



Pediatric End-of-Life Care Needs in Switzerland (PELICAN) Summary

Cignacco E; Zimmermann K; Bergsträsser E (2012 – 2015)

Background: Children living with life-limiting conditions have always been part of the health care system. Although there have been dramatic improvements in medical care, hundreds of children continue to die annually. The field of paediatric palliative care (PPC) and end-of-life (EOL) care is based on the principle that an interdisciplinary team should care for patients and their families. However, evidence on how to provide optimal PPC and EOL care covering the needs of children and their families is scarce and lags substantially behind that in the adult world. Few is known on how EOL care – defined as the last four weeks of life in this study - is presently provided in the Swiss health setting. The presented study **Paediatric End-of-Life Care Needs in Switzerland [PELICAN]** covers paediatric EOL care and will contribute to a comprehensive understanding of EOL care in Switzerland by analysing retrospectively medical charts of children/young people between 0 - 18 years who died in the years 2010 and 2011 in Switzerland. A survey instrument will be developed and pilot tested to assess the perspectives of families who have experienced the loss of a child. After the development pilot testing and adaptation of the instrument a survey with parents who lost a child in the years 2010 and 2011 will take place. Furthermore, the experiences and needs of health professionals working in the field of pediatric EOL will be explored.

Aims and methods:

PELICAN 1: Aim 1: Retrospective analysis of cases of death during a two-year period (2010 and 2011) by chart review (n = 320). The four most common illness-related causes of death in childhood will be regarded: 1) life-limiting conditions of the neonate (birth to 4 weeks of age) 2) cancer (all cancers), 3) neurological conditions, 4) cardiac diseases. **Method:** Retrospective, secondary data analysis.

Aim 2: Development and validity and reliability testing of a questionnaire to explore parent's experiences and needs in the EOL care of their child (n=320) **Method:** psychometric testing.

PELICAN 2: Aim: To explore and describe retrospectively parent's experiences and needs in the EOL care of their child. **Methods:** Cross sectional survey by a questionnaire and interviews by semi-structured questioning using thematic analysis of interviews.

PELICAN 3: Aim: To explore health care professional needs in pediatric EOL-care by focus group interviews.

Expected value of the project: We expect to receive essential epidemiologic data which will serve as a baseline to plan and extend urgently needed EOL care services for children and their families. This baseline is also needed to develop further more specific research including interventional studies and international research collaboration. In addition, effective palliative and EOL care may be associated with greater quality of life and quality of care and increased satisfaction of those who are involved, – patients, families and professionals. Thus, it may reduce over-utilization of healthcare equipment and costs at EOL care.