

Summary of the PhD Thesis

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Year of completion	2016
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Curriculum Vitae

Karin Zimmermann holds a degree in paediatric nursing with more than 20 years of clinical experience, mainly in the field of paediatric haematology/oncology. In 2016 she received her doctorate at the University of Basel, Department of Public Health - Nursing Science with her dissertation "Paediatric End-of-Life CAre Needs in Switzerland (PELICAN): Current end-of-life care practices and the perspectives of bereaved parents". Currently, she is a lecturer at the University of Basel, Department of Public Health - Nursing Science, and a postdoctoral researcher, half in Basel and half at the Competence Center Pediatric Palliative Care at the University Children's Hospital Zurich. At both locations Karin Zimmermann together with PD Dr. med. Eva Bergsträsser from the University Children's Hospital Zurich leads the SPhAERA research project (Specialised Paediatric Palliative CaRe: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings).



Description of the project

Paediatric End-of-Life CAre Needs in Switzerland (PELICAN): Current end-of-life care practices and the perspectives of bereaved parents

Despite continued advancements in medical care and improved survival or life expectancy, childhood deaths due to complex chronic conditions (CCC) or prematurity are inevitable. Deaths during the first year of life constitute approximately 50% of disease-related deaths, the causes of which include perinatal complications, prematurity, or congenital anomalies. Beyond the age of one year, the three

most common life-limiting CCCs are neurological/neuro-muscular and cardiovascular conditions (including genetic disorders), and malignancies. The majority of disease- and pre-maturity-related deaths occur in hospitals and for children dying at home, hospital use in their terminal stage is high. Symptom burden and reliance on medical technology has been reported to be considerable. Circumstances and characteristics of deaths, however, are known to vary by age and medical conditions. When facing the death of their child, parents experience an unimaginably painful life event and severe crisis that affects the whole family for life. In this highly stressful time parents are confronted with uncertainty and are required to make difficult decisions, e.g., withdrawal of life-sustaining interventions. Their need for compassionate professional support is high. Paediatric palliative (PPC) and end-of-life (EOL) care emerged as a medical subspecialty aimed at meeting the specific needs of seriously ill children and their families. Meeting these needs requires a comprehensive and integrative approach from a compassionate and skilled multidisciplinary team. This dissertation is embedded in the PELICAN study (Paediatric End-of-Life CARE Needs in Switzerland, 2012–2015). The overarching aims of the nationwide PELICAN study were to provide comprehensive information and to understand the current practice of EOL care (i.e. in this study, the last 4 weeks of life prior to death) in paediatric settings in Switzerland (hospital and community care) (PELICAN I) and to explore and describe parental perspectives (PELICAN II QUAN3qual) and the perspectives of the healthcare professionals involved (PELICAN III). Based on the results, recommendations for best-practice during this highly vulnerable and critical phase of life not only for the affected child but also for the family will be formulated. The dissertation comprises PELICAN I and the quantitative part of PELICAN II, including the development and testing of the Parental PELICAN Questionnaire (PaPEQu). Four articles were integrated including the PELICAN study protocol (Bergstraesser et al., 2015) and a methods paper about the development and testing of the PaPEQu (Zimmermann et al., 2015).

PELICAN I reports on patterns of care at EOL in neonates and children with complex chronic conditions. Data from 149 paediatric patients who died in the years 2011 or 2012 due to a cardiac, neurological or oncological condition, or during the neonatal period were collected in 13 hospitals, two long-term institutions and 10 community-based healthcare service providers throughout Switzerland. Sixty-two percent of the patients died in intensive care units, 84% of them following the withdrawal of life-sustaining treatment. Reliance on invasive medical interventions was prevalent, and the use of medication was high, with a median count of 12 different drugs during the last week of life. Patients experienced an average number of 6.42 symptoms. The prevalence of various types of symptoms differed significantly among the four diagnostic groups. Only half of the patients who spent days at home received community-based healthcare. The study provides a comprehensive overview of current EOL care practices in a real-life setting of different health-care providers and the findings provide a knowledge base for paediatric palliative care teams (Zimmermann et al., 2016a). PELICAN II reports on the results of the survey with the newly developed PaPEQu. Responses regarding parental experiences and perceived satisfaction are described. Differences between the four diagnostic groups are analysed using a generalized estimation equation to account for the dyadic data structure. Of 307 eligible families, 267 could be contacted and 135 (51%) consented to participate in this questionnaire survey. Our findings show positive parental experiences of their child's EOL care and high perceived satisfaction with the care their child received. Parents of a child with cancer rated their experiences highest in most of the six quality domains and reported the highest satisfaction with care. The lowest scores were mainly reported by parents from the neurology group, with the exception of the shared decision making domain, where parents of neonates reported significantly less positive experiences. Although positive in general, our study results suggest some areas for improvement. The integration of specialised paediatric palliative care has the potential to minimise lost opportunities to support and assist parents (Zimmermann et al., 2016b). The dissertation concludes with the recognition that urgently needed data to advance the development of PPC in Switzerland is now available. It also recognises, however, that we are challenged to demonstrate the effectiveness of PPC services in order to grow out of the infancy of this medical sub-specialty.

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Zimmermann, K., Cignacco, E., Engberg, S., Ramelet, A.-S., Von der Weid, N., & Eskola, K. (2016). Patterns of care at end-of-life in neonates and children with complex chronic conditions: A nationwide chart review across different care settings. *Manuscript submitted for publication*.

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