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Post Intensive Care Syndrome in Swiss Paediatric survivors and their Families (PICSS-PF): a national, multicentre, longitudinal study protocol

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ABSTRACT

Introduction Paediatric intensive care units (PICUs) survivors and their families often experience widespread morbidity and psychosocial consequences after discharge, known as post-intensive care syndrome in paediatrics (PICS-p). In Switzerland, more than 5000 children are admitted to PICUs each year, and despite the high survival rate, there are no data on post-PICU recovery. This study aims to investigate PICS in children and families and identify its associated factors.

Methods and analysis This is a national, multicentre, longitudinal, observational study that includes PICU survivors, main family caregivers and siblings (n=1300) recruited from the eight Swiss accredited PICUs with follow-up at discharge, 1, 3 and 6 months after discharge from the PICU. Data will be collected on the domains of physical, emotional, social and cognitive health, as well as factors affecting the outcome related to demographics, clinical specification, PICU and family environment, as well as community and social resources. Structural equation models and growth mixture models will analyse the outcomes, and the heterogeneity of recovery that shed light on the diverse recovery experiences of children and their families. The study identifies risk and protective factors with a focus on the influence of social and familial resources. It will also explore the mutual impact of the child's recovery and parent/sibling psychosocial health.

Ethics and dissemination The protocol is approved by the CER-VD ethics committee. Participants will be provided with verbal and written explanations of the study, and their privacy and anonymity will be protected throughout the process. The results will be presented at local and international conferences.

Approval number Swiss ethics committees ID: 2022-02128, representing the eight cantons for both French and German-speaking parts of Switzerland.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study encompasses all accredited paediatric intensive care units within Switzerland.
⇒ The study is being conducted in three languages of German, French and English.
⇒ We investigate physical, psychological and social outcomes in children and their families.
⇒ We determined the risk factors from individual, family, community and society factors influencing the recovery process.
⇒ We use advanced statistical models to discover potential heterogeneities within our population.

INTRODUCTION

In recent decades, advances in therapy and care have decreased the mortality rate of children who needed a paediatric intensive care unit (PICU) admission. However, this has led to a higher number of survivors with moderate to severe morbidity.[1] Recent studies indicated that after discharge from the PICU, many children may experience physical and cognitive impairment that affects their daily life.[2 3] Furthermore, both children and their parents experienced emotional symptoms consistent with post-traumatic stress disorder (PTSD), anxiety and depression.[4–6] After PICU discharge, families of PICU hospitalised children demonstrated decreased quality of life due to impaired family functioning, and interruption in employment and social life.[7–10] Moreover, many of the siblings experience emotional distress and behavioural changes.[6 11]

These adverse outcomes in PICU survivors and their families have been described as postintensive care syndrome in paediatrics (PICS-p),[12] which has been categorised into four domains of physical, emotional, cognitive and social for children, and two domains of social and emotional for families. They also consider different potential recovery trajectories for children and their families.[4]

These adverse outcomes can persist for months to years and negatively impact children's development and family psychosocial health.[13 14] Therefore, for these children and their families, the mortality rate alone as an outcome measure can no longer be a sensitive indicator of successful treatment in the

PICU.[3] Current worldwide evidence shows a large heterogeneity between studies in terms of child age, developmental stage and clinical characteristics. Additionally, they mostly measured PICS outcomes related to one of the four domains and did not address comprehensively factors that could affect the results, especially in the context of child–family dyads. The lack of evidence is highlighted in the Swiss PICU population, which is mainly a mixed PICU with neonatal intensive care (NICU) with more than 5000 children treated in the PICUs every year.[15] We currently lack a robust understanding of how to characterise post-PICU challenges in paediatric populations and their family. Routine data collected in patients in the PICU recorded in the Swiss national registry are limited to care characteristics and mortality and do not provide information on the cognitive and developmental status of children during and after their stay in the PICU, nor on their family health.

We aim to build our study on the existing work of Manning *et al* and Curley and Scott in the UK and the USA,[16 17] as well as adding novel measurements and a conceptual framework that considers different systems, family, community and society resources around the child[18] in investigating the influential factors. This will allow us to have Swiss PICU survivors' data comparable to international data while providing new insights. We aim to answer to the following questions:

1. What are the health outcomes and recovery of PICU survivors and their families?
2. Who is at risk of the worst outcome and recovery?
3. What are the modifiable risk and protective factors for better outcomes?

The specific objectives are to:

1. Describe the physical, emotional, social and cognitive functioning of PICU survivors, their siblings and their primary family caregiver at the time of PICU discharge and its changes during the 6-month period after PICU discharge.
2. Explore heterogeneity within the outcome's trajectories over the 6-month post-PICU discharge period.
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 discharge outcomes and recovery over the 6-month post-PICU discharge period in paediatric survivors and their family.
4. Demonstrate the bidirectional effect of child's and family outcomes on each other over the 6-month post-PICU discharge period.

METHODS AND ANALYSIS

Design

A national, multicentre prospective cohort study that is conducted from December 2023 and will continue until January 2025.

Population

PICU survivors, their main family caregivers and siblings (n=1300) from the eight accredited PICUs in Switzerland with a total of 100 beds and more than 5000 admissions per year. Five of the PICUs are from tertiary hospitals in Basel, Bern and Zurich (German speaking) and Geneva and Lausanne (French Speaking); three PICUs are from regional hospitals in Chur, Luzern and St-Gallen (all German-speaking). Except for the Lausanne PICU, all other PICUs are mixed PICUs (PICU that includes NICU).

Eligibility criteria

PICU survivors:

1. Aged between 1 day (corrected gestational age) and 18 years old.
2. Being in PICU for more than 48 hours.
3. Able to answer the questionnaires in English, French or German (>8 years).
4. Alive at the time of discharge.

Family caregiver inclusion criteria:

1. Only one of the parent or legal guardians who lives with the child and has the main responsibility of the child.
2. Agreeing to participate (signed consent).
3. Being able to answer the questionnaires in English, French or German.

If applicable one sibling of the PICU survivor who is:

1. Only one of the siblings who lives with the PICU survivor (more than 4 days a week).
2. Older than 8 years.
3. Able to self-report questionnaires in English, French or German.

Exclusion criteria: (a) either parent or child rejects participation and (b) child passed away during PICU stay or during the study.

Study procedures

The Post Intensive Care Syndrome in Swiss Paediatric Survivors and their Families (PICSS-PF) project started by forming the PICSS-PF research consortium that includes all eight PICU medical and nursing heads, as well as nurse collaborators, and by writing the protocol, seeking and obtaining funding, collecting questionnaires in the two main languages spoken in Switzerland, namely French and German, as well as English to maximise study participation, and translating questionnaires that did not have validated translations based on 'good practice principles for translation'.[19] Different versions of information sheets and consent forms were prepared, including 7 sheets based on the target participant and their age in the three different languages for the 8 different participating centres, 168 versions in total.

The study data will be collected and managed using REDCap electronic data capture tools hosted on a secured server at the University Hospital of Lausanne. REDCap was set up and tested for complete automated longitudinal data collection in three arms (survivors, parent,

sibling). The study educational package was developed to train study nurses to be familiar with the conduct of the study, the recruitment and the entry of REDCap data at each site. At each site, two study nurses and physicians are assigned to screen, and obtain consent, and contact information of the participants. All eligible patients/families will be invited and the number of rejections of participation will be recorded. Families will be recruited after they meet the inclusion criteria,

Data collection started in May 2023 and will continue for 18 months. Survivors' and families' initial characteristics, their preference way of communication (text message, email, paper based posted to their address), as well as child clinical data will be extracted from electronic health records (EHRs) by study nurses/physicians and inserted in the central REDCap system of Lausanne University Hospita.

Data for children, families and siblings (when appropriate) will be collected at five time points: predischarge (retrospectively at the time of discharge), discharge, 1 month, 3 months and 6 months after discharge (prospectively). This will be through online, self-reported (for parents and children >8 years) and parent-reported (children <8 years) questionnaires via a hyperlink sent to their email address or phone number. For those families who prefer paper-based questionnaires, the questionnaires will be sent with a prepaid return envelope. The total estimated time to complete the questionnaires by parents is 45–60 min, and for children and siblings 20 min. Each family will be offered a 30 CHF gift card, after completing all questionnaires at each time point, as a way of appreciation.

Questionnaires that are received by post will be entered into the REDCap system by one of the Lausanne lead team (ZR) and will be securely stored at CHUV, in locked lockers after deidentification. The lead research team will oversee the coordination/facilitation of the recruitment in all sites. The nurse collaborators will be asked to inform the PI right away if any deviation is made.

Data quality: the quality of data entry will be regularly checked by assessing REDCap entries. The quality of data entry will be ensured by direct data entry using an online questionnaire linked to REDCap. The quality of data analysis will be continuously checked between ZR and A-SR, and, if necessary, by an external statistician. For quality assurance purposes, the ethics committee may visit the research sites. Direct access to the source data and all project-related files and documents will be granted on such occasions.

Measures

The outcomes measures of this study are related to the post-PICU discharge physical, emotional, social and cognitive functioning of PICU survivors, and the social, emotional, and physical health of the sibling and primary family caregiver. The measurements in each domain were chosen by reviewing the literature and selecting the ones that were deemed relevant and most widely used. Online supplemental appendix A is a summary of all measures, questionnaires, measurement time points, scoring and psychometrics.

Regarding survivors' physical outcome readmissions, technology dependence, body mass index z-score and paediatric quality of life in physical, emotional, social and school domains will be measured. Regarding survivors' emotional and social outcomes PTSD, and behavioural problems will be measured, and survivors' cognitive outcomes will be measured by cognitive functioning assessment.[20]

Regarding the psychological outcomes of the family caregiver PTSD,[21] anxiety and depression will be measured.[22]

Family caregiver physical outcomes will be measured by assessing their sleep impairment,[23] and family functioning in eight domains of physical, emotional, social, and cognitive, communication, worry, daily activities, and family relationships.[24]

Sibling outcomes will be measured by assessing their behavioural problems and quality of life in physical, emotional, social and school life dimensions.

To study influential factors, the risks and protectors, systems around the child/family and the context they live in were considered.[18] All potential influential factors will be collected 48 hours after PICU.

Regarding the demographic and clinical characteristics of survivors, the nurse of the PICU will extract the following measures using EHR: gender, age and nationality, admission to the PICU and diagnosis of discharge, type of admission, length of stay in the PICU and hospital, destination after discharge from the PICU, state of sepsis, cerebral performance and level of consciousness of the patients based on their eye reactions, verbal and motor responses,[25] mobility of the patient, respiratory support, length of mechanical ventilation, nutrition status (parenteral nutrition, enteral nutrition and feeding difficulty at PICU discharge).

PICU characteristics will include 60-day post-PICU mortality rate, PICU nurse to patient ratio at the time of patient admission, patient education programmes and satisfaction of the programmes, post-PICU discharge visits satisfactions.

Sibling characteristics will be collected self-reportedly by one of the patient's siblings who is engaged in the child's care and is above 8 years of age including their gender, age and caring activities with six domains of domestic, emotional, financial, household, personal and sibling aspects.[26 27]

The characteristics of the family caregiver will include: their relationship to the child, gender, age, nationality, immigration status, educational level and employment. The general physical health of family caregivers before hospitalisation (retrospectively) and at the PICU discharge time will be reported using the general physical health questionnaire.[28] The PICU experience of the family caregiver related to five domains of information, care and cure, organisation, parental participation and

professional attitude will be reported using the PArent EMpowerment Questionnaire in THe Intensive Care-30.[29]

Family characteristics measures will include the existence of committed relationships, language barriers and poverty level based on the number of family members and the Swiss poverty line.[30]

Community and social resource measures will consist of perceived social supports with five domains: attachment and intimacy, social integration, nurturing behaviours, worth reassurance and availability of help for information, emotional support and material,[31] as well as the size and type of network for seeking information and help, and access to healthcare.

Statistical analysis plan

Data will be checked for any errors, missing, normality of the variable's distributions, linearity of relationships, outliers and collinearity. SPSS (IBM) V.26 and MPLUS (Muthen and Muthen, Los Angeles, California, USA) V.8.4 will be used to perform the analysis. To describe the physical, emotional, social and cognitive functioning in PICU survivors, their siblings and primary family caregivers at PICU discharge, descriptive statistics including number, percentage, central tendency and dispersions will be used. To describe the 6-month trajectories of physical, emotional, social and cognitive functioning of PICU survivors and their siblings and primary family caregivers after PICU discharge, spaghetti plots will be used.

To explore heterogeneity among outcome trajectories in PICU survivors and their siblings and primary family caregivers after PICU discharge structural equation, latent growth mixture models will be used. These models, in addition to handling observed and latent variables, tease out potential heterogeneity among the recovery trajectories. The model will start with two classes/profiles, and more profiles will be added until no improvement in the model is seen. Model improvement will be based on Akaike information criteria and Bayesian information criteria; a lower value shows a better model. Also, the bootstrap likelihood ratio test will be performed to see if the k-profile model is significantly better than the k-1 profiles model.

To identify associated characteristics with the baseline outcomes and with the potential heterogeneities in the outcome recovery, structural equation models (SEM) path models will be used, which can handle latent and observed variables, non-normality, heteroskedasticity and non-linear associations. To judge the fit of the model, the Comparative Fit Index, the standardised residual root mean squared error of approximation and the root mean squared error of approximation with a cut point of >0.95, <0.08 and <0.06, respectively, and the relationships will be reported using standardised beta coefficients and p values. Considering a p value of 0.05 as a significant result.

To demonstrate the bidirectional effect of child and family outcomes on each other over time, bidirectional longitudinal SEM will be used. These models, in addition to handling observed and latent variables, can look at the dyadic influence of child and family on each other while looking at changes over time.

It is worth noting that due to the diversity in age and clinical characteristics within the data to be collected, we may also conduct subgroup analyses for each of our objectives.

Sample size

In terms of estimating power, we will use SEM with maximum likelihood with a robust estimator. In estimating power for these techniques, the focus is on the quality of the model and the power to reject the null for the 'focal parameters'—those that reflect the relationships of interest. The common model fit indices that are used in calculating the sample size and power analysis is the root mean square error of approximation (RSMEA). Assuming a moderately good model, a realistic and accessible value of RSMEA=0.02, with a power of 0.80 and df=50, we need to have 400 cases.[32] Assuming 20% attrition, we aim for 500 families. The following formula will be used to calculate df, df=(K (K–1))/2)–P, K=number of variables, p=number of parameters.[32] In addition, using alternative statistical methods, a similar study estimated 300 cases as enough sample size regarding 20% attrition during the study, detecting small and medium effect size in many of the outcomes and with 80% power.[17] Therefore, we aim to have 500 children, 500 parents and 300 siblings. Regarding the admission rate in Swiss PICU and our inclusive inclusion criteria, we will have enough sample size. However, we can explore alternative approaches in the event of a reduced sample, including making composite or latent variables, compacting appropriate measures or including only significant bivariate associations in the last models.

Patient and public involvement statement

The initial idea of this research came from talking to the families that had their children hospitalised in the PICU.

Patients were involved in pretesting the questionnaires and modifying the instructions.

The study results will be disseminated through our PICSS-PF website: https://wp.unil.ch/picss-pf/

Ethics and dissemination

This multicente study has been approved by the CER-VD as the lead centre of the Swiss ethic committees: 2022-02128, representing the eight cantons for both French-speaking and German-speaking part of Switzerland with the selection of the canton of Vaud as the primary ethic committee. The seven forms are: consents for parents' participation, for children aged less than 11 to be signed by their legal guardian, 11–14 to be signed by the child and legal guardian, more than 14 to be signed by the child, as well as three consents for the siblings regarding their age range, online supplemental appendix B. Children under 11 years of age will also receive a verbal explanation and give verbal assent (art. 21 LRH).[33] Written consent and verbal assent will be collected from adults

and children after explaining the study to caregivers, legal guardians and children, and giving enough time to reflect at least 48 hours. We will ensure participants' right to dignity, privacy and health. The anonymity of the participants will be ensured when the data are presented at scientific meetings and the results are published.

Questions about anxiety and depression, or child functional status, or recalling PICU experiences may pose discomfort or distress to caregivers and older children. In that case, they will be offered psychological support that is already in place in our clinical practice. Children, their parents and siblings can withdraw from the study at any time without justification. After withdrawal, they will not be contacted, and no more information or data will be collected from them. Their previous data will be anonymised, and their name and identifiers will be deleted.

Expected limitations and dissemination

Incomplete data are a potential problem. Close monitoring and follow-up of participants should reduce that risk. To reduce the bias of drop-out, lost to follow-up and missing values, we will recruit 20% more participants, increase our response rate by using research documents in German, French and English, and short questionnaires, by sending reminders, and offering some incentive according to ethics regulations.

In terms of missing values, we will perform comparison analyses between participants and non-participants, as well as missing value analysis such as the Little MCAR test. We will use robust estimators (full information maximum likelihood estimator for our analysis. This estimator handles the missingness by estimating coefficients from all the available values. Moreover, some measures can still compute scores with missing data, like PedsQL up to 50% missing.

There may be limitations to generalisability in any study. The result of this study can be generalised to children and their families after PICU discharge in Switzerland, and other countries that have similar contexts. In our design, we are as inclusive as possible, and we will handle the variation in our analysis by collecting data on potential confounders and controlling them.

The aggregated results of this study will be communicated to all healthcare professionals from the participating PICUs and the paediatric intensive care postgraduate education departments. It will also be available to the participants on their request. Key messages of the study results will be communicated through our personal and our official PICSS-PF website https://wp.unil.ch/picss-pf social media to the public. The study and the results will also be presented at local, national and international conferences.

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Contributors ZR initiated and designed the study and performed the literature search as a postdoctoral fellow under the supervision of A-SR. JCM and M-HP contributed to the study design as coinvestigators. ZR drafted the manuscript and all coauthors A-SR, M-HP and JCM contributed to revisions of the manuscript and approved the final version and take full responsibility for the final article and controlled the decision to publish.

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Disclaimer The sponsor and the funders will not have any influence over data collection, management, analysis, and interpretation of data, or writing of the report, and the decision to submit the report for publication.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication One hundred sixty-eight different consent forms depending on the role and the age of participants, the language they speak and the centre they are hospitalised were prepared and submitted to the Swiss Ethics (the English versions are attached as online supplemental appendix B).

Provenance and peer review Not commissioned; externally peer reviewed.

Author note Project data will be handled with the uttermost discretion and is only accessible to authorised personnel who require the data to fulfill their duties within the scope of the research project. In the CRFs and other project-specific documents, participants are only identified by a unique participant number. Each patient will have an ID code and this unique identifier will be used for data analysis. Access to the data from this project will be secured and restricted to authorised persons. All coded data will be analysed according to the indications provided in this protocol and with respect to data protection. No publication or report of any kind will contain the names of patients or any identifying characteristics of a single patient. No online or written document or communication will refer to participants personal details. Identifiers (name, surname, email or postal address and phone number) collected via REDCap will be flagged in the REDCap system, so they get stored separately in the REDCap system. Only the project leader and the sponsor representative (ZR and A-SR) in Lausanne will have access to these data and identifiers afterward. Identifiers will only be used for recontacting the participants for study follow-up. The coded data and identifiers of the participants will be stored

in a separate locked file on the secured CHUV server. Paper-based data received by post in preaddressed sealed envelopes at the research team at the IUFRS will be entered into the REDCap system by the Lausanne lead and will be stored in a locked cabinet after deidentification at CHUV. Data processing is subject to the Federal Data Protection Act of 19 June 1992. The Ethics Commission and the competent cantonal authorities may request the original data of the study at any time. The results will be published in aggregated form and participants will not be recognised.

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