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Caring for Children Who Are Technology-Dependent and Their Families

CE 1.0 Contact Hour

The Application of Watson's Caring Science to Guide Nursing Practice

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Advancements in the medical field have resulted in an increased number of children with complex chronic conditions that may depend on technology to sustain or optimize life. Given that nurses provide substantial physical and emotional care for these children and families during their frequent hospitalizations, the development of an authentic caring relationship is imperative. A critical review of the literature examining the experiences and unmet care needs of this population was carried out and analyzed using Watson's Caring Science to explore how nurses can create an authentic caring relationship and environment for children who are technology-dependent and their families. **Key words:** *children*, *critical review*, *nursing*, *nursing theory*, *pediatrics*, *technology-dependent*, *Watson's Caring Science*

THE aim of this article is to explore how nurses can develop a caring relationship and environment for children who are technology-dependent and their families. To achieve this aim, a critical review of the literature examining the experiences of this vulnerable population was carried out and analyzed through Watson's Caring Science. Watson's Caring Science provides a theoretical and pragmatic framework that engages the compassion and authentic human caring inherent to nursing practice. Leveraging critical review methodology, this article provides nurses with an understanding of the unique relational and caring needs of children who are technology-dependent and their families. Implications to further develop and enhance pediatric practice, education, and research are provided.

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BACKGROUND

Advancements in medical technologies and treatments have resulted in improved survival rates and long-term management of children with acute and chronic illnesses. Children with special health care needs are a unique and resource-intensive population within the pediatric health care system.[1] These children and youth are often defined as those "who

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Statements of Significance

What is known, or assumed to be true, about this topic?

- Studies emerging from the United States and Canada have shown an increased prevalence of children with complex chronic conditions within pediatric hospitals.
- Nurses provide substantial physical and emotional care for children who are technology-dependent and their families during their often frequent hospitalizations, thus requiring special human caring practices to attend to these children and their families.
- Nurses have the unique opportunity to attend to the child and family's relational and emotional needs within the hospitalized setting through the development of an authentic caring relationship.

What this article adds?

- Through the application of Watson's Caring Science, this article explores how nurses can create a caring relationship and environment for children who are technology-dependent and their families within the hospitalized setting.

have or are at increased risk of chronic physical, developmental, behavioral, or emotional conditions and require health care and related services of a type or amount beyond that required by children generally."[1(p138)] Within this population, an emerging subgroup of children with severe medical fragility and complex chronic conditions that often depend on technology to sustain or optimize life is present.[2–5] Children who are technology-dependent have a variety of complex diagnoses including severe neurological impairments and acquired or congenital multisystem diseases that rely on the use of technologies such as gastrostomies, tracheostomies, oxygen, and/or mechanical ventilation.[5,6]

The Office of Technology Assessment proposes that this population may be characterized on the basis of the presence of a "medical device to compensate for the loss of vital bodily function and require substantial and ongoing nursing care to avert death or further disability."[5(p3)] Moreover, it is recognized that this type of nursing care may be provided by a range of individuals, including nursing professionals and/or trained parents/caretakers.[5] Although we present this characteristic, we recognize the problematic consequences that may further marginalize this vulnerable population by imposing a restrictive and narrow definition. Thus, we remain inclusive and broad when describing/identifying this population to encompass the wide variety of characteristics and conditions present within this population of children.

Children who are technology-dependent require substantial health care resources and experience frequent hospitalizations and unplanned readmissions.[4,7–9] A cohort study emerging from Ontario, Canada, suggests that children with medical complexity represent less than 1% of the pediatric population while accounting for more than one-third of their entire province's pediatric health care spending.[7] Of this pediatric population, approximately 12% required the use of technology to assist or prolong life.[7] Furthermore, studies emerging from the United States have shown an increased prevalence of children with complex chronic conditions within pediatric hospitals.[3,10–13] This increasing population of children has been shown to account for an estimated 75% to 92% of technology assistance–related procedures. This increased use of acute care services, and the frequent advancements in life-sustaining technologies, highlights the importance for nursing professionals to be prepared to

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care for the diverse needs of this vulnerable population.

Children with medical fragility require substantial and long-term nursing care both within and outside the hospital setting.[14] Nurses must be competent in their psychomotor skills when caring for these children, given their risk for adverse health outcomes such as airway obstruction or accidental death from technology malfunction.[9,15] However, despite reported financial burdens,[16,17] disturbed home life,[18] increased stress levels,[19] increased rates of depression,[17,19] and decreased ability to establish trusting provider-parent relationships,[20] there continues to be a lack of emphasis "on the emotional and social needs of these children and their families."[14(p38)] Given that nurses provide physical and emotional care for these families during their frequent hospitalizations, the development of an authentic caring relationship is imperative.[21] Despite this relationship being fundamental to providing compassionate and ethical nursing care, this concept remains critically understudied in the literature.

Watson's Caring Science

Watson's Caring Science provides an insightful framework to explore the act and process of care for children who are technology-dependent and their families. This theoretical framework engages the compassion and care inherent to nursing practice, providing a critical lens to examine this phenomenon. While theoretical, Watson's Caring Science can be pragmatically applied to the clinical environment, providing nurses with proposed strategies to incorporate into their own practice. The following section provides a brief overview of Watson's Caring Science, its core concepts, and the 10 Caritas Processes. Using this framework to analyze literature regarding the experiences of children who are technology-dependent and their families provides the necessary critical lens to reveal how nurses can begin to address the caring and relational needs of this vulnerable population.

Dr Jean Watson began the development of the Theory of Human Caring to refocus the art and science of care away from the dominant biomedical, technological, and curative model surrounding nursing practice.[22] Watson believes and affirms that human-to-human caring should remain foundational to the nursing discipline.[22] Now known as Watson's Caring Science, this theory has developed into a "theoretical, philosophical, and ethical framework,"[23(p469)] placing the art and science of care at the core of the nursing discipline.[22] Watson's theory achieves a greater level of awareness into the various physical and nonphysical dimensions of human care by encouraging nurses to draw upon their artistic, aesthetic, spiritual, empirical, political, and ethical ways of knowing to achieve a higher level of human connectedness with their patients.[22,24,25] Watson's Caring Science further explores the connectedness between humans and their lives while placing great emphasis on the relations between the nurse and the patient.[22] These assumptions allow a deeper understanding into the inner subjective phenomenon of human care experiences of nursing practice, one that could not be achieved by the prevailing objective biomedical-technological model.[22]

This theory challenges nurses to look beyond the physical space and appearance of a patient to attend to each unique individual and his or her relational needs.[22] Both the nurse and the patient must be present in mind, body, and spirit to begin the development of a reciprocal and mutually beneficial caring relationship.[22] It is by acknowledging the unique experiences of another that new meanings of life and healing may occur.[22] Within Watson's Caring Science theoretical framework emerges the transpersonal caring relationship, the caring moment, and the Caritas Processes.[22] These core concepts are essential for the exploration of hospitalized nursing care for children who are technology-dependent and their families.

At the foundation of the caring process, arises the concept of transpersonal caring.[22] This begins with the acknowledgment of each

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person's experiences, perceptions, and spirit beyond that of the physical body.[22] Being engaged and immersed within a transpersonal caring relationship affects all those involved, creating new meanings of life, illness, and healing that extend beyond that single moment in time.[22] It is important to note that this relationship is mutually beneficial, creating room for personal growth and healing for patient and nurse. What emerges is an authentic caring moment, where both the nurse and the patient begin to enter into each other's unique phenomenal fields, achieved by going beyond that of the physical body to see, recognize, and appreciate each individual on a deeper, more spiritual subjective level.[22] Although one cannot truly know another's unique frame of reference, experiences, and life histories, it is in this moment that each individual strives to create the opportunity for mutual growth and healing.[22] This presence and connectedness withholds the power to create a moment transcending space and time.[22]

Caritas Processes

The 10 Caritas Processes are located at the structural core, providing a universal language of human caring and a foundation to this philosophical and theoretical framework.[22] Watson's 10 Caritas Processes provide nurses with a guiding set of principles and language to create and engage in caring relationships and environments with their patients.[22] Enacting these Caritas Processes should occur in conjunction with the foundational, technological, and clinical knowledge each nurse brings to his or her personal and professional practice.[22] It is during daily interactions, procedures, and tasks with patients and families that the Caritas Processes guide nurses' knowledge, intentionality, and consciousness toward authentic care. Watson[22] outlines each Caritas Process by describing its focus on altruistic human values, authentic presence, sensitivity to self and others, trusting relationships, negative and positive emotions, problem solving, healthy and respectful environments, preserving human dignity, and openness to miracles.[22]

Watson's Caring Science provides the ability to examine the nurse-patient relationship in the midst of constraining hospitalized environments. In previous work, Revels et al[26] used Watson's Caring Science as a guiding framework to explore how nurses can provide authentic and dignified care to their palliative care patients in the often chaotic emergency department environment. However, this framework has yet to be used to explore and analyze the nurse-family relationships of this unique and growing pediatric population. The theoretical and pragmatic application of Watson's Caring Science to this clinical context and setting uncovers a new and insightful perspective on this phenomenon to support nursing care. Watson's Caring Science provides the theoretical and pragmatic framework to explore how nurses can move beyond the complex technologies and hospital institutional environments to attend to the needs of children who are technology-dependent and their families. This challenges nurses to reposition themselves within a caring foundation, encouraging them to draw on their multiple ways of knowing to look beyond that of the acute and technical needs of children and their families. The following sections describe and examine the implications of Watson's Caring Science to the nursing care of children who are technology-dependent and their families.

AIMS

This article aims to explore how nurses can create and foster a theory-guided authentic caring relationship and environment for children who are technology-dependent and their families within the hospitalized setting.

DESIGN

Critical reviews move beyond a simple summary of current literature to provide an analysis and synthesis of identified articles

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of interest with a level of conceptual innovation.[27] It provides the ability to examine and explore a current body of knowledge while acting as starting point and foundation for future work.[27] As such, a critical review of published literature exploring nurse-child-parent relationships, unmet care needs, and patient and family experiences of children who are technology-dependent was conducted and analyzed using Watson's Caring Science as a guiding philosophical framework.[22]

METHODS

This article began its development with a critical review of published literature exploring the care needs and health care experiences of children who are technology-dependent and their families. Although critical reviews do not require the reporting of search, synthesis, and analysis methods,[27] the authors have chosen to do so to increase transparency. A series of search strategies were implemented in 2 electronic databases (PubMed, CINAHL) using a combination of key words and MeSH headings such as child*, youth, adolescent*, family*, technology dependent, ventilator dependent, medically complex, medical complexity, complex medical needs, medically fragile, complex chronic conditions, car*, caring science, and theory of human caring, separated by the Boolean operators AND and OR. Databases were searched from origin to present. Limiters included only English language. Relevant literature in both the hospitalized and home care settings was retrieved. Although this article focuses on exploring nursing care within the hospitalized setting, the authors believed certain concepts could be borrowed from the home care setting and incorporated into hospital-based practice. Reference lists of relevant articles were also hand searched to identify any additional literature. Finally, alignment of themes and concepts associated with Watson's Caring Science as they relate to the discourses of these children and families were identified and explored. Furthermore, using Watson's Caring Science as a guiding theoretical framework, strategies for nursing practice were identified and examined.

DISCUSSION

In alignment with critical review methods, the following section presents an in-depth analysis of identified studies resulting from our search of the literature.[27] Using Watson's Caring Science as a guiding philosophical framework, the following sections explore the current unmet relational needs of children who are dependent on technology and their families within the hospitalized setting. Although all 10 Caritas Processes are relevant, in particular, the fourth, fifth, and seventh are explored in-depth, given their particular application to caring for this unique population in relation to their emerging discourses and experiences within the literature.

Developing a helping-trusting caring relationship

"Developing a Helping-Trusting Caring Relationship"[22(p71)] is Watson's fourth Caritas Process. This process reminds nurses that the nurse-patient relationship is built on the authenticity of the human presence. It is a process of being and becoming more conscious in the world and environment that we all share.[22] Unfortunately, the ever-changing and high-paced hospitalized environment can create barriers and challenges to the development of trusting relationships between the child, family, and provider.[28] Relationships between nurses and the families of children who are technology-dependent are often developed over years of short- and long-term hospital admissions.[29] These parents expressed the need for higher-quality care within the hospitalized setting, identifying factors such as being too busy or understaffed as barriers for inpatient nurses to provide optimal care for these vulnerable children and families.[30] The following section utilizes Caring Science's fourth Caritas Process as a

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philosophical framework to critically analyze the relationships between the nurse, child, and family.

The importance of developing a relationship grounded in trust has been identified by both parents and nurses as one of the essential needs when caring for the hospitalized child who is technology-dependent.[31,32] Parents have gone as far as by proposing that this relationship is key to facilitating optimal care for their child.[31] However, parents of children with technology dependence have reported difficulty establishing trusting relationships with their health care providers.[20] Parents have expressed the need to be respected and listened to, becoming disappointed and frustrated with the quality of care provided by nurses who were lacking these compassionate and ethical qualities.[33] As Watson states, it is about "human presence, authentic listening, hearing, and being present for another in the moment."[22(p73)] Nurses who are able to apply these fundamental nursing skills within their everyday practice create the ability to generate the trust and care needed to establish an authentic relationship with these vulnerable patients and their families.[22] While exploring hospital nursing care of a child with chronic illness,[34] findings were in alignment with Watson's Caring Science's principles. This study acknowledged that although the chaotic and often understaffed hospital environment may serve as a barrier, it is essential that nurses remember to truly listen to their patients and families.[30,34] Nurses must be mindful to re-center themselves before and after their encounters with patients and families.[22] Authentic listening involves being present in the moment, temporarily disregarding thoughts about previous or future tasks at hand, to be able to actively hear and observe the meaning within their stories. Developing this helping-trusting caring relationship requires commitment from pediatric Caritas nurses to take the time during their interactions with patients and families to enact authentic listening and presence despite the environmental challenges in which they are surrounded.

During Ford and Turner's[29] study exploring the stories of pediatric nurses caring for hospitalized children with technology dependence, nurses spoke of allowing parents to see and engage with their personal and inner-self beyond that of their professional identity. It was this open connection that nurses identified as a key component to fostering the development of a trusting caring relationship with their patients and families.[29] These nurses have also voiced great importance on achieving an authentic relationship with children who are medically fragile and their families, as this connection becomes mutually beneficial by facilitating their own personal and professional growth.[29] The descriptive accounts by these pediatric nurses are in alignment with the concepts presented within this fourth Caritas Processs.[22] Watson[22] recognizes these relationships as core to nursing practice. This relationship starts at the place of self, identifying the nurse's presence and actions as a critical component in the development of a transpersonal caring relationship.[22] Amongst the technology and restrictive environment, Caritas pediatric nurses must challenge themselves to remain authentic, reflective, and mindful while allowing room for human connection.[22] Ford and Turner[29] concur by stating that the first pragmatic step in the development of an authentic relationship with a child who is chronically ill is ensuring nurses present themselves in an open, honest, and personable manner. Furthermore, engaging within this transpersonal caring relationship has been shown to increase a nurse's love for the profession and achieve a higher sense of fulfillment.[24] To achieve this openness, nurses are encouraged to start each shift by setting mindful intentions for the day.[22] In this inner place of stillness, nurses may begin to set their caring intentions to incorporate their full authentic self in each human-to-human interaction they may encounter.[22] By incorporating these Caring Science principles into daily practice, pediatric nurses are able to create opportunities to grow personally and professionally while positively impacting all those involved.

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Parents of this vulnerable population have expressed their desire for nurses to provide genuine care to their child by attending to the person beyond their physical and technology-based needs.[17,21,31,33–36] This included acknowledging each child as an individual with their own unique life stories and experiences.[21,33] Perhaps more impactful, in a phenomenological study exploring the lived experience of children who are ventilator-dependent, participants affirmed that nurses failed to acknowledge their status as a human being.[37] Conveying an appreciation of life, beyond that of the illness and technology, is an essential competency of the pediatric Caritas nurse to sustain transpersonal caring relationships with their patients.[22] By developing an increased consciousness to the needs of patients and their families, nurses open up the ability to recognize, listen, and acknowledge the life of another.[22] As Watson states, "When one is able to engage in presence and truly listen to and hear another person's story, that may be the greatest healing gift of all."[22(p74)] This challenges nurses to move beyond the biomedical paradigm of "caring" for their patients. Although pediatric nurses may adequately attend to the acute and physical needs of these vulnerable children, patients and families are often left feeling unsupported and uncared for during hospitalization.[6,20] Watson's Caring Science provides pediatric nurses with the ability to attend to children's technology-based needs while honoring the life of these children. While completing a medical intervention, Caritas nurses must display competence to seize this time with their patients to get to know their lives outside of the hospital walls. Whether it is as simple as getting to know their favorite toy or activity, this acknowledgment of their personal life has the power to transform the moment for both nurses and patients into one rooted in love and care.

Expression of positive and negative feelings

Frequent and repeated hospitalizations, such as those experienced by this vulnerable population, have been shown as a major period of stress and anxiety for families.[38] A variety of emotions, such as fear, guilt, frustration, grief, and/or anger, may be felt by these parents during their child's hospitalization. The health of children and their parents has been shown to benefit from nurses acknowledging these emotional burdens as normative behaviors while hospitalized.[38] Research suggests that being able to create a safe and supportive environment for these children and parents to express surges of emotions is an essential component to the caring relationship.[31] Nurses' ability to attend to all emotions and feelings is a fundamental component to the development of a caring relationship. Watson explored this practice within her fifth Caritas Process as "Being Present to, and Supportive of, the Expression of Positive and Negative Feelings."[22(p101)]

Once again, Watson highlights the importance of being fully present, in mind, body, and soul, such that the patients can begin to embrace and express their emotions from deep within.[22] Nurses must be open to hold the emotions of another without hesitation or reluctance, recognizing that no emotion is invalid or unworthy to experience.[22] It is this ability to listen and accept both negative and positive experiences that creates the foundation for a transpersonal relationship and caring moment.[22] Parents have expressed the need to talk through their various and often conflicting feelings with an individual outside of their family circle.[38] Watson elaborates on this concept by stating that "the nurse in a given moment may be the only person who is able to hear and receive another person's story and emotions, thus helping the person find deeper meaning in his or her situation."[22(p105)] Parents and children may express frustrations with the health care system such as wait times, failed treatments, or having little answers to their complex conditions. Furthermore, parents may feel a deep sense of worry and uncertainty, given their child's often fragile health status. Although it may be challenging for pediatric nurses to stand witness to these frightful emotions,

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Watson[22] reminds us that this release of emotion from patients and families can be transformed into a moment of healing and growth. Being accepting and open to all positive and negative expressions is essential to the practice of pediatric Caritas nurses caring for children who are technology-dependent and their families.

Transpersonal teaching-learning

Health policies and programs have supported the shift from hospital to home-based care for children with complex medical needs who are technology-dependent.[39] Given this change in care provision, parents are often taught to perform skilled medical and nursing interventions for their child. Unfortunately, there is a paucity of literature exploring the experiences of parents and children when adapting to a new life with technology-assistive devices. Rather, the literature focuses primarily on the role of the parent during the frequent hospitalizations after their initial discharge home. Given their active involvement in the everyday care for their child's technological, medical, and emotional needs, parents want to be recognized as experts in the child's care during hospitalization.[6,14,20,30,33] These concepts will be further investigated using Watson's seventh Caritas Process, "Engage in Genuine Teaching-Learning Experience that Attends to Unity of Being and Subjective Meaning."[22(p125)]

In this Caritas Process, Watson[22] explores the role of teaching within nursing practice. Teaching is viewed as much more than the transfer of knowledge from the nurse to the patient; rather, it is a momentous process influenced by the trusting relationship.[22] The nurse must be open to the sharing of power and control within the teaching-learning process, moving away from previous authoritarian practices.[22] For the child and the family that are newly adapting to life with a technology-assistive device, the Caritas pediatric nurse must be able to identify the patient and family's readiness to learn during this often overwhelming and emotional time. Watson[22] reminds nurses of the importance of recognizing each patient as an individual, as families will differ in their readiness to learn and in their perceptions toward the teaching content. It is this acknowledgment of individualized teaching needs that the teaching-learning process can become transpersonal, thus affecting all those involved.[22] With every transpersonal teaching relationship, the nurse will themselves experience a lesson in tending to the unique needs of future patients and families. If nurses sense that their teaching style or content is not connecting with the child and/or parents, they must not be afraid to step back from the moment, take another approach, ask for guidance, or inquire into their readiness for knowledge.[40] By incorporating these principles into each teaching encounter, nurses are able to facilitate a teaching environment for children and families grounded in care and trust.

This Caritas Process was chosen to examine the concept of the expert parent, as it challenges nurses to be open to the reciprocity of the teaching-learning process.[22] Parents who have been caring for a child who is technology-dependent at home hold a significant amount of knowledge about their child's individualized care needs. This creates a unique and dynamic relationship between the nurse, patient, and family. Caring Science provides nurses with the strategies to create a self-reflexive practice by being aware of not only one's knowledge and beliefs but also those of others.[22,25] Parents feel an increased sense of trust with nurses who ask for their expertise and incorporate it into the care they provided for their child.[33] It is imperative that Caritas pediatric nurses must themselves be ready and open to learn from both parents and children in order to provide optimal and compassionate care during their hospitalization. In fact, Watson[22] stipulates that the first step in the teaching-learning process is seeking to learn what is already known by the individual. This step should be completed upon admission and continued throughout their hospitalization. By remaining in the frame of reference

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of the parent or child, the nurse is able to facilitate the cocreation of a trusting and supportive teaching-learning environment.

CONCLUSION

Children who are technology-dependent are a unique and resource-intensive population within the pediatric health care setting.[2,4] Their medical fragility and complex technologies place them at a greater risk for adverse health outcomes, resulting in frequent hospital readmissions.[9] With continuous advancements in medical technologies, it is essential that we address the care needs of this vulnerable population of children and their families. Nurses have the unique opportunity to advance practice through theory-guided approaches to meet their relational and emotional caring needs within the hospitalized setting. As outlined in this critical review, Watson's Caring Science and the 10 Caritas Processes provide nurses with a philosophical, theoretical, and practical disciplinary framework to attend to the unmet care needs of this population while overcoming the institutionalized barriers surrounding the nursing practice.

RELEVANCE TO NURSING PRACTICE, RESEARCH, AND EDUCATION

As discussed earlier, advancements in medical technologies will likely result in the growth of children who depend on technology to sustain or optimize life. Given that nurses work more closely with patients and families than other health care professionals,[41] it is imperative that nurses gain a greater understanding of how a theoretical disciplinary foundation to their practice can help advance the relational, human caring needs for this population of children with medical fragility. However, nurses are not only challenged by the fast-paced biomedical environment that is a characteristic of the acute care setting but also children's technology-based interventions may distract nurses from attending to their underlying emotional needs.[42] Nurses must develop the proficiency to care for both the lifesaving technologies and the emotional human caring needs of children and their families. Possessing the ability to care for one or the other is not sufficient to providing compassionate, ethical, and moral nursing practice.[42]

The integration of Caring Science into everyday clinical practice challenges nurses to look beyond that of the physical-objective focus in order to develop deep human-to-human connections and caring relationships.[22] While practicing in a deeply biomedical and technology-focused environment, it is crucial that nurses recognize and refocus the importance of caring theory within the nursing discipline.[43] Despite little recognition in this area of practice, Caring Science can be uncovered within nurses' everyday interactions with patients and families. Proposed nursing strategies, and their implications to clinical practice, have been highlighted throughout the discussion of this article with the aim to enhance pediatric nursing practice while caring for these medically complex children. These strategies may be presented to nurses new to the profession or new to those caring for others with this complex population.

This exploration and review of the literature revealed a clear lack of research exploring nursing practice and care of children who are technology-dependent within the hospitalized setting. Future nursing research, using Watson's Caring Science as a philosophical underpinning, is warranted to explore discipline-specific nursing interventions that can promote optimal care for these children and their families. Furthermore, given the lack of research in this area, educational initiatives or interventions should be explored and evaluated to guide nurses in helping children and families adjust to new life with a technology-assistive device. These research initiatives will guide the development of philosophical, theoretically oriented health policies and practices, supporting children who are technology-dependent, and their families.

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