Getting started: Setting up a research project in paediatric palliative care

Manya Hendriks, PhD, Department of Neonatology, University Hospital Zurich, University of Zurich, Switzerland.
Karin Zimmermann, PhD RN, University Children’s Hospital Zurich; Department Public Health – Nursing Science, University Basel

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Vulnerable research populations

“Research projects involving particularly vulnerable participants are only ethically justifiable and permissible if the principle of subsidiarity is respected: particularly vulnerable persons may only be involved in a research project if equivalent findings cannot be obtained by other means.”

Thus, for example, a research project involving children or families of a critically ill (unborn) baby may only be carried out if, for scientific reasons, the knowledge sought can only be obtained by this research population.

Finding the Balance

**FIG. 1.** Conceptual model. Conducting pediatric palliative care research requires a delicate balance of weighing the burdens and benefits in this vulnerable population. Word size and color correlate with frequency of finding.

Challenges for Paediatric Palliative Care Research

- Presumed burden of PPC research upon participants
- Patient diversity and small population size
- Interdependences and dynamic interactions, and disease processes over time
- Workforce and infrastructure limitations
- Outcomes and measurement

**SPhAERA**: Specialised Paediatric Palliative Care: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings

This study's overall target is to evaluate the effectiveness of SPPC and to report on its potential to improve patient-, family-, health professional-, and healthcare-related outcomes. Further objectives are to determine whether the provision of SPPC reduces the utilization of healthcare resources and direct and indirect health-related costs for families.

![Diagram showing recruitment and data collection timeline and clinical, service, and economic outcomes.](image)
Challenges and Efforts: SPhAERA study

**CHALLENGE**

Patient diversity and small population size

Interdependence and dynamic interactions, and disease processes over time

Outcomes and measurement

Presumed burden of PPC research upon participants

**SOLUTIONS**

Multi-centre study

Longitudinal assessment (1 to 2 years) on the family level, i.e. parents, siblings, patient

Clinical: QOL on all levels

Service: Health service utilisation

Economic: Cost analysis

Assessment of research benefit and burden

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Impact of the SPhAERA study

• Expand current knowledge
• Relevant outcome data on the family, professional, and health system level
• Facilitate further development and sustainability of PPC in Switzerland
• Improve quality of care for children with life-limiting conditions and their families internationally
FamKom: A Mixed Methods Study on Perinatal Palliative Care Services in Switzerland

The goal of this nationwide study is:

**Part 1: Survey**
- to assess perinatal palliative care practices of healthcare professionals working in Swiss level III neonatal intensive care units (NICUs) (N=428)

**Part 2: Audio-recording**
- to prospectively analyze perinatal PC consultations (i.e. HCPs-parent communication) in clinical practice (N=45)

**Part 3: Focus groups**
- to develop communication strategies with HCPs for perinatal palliative care (N=16)
Challenges and Efforts: *FamKom Study*

**CHALLENGE**

- Patient diversity and small population size
- Workforce and infrastructure
- Presumed burden of PPC research upon participants

**SOLUTIONS**

- Multi-centre study; Longer data collection process
- Centre-specific adaptations and Multidisciplinary approach
- Close collaboration with clinicians as clinical gatekeepers
Impact of the FamKom Study

Potential to lead to:
- Better understanding of palliative care consultations
  - quantitative aspects of communication
  - qualitative aspects of the interactions
- Avoiding problems with recall bias
- Strengthening nationwide collaborations of perinatal palliative care
- Initiating a national approach to perinatal palliative care situations
- Designing evidence based educational tools for communicating with families in perinatal palliative care settings
Conclusions

Research in Paediatric Palliative Care needs to think outside the beaten and narrow path of conventional clinical research:

– Ethical considerations
– Interprofessional collaboration
– Research infrastructure and groups
– Advanced research designs, e.g.:
  – comparative effectiveness research,
  – mixed-methods,
  – implementation science
Thank you for your attention!

Project Team:
Dr. Karin Zimmerman, PhD RN
PD Dr. med. Eva Bergsträsser
Prof. Dr. Michael Simon, PhD RN
Prof. Dr. Günther Fink
Anne-Kathrin Gerber, MA Health Sciences
Stefan Mitterer, MPhil Health Economics

Contact:
karin.zimmermann@kispi.uzh.ch

Project Team:
Dr. sc. med. Manya Hendriks, PhD
Dr. med. Deborah Gubler, PhD
Prof. Dr. med. Jean-Claude Fauchère
Antonio Boan-Pion, MSc

Contact:
manyahendriks@usz.ch