnect exists between their conceptual definitions and their methodological development and implementation, which diminishes their effectiveness in practice (Kieft *et al.*, 2018). Many indicators lack robust scientific evidence to support their validity and reliability, with insufficient data on key variables, selection criteria, and indicator levels (Kieft *et al.*, 2018). Moreover, some studies lack a conceptual framework to inform their investigations into nursing-sensitive indicators, resulting in inconsistencies in their application and interpretation. (Gormely, Connolly and Ryder, 2024; Afaneh, Abu-Moghli, and Ahmad, 2021). Additionally, nursing sensitive indicators are categorised at multiple levels within the healthcare system, which contributes to the existing lack of clarity. At the clinical level, they focus on individual patient care and outcomes. At the unit or ward level, they assess the performance of specific hospital units, such as emergency departments (e.g. Borg *et al.*, 2023). At the hospital level, they provide a broader view of performance across the institution (e.g. Oner *et al.*, 2021). At the system

level, they evaluate performance across multiple hospitals or healthcare facilities both nationally and internationally (e.g. Sullivan et al., 2023). A further challenge lies in the lack of consensus on the methodologies used to identify these indicators. Various methods are employed to develop nursing-sensitive indicators, reflecting the diverse approaches researchers take. For example, many studies use the Delphi method to achieve expert consensus, as seen in the work of Sullivan et al. (2023). Others rely on systematic or integrative reviews, as demonstrated by Oner et al. (2021). Additionally, clinical or administrative databases have been used to identify relevant indicators, as evidenced by studies like Mainz et al. (2023). These varied methodologies highlight the ongoing efforts to enhance the understanding and measurement of nursing-sensitive indicators.

4.2. Nursing-sensitive indicators in children and young people's nursing

Only a limited number of studies have specifically addressed nursing-sensitive indicators for children and young people. For example, Sullivan et al. (2023) identified a preliminary global core set of nursing-sensitive indicators and constructs for paediatric oncology. Their findings highlighted broader constructs relevant to all areas of nursing for children and young people, such as patient and family education, suggesting the absence of a comprehensive set of indicators for this population. Illustrating the variance in terminology previously mentioned, Amatt et al. (2023) conducted a systematic review to identify nurse-sensitive outcomes in acute paediatric nursing contexts. They identified fifty-seven nurse-sensitive outcomes, the majority categorised as outcomes, including patient/family experience, medication errors, and pressure ulcers. Notably, family-centred care appeared among the process attributes, while structural attributes were the least represented. The review, however, included only fourteen studies, many reporting minimal attributes across structures, processes, and outcomes. In developing the Quality Care Metrics for Acute Children's Services in Ireland, Brenner et al. (2019) conducted a two-round Delphi study and a consensus workshop with a diverse group of stakeholders. This process resulted in the development of eight process metrics and sixty-seven associated indicators for children's and young people's nursing in acute services only. The study stressed the need for metrics addressing care in the community and the growing number of children and young peoples with life-limiting conditions. Sakagami, Nakayama, and Konishi (2022) developed home-visit nursing quality indicators for medically complex children in Japan, applying Donabedian's (1988) model. The model was developed following a forty-two-item scale and a survey distributed to home-visiting agencies. Though limited by its small sample size, the study identified thirty-five indicators, focusing on safe care protocols, interprofessional collaboration, and outcomes related to family caregiving skills and stable home environments. Despite these studies nursing-sensitive indicators for care of children and young people remain underdeveloped, and insights from adult care often lack relevance for younger populations (Amatt et al., 2023). Developing nursing-sensitive indicators for the care of children and young people with complex and integrated care needs requires a solid framework that clearly demonstrates how nursing contributes to quality care (Schang, Blotenberg, and Boywitt, 2021).

5. Conceptual frameworks

The use of conceptual frameworks is essential in defining and categorising quality measures and nursing-sensitive indicators. Frameworks give structure to abstract concepts and help organise complex phenomena (Meleis, 2017). One of the foundational models in quality measurement is Donabedian's (1988) structure-process-outcome framework (1988), which categorises healthcare quality into three interconnected domains: structure (physical and organisational elements), process (care services and interventions), and outcomes (patient results). This model has been pivotal in nursing research, guiding the examination of how care structures and processes influence patient outcomes (Amatt et al., 2023; Oner et al., 2021). While Donabedian's framework provides a strategic approach to categorising quality measures, relying exclusively on this linear model can limit the development of more nuanced and context-specific indicators (Schang, Blotenberg, and Boywitt, 2021). These authors highlight several threats to the content validity of indicator sets, including the omission of relevant indicators, the overrepresentation of certain measures, and the inclusion of irrelevant ones. To address these limitations, alternative and expanded frameworks have emerged in nursing, offering a more comprehensive view. These frameworks integrate not only broad principles of care but also specific fields of nursing practice and diverse clinical contexts.

The Nursing Care Performance Framework developed by Dubois et al. (2013) is based on Donabedian's (1988) framework. It also incorporates elements of systems theory and the Structure of Social Action Theory (Parsons, 1960). This framework provides a comprehensive view of nursing care performance across a series of interconnected subsystems, broken down into fourteen dimensions, including acquiring, deploying, and maintaining resources, transforming resources into services, and producing changes in the patient's condition. In subsequent research, Dubois et al. (2017) identified a subset of twelve cross-cutting indicators that demonstrate adaptability across specialties and care contexts, including home care. Similarly, Sim et al. (2018) developed a comprehensive framework building on Donabedian's (1988) framework that includes diverse constructs reflecting a holistic perspective of nursing practice. This framework highlights the importance of patient and organisational characteristics, workload, safety, and collaboration in understanding nursing outcomes. The co-development of this outcome's framework with input from both nurses and patients demonstrates the necessity of incorporating multiple perspectives into the design of nursing-sensitive indicators. Expanding on this work, the lead author contributed to the development of the Australian Nursing Outcomes Collaborative data registry, which includes structural and safety indicators as well as patient-reported outcomes (Sim et al., 2019). In adult acute general care settings, Oner et al. (2021) developed a comprehensive framework that integrates Donabedian's (1988) framework with other established frameworks, including those from the National Quality Forum (2004) and the American Nurses Association (1995). This integration exemplifies a setting-specific framework, as it tailors quality measurement and evaluation methods to the unique characteristics and needs of adult acute care environments. Using this multi-dimensional approach, Oner et al. (2021) categorises nursing-sensitive indicators into four

groups: organisational-focused structural indicators, nursing-focused process/intervention indicators, nurse-focused outcome indicators, and patient-focused outcome indicators. This reinforces the need for frameworks that not only focus on nursing care but also incorporate broader organisational factors.

In the context of children's and young people's acute care nursing, [Amatt et al. \(2023\)](#) applied [Donabedian's \(1988\)](#) model in a study to develop nursing-sensitive indicators for children's acute care. Drawing on [Heslop and Liu's \(2014\)](#) seminal concept analysis, which used both [Donabedian's \(1988\) framework and Holzemer's \(1994\) outcomes model](#). The inclusion of [Holzemer's \(1994\) model](#) allows for consideration of the relationships between the patient, nursing care, and the healthcare environment. An example of a framework for a specific clinical context is [Sullivan et al.'s \(2023\)](#) study in paediatric oncology. This international study employed a dual-framework approach, combining [Donabedian's \(1988\) framework](#) with the Compassionate Collaborative Care Model ([Pfaff and Markaki, 2017](#)). This combined model enhances [Donabedian's \(1988\) framework](#) by integrating dimensions of compassion, empathy, teamwork, and communication, highlighting the importance of interprofessional collaboration and individualised care in improving outcomes. Such models demonstrate the potential to incorporate both traditional quality measures and more distinctive elements of care into the evaluation of nursing care. While various frameworks have been used to categorise nursing-sensitive indicators, developing indicators for children and young people with complex and integrated care needs requires a more nuanced understanding of children's and young people's nursing.

Identifying a nursing model with broad constructs that can be integrated with [Donabedian's \(1988\) framework](#) is essential for addressing the unique needs of children and young people with complex and integrated care needs. Additionally, a robust conceptual model that encompasses key aspects of children's and young people's nursing is crucial when developing specific nursing-sensitive indicators, ensuring a meaningful link between nursing actions and patient outcomes. Using nursing theory in this process helps clarify the unique contributions of nursing and provides a structured approach to understanding its impact on patient care. Additionally, grounding nursing-sensitive indicators in theory and evidence ensures they reflect the core values of children and young people's nursing, ([McDowell et al., 2023](#)). However, the fundamentals of children's and young people's nursing, as described by [Clark, Glasper, and Richardson \(2017\)](#), are difficult to measure. These include prioritising the best interests of the child, upholding their rights as outlined in the Convention on the Rights of the Child ([United Nations Human Rights Office of the High Commissioner, 1989](#)), and focusing on advocacy and participation in care. Quantifying how nurses help children and young people reach their full health potential through health promotion at all levels is also challenging. Respectful communication, child and family-centred care, and the complexities of safeguarding are central but difficult to measure. Every interaction is an opportunity to enhance the health knowledge of both the child and their family, yet capturing this in measurable terms remains elusive. The absence of a universally agreed-upon, well-defined conceptual model in this field hinders the accurate measurement of nursing's contributions, making it challenging for children's and young people's nursing to differentiate itself from other areas of nursing ([McDowell et al., 2023](#)). While child-centred and family-centred care, grounded in child attachment theories, are often linked to this field, they inform practice rather than forming a complete theoretical framework ([Carter et al., 2024](#)). Additionally, research on the experiences of children, young people, and families with these care approaches remains limited. One exception is [O'Connor \(2023\)](#), who advocates for developing evidence-based, nursing-sensitive quality care metrics in Ireland to assess the application of child- and family-centred principles in the nursing care of hospitalised children and their parents. Proposed metrics include communication, negotiation, and care planning based on child- and family-centred care. Historically, nursing theories have shaped the practice of children's and young people's nursing. Casey's Model of Nursing, developed in the 1980s, influenced the partnership approach to care, focusing on the relationships between the child, family, health, environment, and nurse ([Casey, 1988](#)). Building on this, the Nottingham Model offered a more holistic approach, emphasising interdisciplinary collaboration ([Smith, 1995](#)). Over the decades, research has evolved the concept of partnership into family-centred care and related approaches ([Carter et al., 2024](#)).

A more contemporary model is now required which incorporates advancements in children's and young people's care while recognising children's and young people's rights outlined in the [United Nations Convention on the Rights of the Child \(1989\)](#). Novel models, such as the Paediatric Nursing Excellence Model developed by [McDowell et al. \(2023\)](#), include core principles tailored to the care of children and young people. This model highlights five key domains: engagement, values, principles, care delivery, and continuous improvement, with developmentally appropriate care at its centre. One of the primary objectives in developing this model was to support the creation of national paediatric-specific quality indicators in the United States. This model reinforces the idea that nursing-sensitive indicators must capture more than just physical care; they should also incorporate elements such as patient engagement, communication, and the emotional well-being of children, young people, and their families. Another promising model for adaptation is the Fundamentals of Care Framework, a point-of-care nursing theory which has three core dimensions: the nurse-patient relationship, integration of care, and context of care ([Kitson, 2018](#)). Fundamental care refers to the actions taken by nurses to address a person's basic physical and psychosocial needs, ensuring their overall well-being. This is achieved by fostering a positive, trusting relationship with both the patient and their family or caregivers ([Kitson et al., 2023](#)). Additionally, the care environment must support the development of relationships and the integration of care needs, ensuring comprehensive and compassionate care in any healthcare setting. Ongoing efforts are dedicated to enhancing the measurement and reporting of fundamental care through nursing-sensitive indicators, with the goal of highlighting the positive impact of effective, person-centred care on patient recovery, well-being, and overall healthcare outcomes ([Mainz et al., 2023](#)). While extensively studied in adult nursing, its application in children's and young people's nursing remains underexplored. Adapting this framework could help develop indicators that reflect how well nurses meet the unique physical, emotional, and developmental needs of children and young people with complex and integrated care needs ([Mudd et al., 2020](#)). While the Paediatric Nursing Excellence Model serves as a valuable starting point, it is grounded in a North American perspective and lacks a universally applicable theoretical foundation. To ensure the effectiveness of nursing-sensitive indicators, they must be adaptable to diverse healthcare contexts, including integrated healthcare systems and home care settings. Iterative

frameworks, like the Fundamentals of Care, offer flexibility for adaptation across different cultural and healthcare environments, enhancing their global relevance. A common language and framework for measuring quality care are essential to ensure all stakeholders understand the purpose of measurement, what should be measured, and how to measure it effectively (Hargreaves et al., 2019). Without this clarity, confusion may arise regarding the intentions and applications of the nursing-sensitive indicators. Nursing conceptual models, along with Donabedian's (1988) quality model, offer valuable guidance in developing and categorising nursing-sensitive indicators. However, the ongoing lack of consensus on how to define and measure nursing's contributions presents significant challenges, hindering the development of effective and meaningful indicators.

6. Conclusion

Nursing plays a vital role in delivering child and family-centred care, significantly impacting children's and young people with complex and integrated care needs functional abilities and quality of life. For this population, the development of nursing-sensitive indicators remains critical yet underdeveloped. Despite decades of effort, a universally accepted definition of nursing-sensitive indicators has not yet emerged. Existing studies, though valuable, are fragmented and primarily focused on adult populations, limiting their relevance to younger populations. This gap impedes the ability to effectively measure, monitor, and improve nursing care quality, particularly for this vulnerable group. Key challenges include inconsistent terminology, varied methodologies, and the limited inclusion of community and home care settings. Current indicators often fail to capture the holistic, family-centred, and developmental aspects essential to children's and young people's care. To ensure high-quality care and improve outcomes for this population, it is essential to develop a comprehensive and standardised set of nursing-sensitive indicators that reflect their unique needs. As the healthcare landscape evolves, it is crucial to take strategic action now, preparing the nursing profession to meet the dynamic demands of this vulnerable population.

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