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Original Article

An Evolutionary Concept Analysis of Pediatric Hospice and Palliative Care

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Purpose: This study aimed to clarify the concept of pediatric hospice and palliative care through conceptual analysis. It also sought to identify the differences between related concepts such as pediatric death care and pediatric spiritual care, in order to provide foundational data for the development of nursing theory and knowledge. **Methods:** A conceptual analysis of pediatric hospice and palliative care was conducted using Rodgers' evolutionary method. Out of 5,013 papers identified, 28 were selected for detailed reading and analysis. **Results:** Pediatric hospice and palliative care encompasses physical, psychological, social, mental, spiritual, and family care for children with acute and chronic diseases with uncertain prognoses ahead of death, as well as their families. Effective pediatric hospice and palliative care will require multidisciplinary team nursing, effective communication, and supportive policies. **Conclusion:** The findings of this study suggest that providing pediatric hospice and palliative care will lead to improvements in pain relief for children and families, the efficiency of responses to death in children, and the quality of life for children and families. The significance of this study is that it clearly clarifies the concept by analyzing pediatric hospice and palliative care using an evolutionary method.

Key Words: Pediatric nursing, Hospices, Palliative care, Concept formation

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INTRODUCTION

Hospice care originated with the Sisters of Charity in Dublin, Ireland, in 1815. By 1877, it had evolved to include home visits for terminally ill patients. In the 1950s and 1960s, it was commonly known as "terminal care" [1]. Over time, hospice care became closely linked with palliative care, especially for cancer patients, and is now referred to as hospice and palliative care [2].

The World Health Organization defines palliative care for children and adolescents as active and comprehensive physical, psychological, and spiritual care, including support for their families [3]. Stayer [2] describes pediatric palliative nursing as alleviating physical and psychological suffering, fostering open communication with children and their families, and providing individualized and systematic nursing care from diagnosis through a multidisciplinary approach [3]. The understanding of death varies between children and adults according to developmental stages [4], and children and adolescents may express their emotions inaccurately, significantly influenced by their parents and family during treatment [5]. This suggests that pediatric hospice and palliative care should consider the growth and developmental stages of children and adolescents [1,6] and provide individualized hospice care based on the disease process [5]. Thus, pediatric hospice and palliative care involve special principles and values that are different from those for adults, making it difficult to apply adult hospice and palliative care directly to children and adolescents.

Nurses have the responsibility to care for children and adolescents facing the end of life and to ensure that they and their families are supported to end life well. However, there is a tendency to perceive pediatric hospice and palliative care as merely giving up treatment, reflecting an inaccurate understanding of the concept. Providing hospice and palliative care to pediatric patients is seen as more challenging than for adults [A7]. Additionally, nurses caring for children and adolescents report experiencing confusion about the difference between palliative care for children with terminal illnesses and curative care, as well as what constitutes the best care for children [7].

Due to the lack of a clear definition of pediatric hospice and palliative nursing, nurses may encounter difficulties in practice and communication challenges with other healthcare professionals. Therefore, this study aimed to provide a clear definition of pediatric hospice and palliative nursing through conceptual analysis.

Concept analysis provides a foundation for theory development and knowledge advancement by clarifying the complexities and ambiguities of real-world phenomena. Rodgers [8] suggested that concepts in nursing should be defined flexibly according to the era, as they are not static but continuously evolving. The concept of hospice and palliative care has undergone dynamic changes since the 1810s. It is necessary to analyze the concept of pediatric hospice and palliative care using an evolutionary approach to identify antecedent factors, attributes, and outcomes in accordance with temporal trends. Therefore, the purpose of this study was to analyze the concept of pediatric hospice and palliative care using Rodgers' evolutionary method [8], to clarify its antecedent factors and outcomes in accordance with socio-cultural contexts and temporal trends. Additionally, through concept analysis, it aimed to elucidate the attributes of the concept and identify antecedents and outcome factors, providing knowledge to nurses caring for pediatric patients. The results of this study are expected to contribute to a clearer understanding and communication of pediatric hospice and palliative care, and to establish the basis for interventions in pediatric hospice and palliative care, thereby facilitating the provision of high-quality nursing care.

METHODS

1. Study design

This study is a concept analysis aimed at identifying the attributes, antecedents, and outcomes of pediatric hospice and palliative care using Rodgers' evolutionary concept analysis method [8], which takes into account the passage of time and societal-cultural contexts.

2. Data collection and analysis process

This study analyzed the concept of pediatric hospice and palliative care based on Rodgers' evolutionary method [8]. The specific data analysis collection and analysis procedures are outlined below.

1) Determine the concept of interest.
2) Collect relevant data to elucidate the attributes and contextual basis of the concept.
3) Identify the contextual basis of the concept through data analysis.
4) Clarify the concept by analyzing alternative terms and related concepts.
5) Define the attributes and characteristics of the concept.
6) Provide model cases to enhance clarity of the concept.
7) Analyze the antecedents and outcomes of the concept.
8) Determine hypotheses and implications for concept development and practical application.

The data collection period spanned from September 26, 2022, to October 10, 2022. A literature search was conducted from 1980, when hospice care began to be introduced in earnest in the UK, to September 2022. To identify the attributes, antecedents, and outcomes of pediatric hospice and palliative care in domestic literature, the following keywords were used: "hospice," "hospice palliative," "pediatric hospice," "pediatric hospice palliative," and "end-of-life care" in Korean. These terms were searched using the Research Information Sharing Service (RISS) provided by the Korea Institute of Science and Technology Information (KISTI), the Korean Studies Information Service System (KISS), and Google Scholar. For international literature, publications in English were searched using CINAHL, Medline via PubMed, and Google Scholar, with the keywords "hospice," "palliative," "hospice care," "palliative care," "hospice palliative care nursing," and "pediatric."

After searching the literature using the provided keywords, the titles and abstracts of the papers were reviewed to select the documents for analysis. A total of 5,013 papers (1,412 in Korean and 3,601 in English) were retrieved through search engines. Among these, 2,557 duplicate papers (1,275 in Korean and 1,282 in English) were excluded (Figure 1). In the first screening phase, papers that did not match the subject (88 in Korean and 2,171 in English) or were conference proceedings (including poster presentations) and not original research (35 in Korean and 106 in English) were excluded.

A total of 56 papers selected for the second screening stage underwent review by all researchers, and the final analysis included 28 papers that utilized pediatric hospice and palliative care as a variable (Figure 1). We excluded 21 papers that did not adequately explain relevant concepts or characteristics and dealt with perinatal or neonatal palliative care. These papers were excluded because the content of care provided and the focus of practice were different from pediatric palliative care, and the clinical processes differed. Additionally, seven papers focusing on neonates and infants were excluded.

The data analysis was conducted sequentially according to the evolutionary method proposed by Rodgers. To clearly understand the concept of pediatric hospice and palliative care, the full text of each paper was thoroughly read. Then, based on Rodgers' concept analysis elements (attributes, antecedents, outcomes, alternative terms, and related concepts), the papers were classified and organized. Three researchers independently categorized the elements of concept analysis for each piece of literature and, through several discussions and agreements, derived the attributes, antecedents, and outcomes of pediatric hospice and palliative care.

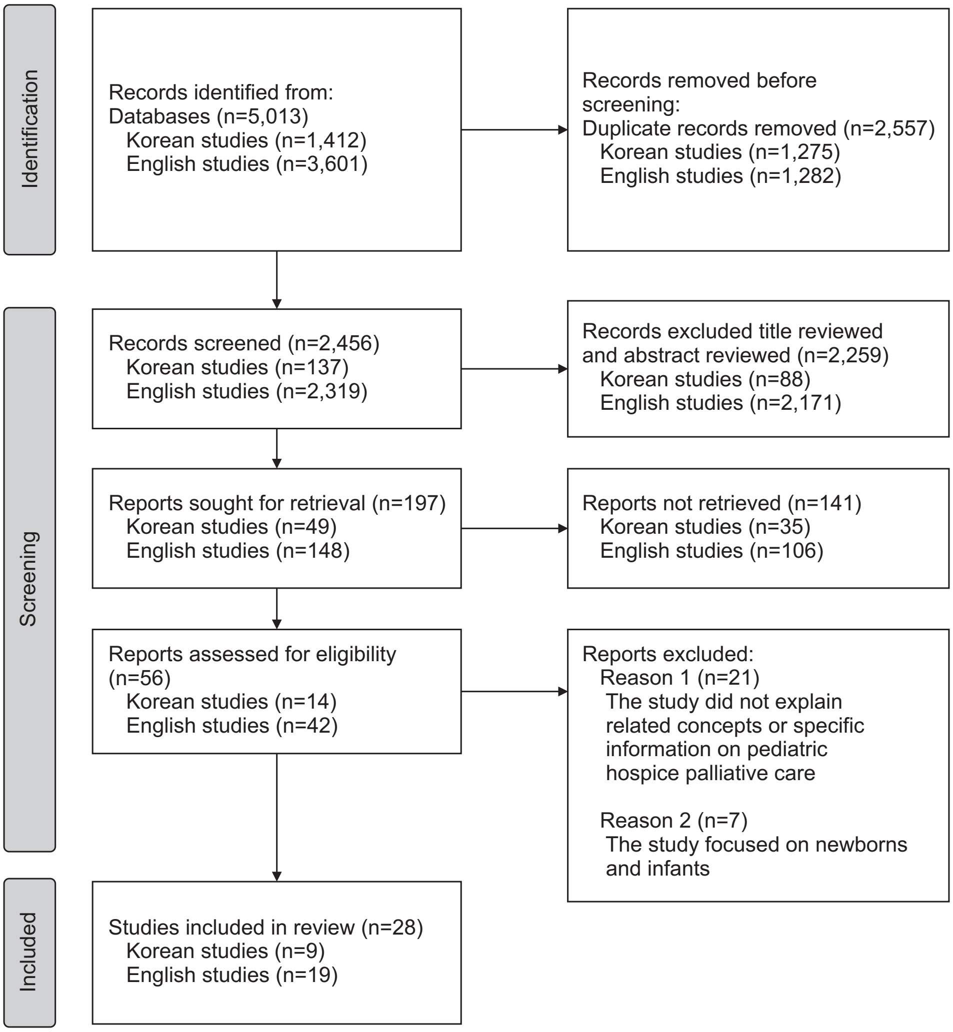

Figure 1. Prisma flowchart of pediatric hospice and palliative care.

RESULTS

In this study, we identified the concept of pediatric hospice and palliative care, collected relevant data to clarify its attributes and contextual basis, and derived the attributes, antecedents, and outcomes of pediatric hospice and palliative care through data analysis.

1. Alternative and similar terms of concepts

We clarified the concept of pediatric hospice and palliative care by analyzing alternative terms and similar terms that convey related concepts.

1) Alternative terms

Alternative terms are used interchangeably with similar or identical meanings, without altering the essence of the concept [8]. In the context of pediatric hospice and palliative care, an alternative term can be "pediatric end-of-life care." Min [9] noted that end-of-life care is often synonymous with hospice care and is commonly referred to as "end-of-life management," "end-of-life care for hospice," or "management of terminal patients". Additionally, as part of palliative care, it involves nursing care for patients and their families facing imminent death, aiming to maintain the quality of life and personal dignity of terminally ill patients, providing holistic care to meet social, psychological, physical, and spiritual needs [10]. Particularly in pediatric end-of-life care, nursing should consider individual factors based on the child's developmental stage and provide comprehensive end-of-life care that is individualized yet family-centered, as the scope of care extends to the child's family [11,12]. Furthermore, as pediatric end-of-life care includes making end-of-life decisions, managing physical symptoms like pain, and explaining negative prognoses to families [13], the concepts of pediatric end-of-life care and pediatric hospice and palliative care are similar and can be used interchangeably as alternative terms.

2) Similar concepts

In Korea, hospice and palliative care, as well as spiritual nursing, are often used interchangeably as similar concepts [A26]. Spiritual nursing involves providing active care or nurturing actions in response to the spiritual aspects inherent in humans [14]. In pediatric spiritual nursing, it is crucial to understand the spiritual needs of children and adolescents within the context of their growth and developmental processes, as these needs can significantly influence various health issues and character development [15]. While hospice and palliative care are limited to specific periods and events such as death and separation, spiritual nursing spans the entire lifespan, from birth to death, without restriction by time or specific events. Additionally, there is a fundamental difference between spiritual nursing and psychological nursing, as spiritual nursing focuses more on methodological approaches [16].

2. Attributes of the concept

Clarifying the attributes of a concept is the most crucial task in concept analysis, as it helps answer the question, "What are the characteristics of the concept?" These attributes constitute the real definition, rather than a dictionary definition [8]. Pediatric hospice and palliative care, as repeatedly manifested in the literature, encompasses the following attributes: 1) nursing care that considers the growth and development of children and adolescents; 2) nursing care that addresses the physical, psychological, social, mental, and spiritual needs of children and adolescents; 3) family-centered care, 4) care that is focused on children and adolescents facing uncertain prognoses and chronic illnesses nearing the end of life, as well as their families.

1) Nursing care that considers the growth and development of children and adolescents

Pediatric hospice and palliative care involves individualized care tailored to the growth and developmental stages of children and adolescents is necessary. Children differ from adults, and their understanding of death varies according to their developmental stages [3]. Understanding the rapidly changing physical, emotional, social, cognitive, and spiritual development of children and adolescents with life-limiting conditions is crucial when caring for them [17]. It is especially important to consider the growth and developmental stages of children and adolescents when assessing or managing a child's pain and dealing with the concept of death [A18,A26].

The understanding of illness and death varies according to the intellectual developmental level of children and adolescents. When faced with difficult-to-comprehend facts, children and adolescents can experience a range of emotions, including instability, sadness, anger, insecurity, and fear [A12]. The hospice and palliative care team should aim to understand the disease experience from the perspective of children and adolescents to better support them and their families in coping with death or terminal illness [A2]. It is necessary to use language appropriate to the growth and developmental stages of children and adolescents. Nurses should use concrete language to avoid confusion and unnecessary fear [A9] and provide individualized hospice nursing care that considers the disease process based on children and adolescents' growth and developmental stages [A18].

2) Nursing care that addresses the physical, psychological, social, mental, and spiritual needs of children and adolescents

Koo et al. [A16] emphasized the importance of managing children's uncontrollable physical pain in pediatric hospice and palliative care. Multidimensional considerations based on developmental stages and patterns of pain are necessary [A26], and age-appropriate physical nursing care should be provided [A18,A22,A27]. Additionally, psychological nursing is crucial because children and adolescents often experience emotional difficulties such as anxiety and depression [A19]. Engaging in various play therapies to alleviate sadness and sorrow [A8] and encouraging communication between parents and children about death help understand the psyche of children and adolescents [A5,A25]. Moreover, for hospitalized children and adolescents, informing teachers, peers, and friends about the characteristics of their diseases [A8], assisting them in attending school [A14], and providing social nursing considering multicultural backgrounds, financial status, and educational levels are essential [A26]. Emotional nursing for chronic sadness is also necessary [A9], and in cases of severe depression or suspected anxiety symptoms, considering antidepressant medication is advised [A19,A27]. Furthermore, facilitating meetings with clergy when children desire religious support [A15] and providing spiritual nursing to help children and adolescents understand and accept their current situation through serious discussions about death and the afterlife are important [A1].

3) Family-centered care

Pediatric hospice and palliative care aims to meet the needs of children and adolescents facing end-of-life situations, as well as their families, by providing care in life-threatening circumstances [18]. This type of care emphasizes supporting families [A19,A20,A22,A23,A27]. Maximizing family involvement is crucial for improving pediatric hospice and palliative care, where "family" includes not only immediate relatives but also extended family and community members [A25]. Pediatric hospice and palliative care should maintain ongoing partnerships with children and families, adopting a comprehensive and holistic, family-centered approach [A1,A6]. This approach can enhance quality of life, alleviate suffering, and assist in medical decision-making, representing both an art and science of care centered on children and families [A9]. The focus is on caring for the entire family, emphasizing the comfort and well-being of both children and their families [A8]. Additionally, siblings of children facing end-of-life situations also require attention and care [A8,A25]. Therefore, pediatric hospice and palliative care involves helping pediatric patients and their families make the best possible decisions regarding treatment and care [A18].

4) Care that is focused on children and adolescents facing uncertain prognoses and chronic illnesses nearing the end of life, as well as their families

Pediatric hospice and palliative care is nursing provided to children facing life-threatening situations or those with life-threatening illnesses nearing the end of life [A15,A18,A22,A25]. Yu and Bang [A28] stated that the diseases experienced by patients who receive pediatric hospice and palliative care include not only pediatric cancers but also heart diseases, congenital malformations, central nervous system disorders, degenerative diseases, neurofibromatosis, various rare diseases, and the sequelae of various accidents. Pediatric hospice and palliative care targets children with limited life expectancy or uncertain prognoses facing imminent death due to acute or chronic illnesses [A2,A6,A17A19,A20]. Other studies have described the target as including children who are dying [A8] or children suffering from serious illnesses [A20].

3. Model case

This model case was developed by researchers, including nurses who have worked in a pediatric hematology department for over 10 years. These researchers aimed to illustrate the attributes of the concept of pediatric hospice and palliative care, particularly focusing on the aspects of "facing death, physically and spiritually."

"One day, my 7-year-old child kept falling down, had frequent nosebleeds, and bruised easily, so we took them to the nearby pediatric clinic. The doctor there suggested we go to a university hospital, so we anxiously went to one in Seoul. After various tests, the attending physician explained my daughter's condition. She was diagnosed with acute myeloid leukemia, and we were told that although chemotherapy would begin, there was no guarantee of a cure (targeting children and families with uncertain prognoses facing imminent death or chronic illnesses). Initially, I couldn't believe it was happening. We endured a difficult year in the pediatric oncology ward. One day, the attending physician called me and suggested we try pediatric hospice and palliative care services (palliative care policy). I didn't understand what that meant at first, but after some explanations, I did. Eventually, a team was formed to care for our child, and although I was hesitant at first, I agreed because the doctor was very persuasive. A few days later, three members of the pediatric hospice and palliative care team—the attending physician, a nurse, and a social worker—came to meet us (interdisciplinary team nursing). They coordinated with various specialists within the hospital (nutritionists, pharmacists, physical therapists, clinical psychologists, etc.) to maintain ongoing communication with me and my child (effective communication). The nurse, in particular, used picture books and media to explain my daughter's condition in an easy-to-understand way and listened carefully to her stories (considering pediatric growth and development in nursing). However, my soon-to-be 8-year-old daughter often wondered why she couldn't go to school or meet her friends, and she would sometimes get angry and cry without warning. Seeing her like that broke my heart. I felt so frustrated, sometimes crying silently in the bathroom, and I couldn't sleep for days. The nurse and social worker from the pediatric hospice and palliative care team invited my daughter's friend over to spend time with her. They explained her symptoms in a way she could understand, listened to her stories, and made efforts to spend more time with her. During her hospitalization, my daughter experienced shortness of breath and overall body pain. We tried giving her painkillers through injections, but she resisted strongly and couldn't cooperate. However, when she was immersed in virtual reality therapy (VRT), appropriate pain relief measures were applied (physical nursing). We also discussed my daughter's death with a nun, who taught her how to pray, and we prayed together during treatment. My daughter expressed that she was no longer confused, her anger decreased significantly, and unlike before, when she was irritable and whining, she started to focus on small daily plans, like completing a dollhouse with me, and began to talk about her emotions. We even talked about the afterlife (pediatric physical, psychological, social, and spiritual nursing). I felt much relieved as I separately talked to the attending physician, social worker, and nurse, who addressed my current difficulties and provided the necessary support (family nursing). Our daughter still continues her previous treatment, but her physical pain has lessened significantly after receiving pediatric hospice and palliative care. Both my daughter and I feel much better psychologically (relief of pain for children and families). Thanks to pediatric hospice and palliative care, I am now spending precious time with my daughter, and she will soon receive treatment at home. She is so excited about going home and talks to the nurse and social worker every day. Going home doesn't mean our child is cured. Initially, I didn't want to think about my child's death, and I said I would follow her in death if it happened. However, through multiple discussions with the nurse about my daughter's death and participating in programs together, I was able to come to terms with the reality of my child's death (effective coping with accepting pediatric death).

4. Antecedent factors of the concept

Antecedent factors refer to events or phenomena that occurred before the emergence of a concept and can be identified by asking, "What past events or phenomena are associated with the concept?" The following antecedent factors of pediatric hospice and palliative care have been identified in the literature: 1) interdisciplinary team nursing, 2) effective communication, and 3) pediatric hospice and palliative care policies.

1) Interdisciplinary team nursing

An interdisciplinary team consists of various professionals essential for comprehensive care, including doctors, nurses, social workers, clergy, specialized therapists (such as physical, occupational, music, and art therapists), dietitians, pharmacists, and volunteers, all dedicated to patient and family care [19]. In hospice and palliative care, these teams address not only physical, psychological, and social needs but also manage end-of-life and bereavement care. They assist patients and families in preparing for end-of-life, providing appropriate care, education, and support to help families cope with grief and loss through regular and systematic bereavement care services [A7]. Pediatric hospice and palliative care also follow an interdisciplinary team approach [A8,A9,A27]. According to Williams et al. [A27], a critical aspect of pediatric hospice and palliative care is ensuring sufficient access through team members, highlighting the need for specialization to deliver comprehensive services [A20]. This approach ensures that various elements of care function cohesively, with efficient communication and collaborative attitudes among team members being crucial, alongside each member's specialized knowledge and skills [13].

2) Effective communication

In pediatric hospice and palliative care, effective collaboration and communication among interdisciplinary team members are essential for leading the function of these teams. Within this framework, it is crucial to clarify the goals of the team and individual roles while focusing on the needs of patients and caregivers. This approach increases satisfaction among team members, builds trust, achieves positive work outcomes through regular meetings, and enhances satisfaction with hospice and palliative care for patients and families [A3].

Using a variety of communication methods is necessary, particularly with young children due to their frequent limitations in self-expression [A12]. In pediatric hospice and palliative care, communication among the family, healthcare providers, interdisciplinary teams, and children regarding the child's health status is crucial for nursing interventions [A6]. Williams et al. [A27] emphasized that healthcare professionals should possess the qualities and skills to facilitate smooth communication with pediatric patients and their families. Communication is foundational to treatment [A1,A14] and is a core element of nursing [A8], and effective communication must consider the cognitive development of pediatric patients [A27]. As everyone is involved in the child's journey, obtaining clear and accurate information about the pediatric patient's health status and maintaining effective communication with families and interdisciplinary teams are crucial for all involved [A17].

3) Pediatric hospice and palliative care policies

The United Kingdom pioneered pediatric hospice care by establishing Helen House, the world's first hospice for children, in 1982. In 1995, representatives of pediatric hospices gathered and issued guidelines for effective pediatric hospice care, leading to the establishment of the Association of Children's Hospices [A6]. In the United States, interest in pediatric hospice and palliative care grew following the 2010 amendment of the Social Security Act (Section 2302), known as "Concurrent Care for Children." This law allowed eligible children to receive hospice and palliative care alongside standard treatment, improving pediatric patients' and their families' quality of life [20].

In South Korea, the National Cancer Center Research Institute established 32 principles and standards for the Korean hospice and palliative care program in 2002 [21]. The first pilot project for end-of-life patient hospice care began in 2003, and by 2015, South Korea had implemented a hospice and palliative care health insurance fee system. The government institutionalized hospice care through pilot projects, developing models for hospice and palliative care services, and creating educational programs for hospice and palliative care practitioners [A18]. Subsequently, in July 2018, pediatric palliative care pilot projects were officially launched at Seoul National University Children's Hospital and Severance Hospital. As of January 2021, nine hospitals nationwide participated in the pediatric palliative care pilot project [22].

5. Conceptual outcome factors

In evolutionary concept analysis, outcomes refer to phenomena occurring after the emergence of a concept, which helps further clarify the concept's domain [8]. The outcomes of pediatric hospice and palliative care were identified by asking, "What changes occurred as a result of pediatric hospice and palliative care?" and were categorized. According to the literature, the outcomes of pediatric hospice and palliative care as: 1) alleviation of pain for pediatric patients and their families, 2) efficient coping with pediatric patient deaths, and 3) improvement in the quality of life for pediatric patients and their families.

1) Alleviation of pain for pediatric patients and their families

The purpose of pediatric hospice and palliative care is defined as "preventing and alleviating pain, enhancing the quality of life for children and families at each stage of development or supportive systems" [23]. This type of care considers the growth and developmental stages of children, aiming to reduce physical pain and alleviate psychological anxiety for pediatric patients [A12]. The hospice care needs of parents of children with cancer show the highest demand for physical care, with pain management, fear management of the child's death, grief management for the child, nutritional management, and management of physical symptoms ranked in that order [A12]. In pediatric hospice and palliative care, the demand for pain relief nursing for children and families is highest [A12]. Since pain is a significant source of suffering for children with terminal illnesses, effective pain management should be prioritized [A15]. The child's age and cognitive abilities influence the ability to communicate about pain. Therefore, the pediatric hospice and palliative care team should be able to assess the likelihood of pain occurrence, objectively evaluate pain, and possess both verbal and non-verbal communication skills to alleviate the child's suffering effectively [A27].

2) Efficient coping with pediatric patient deaths

For pediatric hospice and palliative care, parents should engage in age-appropriate communication with pediatric patients about illness and death, starting from the initial diagnosis [23]. Kreicbergs et al. [24] presented research on parents in Sweden who lost children to cancer. The study showed that parents regretted not discussing death after sensing their child's death was imminent. Particularly, parents of older children regretted not discussing the child's death more, and those who did not talk about death experienced higher levels of anxiety after the child's death [24]. Most pediatric patients in hospice wards are aware of the severity of their illness. Even if not directly informed, they are cognizant of its outcome and are willing to discuss such topics [24]. If a child is aware of their pain or impending death, denying it only erodes their trust and instills fear [A18]. Therefore, in pediatric hospice and palliative care, as families often experience psychological conflicts and distress, it is crucial to actively support and encourage families to communicate with the child about death, as they know the child best [A15].

3) Improvement of quality of life for pediatric patients and their families

Following a global trend, there is a growing emphasis on quality of life throughout the medical and nursing fields in South Korea. Consequently, patients facing end-of-life situations due to malignant or terminal illnesses also have the right to enjoy quality of life. Since meaningfully prolonging or curing the lives of terminal cancer patients is impossible, there is increasing recognition of the importance of hospice and palliative care in enhancing the quality of life during the remaining period [25]. Providing comprehensive care encompassing physical, social, psychological, and spiritual aspects to patients and their families is gaining more prominence [6]. This applies not only to adults but also to pediatric patients with terminal illnesses. Pediatric hospice care aims to improve the quality of life for pediatric patients and their families. Therefore, it aims to empower children and families to make the best possible decisions regarding treatment and care [26]. In 2007, the Children's Hospice & Palliative Care Coalition's Professional Advisory Committee stated that the purpose of pediatric hospice and palliative care is to prevent and alleviate suffering and to maximize the quality of life for children and families at each stage of development [A6].

6. Hypotheses and implications

In this study, a conceptual map, as shown in Figure 2, is presented in order to clearly depict the results of concept analysis. The concept is clarified by identifying the implications of the concept, even when used interchangeably with surrogate terms

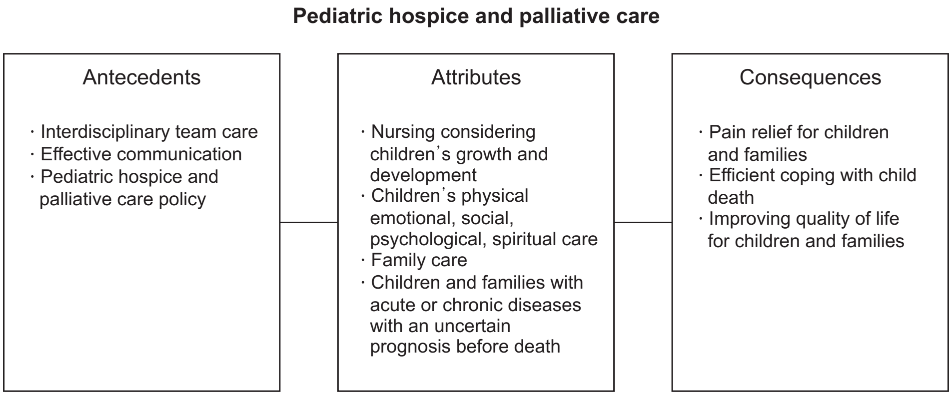

Figure 2. Conceptual diagram of pediatric hospice and palliative care.

and expressed with different attributes. Therefore, interdisciplinary team nursing, effective communication, and appropriate policies should be prioritized for pediatric hospice and palliative care. Pediatric hospice and palliative care can alleviate the suffering of pediatric patients and their families, enable efficient coping with pediatric deaths, and improve the quality of life for both pediatric patients and their families. Ultimately, pediatric hospice and palliative care encompasses physical, psychological, social, emotional, and spiritual nursing, with consideration of pediatric growth and development. It also involves family nursing aimed at children and adolescents with uncertain prognoses facing acute or chronic illnesses, as well as their families.

DISCUSSION

Pediatric hospice and palliative care aims to meet the needs of children and adolescents facing end-of-life situations and their families by providing care, fulfilling decisions regarding treatment and care, and improving their quality of life by empowering them to make the best possible choices [18]. Due to children's incomplete expressive abilities and differing understandings of death compared to adults, it is crucial to tailor hospice approaches to their cognitive abilities and developmental stages [A18]. However, in Korea, the concept of expanded pediatric hospice and palliative care has not been properly established, and even the development of palliative care in the national cancer management program has primarily focused on end-of-life care for adult cancer patients [4]. This study attempted to clarify the concept of pediatric hospice and palliative care and understand the contextual flow of antecedents and outcomes within this context. Through this, we aim to highlight the positive impact of pediatric hospice and palliative care on the quality of life of children and adolescents. Additionally, we believe that more professional and desirable nursing practices can be achieved by striving to implement high-quality pediatric hospice and palliative care.

The first attribute of pediatric hospice and palliative care is that it targets children and adolescents with uncertain prognoses due to life-threatening acute or chronic illnesses, along with their families. The Korea Hospice Association specifies that pediatric hospice and palliative care are intended for children under 18 years old diagnosed with terminal illnesses such as cancer, congenital anomalies, neurological disorders, cardiovascular diseases, and AIDS, with an expected lifespan of approximately one and a half years or less [13]. Pediatric hospice and palliative care require a differentiated understanding based on the cause of death, as the reasons for pediatric end-of-life care differ from those for adults. Additionally, the perceptions and needs of children, adolescents, and their families regarding hospice and palliative care may vary.

Second, the attributes of pediatric hospice and palliative care include considering the growth and development of children and adolescents. This type of care is tailored to their specific developmental stages. Understanding how the concept of death evolves as children and adolescents grow is crucial for grasping the psychological aspects they experience during death and loss. Children and adolescents facing death and loss must navigate confusing and painful emotions they have never encountered before. They often experience emotions such as sadness, anger, anxiety, and fear, which may be difficult for them to comprehend given their cognitive abilities. During this process, parents and members of the hospice and palliative care team may inadvertently evaluate children and adolescents based on their own experiences and project their pre-existing conflicts onto them.

Therefore, the hospice and palliative care team must understand death from the perspective of children and adolescents to assist them and their families in coping with pediatric end-of-life or terminal illnesses. Children and adolescents understand death in a way that is influenced by their family, society and culture, education, religion, media, and cognitive-developmental stages [27], as well as behavioral and emotional factors. Even among children and adolescents of the same age, there is a significant difference between those who have experienced end-of-life situations within their families and those who have not. Factors such as an understanding of illness and prognosis, limited choices, and understanding of medications vary. Behavioral factors may include physical inactivity, social withdrawal, and medication administration routes, while emotional factors may involve anxiety about end-of-life, fear of separation, fear for family members, anger, sadness, and depression [28]. Therefore, pediatric nurses should approach pediatric hospice and palliative care with an appropriate understanding of the growth and development of children and adolescents. Pediatric hospice and palliative care requires a different understanding and approach than adult hospice care, tailored to the growth and development of children and adolescents. To promote the activation and establishment of pediatric hospice and palliative care, it is essential to develop educational programs based on surveys of demands for pediatric hospice and palliative care.

Third, pediatric hospice and palliative care encompasses physical, psychological, social, emotional, and spiritual care for children and adolescents. As the hospice team members with the most contact with children and adolescents, nurses should provide holistic care that includes physical, psychosocial, and spiritual aspects [25]. Pediatric hospice and palliative care involves symptom management, patient and family education, nursing counseling, family guidance, end-of-life care, and maintaining optimal health status according to the patient's condition in daily life, ensuring that patients receive care in a comfortable and safe environment [A22, A27]. However, while the social and spiritual aspects of pediatric hospice and palliative care are crucial for comprehensive nursing, the related literature remains inadequate, indicating the need for further research in the future.

Lastly, pediatric hospice and palliative care is a family-centered approach. The goal is to empower families to be the decision-makers in the treatment and care process, enabling them to make the best possible choices [26]. Hemelstein [A8] described family-centered pediatric palliative care as both an art and a science that improves the quality of life for children and adolescents with life-threatening illnesses, focusing on pain relief and assisting in medical decision-making. This highlights the importance of involving the entire family in pediatric hospice and palliative care. However, parents may struggle to accept life-limiting illnesses and the potential death of their children, often feeling resistant to the concept of hospice. They may not view hospice as applicable to their child and instead hold onto hope for life extension through medical advancements [25]. Therefore, nurses should work to instill a correct perception of hospice in children, adolescents, and their families, foster a positive attitude toward death, and strive to provide comprehensive and high-quality hospice care.

Several key antecedents can be identified for the successful implementation of pediatric hospice and palliative care: interdisciplinary team nursing, effective communication, and pediatric hospice and palliative care policies. Currently, there is a positive shift in public perception towards hospice care in Korea, and medical institutions are gradually embracing this change. Online programs tailored to professionals' educational needs and demands are being developed to improve skills and attitudes through various channels such as group education, practical training, and community engagement, facilitating mutual exchange between learners and instructors [29]. Moreover, most pediatric nurses recognize the importance of interdisciplinary teamwork across various treatment areas to provide holistic care for patients [A21]. Based on the attributes and antecedents of the concept, the outcomes of pediatric palliative care and hospice nursing can be identified as follows: alleviation of suffering for pediatric patients and their families, effective coping mechanisms for pediatric patients to accept death, and improvement in the quality of life for pediatric patients and their families. Thus, pediatric palliative care and hospice nursing can enhance the quality of life by addressing the needs of pediatric patients and their families as a unified entity, employing a multidisciplinary team approach that respects and supports them.

The main advantage of concept analysis is that it provides theoretical and operational definitions that can be utilized in theory and research [30]. This study employed Rodgers' evolutionary method to clarify the meaning and attributes of pediatric hospice and palliative care through concept analysis. Based on this study, it is recommended to apply hospice and palliative care tailored to children and adolescents by reflecting on the identified attributes and characteristics to enhance outcome factors and applying antecedents. Furthermore, the concept analysis of pediatric hospice and palliative care indicates that improvements in medical culture and systems, in addition to individual efforts, are necessary. In the future, South Korea will need various experts from fields such as medical services and social welfare systems to collaborate in developing diverse programs for pediatric palliative care and hospice nursing. Since this study conducted concept analysis using literature available in Korean or English, further research is necessary to explore additional influencing factors not addressed in this study.

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CONFLICT OF INTEREST

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AUTHOR'S CONTRIBUTIONS

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SUPPLEMENTARY MATERIALS

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Appendix 1. Studies Included in Concept Analysis (Alphabetical Order by Author).

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