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Palliative Care in Children with Severe Neurological Impairment and Their Family: A Concept Analysis

Sheena Adu-Assiamah

Department of Nursing, St. Theresa Catholic Hospital, Ghana College of Nurses and Midwives, Accra, Ghana
Email: sheenza3@gmail.com

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Abstract

Children with neurological disability have varying symptoms that manifest in various ways which sometimes extend beyond physical effects to include psychological, social and spiritual aspects. Due to the increasing disease burden associated with severe neurological impairment in children, it has become necessary to initiate palliative care which will enable children to have improved quality of life, resilience and comfort. Early diagnosis and effective management are essential for the patient to attain optimal health and enhanced well-being. Unfortunately, confusion regarding palliative care in children with neurological disorders alongside limited research and policy developed in this area, hinders the provision of this essential service. This paper provides a detailed analysis of the concept of palliative care in connection to severe neurological disorders in paediatric populations using the Walter and Avant framework. This analysis clarifies defining attributes, antecedents, consequences and empirical referents thereby strengthening conceptual clarity for clinical practice, academic and research. This concept analysis model case exemplars to illustrate utilization of paediatric palliative care for healthcare professional to understand the needs of children and their families as they facilitate the integration of families into palliative care for children with severe neurological disorders. In conclusion, palliative care for children is not an end-of-life treatment rather a progressive, inclusive therapy that runs concurrently with specialist medical treatment as needed by the child.

Subject Areas

Nursing

Keywords

Concept Analysis, Paediatric Palliative Care, Quality of Life, Neurological

Disorders, Family Centered Care

1. Introduction

Paediatric palliative care concept is gaining greater attention globally as a critical medical discipline addressing disease burden and life limiting illness. In sub-Saharan Africa, the concept is under-utilized for varying reasons amidst high morbidity and mortality burden [1]. Some challenges associated with the initiation and use of palliative care in children include social misconception, lack of trained health care professionals, policy and implementation limitation. Concept analysis is an efficient tool for achieving clarity on complex phenomenon or idea such as paediatric palliative care and bring to bear how it can be operationalized both theoretically and practically. Concept analysis provides meaning and appropriate interpretation to complex phenomena for effective application considering its use across various disciplines. It is an "evolutionary process of addressing contemporary issues by emphasizing dynamism and interrelationship in reality" [2]. Palliative care by World Health Organization (WHO), refers to "an approach that enhances quality of life of patients and their families dealing with life threatening illness. It reduces and relieves pain by early detection, assessment and treatment plan, which can be physiological, psychological, social and spiritual" [3] [4]. WHO further defined paediatric palliative care as "providing care to the child's body, mind and spirit; this also involves providing support to the child and family members. The care starts once the illness is detected and continuous regardless of whether or not a child receives treatment directed at the disease" [5] [6]. Severe neurological disorders in children such as cerebral palsy with neurodegeneration, spinal muscular atrophy, leukodystrophies and severe epileptics encephalopathies have been observed to have chronic functional deterioration, higher symptoms burden and shortened life expectation which require palliative therapy to support both the child and family throughout the treatment trajectory. While medical technology advancement has prolonged survival in children with severe neurological impairment leading to increased life expectancy for patients, there is no guarantee for improvement in quality of life. That is why, palliative care has emerged as a crucial element of care for these children [7]. Without any doubt, the duration of palliative care as required by children with severe neurological disorders is child specific, varies by individual situation and age presentation; this makes it hard to predict. In some situations, it is limited to early years of life (for patients who had the condition since birth), others may require palliative care for longer periods, while those with late-stage presentation, receive palliative care until their death [6].

Palliative care, when started late, fails to maximize the benefits and impact the child and family would have achieved through the intervention. Patients and family face challenges in navigating the complex healthcare system to obtain quality healthcare across various therapy providers. Experiencing symptoms burden such

as pain, tiredness, seizure contributes to poor outcomes and impacts the quality of life of the child and family. Palliative care ensures that patients sufferings and treatment complexity challenges are minimized [3]. Early initiation of palliative care in the treatment process will be beneficial to the patient and family since the family is provided with the needed supportive care to see their child though healthcare, wellbeing or death. Although, there is a worldwide advocacy for healthcare institution to integrate palliative care into the paediatric treatment process at all level of care, palliative care in paediatric neurology still presents with challenges regarding its application and implementation. Variation in definition and implementation contributes to delay in referral to appropriate healthcare provider, fragmented care and not making appropriate use of existing palliative care services. This concept analysis is necessary to provide insight into the meaning of palliative care in children with severe neurological disorders and underscore its importance in promoting health, wellbeing and maintaining patient's dignity. This paper applies the walker and avant framework to conceptualize the concept of palliative care in children with severe neurological disorders.

2. Aim

This paper explains the concept of paediatric palliative care in relation to managing patient with severe neurological conditions and distinguish it from curative, hospice and end of life care.

3. Materials and Methods

This concept analysis of paediatric palliative care was conducted using the eight-step method proposed by Walker and Avant [8]. The Walker and Avant eight steps framework was selected because it provides a systematic and structured approach for clarifying concepts and identifying their defining characteristics within nursing and healthcare research. The approach facilitated an in-depth examination of paediatric palliative care, particularly in relation to children with severe neurological conditions. The eight steps were applied sequentially throughout the analysis process. The first step involved selecting paediatric palliative care as the concept of interest because of its increasing relevance in caring for children with complex and life-limiting neurological disorders. The purpose of the analysis was subsequently established to clarify the meaning, scope, and application of paediatric palliative care and to strengthen conceptual understanding for clinical practice, education, and research. Uses of the concept were then explored across nursing, medicine, psychology, social work, and public health literature to identify how paediatric palliative care has been defined and interpreted in different disciplines. Defining attributes were extracted from recurring themes identified across the literature, followed by the construction of model and related cases to illustrate the application of the concept. Antecedents and consequences associated with paediatric palliative care were then identified and synthesized. Finally, empirical referents were determined to describe observable manifestations of the concept in

clinical practice. Supporting literature was identified through a comprehensive search of electronic databases, including PubMed, CINAHL, Scopus, and Google Scholar. Search terms included combinations of keywords such as "paediatric palliative care", "pediatric palliative care", "children", "severe neurological conditions", "neurological impairment", "life-limiting illness", "quality of life", "concept analysis", and "family-centered care". Boolean operators ("AND" and "OR") were used to refine and combine search terms. Literature published in English, primarily within the last ten years, was prioritized to ensure relevance and modern-day understanding of paediatric palliative care practices. Seminal literature and foundational studies outside the specified time frame were also included where necessary to provide theoretical and conceptual context. The literature selection process involved screening titles and abstracts for relevance to the concept of palliative care in children with severe neurological conditions. Full-text articles were reviewed to assess their contribution to conceptual clarification, defining attributes, antecedents, consequences, and empirical referents. Duplicates and studies with limited relevance to the concept under investigation were excluded. The final body of literature provided the theoretical and empirical foundation for the concept analysis.

4. Selection of the Concept

As regular practice, palliative care comprises varying principles that address the coping mechanism of patients and their capability to live comfortably despite being under the impact of different medical ailments. The aim of palliative care is to ensure a holistic approach to the provision of healthcare services that ensure improvement of the quality of life for the patient as well as their family caregiver. There are numerous studies that indicate the need for understanding paediatric palliative care in recent times because of the increasing survival rate of neurologically challenged children. It has also been observed that there are many unmet healthcare needs among such populations. Addressing the stress and complications arising from the burden of severe childhood neurological disease require both multidisciplinary care and involvement of parents. Hence, healthcare services that places importance on holistic family centered approach cannot be underscored. Thus, the selection of the concept for further discussion is important.

5. Definition of Paediatric Palliative Care

The word "palliative" has its roots from the Latin language, where the word "pallium" means cloak [9]. Palliative care aims to improve the quality of life of patients in terms of functionality and reduce their suffering even if curative treatment is not possible anymore. Various organization and policies have defined paediatric palliative care. WHO remains a strong voice and advocacy organization in paediatric palliative care and maintains that paediatric and adult palliative care have differences and further emphasizes that palliative care in children starts from time

of diagnosis of the illness and continue whether or not the child receives any treatment for the illness [4] [10]. The European Association of Palliative Care (EAPC) also define paediatric palliative care as "the active and total care of the child's body, mind and spirit beginning immediately from diagnosis, continuing through death and beyond into the family's bereavement" [5] [6]. These definitions represent paediatric palliative care as holistic approach alongside curative processes provided in health facilities, homes and communities. These definitions try to project the consequence of life threatening and life limiting diseases on children and their families. Despite this, the definition sometime maybe interpreted to mean the same as hospice and end of life care. Palliative care in children differs from hospice care, end-of-life care, and curative care in its scope, timing, and goals. Paediatric palliative care is a comprehensive, family-centered approach aimed at improving the quality of life of children with serious or life-limiting conditions through the prevention and relief of physical, psychosocial, and spiritual suffering, and it can be introduced at any stage of illness alongside disease-directed treatment [11]. In contrast, hospice care is generally provided when curative treatment is no longer being pursued and the focus shifts entirely toward comfort and support during the final phase of life. End-of-life care represents a component of palliative care specifically directed toward care during the period immediately preceding death, emphasizing comfort, dignity, and preparation for death. Both approaches are holistic and family centered, addressing the medical, emotional and spiritual concerns of the whole family. The main difference however is, palliative care is given while the patient receives curative care concurrently while hospice doesn't involve curing the child [5]. For children, developmentally sensitive care depends on physical and psychological development of the child, involving the parent is of extreme importance as the child is wholly dependent on the parent [9] [12].

Definition of Palliative Care across Various Health and Social Disciplines

Paediatric palliative care in medicine emphasizes symptom management and disease process. There is greater emphasis on pain management, prognosis and decision regarding treatment options in the best interest of the child and family [13].

Paediatric palliative care from the perspectives of psychology, focuses on emotional and cognitive adaptations and issues such as anxiety, depression, grief, coping and life experience. There is greater emphasis on psychological hardiness and existential concerns [14].

In social works, paediatric palliative care emphasizes the viewpoint from socio-context and system approach. It addresses issues like family relationship, financial challenges, caregiving burden and access to equitable healthcare [15]. Social workers facilitate advanced care planning and resource integration for better quality care.

Spiritual and religious services for paediatric palliative care, address making

meaning of life, faith, religion and existence issues [16]. Religious organizations are instrumental in exploring concerns on meaning of life, suffering, hope and belief about death. Such care involves a spiritual leader who ensures that there is dignity in the experience of the patient and end-of-life care when cure is no longer available.

Within the discipline of public health, paediatric palliative care concentrates on the issues of availability of palliative care within the community and policy matters pertaining to the implementation of paediatric palliative care in health care systems together with the early introduction and community-based care [17].

Within the discipline of bioethics, paediatric palliative care centers around decision making and morals that ensure patients safety. It is concerned with problems related to ethical decision-making regarding issues of autonomy, beneficence, non-maleficence and decision related to sustaining life [16].

6. Understanding Palliative Care Nursing

Palliative care nursing encompasses holistic and consistent bedside, home and community-based care services. Comfort, dignity, advocacy and education for the patients and their families are the core elements of nursing. Nursing plays an essential role in coordination and emotional supports of patients [18]. In nursing, palliative care is viewed as a rational and empathetic practice that embraces compassion in the delivery of healthcare service.

The national conference on classification of nursing disorders has formulated numerous nursing diagnosis toward palliative care and symptoms management. These nursing diagnoses focuses on improving patients' quality of life through effective management of symptoms including pain, dyspnoea, nausea, etc.; alongside psychosocial support and family-centered services. Due to holistic nature of care provided in paediatric palliative services, there are multiple taxonomies on NANDA-1 that are related to palliative care. This taxonomy domains related to palliative care includes domain 4 (activity/rest), domain 12 (comfort) and domain 10 (coping/stress tolerance). Such domain work together to help to attain the aim of holistic care. Other nursing diagnosis such as acute/chronic pain, fear/death anxiety, impaired comfort, fatigue, anticipatory grieving and family coping compromised addresses different needs physically, emotionally and spiritually [19].

Use of the Concept in Nursing Care

Children with severe neurological disorders receive palliative care in many contexts within the delivery of health services. These include:

Clinical practice: the term palliative care is now increasingly used in paediatric neurology as a holistic and multidimensional approach, not only during the end-of-life phase of the disease but throughout the course of the disease. It ensures that these children have access to specialized health care to relieve stress and improve the quality of life of the patients and their relatives. Paediatric palliative care is delivered by a multidisciplinary healthcare team comprising nurses, physicians, social workers, clergy, among others [20].

Education: integration of palliative care curriculum in the training of nursing practitioners is a pragmatic medium to enhance the knowledge on the principles of palliative care in nursing. This will create the opportunity for nurses to gain knowledge about the concept and integrate it in the practice from the initial stage of care delivery [21].

Research: assessment of the quality of life, symptom burden and how it affects the patients, their families and professional healthcare provide can go a long way in assessing the impact of treatment process and hence providing an avenue for appropriate action to ensure that children, their families and healthcare providers are adequately supported against compassion fatigue and burnout [21] [22].

Policy: although palliative care may not be a new concept, there is little knowledge of its integration in the management of children with severe neurological illness [20] [23]. Most often, health facilities lack proper policies and protocols to guide implementation of paediatric palliative care interventions for this population. Countries should put in place national paediatric palliative care policies and protocols to support its implementation across all level of care.

7. Defining Attributes

Attributes are essential features consistently ascribed to a concept. Concept is situational in nature to its domains and has undeniable features and characteristics which are typically associated with it [8]. An integrative and holistic approach aimed at alleviating pain and suffering in children with neurological impairment is the hallmark of paediatric palliative care. It is an all-encompassing approach stated early in the diagnostic phase and sustained throughout the entire process of the treatment to facilitate health, wellness and quality of life of both child and family. The attributes of paediatric palliative care for children with severe neurological disorders include: 1) Co-initiation in synchronously with disease-oriented therapy; 2) A holistic approach targeting physio-psychosocial and spiritual well-being of the patient; 3) A family focused developmental approach; 4) Symptoms assessment and management; 5) Multidisciplinary teamwork; 6) Evidence based decision making regarding medical and ethical consideration; 7) Consistency in care provision throughout various levels of healthcare and disease progression. These attributes distinguish paediatric palliative care from acute, curative or purely end of life care.

8. Scenario for Case Analysis

A six-year-old child demonstrated coordination and gait abnormalities present to the clinic. Child was born at full term via normal vaginal delivery and had normal birth weight. He was noted to have a history of mild cognitive and speech delay but met all motor developmental milestones on time. Current symptoms were recognized when child was 2 years old; however, his parents were reluctant to consult a specialist until they notice the symptoms became progressively worsen. Child is now unable to walking and falls frequently while siting. He is unable to

perform typical play activities for his age. His handwriting has become tremulous. Recently, he was admitted to the hospital twice due to pneumonia caused by aspiration. Family history revealed no case of neurological disease. General Physical examination findings are unremarkable. Neurological examination: mental status-alert and cooperative. Speech—bubbling with dysarthria. Cranial nerve—pupil are equal, round and relative to light, dilated blood vessels on the sclera. Smooth pursuit gaze is difficult. Facial symmetric is present. His tongue is midline, without fasciculations. Motor—generalized hypotonia and reduced strength in all extremities 3/5. Coordination-there is significant dysmetria on finger to nose testing bilaterally. Sensory-normal light touch, temperature, vibration and proprioception. Gaits-there is truncal ataxia while sitting. He has severe ataxic gait and cannot walk without assistance. Reflexes-1+ throughout planter flexor responses. Brain MRI-mild atrophy of the cerebellar and vermis. Child is diagnosed with ataxia telangiectasia. Since ataxia telangiectasia is a progressive childhood debilitating disorder which led to dysfunction and profound disability in the affected children, the child and parents were referred to a multidisciplinary paediatric neurology team with palliative care service. Most children with ataxia telangiectasia are wheelchair bound and dependent on family by age 12 years for activities of daily living. The family is uncertain about the treatment trajectory and possible health intervention available to support their child.

8.1. Case Model

A six-year-old child from a family of five who has a disease of ataxia telangiectasia is under the care of a paediatric neurology specialist with a paediatric palliative team. Since the time of diagnosis, the care of this child has been managed by the entire team for his medical needs with the palliative group addressing problems such as pains, trouble eating, family anxiety and home care services. The parents and siblings of this child received psychosocial care while spiritual care is given based on their belief system. The child and family have frequent meetings with healthcare providers concerning decision making regarding his care. This model case demonstrates the defining attributes of paediatric palliative care by illustrating a holistic and interdisciplinary approach to care that addresses the child's physical, emotional, social, and spiritual needs. The active involvement of the family in care planning and decision-making further reflects the family-centered nature of paediatric palliative care. In addition, the emphasis on symptom relief, continuity of support, and quality of life throughout the illness trajectory operationalizes the core characteristics of the concept.

8.2. Borderline Care Case

A six-year-old child who belongs to a family of five. The child is diagnosed with ataxia telangiectasia is under the care of paediatric neurology specialist. Since the time of diagnosis, the care focuses on managing pain and muscular dysfunction. The parents and siblings of this child were not involved in decision making concerning their child's treatment. The child and family sometimes meet with

healthcare providers concerning decision making regarding his care. In this case, apart from the provision of symptoms control through pain management and muscle function, there was no psychosocial intervention involved. This borderline case demonstrates only a partial representation of paediatric palliative care because some defining attributes are present while others are absent. Symptom management and medical support may be evident; however, the limited integration of psychosocial, spiritual, and family-centered components weakens the comprehensiveness of care. The absence of fully coordinated interdisciplinary involvement indicates that the concept has been partially operationalized.

8.3. Contrary Case

A six-year-old child from a family of five is being managed for ataxia telangiectasia. Since the time of diagnosis, the care is focused on aggressive therapy. The child and family occasionally receive information from the medical team on the child's progress. The parents and child do not receive any psychosocial or spiritual support. The family is not involved in the planning of care for the child. This contrary case lacks the essential defining attributes of paediatric palliative care and therefore does not represent the concept. The focus remains solely on disease treatment and clinical interventions without consideration of holistic support, quality of life, family participation, or multidimensional care needs. The absence of interdisciplinary collaboration and compassionate family-centered care clearly distinguishes this scenario from paediatric palliative care practice.

9. Antecedent

The antecedent of palliative care has its foundation deeply-rooted in the accent act of providing care to terminally individuals. Antecedent refers to events that happen before the occurrence of a situation. The basic principles of palliative care involved offering comprehensive, coordinated whole-person care to the patient and their family members [24]. These principles have made health practitioners dedicated to enhancing palliative and end of life care services, as well as attending to the various needs of both the patient and their family members. Nevertheless, the practice has changed over time to include not only dying individuals but also those with life-limiting conditions [11]. A major distinctive practice of paediatric palliative care involves patient family centered care. Patient-family centered is a major focus of paediatric palliative care because both the patients and their families are supposed to participate actively throughout the process and exhibit their dedication in ensuring the wellbeing and quality life for the child. If there is sufficient psychosocial support, the patient can enjoy a high quality of life. Moreover, palliative care for children accents mutual obligation among family members and healthcare professionals safeguarding mutual respect and commitment towards care plan implementation [25]. The teamwork of all stakeholders sets up the stage for early recognition of disease burden, diseases deterioration and impairment in function, which will fast track comprehensive care and support in order to cope with stress within the child's family environment.

10. Consequences

Consequence pertaining to the use of paediatric palliative care for a severely impaired child with neurological disorders include a broad spectrum of multidimensional implications, including clinical, psychological, ethical and systemic health care [20].

Child focused (clinical consequences)

The most important consequences of paediatric palliative care for a child with severe neurological impairments is the ability to manage distress symptoms including pain, convulsion, spasticity, eating difficulties and breathing problems. Numerous studies confirm that symptoms control is an essential focus for a child with severe neurological conditions [26]. Through paediatric palliative care, suffering maybe alleviated and the child experiences less physical discomfort, get better sleep, improve feeding and psychological wellbeing which improves the quality of care rendered and overall quality of life of the child. Care becomes proactive rather than reactive to crisis [23]. Paediatric palliative care prioritizes quality of life instead of curing a disease [26]. However, the strength of this evidence varies across different culture and environment thus findings should be interpreted within the context of limited paediatric-specific research and diversity of study populations.

Effects on psychological status (of child and family)

The families of children with neurological disorders lives in constant fear of permanent disability, loss and uncertainty. Paediatric palliative care helps families to cope better in terms of counselling and bereavement preparations which lead to addressing family concerns and coping [26]. The family gains more confidence in taking care of the sick child. There is also evidence of reduced anxiety among families due to continuous assistance from professional caregivers. Families have an active role in treatment decision and planning of care that correspond with the family needs, values and beliefs leading to family empowerment [23] [26].

Effect on social levels

The family caregivers burden decreases significantly through paediatric palliative care as it offers respite services. However, complicated care and prolonged illness can still affect family caregivers' well-being and increase their chance of compassion fatigue. Therefore, while, paediatric palliative care alleviates some burden, it cannot solve all challenges related to it [22] [26].

Health systems and economic effects

Paediatric palliative care helps decrease cost for the health system along with improving patient outcomes. Varied literature reported decreased hospitalization rate among patients and fewer number of days spent in hospital. This becomes particularly significant when the long-term impact of severe neurological disorders and its treatment plan in developing children is critically analyzed [27].

Ethical consequences

The provision of paediatric palliative care promotes ethical decision making and patient/family autonomy. The rate of futile interventions and emotional dis-

tress is minimized or prevented. The family has a robust support system that provided detailed information to the family to make informed decisions and choices for the child. Based on child's level of development, their input is considered in treatment and support plans. Nevertheless, families may face challenges in making decision and may feel that the treatment involves giving up hope for their child's survival [28] [29].

Developmental and long-term consequences

Unlike other ailments necessitating paediatric palliative care, neurological disorder usually affects the child at an early age and continue for many years. Provision of paediatric palliative care in childhood neurological disorders ensures appropriate growth and development of the child within his or her limits and planning for the transition care into adulthood if the child survives [20]. Children have better quality of life and less medically-oriented life, enabling age-appropriate developmental experience.

Consequence for healthcare providers

Effective communication between parents and healthcare professionals is promoted. The child receives comprehensive care and healthcare professional enjoys professional fulfillment. However, healthcare professionals may suffer compassion fatigue and emotional exhaustion due to the prolong intimate contact with the families [30].

Paediatric palliative care with all its strengths faces challenges due to lack of personnel adequately trained in providing the service; escalating medical cost, stressful experience of families navigating cumbersome healthcare space to obtain this specialist care, policy challenges in implementing and sustaining palliative care services for children with neurological disorders among others. There are reports of cultural and religious misconceptions about palliative care which further discourages families from effectively utilizing the services [30] [31].

11. Empirical Referents

Empirical referent represents tangible criteria which shows the presence and utilization of the construct being discussed. These are observable entities that affirm the existence of delivery of palliative care in children, often reflecting fundamental attributes such as holistic treatment, inter-professionalism and family-oriented. Empirical referent of paediatric palliative care in the case of children with severe neurological disability includes observable elements of holistic, continues and orchestrated practice level. The implementation of palliative care in the treatment of such children has revealed consistent attention to quality of life, comfort and involvement of families throughout their treatment journey [23]. The empirical referents of paediatric palliative care can be operationalized through specific observable and measurable indicators that demonstrate the presence and implementation of the concept in clinical practice. These indicators provide practical evidence that the defining attributes of paediatric palliative care are being translated into care delivery.

In terms of clinical manifestations, the delivery of paediatric palliative care can be viewed as proactive and persistent management of complex symptoms of severe neurological conditions. Documented symptom assessment and management serve as key empirical referent. This reflects in routine assessment and recording of symptoms such as pain, seizures, respiratory distress, feeding difficulties, spasticity, sleep disturbances and other sources of discomfort. Evidence of individualized symptom management plans and ongoing evaluation of symptom burden similarly demonstrates active efforts to relieve suffering and enhance comfort [26]. The presence of structured care services and anticipatory guidance addressing these symptoms shows how paediatric palliative care concepts are implemented. Overtime, this translates into better physiological stability and increased functionality for the patient [23].

Other than physiological care, empirical evidence for paediatric palliative care can be seen in the incorporation of psychosocial and emotional support into everyday care. Early and continuous inclusion of family exists in the management of children with severe neurological disabilities. Neurologically impaired children often exhibit communication disorders such that any sign of distress will require effective multidisciplinary involvement as they cannot easily express their needs [20]. Psychological counselling to the child and family members, along with efforts to provide comfort, encourage therapeutic interaction and create meaning representing the overall effort to prioritize quality of life to alleviate suffering and distressing factors, not just symptoms [24] [29].

Another empirical evidence involves the working relationship between healthcare professionals in ensuring interdisciplinary approach to care in which different professionals offer unique but integrated skills when caring for the child. Collaboration among medical personnels, nurses, rehabilitation therapist, psychosocial practitioners and spiritual counsellors represent the practical application of the philosophy [20] [26] [30].

Family participation in care planning and decision-making represents another important empirical referent. Families do not simply receive information but actively participate in the care process. Active and honest communication about care, prognosis and preferences demonstrate family centered care. This may be observed through documented family meetings, shared goal-setting discussions, parental involvement in treatment decisions, and records of advance care planning conversations. The active inclusion of parents and caregivers reflects the family-centered nature of paediatric palliative care. It boosts parents' confidence, minimizes decision conflicts and enhances the partnership with healthcare professionals [20].

Multidisciplinary review and collaborative care processes provide evidence of interdisciplinary practice, especially from hospital to home [27] [30]. Neurological illness in children needs long term support, commitment and guidance. Continuity and coordination of care across hospital and home settings also function as important empirical referents. This resolves any fragmented care and abandon-

ment of the child by the family or healthcare providers. The existence of clear care protocols, continuity of care and community services signifies a proven practice that goes beyond hospital walls. Observable evidence includes discharge planning records, home-care referrals, community follow-up arrangements, continuity of treatment plans across settings, and regular communication between hospital and community care providers. With advancing illness, paediatric palliative care gains further significance in the type of end-of-life care offered. It entails moving away from harmful procedure to care aimed at ensuring the dignity of the patient and the wishes of the family. Many families may have fear of being abandoned during this challenging period.

With regards to child neurology, the notion of empirical referent can be seen as related to age-specific-developmental focused care [32]. The continuity of care for an extended period of time, the modification of care according to different stages of development and creating opportunities for interaction and comfort can be viewed as palliative services.

Additional empirical referents include documentation of goals-of-care discussions, quality-of-life assessments, advance care planning processes, spiritual care interventions, and reduced reliance on unnecessary invasive interventions when such decisions align with family preferences and the child's best interests. These elements demonstrate that quality of life is not solely defined by functional ability but by the child's capacity to experience comfort, compassion and dignity.

Collectively, these observable indicators provide measurable evidence that paediatric palliative care is being implemented in a manner consistent with its defining attributes of holistic care, family-centeredness, interdisciplinary collaboration, quality-of-life enhancement, and continuity of care (see **Figure 1**).

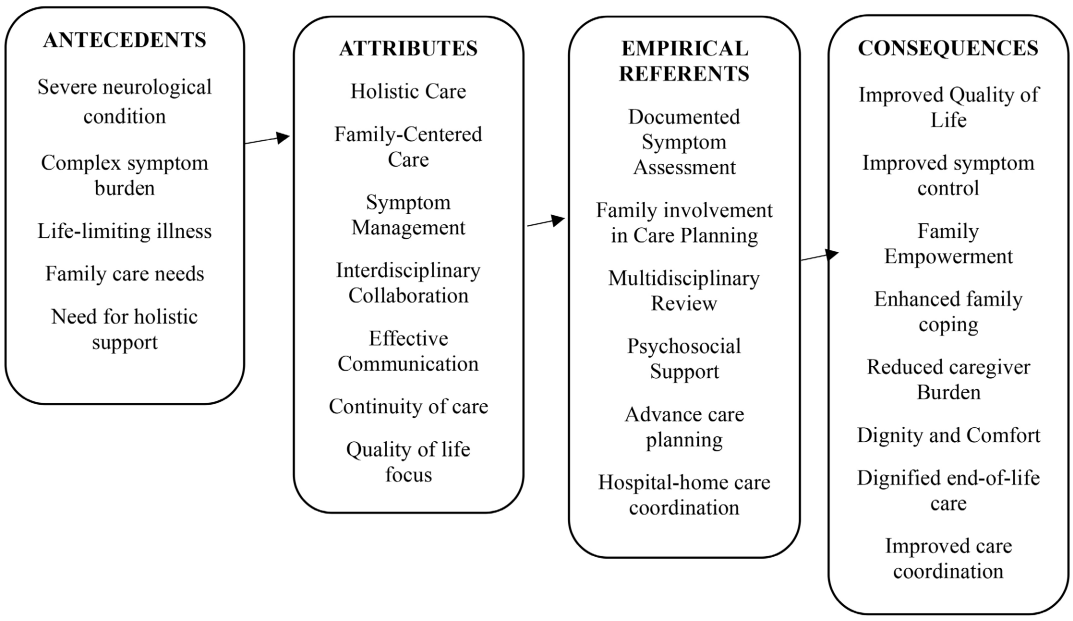

Figure 1. Diagram outlining the core component of paediatric palliative care using the Walker and Avant framework.

12. Discussion

Paediatric palliative care is an active, holistic and family centered approach to healthcare which goes beyond conventional understanding of end-of-life care. Given the prolonged disease trajectories, high symptom burden, and extensive caregiving demands associated with severe neurological conditions, paediatric palliative care appears particularly valuable in promoting continuity of care, facilitating communication, supporting decision-making and enhancing family-centered care, even when broader healthcare utilization and economic outcomes remain less certain. Within the paediatric neurology context, one of the most consistently supported focus is improved alignment of care with the complex and evolving needs of the children and families. Existing literature highlights that paediatric population with severe neurological conditions differ from other children due to the prolong nature of the illness, high level technology dependence and continual caregivers' burden. This paper has described the need for long term support, family centered approach with a multidisciplinary neuro-palliative care model that extends beyond end-of-life care and focuses on improving symptom management, quality of life of the child and caregivers' support. Apart from symptoms management, paediatric palliative care emphasizes improving the general quality of life for children who suffer from life limiting illness. Also, this paper brings forth supporting evidence to the defining attributes in the concept analysis. This review indicated children with severer neurological impairment and their family caregivers identified symptoms control, support, normalcy, security, empowerment and coping as core outcomes of paediatric palliative care, reiterating the importance of interdisciplinary nature of implementing and measuring the concept. From this evidence-based analysis, paediatric palliative care involves early initiation, interprofessional collaboration and continued intervention throughout the process of the illness using both pharmacological and non-pharmacological methods. Also, this review has described the value of specialized home-based paediatric palliative care services in ensuring continuity of care and improved disease burden management for children with neurological disorders and strong livelihood for reduced health care cost for families. The defining attributes such as holistic nursing care, effective communication and shared decision making were recurrent in the practice of paediatric palliative care. The antecedents were also important indicator for rendering paediatric palliative care, while consequences illustrated significant relief from suffering, improvement in coping among families as well as utilization of health care services. Empirical referents demonstrated real life evidence to the practice of paediatric palliative care. Paediatric palliative care promotes respect for local belief around illness and death; it involves faith leaders and support cultural norms of the family. This paper is a concept analysis thus literature was based on selected articles. The primary limitation of this concept analysis is that its findings are derived from theoretical implication and synthesis rather than primary empirical investigation. Therefore, the analysis is dependent on the scope, quality and perceptions within selected literature. Thus, alternate

interpretation may emerge from other bodies of evidence. Also, despite efforts to conduct a comprehensive review, relevant studies may have been omitted due to publication, language or database restrictions. Lastly, applying one conceptual framework across diverse neurological settings may limit its application in other settings. While identified attributes, antecedent, consequences and empirical referents provide relevant conceptual foundation, their manifestation across clinical population and service areas may differ. Future research should explore the application and contextual adaption of the concept in diverse paediatric palliative care settings.

In conclusion, paediatric palliative care implies a new way of approaching care based on compassion, ethical care delivery and coordination. Efficient delivery of paediatric palliative care is necessary in caring for children with severe neurological conditions. Paediatric neurology nurses can use the concept of paediatric palliative care for better care planning and advocacy.

13. Implication for Nursing Practice, Education and Research

Nurses in clinical areas should advocate for early referral and incorporation of paediatric palliative care services in regular neurological care for children with serious neurological conditions. Also, palliative care services should be made available in neurodevelopmental clinics for early identification of children who may require such services.

In nursing education, the curriculum should incorporate palliative care principles into all educational levels of nursing tutoring. Paediatric palliative care principles can be explored and examined to develop a conceptual framework and the development of robust outcome indicators.

14. Conclusion

Applying the Walker and Avant framework, this paper offers a well-defined comprehensive view of the concept of palliative care for children suffering from serious neurological conditions. This will facilitate uniform implementation of the concept in practice, guide further research and influence policy making to enhance the quality of care provided to such patients.

Conflicts of Interest

The author declares no conflict of interest.

References

[1] Amery, J. (2009) Cildren's Palliative Care in Africa. Oxford University Press Inc.

[2] Rodgers, B.L. (1989) Concepts, Analysis and the Development of Nursing Knowledge: The Evolutionary Cycle. *Journal of Advanced Nursing*, **14**, 330-335. https://doi.org/10.1111/j.1365-2648.1989.tb03420.x

[3] WHO (2018) Why Palliative Care Is an Essential Function of Primary Health Care.

Technical Series on Primary Healthcare, 1-20.

[4] WHO (2020) Palliative Care Fact Sheet. WHO, E1.

[5] European Association of Palliative Care (EAPC) Taskforce (2007) IMPaCCT: Standards for Paediatric Palliative Care in Europe. *European Journal of Palliative Care*, **14**, 109-114.

[6] Benini, F., Spizzichino, M., Trapanotto, M. and Ferrante, A. (2008) Pediatric Palliative Care. *Italian Journal of Pediatrics*, **34**, Article No. 4. https://doi.org/10.1186/1824-7288-34-4

[7] Akard, T.F., Hendricks-Ferguson, V.L. and Gilmer, M.J. (2019) Pediatric Palliative Care Nursing. *Annals of Palliative Medicine*, **8**, S39-S48. https://doi.org/10.21037/apm.2018.06.01

[8] Walker, A. (2014) Strategies for Theory Construction in Nursing. 5th Edition, Pearson, 198-190.

[9] Agrawal, U.S., Sarin, J. and Garg, R. (2023) Nursing Perspective of Providing Palliative Care to the Children—A Narrative Review. *Journal of Health and Allied Sciences NU*, **14**, 157-162. https://doi.org/10.1055/s-0043-1769081

[10] Fraser, L.K., Bluebond-Langner, M. and Ling, J. (2020) Advances and Challenges in European Paediatric Palliative Care. *Medical Sciences*, **8**, Article 20. https://doi.org/10.3390/medsci8020020

[11] WHO (2018) Integrating Palliative Care and Symptoms Relief into Paediatrics. WHO.

[12] Adu-Assiamah, S. (2022) Exploring Psychosocial Experiences of Parents with Children Undergoing Cancer Treatment at Korle-Bu Teaching Hospital. *Open Access Library Jounrnal*, **9**, 1-17. https://doi.org/10.4236/oalib.1108429

[13] Cherny, N.I., Radbruch, L. and Board of the European Association for Palliative Care (2009) European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care. *Palliative Medicine*, **23**, 581-593. https://doi.org/10.1177/0269216309107024

[14] Breitbart, W. (2017) Meaning-Centered Psychotherapy in Palliative Care. Oxford University Press.

[15] Parker, O., Demiris, G. and Wittenber-Lyles, E. (2012) Interdisciplinary Tema Communication in Hospice and Palliative Care. *American Journal of Hospice and Palliative Medicine*, **29**, 435-441.

[16] World Hospice Palliative Care Alliance (2020) Global Atlas of Palliative Care. 2nd Edition, WHO, 1-120.

[17] Knaul, F.M., Farmer, P.E., Krakauer, E.L., De Lima, L., Bhadelia, A., Jiang Kwete, X., *et al.* (2018) Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage: The Lancet Commission Report. *The Lancet*, **391**, 1391-1454. https://doi.org/10.1016/s0140-6736(17)32513-8

[18] Ferrell, B. and Coyle, B. (2015) Oxford Textbook of Palliative Care. 4th Edition, Oxford University Press.

[19] NANDA International, Inc. (2024) Nursing Diagnosis Definition and Classification 2024-2026. Thirteenth Edition, Thieme Medical Punlisher, 1-677.

[20] Draper, L. (2024) Pediatric Palliative Care: A Place for Hope. *Science Perspective*, **121**, 204-205.

[21] Levine, A., Winn, P.A., Fogel, A.H., Lelkes, E., McPoland, P., Agrawal, A.K., *et al.* (2023) Barriers to Pediatric Palliative Care: Trainee and Faculty Perspectives across

Two Academic Centers. *Journal of Palliative Medicine*, **26**, 1348-1356. https://doi.org/10.1089/jpm.2022.0580

[22] Aldas, S., Ersoy, M., Durukan Tosun, M., Ozgokce Ozmen, B., Tunc, A. and Sahin, S. (2025) Assessment of Caregiver Burden and Burnout in Pediatric Palliative Care: A Path toward Improving Children's Well-Being. *Healthcare*, **13**, Article 1583. https://doi.org/10.3390/healthcare13131583

[23] Braybrook, D., Coombes, L., Scott, H.M., Harðardóttir, D., Roach, A., Bariuan, J., *et al.* (2025) What Constitutes High-Quality Paediatric Palliative Care? A Qualitative Exploration of the Perspectives of Children, Young People, and Parents. *The Patient-Patient-Centered Outcomes Research*, **18**, 539-561. https://doi.org/10.1007/s40271-025-00744-8

[24] Tanaka, T.D.L., Mendes, J.D.S.A., Barreto, J.R.F., Figueiredo, J.T.R., Sotolani, B.L., Coquemala Júnior, C.N., *et al.* (2024) Palliative Care Fundamental Principles and Interdisciplinary Approaches. *Revista de Gestão Social e Ambiental*, **18**, e07174. https://doi.org/10.24857/rgsa.v18n8-146

[25] Zaider, T. and Kissane, D. (2009) The Assessment and Management of Family Distress during Palliative Care. *Current Opinion in Supportive & Palliative Care*, **3**, 67-71. https://doi.org/10.1097/spc.0b013e328325a5ab

[26] Ribbers, S., Wager, J., Hartenstein-Pinter, A., Zernikow, B. and Reuther, M. (2020) Core Outcome Domains of Pediatric Palliative Care for Children with Severe Neurological Impairment and Their Families: A Qualitative Interview Study. *Palliative Medicine*, **34**, 309-318. https://doi.org/10.1177/0269216319885818

[27] Chong, P.H., De Castro Molina, J.A., Teo, K. and Tan, W.S. (2018) Paediatric Palliative Care Improves Patient Outcomes and Reduces Healthcare Costs: Evaluation of a Home-Based Program. *BMC Palliative Care*, **17**, Article No. 11. https://doi.org/10.1186/s12904-017-0267-z

[28] Downing, J., Knaul, F.M., Kwete, X.J., Arreola-Ornelas, H., Bhakta, N., Rosa, W.E., *et al.* (2026) The Global Need for Paediatric Palliative Care: The Evolution of Serious Health-Related Suffering in Children Aged 0-19 Years from 1990 to 2023. *The Lancet Child & Adolescent Health*, **10**, 167-178. https://doi.org/10.1016/s2352-4642(25)00338-4

[29] Weaver, M.S., Mooney-Doyle, K., Kelly, K.P., Montgomery, K., Newman, A.R., Fortney, C.A., *et al.* (2019) The Benefits and Burdens of Pediatric Palliative Care and End-Of-Life Research: A Systematic Review. *Journal of Palliative Medicine*, **22**, 915-926. https://doi.org/10.1089/jpm.2018.0483

[30] Ajambo, M., Mwaka, S., Nyanzi, J.G., Nalwanga, D., Balagadde, J. and Rujumba, J. (2026) Paediatric Palliative Care Following Hospital Discharge: Prevalence and Factors Associated with Non-Continuity of Palliative Care for Children with Cancer in Busoga Sub-Region-Eastern Uganda; a Mixed Methods Study. *PLOS Global Public Health*, **6**, e0004210. https://doi.org/10.1371/journal.pgph.0004210

[31] Holder, P., Coombes, L., Chudleigh, J., Harding, R. and Fraser, L.K. (2024) Barriers and Facilitators Influencing Referral and Access to Palliative Care for Children and Young People with Life-Limiting and Life-Threatening Conditions: A Scoping Review of the Evidence. *Palliative Medicine*, **38**, 981-999. https://doi.org/10.1177/02692163241271010

[32] van Driessche, A., La Rondelle, L., Boelen, P.A., Brunetta, J., Kars, M.C., Spuij, M., *et al.* (2025) Characteristics of Child Development in the Context of Serious Illness: A Scoping Review. *BMC Palliative Care*, **24**, Article No. 113. https://doi.org/10.1186/s12904-025-01751-0