



ChrOnic CriTical illness in Pediatric intensive care in Switzerland (OCToPuS)
Needs and psychosocial outcomes of families



ABSTRACT

BACKGROUND: Chronic critically ill (CCI) children are characterized by prolonged intensive care unit (ICU) length of stay, repeated ICU admissions, and a dependence on technologies to sustain vital functions. They represent until 5% of the total paediatric ICU admissions but may account for up to 80% of the total ICU cost. Their mortality rate is high compared to the overall ICU children, and a high proportion of survivors live with disabilities, poor quality of life, and psychological impairments. When a child is hospitalised in ICU, it affects the entire family unit with parents experiencing high anxiety (50%), stress (80%) and post-traumatic stress disorder (30%). Parental stress is associated with poor family functioning that in turn negatively impact children's psychological health. Following the initial acute phase in ICU, families become more familiar with the environment and develop knowledge about the medical needs of their child. When they get more involved and participative, they also feel less informed as the weeks goes by. Needs of clear communication and individualized coordinated care are often unmet. The literature specific to CCI patients and families is scarce. Because family support interventions is highly context-dependent, it is essential to build up a body of knowledge related to the experiences and needs of families with CCI children in Swiss PICUs, prior to developing a model of care for this specific vulnerable population. This national study involving all PICUs in Switzerland is part of the overall OCToPuS project and, to the best of our knowledge, the first to specifically focus on CCI families.

AIMS & OBJECTIVES: The main of this study is to measure the impact of CCI hospitalization on families over time with the following specific objectives:

- To identify needs of families of CCI children over time throughout the PICU hospitalization (*Quantitative*)
- To identify the following psychosocial outcomes: perceived stress, PICU-related sources of stress, perceived child's quality of life and family functioning of families of CCI children over time throughout the PICU hospitalization (*Quantitative*)
- To identify risk factors of high stress, poor family functioning and unmet needs of families of CCI children during a PICU hospitalization (*Quantitative*)
- To explore specific needs, sources of stress, and family functioning emerging in families of CCI children during a PICU hospitalization (*Qualitative*)
- To interpret in what extent needs, sources of stress, and family functioning of families of CCI children converge or diverge from those of the PICU families (*Mixed-methods*)

METHODS: This multicentre national mixed methods study will be conducted in the eight accredited pediatric intensive care units (PICU) in Switzerland. Over an eight-month period, a convenience sample of CCI families (dyads) will be invited to complete validated questionnaires addressing their needs, family functioning, perceived stress and sources of stress. Family members will also evaluate their child's quality of life prior and after PICU admission. Assessments will be done at various time points during the PICU hospitalization, and one month post-PICU discharge. A smaller purposive sample of the participants will then be invited to semi-structured interviews. Authorizations for use and translation have been granted for all of the above questionnaires. The project has been submitted for ethics approval.

EXPECTED OUTCOMES: The results of OCToPuS will inform clinical practice with the ultimate goal to provide meaningful and comprehensive recommendations to support families and healthcare professionals in Switzerland and beyond.