# Exploring the notion of technologically dependent children: Findings from a review of the literature

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## Abstract

**Background:** Literature has highlighted various effects that technologically dependent children have on their parents and the healthcare system. In this review article, we explored the challenges associated with raising such children as well as the impact that they may have on those around them and the healthcare system. **Method:** We searched databases such as Google Scholar, PubMed, Medline CINHAL Plus, and Science Direct. Scientific papers published in English between 2010 and 2018 pertaining to technology-dependent children were selected for inclusion. We reviewed 13 primary research articles relevant to the topic of interest. **Results:** The findings revealed that technological dependence alters the lifestyle of both children and their families. The life of these children and their parents is different when compared to those who are not dependent on medical technology since parents and siblings have to plan their daily routines based on the needs of the technology-dependent children. Parents described playing both parenting and nursing roles in taking care of these children and changing their home environment to a 'mini-hospital' when it came to providing medical care to these children. The responsibilities associated with the care of ventilator-dependent children changed drastically when the mothers took over from the care-giving nurses. **Conclusion:** Technological dependence is crucial in shaping the lifestyles and routine activities of families, mainly parents, and siblings of these children. It also has a significant impact on the responsibilities that the family members, especially mothers have to fulfill in providing home-based medical care to their children. Additionally, when nurses were inquired about transitioning care from hospital to homes and preparing mothers for home care, they reported finding it hard to trust the mothers to provide the same level of medical care in the homes as they did in the hospital.

***Keywords**:* Technology-dependent children, roles, nurses, parents, families.

## Introduction

Technology-dependent children require certain medical devices and/or equipment to compensate for the loss of one or more vital body functions as well as additional nursing care to function effectively and lead a quality life (Okido, Zaro, & Lima, 2015). This can be provided in the form of tracheostomy, artificial nutrition, intravenous drug therapies, mechanical ventilation, gastrostomy assisted nutrition, oxygen therapy, renal dialysis, or a combination of these methods (Haffner & Schulman, 2001). Approximately, 20% of all pediatric patients are technologically dependent and this accounts for 61% of all healthcare use by this population (Newacheck & Kim, 2005). These children have special health needs compared to healthy children of the same age and the concomitant use of medical devices places an additional burden on the health care system (Golden & Nageswaran, 2012). There is a need to provide these children with complex and continuous therapeutic and rehabilitation regimens based on the latest research (Neves & Cabral, 2008).

## Background

Numerous sources in the literature focus on technologically dependent children (Cohen et al., 2011; Glendinning, Kirk, Guiffrida, & Lawton, 2001; Haffner & Schurman, 2001). The vast majority of these resources shed light on medical aspects including the classification of medical conditions and the various technologies being utilized in healthcare provision to sick children. They also focus on the social issues revolving around the use of technological devices in these children such as the burden on the healthcare system as well as the psychological impact they may have on their families (Cohen et al., 2011; Newacheck & Kim, 2005). Data on the role of healthcare providers also delves into the importance of effective collaboration between nurses and parents to optimize medical care being provided to these children. In turn, the literature about the role of healthcare providers talks about the collaboration between nurses and parents to provide optimum care to these children (De Souza Esteves, Da Silva, Santos da Conceição, & Dórea Paiva, 2015).

There are several different ways to describe technologically dependent children, most of which are rather too simplistic. In this review article, we, therefore, aimed to compare the findings in the available literature with D Allen's conceptualization of technologically dependent children (2015). In addition, we explored the complexities associated with raising and providing medical care to these children in greater detail. Some of these include the social and emotional issues involved in taking care of these children and the practical implications that might have on the family members.

## Methods

Articles relevant to the topic of interest were obtained from databases including Google Scholar, PubMed, Medline CINHAL Plus, and Science Direct using the following the combinations of search terms and phrases such as 'technology-dependent children' 'ventilator-dependent children,' 'families' experiences of TCD', 'Parents and TCD', 'Nurses and TCD' and 'Care for technology-dependent children'. Studies from both developed and developing countries published in English were shortlisted for further review. Both full-text research articles and some abstracts (where full-text articles were not available) were included in the study for analysis. In

addition, scientific primary research papers that were published in English between 2010 and 2018 relevant to the subject of technology-dependent children were selected for inclusion. The principal author examined 13 primary research articles meeting the inclusion criteria. Findings from both quantitative and qualitative studies were reviewed and analyzed.

## Findings

In the available literature, different authors define the phrase 'technology-dependent children' (TDC) in various ways. For instance, according to some authors, it refers to 'high-tech' dependent children, such as those dependent on a mechanical ventilator. Others also include 'low-tech' dependent children, for example, those requiring a colostomy in the definition (Wang & Barnard, 2004). The definition seems rather straightforward and can be summarized as those children having some kind of technological needs (De Souza Esteves et al., 2015). However, the same definition can be perceived as vague by some because it neither defines the type of technology being utilized nor the type of medical care being provided to these children.

Some authors consider technology-dependent children as simply those who require medical devices such as tracheostomies, feeding tubes, or mechanical ventilation without further classifying them into high or low tech-dependent children (Haffner & Schurman, 2001). This definition merely takes into account the technology required by the child without addressing the type of medical care he or she may require. In contrast, the United States Congress Office of Technology Assessment (OTA) has defined TCD in two different dimensions i.e. the type of technology and the type of care that must be provided to a technologically dependent child. This definition describes TCD as children requiring not only medical devices to compensate for a functional loss but also continuous skilled nursing care to prevent permanent disability as well as reduce morbidity and mortality (Heneghan et al., 2018). In addition, OTA has also identified four separate populations, distinguished from one another by their clinical characteristics, that might reasonably be considered technology dependent: Group I: Children dependent at least part of each day on mechanical ventilators, Group II: Children requiring prolonged intravenous administration of nutritional substances or drugs, Group III: Children with daily dependence on other device-based respiratory or nutritional support, including tracheotomy tube care, suctioning, oxygen support, or tube feeding, and Group IV: Children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near-daily nursing care.

Hence, this definition reflects that children who need additional care but do not need technical equipment, or children reliant on mechanical equipment but do not have additional nursing requirements, are not considered as TCD. According to these definitions and classifications, however, technology-dependent children account for only a small subset of the disabled children population who depend on life-sustaining medical technology and typically require complex, hospital-level nursing care (United States. Congress. Office of Technology Assessment, 1987, p. 3). The latter definition restricts technological dependence on medical care being provided in the hospital but not at home. It is not necessary, though, that medical care is provided by skilled medical staff in the hospital alone. It can also be provided at home by trained parents and other family members (Okido et al., 2015). Similarly, portable medical devices can be operated by trained non-medical people even in home settings to provide care to technology-dependent children. (Glendinning et al., 2001). Literature review shows that the medical needs of

technology-dependent children have led to a transformation in the structure of the healthcare system to address the specific issues of these children. For example, it has been reported in the literature that the medical needs of technology-dependent children have reformed and reorganized the health system to optimize health care for this group (Golden & Nageswaran, 2012; Okido et al., 2015). This also demonstrates a need for qualified health care professionals who provide not only hospital-based but also home and community-based care (Golden & Nageswaran, 2012; Okido et al., 2015). These individuals could potentially be a tremendous source of help for families that are providing medical care to their children at home (Glendinning et al., 2001).

It was also found that authors defined TDC as a subset of children having special health care needs either temporarily or permanently, which required technical proficiency and caused alterations in the role of parents as well as household schedules (Kirk, Glendinning, & Callery, 2005). This definition can be generalized to both children requiring continuous, long-term medical assistance as well as to those requiring less frequent treatment (United States. Congress. Office of Technology Assessment, 1987, p. 3). According to some authors, the concept of TCD has emerged as a consequence of medical advancements that provide quality care to special children. These special children include pre-term infants, children with congenital anomalies, and chronic diseases who require medical technological support (Kirket al., 2005). Others have categorized these medical requirements into technological, developmental, modified standard, pharmaceutical, and mixed care (Fereday, Oster, & Darbyshire, 2010; Moraes & Cabral, 2012). In contrast, OTA has classified these children based on the type of technology. These groups include ventilator-dependent children, children requiring continuous intravenous medications, those dependent on respiratory devices, and children requiring both medical devices and continuous nursing care (Haffner & Schurman, 2001).

Detailed analyses of data revealed that technology-dependent children comprise a diversified patient subset that differ on basis of type of illness, age at the onset of technological dependence, duration of dependence, incidence and severity of the associated disability and the frequency of technology use (Glendinning et al., 2001; Heaton, Noyes, Sloper, & Shah, 2005). In all articles about TDC summarized so far, the role of technology has been generally defined as compensating for the loss of vital bodily function. However, most authors have typically defined the concept of technology-dependent children rather than the technology itself.

In contrast to this, D Allen (2015) has shed light on the concept of technological dependence from a different angle. She explains this viewpoint in light of the Actor-Network Theory (ATN) and the Practice theory. In the first chapter of her book, she talks about the equal contribution from both human and non-human actors as a key feature of the ANT (Allen, 2015 pp. 7). Allen's definition of 'actors' is not just limited to humans who are generally perceived as sensible beings but also to ideas, texts, statements, artifacts, and even material objects. She explains how these entities are equally important in shaping all things that exist in the world. but these comprise all kinds of self-governing figures which give shape to the world and are capable to perform the required tasks. According to her theory, one can also re-assign roles to human and non-human actors to accomplish different tasks and strive for quality improvement. Equally important is the connection between human and/or non-human entities, and it is this interconnection that has a direct impact on everything existing in the world (Allen, 2015, p. 9).

In the healthcare setting, using the ANT means ascribing equal value to both people and things. The non-human entities, in this case, would include various types of data, such as medical records, checklists, guidelines, and algorithms. The human 'actors' (i.e. the medical personnel) must use these to effectively carry out their daily tasks, and in doing so, these non-human factors have a direct influence on those using them. This interconnection and mutual influence between human and non-human actors is what comprises the network of ATN (Allen, 2015, p. 10).

Allen (2015) explained that these networks of actors are dynamic systems of non-homogenous elements which are fleeting and must be actively formed and re-shaped to hold their solidity. Furthermore, they are fundamentally non-coherent and may encompass disagreements and dissimilarities. According to Allen, the delivery and organization of healthcare are challenging. There is excessive reliance on technology that uses engineering techniques and management sciences to provide services and enhance work productivity. She stated that there is an outburst of technologies that draw on systems engineering and management science to justify service procedures and work activity (Allen, 2015, p. 11).

In addition to ANT, Allen gave another theoretical perspective by conceptualizing practices as physical activities that require a range of resources to coordinate certain defined work. This Practice theory principally states that human beings do not connect directly with the world but this interaction is always interceded by mediators which help connect different human and non-human entities. For example, in healthcare, there may be material objects such as surgical instruments, protocols, or paper-based forms. These do not just support human efforts but also alter the nature of the activities being performed. Thus, it would be worthwhile to understand the impact of non-human objects on human players (Allen, 2015, p. 9).

The theoretical perspectives put forward by Allen explain the concept of technology from an entirely different perspective. For example, I recall my experience of providing nursing care to an 8-year-old child who suffered from an accident and was put on ventilatory support due to severe respiratory distress. It would not be possible for me to do so without a mediator and it was the mechanical ventilator which was the non-human player interceding between me and the patient. In addition, multiple human actors (such as the pediatrician, nursing manager, registered nurse, parents, and the housekeeping staff), as well as non-human actors (ventilator, IV infusions, medications, algorithms, checklists, files, monitors and pulse oximeters), were simultaneously playing their roles to optimize care to the child and avoid additional disability.

The mechanical ventilator was providing respiratory support to the child and various human actors were responsible for monitoring and controlling the knobs of the ventilator according to the patient's requirements. At that time, I did not realize how non-human actors facilitate the endeavors of human players. However, viewing from Allen's lens made me appreciate the crucial role of technology in medical care. I could imagine what the condition of the child would have been if both human and non-human actors were not interrelated to play their respective roles in optimizing care. For example, the mere availability of a computer (a type of technology and a non-human actor) can indirectly provide care to TDC in multiple ways. It allows health care providers to monitor the care of TDC from a distance, make electronic

databases for TDC, and also explore literature for recent advancements in the care to be provided to a technologically dependent child.

In contrast to Allen's theory, the articles summarized in the former half of the paper analyzed technology-dependent children from a different perspective. As opposed to that, a paper by Heaton et al. 2005 demonstrates how technology plays an important role in shaping the life experiences of families as well as their day to day schedules. According to this paper, the technological devices were not only programmed according to the needs and characteristics of the children but also keeping in mind the social schedules of the family and their institutional calendars. For example, families reported that they usually programmed peritoneal dialysis to start at a time that permitted the required number of cycles to be finished in time for the children to go to school. Moreover, parents reported working around their schedules on weekends and other non-school days. A few families were allowed to interrupt feeding or dialysis at special times, such as on holidays (Heaton et al., 2005). Besides, the lives of the siblings of technology-dependent children were different compared to their counterparts because they had to plan their routines accordingly. Siblings reported that supporting the technology-dependent child required reassignment of roles and responsibilities and adjustment of daily routines. Taking care of the technologically dependent child and helping out with other household chores would provide a break to the parents who were involved in their care (Heaton et al., 2005).

In addition to this, these authors have explained technical care as a type of care involving a gamut of activities such as supporting and monitoring the child, cleaning and preparing equipment for use, taking care of entry and exit sites, seeking technical support from service providers and sometimes the manufacturers of devices, and provide training to caretakers (Heaton et al., 2005). Furthermore, according to the same paper, technology also influenced the social lives of the affected children. For instance, a few children reported that they felt more energetic following artificial feeding that enabled them to meet with their friends and engage in different social activities (Heaton et al., 2005).

The operational requirements of the technical devices also impacted families of TDC in various ways. For instance, it was challenging for some parents to earn a living and take care of the technologically dependent child at the same time. Parents reported quitting their job owing to the overwhelming demands of technical care. Hence in this paper, the technological, social, and natural time frames of parents of TDC were discordant. They did not just shape the routines and schedules of families but also created difficulties for families and children, hindering their involvement in their academic, work, and social lives.

Analysis of another paper by Kirk et al revealed how technology has altered the role of parents, forcing them to perform dual roles in their life (2005). These parents described their role from both parenting and nursing dimensions. For instance, parents reported that in addition to performing the parenting role, they also performed clinical procedures such as changing tracheostomy tubes, administering oxygen, suctioning airways, inserting nasogastric tubes, and administering injections (Kirk et al., 2005). These parents were also forced to change their home environment into that of a 'mini-hospital'. They reported that the environment of the home was not just transformed but also governed by technology (Kirk et al., 2005). Hence, technology not only changed the roles of parents but may also alter the environment of the home.

Another paper on the topic of interest explored the ethical aspects revolving around the roles and responsibilities of nurses in the hospital-to-home transition of ventilator-dependent children (Manhas & Mitchell, 2014). According to the author, the responsibilities associated with the care of ventilator-dependent children transitioned from nurses in the hospitals to mothers as the patients were discharged home. (Manhas & Mitchell, 2014). Furthermore, the authors have analyzed the role of trust in this transition. According to them, different façades of trust such as confidence, reliance, expectations, security, risk, vulnerability, and power affect the roles of parents and health care professionals in this critical period of transition. Firstly, healthcare professionals found it challenging to trust family members to provide the same level of care to the patient as they did in the hospitals (Manhas & Mitchell, 2014). Moreover, this transition places additional responsibility on the parents but limited nurses are also accountable for limited responsibilities. These responsibilities include preparing parents to be ready to take care of their children at home when nurses are not around. In addition, the transition process requires security and fearlessness on the part of the caregivers at home and the availability of resources to fulfill the requirements of TDC. Hence, this trust is crucial for a smooth transition from hospital to home. An environment of trust is also desirable to facilitate effective communication between nurses and other healthcare professionals, and families. This would make the process of transition a lot more efficient (Manhas & Mitchell, 2014).

Authors in one of their study described the care of TDC and its association with the health care system (Okido et al., 2015). One of the important themes of this paper was based on the hegemony of the biomedical model. According to the authors, explanatory models are shared during the interaction between healthcare professionals and the sick individual. During this interaction, the professional class typically dominates and compels patients and family members to adapt according to the biomedical model of the disease. This influence can be attributed to the social dominance of the professional class, especially those belonging to the healthcare sector (Okido et al., 2015). Thus, during every encounter, a new lay explanatory model is set up, which gains a new meaning between mothers of technology-dependent children and healthcare professionals. This builds incredible care for their children which are invaded by biomedical notions. But parents find it difficult to embrace this new care, as it demands the incorporation of new knowledge and practices that are beyond the knowledge of a layperson. In addition, this dominance of the biomedical model becomes problematic for TDC and sometimes has negative implications as well. For instance, the mother's narratives in this paper revealed that health care professionals discredit the knowledge that mothers have acquired during the whole process. These professionals oftentimes neither listen to mothers nor allow them to share their experiences with them. Thus, there is a lack of communication between these laypeople and trained individuals. If the biomedical model remains prominent and no dialogue occurs, the parents of TCD will do whatever satisfies them and they consider most appropriate, depending on the way he interprets his disease (Okido et al., 2015).

## Conclusion

In summary, the available literature on technology-dependent children sheds light principally on their medical needs. Technology dependent children are those children who require medical devices and sustainable long-lasting care to prevent death and disability. In contrast, Allen describes the concept of technology from a different standpoint. She highlights

that the interaction between human and non-human entities is always facilitated by mediators. In the healthcare system, these mediators could include surgical instruments, protocols, or paper-based forms (2015). Thus, her perspective directs our attention to view technology from a different angle, which in turn, clearly reveals that the care for TDC is not only dependent on human actors but many non-human actors also play an important role.

Moreover, technology plays a vital role in re-shaping routine life activities and schedules of families especially parents and siblings of TCD. It also modifies the roles and responsibilities of health care professionals and family members, especially mothers who have to fulfill dual responsibilities. Besides, trust played an important role in transitioning roles and responsibilities from hospitals to homes. This process of transition required security on the part of the parents and the availability of resources to meet the requirements of TDC and their parents. Lastly, during the entire process of care for TDC, parents and family members may sometimes be ignored and their voices unheard due to the dominance of health care professionals. This social dominance of health care professionals may have negative implications for TDC. This paper explores the concept of technology-dependent children from the perspectives of different authors and invites researchers to understand and explore this topic in greater depth.

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