

**Post Intensive Care Syndrome in Swiss Pediatric survivors and their Families [PICSS-PF]:
A Multi-center Prospective Cohort Study**



Project Summary

«...hospital discharge is, in a way, just the beginning of the journey»[1]

In Switzerland more than 4000 children become critically ill and require life sustaining treatment in Pediatric Intensive Care Units every year [2]. While advances in therapies and care have increased survivorship rates in PICUs, emerging research indicates widespread morbidity of PICU survivors and their family after PICU discharge [3, 4]. Besides struggling with initial critical condition recovery, they deal with acquired comorbidities or altered functioning due to hospitalization [5, 6] that can persist with adverse consequences for children development and families psychosocial health [7, 8].

Experts conceptually have categorized the outcomes of the PICU hospitalization into four domains: physical, emotional, cognitive and social for pediatric survivors, and two domains: social, and psychological for their family members with potentially different trajectory of recovery [3] [9]. Children's health and well-being are interlocked with their family well-being which both are influenced by many factors around them (e.g. available community and society resources). The Bioecological Theory of Human Development (BTHD) specifically emphasizes the bidirectional influences of children and their immediate people including their parents, and siblings [10]. It also provides a comprehensive guide on different influencing factors including intrapersonal (child demographic and clinical characteristics), interpersonal (sibling and parents characteristics), institutional (family unit and PICU environment), and community and society (available resources and networks) level factors [10].

Post intensive care syndrome (PICS) is well described in adult ICU patients [11], but not in children. A systematic review in 2017 identified 19 studies investigating outcomes in PICU survivors with great heterogeneity between studies [12]. With the recent, PICS-p framework and new recommendations for core outcome measures provides a new lens to research post-ICU outcome research in children and their family [13, 14]. However, these core outcome measures are currently not available in the routinely collected data in Switzerland, as part of the minimal dataset for Swiss PICU accreditation.

Within the scope of this study, we aim to collect those necessary data in PICU survivors and their family caregivers and siblings to characterize pediatric PICS. We also aim to identify children and their families at increased risk of impoverished physical and psychosocial health outcomes post PICU-discharge and find potential modifiable risk factors amenable to next steps intervention development. The specific aims of this multicenter, national, longitudinal study are to:

1. Describe the physical, emotional, social, and cognitive functioning in PICU survivors, their sibling and primary family caregiver at PICU discharge and its changes over the 6-month post-discharge period using descriptive statistics and spaghetti plots.
2. Explore heterogeneity within the outcomes trajectories over the 6-month post-discharge period using growth mixture Structural Equation Models (SEM).
3. Identify the risks and protective factors (child's clinical and demographic characteristics, PICU specifications, sibling and caregiver's characteristics, family and social resources) associated with better PICU discharge outcome and with better recovery over the 6-month post-PICU discharge period in pediatric survivors and their family using SEM.
4. Demonstrate the bidirectional effect of child's and family outcomes on each other over the 6-month post-PICU discharge period using longitudinal bidirectional SEM.

The ultimate goal of this program of research is to improve post-PICU transitions of children and their family caregivers, focusing on modifiable risk and protective factors consistent with the roadmap for pediatric and neonatal science in Europe [15], and priorities of the international pediatric critical care research priorities [16].

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