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The Post-Intensive Care Syndrome in Children
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ABSTRACT
Improvements in devices and techniques used to provide life support for patients at intensive care units have reduced patient mortality. Increases in the number of survivors from a critical illness have brought long-term complications experienced during the post-intensive care period into question. The term post-intensive care syndrome (PICS) is defined as a new and deteriorating disorder in the cognitive, mental, and physical health status experienced by the survivor after intensive care unit discharge that might continue for months or even years. Opioid and sedation exposure, the severity of illnesses and injuries, dense life support interventions, length of stay in the intensive care unit, and social isolation constitute risk factors for PICS in children. These factors cause the child to experience deterioration in physical, cognitive, and psychological health domains. Such deteriorations occur on various levels and have negative effects on quality of life. The purpose of this article is to raise awareness and help pediatric nurses to develop an understanding of the condition. Increasing awareness by pediatric nurses about the magnitude and effects of complications after discharge from the intensive care unit will be the first step to protect survivors from new problems, to provide assistance for ongoing problems, and to develop follow-up strategies. PICS-related morbidities affect the majority of children discharged from PICUs. We need to understand the scope of those morbidities and develop efficient nursing interventions accordingly. It is time to expand our goal for critical and noncritical care from life-saving into improvement of functional health status and quality of life.

KEYWORDS
Children; critical illness; pediatric intensive care; survivor

Medical and technological advances in recent years have been leading to the lowest level of mortality in the pediatric intensive care (PICU). In addition to decreasing mortality rates, it was no longer possible to measure success by utilizing only mortality rates; therefore, studies began to focus on evaluating outcomes, morbidity, and well-being (Aspesberro, Zimmerman, & Watson, 2017). The Society of Critical Care Medicine defined post-intensive care syndrome (PICS) as “new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization” (Needham et al., 2012; Rawal, Yadav, & Kumar, 2017). The term PICS is used to describe long-term clinical, psychological, and functional disorders experienced
by both survivors and their families (Elliott et al., 2014). Similar to adults, pediatric survivors of critical illness are at risk in multiple domains regarding long-term impairments. In ‘Society of Critical Care Medicine Conference’ held in 2010, pediatric critical care patients were defined as a risky population in need of searching about PICS more than others (Needham et al., 2012). Even though PICS is well defined in adult critical care literature, the study which is related with that has recently started to appear in the pediatric literature (Herrup, Wieczorek, & Kudchadkar, 2017). PICS in pediatrics, also as known as PICS-p highlights the framework for baseline status, organ maturation, dependence to the family and health recovery level which might possibility effect life of the child for decades (Manning, Pinto, Rennick, Colville, & Curley, 2018).

Critical illness and admission to the intensive care unit (ICU) is a stressful and chaotic situation. Patients in the ICU are exposed to various interventions, but these interventions are necessary for survival. They include life-saving practices such as mechanical ventilation, endotracheal intubation and chest tube insertion, central venous and arterial catheterization, and intensive drug administration (Bennett, 2015; Makic, 2016). Cognitive and psychological stressors often originate from sleep withdrawal, sedation, pain, anxiety, fear, delusions, and delirium. In addition, illness-related functional insufficiency limits the independence of patients causing fear, loneliness, and weakness (Aspesberro et al., 2017).

Post-intensive care sequelae cause not only rising health care expenses but also functional impairments and reduced quality of life. Thus, this syndrome is related to not only undesired long-term limitations in daily life but also reduced levels of quality of life (Choong et al., 2015). Resuscitation density, baseline illness, the severity of the illness, and length of stay (48 h or more) in the ICU are among the important factors affecting the quality of life at after discharge period. Ambuehl, Karrer, Meer, Riedel, and Schibler (2007) showed that one of three children required regular follow-up by a specialist, 8% of children had a poor level of quality of life and 16% of the children had to use medication for a variety of reasons. In the study conducted by Taylor, Butt, and Ciardulli (2003), 10% of children had poor quality of life in 24 months after the PICU. Some studies examining this issue stated that quality of life improved over time (Desai, Law, & Needham, 2011; Vet et al., 2016). For example; Choong et al. (2015) followed the functional outcomes of children after a critical illness prospectively. At the end of this follow-up, the functional state of children in the sixth month was found to be higher than in the third month.

PICS cannot be associated with a specific diagnosis and is challenging to anticipate during the early phase and to identify which patients are at high risk for this illness. However, the severity of the illness is the key factor in determining both the level of functionality and well-being of patients. For instance, among children who had a traumatic brain disorder, those with mid-level or higher injuries had a lower chance of survival or did not acquire new skills appropriate
for their ages (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005). At ICUs, severity of the illness is assessed through scoring systems. The first category for these scoring systems belongs to prognostic scores proposing the mortality risks during admission to ICU. Those scores include cardiovascular and neurologic vital signs, temperature, acid-base and blood gas, biochemistry tests, and hematology tests. The other category is descriptive and identifies outcomes scores related with the course of the illness following the admission (Gulla & Sachdev, 2016). A direct relation is available between the number of organ dysfunction and mortality rates of children so organ dysfunction scoring systems (respiratory, cardiovascular, neurological, hematologic, renal, hepatic vs. gastrointestinal) are commonly utilized as outcome scores in pediatric interventions (Leteurtre et al., 1999). Identifying the severity of the illness is a highly important issue regarding the use of health services sources effectively both in critical care and in post-critical care periods. The post-PICU follow-up and rehabilitation program planned regarding to severity of the illness might enhance the success in the reducing of PICS symptoms.

Young children have less ability in terms of healing process following critical care period as well as gaining new skills appropriate to their ages. The study by Knoester, Bronner, Bos, and Grootenhuis (2008) suggested after 9-month follow-up that children between 1 and 6 years had more lung problems, worse positive mood and worse liveliness than other age groups. Even though negative emotions were among the identified problems for children from all age groups following a critical illness, it was stated that younger children needed more time for healing process. It takes much longer for younger children to get rid of bad experiences—related with cognitive development—such as pain, life support interventions, intensive care environment, etc. As older children are aware of what happens around, surviving itself makes them happier over time (Jokovic, Locker, & Guyatt, 2004; Knoester et al., 2008). It is rather crucial that pediatric nurses should plan their interventions such as family-centered care, atraumatic care, or sedation management in order to reduce morbidities at post-PICU period.

The cognitive, physical, mental, and psychological domains identified in numerous studies examining outcomes for ICU survivors emphasize the PICS framework and the impairment in each domain affects both quality of life and the functioning of the patient at different levels (Desai et al., 2011; Iwashyna, Ely, Smith, & Langa, 2010; Needham et al., 2012). The most common complications for those domains and recommended interventions to ease those complications might be summarized as follows:

**Physical and functional impairment**

Physical impairments after critical illness are loss of muscle mass, neuromuscular weakness, sensory and nociceptive changes, impaired lung function,
fatigue, and weight loss. These physical impairments impede daily functioning and can lead to long-lasting functional disabilities (e.g., limitations in dressing, getting out of bed or getting up from a chair, walking, climbing stairs). One in five children needs special care after intensive care, such as physiotherapy, rehabilitation, speech therapy, or private school (Ambuehl et al., 2007). In long-term stays in PICU, acute loss of skeletal muscle mass often causes physical disability for survivor children. It is difficult for the majority of survivors of critical illness to reach their pre-illness performance. After PICU admission, beginning active or passive exercises as soon as possible, facilitating any early mobilization, collaborating with physiotherapists and occupational therapists to achieve early mobilization are recommended as preventive strategies for musculoskeletal complications in the PICU (Aspesberro et al., 2017; Kondo et al., 2017).

**Neurocognitive impairment**

The major risk factors for neurocognitive impairment are acute brain dysfunction, hypoxia, glucose dysregulation, prolonged mechanical ventilation, severe sepsis, use of renal replacement therapy, and acute respiratory distress syndrome. A study found that children with brain injury or nervous system infection had both lower verbal and visual IQ levels when compared with those in healthy children (Als et al., 2013). It is very challenging for children to perform their tasks at home or school after a period in intensive care, and they might need additional support at school.

**Psychological impairment**

The primary focus of studies, which research psychiatric morbidity after intensive care discharge, is post-traumatic stress disorder. In the study by Dow, Kenardy, Le Brocque, and Long (2013), 6 months after discharge from the PICU, the prevalence of post-traumatic stress disorder was found to be 17–29% for school children and adolescents. In studies examining the reasons for post-traumatic stress disorder, it has been reported that the frequency of invasive procedures increases psychological morbidity. Medical fears weaken the sense of their health control and exposing too many invasive interventions accelerates the progression of post-traumatic stress disorder symptoms in children (Herrup et al., 2017). One-third of children survive from a critical illness reported delusional memories. Benzodiazepine and opiate administration are risk factors for delusional memories, including delirium (Aspesberro et al., 2017). To reduce the prevalence of such risk factors, it is recommended that effectiveness of sedation agents should be evaluated, reevaluated, and sedation evaluation tools should be implemented (Vet et al., 2016). Moreover, the intensive care environment and density of invasive procedures affect the sleep
quality of the child negatively and both sleep disturbances and mood changes are common conditions reported by families during the post-discharge period.

One of the identified interventions to reduce psychological complications of PICS morbidity is the intensive care diaries. They are accepted as a tool to fill up memory gaps of patients. They are written prospectively and address the patient personally. They include summary of admission, narration of daily activities, and transfer notes from ICU. Entries for the diaries are handled by bedside nurses. Family diaries narrate the experiences of family members during ICU admission. It is quite important to be shown positive outcomes of diaries at PICU that have a common use in adult literature. It was suggested in the study by Mikkelsen (2018) that diaries written both by children and by families had a role to signify PICU experiences. Use of diaries in PICU might help children to comprehend their stories better.

Another intervention for psychological morbidities of PICS is support groups. They might be arranged in the leadership of nurses are the other way of supporting both patients and caregivers to improve psychological outcomes (Mikkelsen et al., 2016). Providing some places or planning a schedule for the family members/friends of the patient to support each other, ICU survivors’ coming together at post-discharge period or survivors, friends and family members’ meeting might be rather beneficial to overcome various difficulties emerging from the illness itself.

Even though healing is possible after a critical illness, majority of PICS symptoms continue for months or years. Therefore, a structured follow-up program and an interdisciplinary approach are required for the survivors of ICU. Whereas different follow-up clinical models, supporting patients and led by a nurse, a physician or a multidisciplinary team, are available in adult literature, there is not a consensus on the implementation of follow-up programs in pediatric literature. It is a recommended approach that the patient should be followed by the same team and his/her need of rehabilitation should be ensured in coordination since the treatment of critical illness does not come to end at PICU. Critical care nurses, who have enough knowledge on the present condition of patients and the effect of the illness, should be the core member of follow-up programs.

**Conclusions**

Critical illness and PICUs affect overall long-term pediatric patient outcomes. Increasing number of survivors lead to increased numbers of patients using post-intensive care health services. The objectives of critical care should reach beyond survival and include a multidisciplinary collaboration to both prevent and manage long-term complications. Pediatric nurses must have a comprehensive understanding of long-term complications, familiarity with the nature and severity of critical illness, and effects of intensive care on patients overall to support the development of practices to reduce such complications.


Declaration of interest

The author reports no conflicts of interest. The author alone is responsible for the content and writing of this article.

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