

ORIGINAL RESEARCH





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Abstract

Background The post-intensive care syndrome in pediatrics (PICS-p) framework offers a new understanding of the long-term impact of critical illness on child's and family's health. However, a comprehensive theoretical guide to investigate potential factors influencing these outcomes and recoveries is needed.

Objective The aim of the study is to conceptualize post-intensive care outcomes in children and their families after PICU discharge in the context of the child's surrounding environment and systems.

Method We used Theory Adaptation, a shift in the use and perspective of the Bioecological Theory of Human Development (BTHD), and Theory Synthesis, the integration of BTHD and the PICS-p, to provide a novel PICSS-PF perspective for understanding PICS-p within the broader context of the child and family. This integration helps to see higher-order perspectives to link post-PICU outcomes and child development within the context of child's surroundings.

Results While PICS-p is a model for understanding and studying post-PICU outcomes and recovery in four domains of physical, cognitive, emotional, and social health, the BTHD offers a new lens for a holistic view of the contextual systems and factors affecting the outcomes and recovery. The BTHD contextual systems include intrapersonal (demographics, clinical), interpersonal (adjacent people's characteristics and interactions), institutional (family situations, PICU environment), community, social resources, and networks.

Conclusions Knowing the complex nature of post-PICU outcomes in children and their families, the PICSS-PF helps in the better understanding of the complex interplay of factors that contribute to PICS in children and their families, leading to the development of more effective interventions to address this condition.

Keywords Post-intensive care syndrome, Pediatric health, Socio-Ecological model, Child development, Family

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Background

The World Health Organization (WHO) defined health as "the state of complete physical, mental, social wellbeing and not merely the absence of disease or infirmity." An amendment to this definition included the statement "enjoyment of highest attainable standard of health is one of the fundamental human rights without distinction of race, religion, political belief, economic or social condition" [1], yet, mortality rate remains the main indicator of successful patient outcome in hospitals.

In the recent decade, while advances in intensive therapies and medical care have increased survivorship rates in PICUs, emerging research indicates widespread and significant physical and psychosocial morbidity among both PICU survivors and their families [2, 3]. This is especially true for those with lower socioeconomic status and social supports [4, 5]. After hospital discharge, many children and families must deal with newly acquired conditions or altered functioning, as potential consequence of critical illness and PICU hospitalization [6, 7]. These adverse outcomes experienced by pediatric critical illness survivors and their families in the four domains of physical, emotional, cognitive, and social impairments after PICU have been described as the post-intensive care syndrome in pediatrics (PICS-p) [8, 9].

Child physical and functional health outcomes after PICU discharge can be significant. The literature shows that up to 63% of PICU survivors experience fatigue [10], muscle weakness [11], pain, feeding difficulties, delayed growth, poor sleep hygiene [12], and physical impairment including disabilities and physical dependence that impact their daily life [13]. Likewise, social outcomes reported in older children include struggles with adjustment to school, school absenteeism, identity issues [3, 12, 14], difficulties in engaging with hobbies [15], and delays in personal-social functioning [16].

In relation to child cognitive outcomes after PICU discharge, a systematic review reported cognitive impairment ranges from 3% (significant cognitive decline) to 73% (some degree of impairment), depending on the child's age and the specific outcome measured [10]. Cognitive outcomes included impairment in cognitive ability [10, 17], impaired neuropsychological function up to 6 months after discharge, and changes in intelligence quotient and visual attention up to 12 months after PICU discharge [10, 18]. Underperformance in school and impaired neuropsychological measures have been reported in PICU survivors aged 5 to 16 years [19].

Moreover, overwhelming evidence shows emotional manifestations in children that last months after PICU

discharge in the form of post-traumatic stress disorder (PTSD), anxiety, depression, delusional memories, fear, aggression, and developmental regression [12].

In parents of PICU hospitalized children, emotional manifestations include fatigue, anxiety, and depression, as well as symptoms consistent with PTSD [2, 20-22]. One study showed a drastic increase in mental health diagnoses in parents of PICU survivors, with some receiving anti-depressant and anxiolytic medications [23]. The mental health diagnosis in these families is likely an underestimate and only represents those who sought help [24]. Another study showed that at the time of PICU discharge, 60% of parents are at risk of developing PTSD and 75% are at risk of depression [25]. Besides emotional adverse outcomes, many families experience altered physical health, diminished quality of life, impaired family functioning, and difficulty adjusting to employment and household responsibilities, as well as social isolation [15, 16, 26, 27].

It is important to note that the health and well-being of children and their families are interconnected. While adverse outcomes experienced by PICU survivors can impact the health of their parents and siblings, impaired well-being of families may also negatively affect the recovery of children [2, 5, 9, 28, 29]. For example, Feudtner et al. showed that life-threatening conditions in children were associated with higher rates of healthcare encounters, diagnoses, and medication prescriptions in parents and siblings [30]. Similarly, another study showed an association between parents' PTSD symptoms and children's poor recovery, behavioral issues, and avoidant symptoms [31].

Knowing the struggles of the children and their family post-PICU discharge which can last months if not years later, mortality rate can no longer be the sole indicator of successful treatment in PICUs [3]. A new set of PICU core outcomes has been developed by expert stakeholders and recommended for clinical and research programs. These outcomes are related to the domains of "cognitive, emotional, physical and overall health, as well as specific outcomes such as child health-related quality of life, pain, survival, and communication" [32]. Considering these outcomes within the broader environment and context in which the child and family live in is crucial for understanding critical points of interventions to improve their outcomes and facilitate recovery. We aim to offer a new framework that considers post-PICU discharge outcomes and the trajectory of recovery in children and their families within the context of their environment, to guide future research, clinical programs, and policies.

Methods

Conceptual mapping using Theory Adaptation and Theory Synthesis [8] methods was used to frame theoretical assumptions and possible interactions for understanding post-PICU discharge outcomes in children and families in the context of the systems around them.

Theory Adaptation is a shift in the use and perspective of an existing theory in response to the need for a new perspective to study an existing phenomenon [8]. Theory Synthesis is the integration of multiple theories to introduce a novel perspective to study an existing phenomenon. This method enables researchers to see higher-order perspectives and thereby this allows them to link previously assumed distinct phenomenon and their different domains [8].

For our study, we applied Theory Adaptation to the Bioecological Theory of Human Development (BTHD), a widely used theory in the social sciences for studying children's development and human behavior, to explore the factors that influence post-PICU outcomes and recovery trajectories [33]. We chose this theory as the existing literature describes factor affecting post-PICU outcomes in a non-systematic and separate manner. We introduce the BTHD and discuss its assumptions and benefits. Then, we discuss the PICS-p framework, which is widely used by PICU experts to study PICU outcomes in children and their families. Finally, we use the theory synthesis method to integrate the BTHD into the PICSp framework [8] and introduce our PICSS-PF conceptual framework and its assumptions.

To further specify our Theory Integration, we integrated the outcomes of PICU hospitalization within the broader context of a child's real environment, encompassing their normal developmental trajectory and the contextual factors that shape it. To achieve this integration, we drew upon the theoretical assumptions of the BTHD, to gain insight into the interplay between the contextual factors and health outcomes considered in the PICS-p model. This conceptualization provides guidance for selecting appropriate measures and designing our national study in Switzerland. We entitled this conceptual framework "Post-Intensive Care Syndrome in Swiss Pediatric Patients and Their Families" (PICSS-PF). This longitudinal, observational study will include all eight accredited PICUs in Switzerland and involve a sample of 500 families, with the primary objective of characterizing the occurrence of post-intensive care syndrome over a 6-month period following discharge from the PICU.

Results

BTHD as a comprehensive guide for outcomes' influencers

The BTHD is an evolving theoretical system developed by Urie Bronfenbrenner in1970 as the Social Ecological Theory to advance research into the dynamic interrelations among individuals and their environment. The Social Ecological Theory postulated that to understand human development and behaviors, multiple ecological systems must be considered as influencers. Several modifications and advancements have been made to the Social Ecological Theory, and in 1994, the BTHD was adapted by adding two important components: first, changes over time and second the influence that a child has on their adjacent people while they are also influenced by them. The BTHD emphasizes that if the interaction between the child and their adjacent people persists over time, they will have a bidirectional influence on each other [34, 35].

The BTHD was selected as it views the individual in a holistic manner with specific characteristics who lives in a broader environment and system, which surrounds them, in our case the child. It also considers the bidirectional influence of the child and family on each other, which has been shown to be important. The BTHD places the child at the center of a concentric system around them. These include interpersonal/microsystem, institutional/mesosystem, community/exosystem, and society/ macrosystem. Each system has its unique characteristics and influencers on the child's behavior and development. Regarding the child's intrapersonal characteristics (sex, age, health, developmental stage, and clinical characteristics) are at the center of concentric systems around them.

The four influencing systems around the intrapersonal center include:

1. The interpersonal/microsystem, the *people* in the child's life, such as those at home, school, or daycare, and their characteristics.

2. The institutional/mesosystem, the closest environment in which the child lives and connects with other institutions, including family and school or PICU environment.

3. The community/exosystem reflects the environment in the neighborhood such as churches or mosques, gym, amenities with rules, and norms that can affect the child and family indirectly.

4. The society/macrosystem reflects the farthest away environment, for example, available networks and social resources in a society [36, 37]

Related to the intrapersonal system, some *demographic factors* identified in the literature as being related to post-PICU outcomes include younger age, which is associated with worse functional impairment and higher mortality rate [38, 39]. Boys having higher morbidity and a higher likelihood of PICU admission than girls, while PICU hospitalized girls have a higher mortality rate than boys [39]. Foreign national children show longer PICU hospitalization [40].

Clinical characteristics such as admission type, diagnosis, morbidities, technology dependence, illness severity, organ dysfunction, long PICU stay, rehospitalization, weight and nutritional status, and mobility status can also impact on post-PICU outcomes. For example, unscheduled admission, trauma, oncology, and neurology diagnoses, history of sepsis or meningoencephalitis, and technology dependence such as mechanical ventilation, renal replacement, and heart-lung machines were associated with worse functional and cognitive disability [4, 17, 19]. Illness severity, organ dysfunction, and longer PICU stay were associated with worse functional impairment in children [38]. Nutritional status (underweight and overweight) was associated with worse outcomes, and early mobility was associated with better outcomes and lower infections in PICU children [41-43]. Ventilator dependency at home, tracheostomy, and rehospitalization were also associated with worse psychosocial outcomes in PICU caregivers after discharge [4].

Related to the intrapersonal systems, some potential factors that can be significant in post-PICU outcomes are *parents*' characteristics such as gender, age, pre-behavioral health diagnosis, intellectual ability, language and cultural barriers, experiences in the PICU, and *sibling*'s age, gender, and caring behaviors. For example, in parents, female gender and young age were associated with higher depressive symptoms [44]. Parents with previous psychiatric diagnosis, intellectual disability, language, and cultural barriers have a higher risk of worse psychosocial outcomes after the PICU discharge [4]. Parents' negative emotional experiences in the PICU were related to negative parental outcomes.

Related to the institutional system, family situations and the PICU environment can be essential factors. For example, *family* situations such as committed relationships and family support were associated with lower adverse psychosocial outcomes in parents [4]. Worse economic status was associated with a longer PICU stay and higher mechanical ventilation dependency in PICU survivors [45]. The PICU environment, such as lower general mortality rate in the PICU, nurse patient ratio, and educational and post discharge visit programs, were associated with better patient outcomes [19].

Related to the community system, access to healthcare and friend or extended family support, network size, and density are relevant. Related to the society system, child protective services, and pediatric palliative care service can also be important. For example, transportation challenges are associated with poor outcomes. Friends' and relatives' support, better child protective services, social support, and pediatric palliative care services were associated with better psychosocial outcomes in caregivers of PICU survivors [4, 5]. It is important to note that these examples are not comprehensive, and there may be other factors to consider.

PICS-p framework to study post-PICU outcomes

In 2018, Manning and colleagues developed the PICS-p framework in response to the high comorbidities experienced by children and their families after PICU discharge [9]. This framework, which is the only currently available model for post-intensive care syndrome in children, has been adopted by the pediatric critical care community. The PICS-p framework builds on the post-intensive care syndrome framework proposed by Needham and colleagues explaining outcomes of intensive care unit hospitalization in adult patients and their families [46]. The PICS-p offers a new understanding of the long-term impacts of critical illnesses on children and their families and potential iatrogenic harms on child development, growth, and family functioning following PICU hospitalization [2, 9].

The PICS-p conceptualizes the post-PICU outcomes across four domains for children, including physical, cognitive, emotional, and social health, and two domains for families, including emotional and social domains. This framework also recognizes that recovery can last days to decades, with distinct and different recovery trajectories. Additionally, the framework takes into account a child's baseline condition, their PICU experiences, and the developmental potential of the child, their siblings, and parents as potential influencers of the post-PICU outcomes in children [9].

Integrating PICS-p and BTHD to study post-PICU outcomes To holistically examine post-PICU outcomes and factors affecting both children and their families in our Swiss study, we integrated the PICS-p and the BTHD to form our PICSS-PF conceptual framework. The PICSS-PF conceptual framework encompasses the four domains related to child outcomes from the PICS-p (physical, social, emotional, and cognitive) and the three family outcomes domains (physical, social, and psychological). It also emphasizes the bidirectional interaction and effect between the child and their family on each other's outcomes and recovery. Moreover, the PICSS-PF recognizes the complexity of these outcomes and how they can be influenced by the contextual systems around them from the BTHD, as illustrated in Fig. 1.

The PICSS-PF conceptual framework has six underlying assumptions:



Fig. 1 PICSS-PF conceptual framework. The center highlights the post-PICU outcome domains and different recovery trajectories for children and families, with a focus on the bidirectional influence on each other's health and recovery. Around the center are the contextual systems that influence post-PICU outcomes, with some examples provided

1) PICU survivors may experience adverse outcomes in the physical, social, emotional, and cognitive domains.

2) The family of PICU survivor may experience adverse outcomes in the physical, social, and psychological domains.

3) The PICU survivors and their family may have different trajectories of recovery in each of the mentioned domains.

4) There is a bidirectional influence among the child and their family should be considered together when assessing post-PICU outcomes.

5) Intrapersonal level characteristics are potential influencers of post-PICU outcomes.

6) The four systems around the child, the context in which a child lives, including relatives around the child, clinical and family environments, community, and society, can affect post-PICU outcomes and trajectory of recovery.

Discussion

The hospitalization of a child in the PICU can significantly increase stress levels for both the child and their family. This stress is further compounded by the disruptions to daily routines and recovery from the child's initial condition and any acquired conditions [6, 7, 46]. Children and their families may experience long-term effects on their physical, emotional, and social health and evidently their quality of life [15, 16, 26, 27]. These effects highlight the need to understand the various factors that contribute to the outcomes and the recovery trajectories. As the clinical condition of the child is not the only factor influencing the child and the family health outcomes, it is essential to consider the broader context of their life like social surroundings, interactions with others, and available resources as many of these have been recognized as social determinant of health [47]. This will be in line with the recommendations of the WHO that well-being should encompass physical, mental, and social aspects and defines health as a fundamental human right for all individuals regardless of various contextual factors [1] while many still rely on mortality rates as indicators of successful patient outcomes.

Although the popular PICS-p framework [9] and the set of core outcome measures [32] provided a useful guide to determine the outcome and measurement selection for our Swiss national study, we needed a theoretical framework that could help us to investigate factors affecting these outcomes in a holistic and systematic manner. Our literature review show that many studies focus on the clinical condition of the child and PICU characteristics and consider them as influential factors [4, 17, 19, 38]. However, some studies talked about the importance of higher-order factors in child development, health, and PICU outcomes and mention that "disparities in the risk, care, and outcomes of critical illness in children are prevalent and unacceptable" [48]. Some studies shed light onto the importance of considering the effects of social determinants of health on the child and family outcomes, mostly by addressing disparities in the family environment, economic status, and financial instabilities [45, 49]. PICU families with low socioeconomic status and social supports have higher morbidity and mortality [4, 5]. Also, as discussed in the result, the bidirectional nature of child-family influence on each other wellbeing was evident [2, 5, 9, 28, 29, 30, 50].

Therefore, we adapted and integrated the BTHD [35] with PICS-p [9] and proposed the PICSS-PF conceptual framework. PICSS-PF conceptual framework provides a new lens to holistically and systematically investigate factors affecting post-PICU outcomes and recovery in children and their families by recognizing the complexity of the outcomes and the way they can be influenced by the contextual systems around them. It also acknowledges the bidirectional interaction and effect between the child and their family on each other's outcomes and recovery.

The PICSS-PF conceptual framework helped us in considering and choosing our measurement from the multiple systems and levels of influencers that contribute to the child's and family's experiences and looking beyond the clinical environment and the clinical characteristics of the child. These include the child's intrapersonal characteristics, environment, community, and available social resources. These factors encompass the child's physical and psychological health, developmental stage, and individual characteristics, as well as family caregiver attributes such as gender, age, previous experiences, intellectual disability, language, and cultural barriers which have been found to impact psychological outcomes [44]. Additionally, the framework emphasizes the importance of the family resources, committed relationships [4], support networks, and coping strategies, cultural beliefs, and values. The literature suggests that the quality of care the child received in the intensive care unit, as well as the availability of the ongoing support, and resources after discharge such as protective services, social support, and pediatric palliative care services are associated with improved psychosocial outcomes [4, 5].

The PICSS-PF conceptual framework could also guide other researchers in the selection of measurement for studying the PICS to better characterize the factors that influence it with the purpose of strengthening and refining the potential attributers. This conceptual framework offers a notable advantage to clinically focused frameworks due to its comprehensive nature, surpassing the mere consideration of clinical and demographic aspects of the child. It is important to acknowledge that a substantial sample size would be necessary to effectively examine all multifaceted factors of the model. Nonetheless, with sophisticated analytical models permitting analytical flexibility, such as growth mixture models, meaningful analyses can be undertaken to reflect the real-life environment in which the outcomes occur. Such statistical models would enable the investigation of contextual effects, moderation, and mediation effects, as well as the identification of potential latent groups characterized by varying contextual factors and available resources, facilitating the examination of PICS distinct trajectories [51].

The *clinical implications* can be that by understanding the multiple levels of influence that contribute to PICS in children and their families, healthcare providers can develop thorough and effective interventions during the discovered critical points. This may include screening for social determinants [48], providing individualized family support using a systemic approach, and providing social support, rather than just focusing on the child's individual symptoms. It may also involve connecting families with community resources and providing culturally sensitive care [48, 52].

The utilization of the BTHD framework for elucidating and presenting PICS serves the purpose of capturing the attention of policy makers towards a more comprehensive understanding of the PICS phenomenon. This, in turn, facilitates investment in transitional programs from hospital to home, as well as in rehabilitation programs and social services, focusing on the provision of emotional and physical support required by these families [53]. Such investments aim to enhance the seamless transition of these families to their optimal functional capacity and to allocate resources effectively for followup programs that encompass a broader scope beyond the clinical assessment aspects pertaining to both the child and their family.

Conclusion

Overall, PICSS-PF conceptual framework provides a better understanding of the complex interplay of factors contributing to PICS in children and their families. Researcher and healthcare providers can understand and characterize PICS outcomes and trajectory in a more holistic, context-driven way to develop more effective interventions and to improve the quality of care and outcomes for children and families after PICU discharge. The framework also has the potential to attract attention of the policy makers to the complex health trajectories of PICU survivors and their families and to influence policies to mitigate the burden of PICU stay on patients and families. Additionally, it can have a broader societal impact by enhancing the physical and emotional welfare of both children and their families, thereby fostering a healthier and more efficient populace.

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Code availability

Not applicable.

Authors' contributions

All authors made substantial contributions to the conception of the manuscript (first draft by ZR), thoroughly reviewed, approved it, and are fully responsible for its content. They also gave explicit consent to submit the manuscript before submission.

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Availability of data and materials

Not applicable.

Declarations

Competing interests

The authors declare that they have no competing interests.

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