

Study Titel and Duration

Knowledge needs and empowerment of parents of babies with congenital abnormalities, 2009-2015

Research Questions / Aims

1. Welchen Bedarf an Wissen haben Eltern eines kranken Säuglings/Kindes während dem Spitalaufenthalt und zu Hause?
2. Welche Instrumente für Pflegenden gibt es um den Wissensbedarf der Eltern zu pflegerelevanten Themen zu erfassen?
3. Sind diese Instrumente geeignet um den Wissensbedarf der Eltern eines Neugeborenen mit einer kongenitalen Fehlbildung während des ersten Spitalaufenthaltes zu erfassen?

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Kristin Adler	Literaturrecherche, Fokusgruppeninterviews, Testen der Validität und Reliabilität des angepassten Instrumentes	Literaturrecherche, Fokusgruppeninterviews	Inhaltsanalyse Deskriptiv, Test-Retest-Reliabilität, Interrater agreement	

Study Titel and Duration

Parental Perspectives on their child's end-of-life care: adding insights and richness to primarily quantitative results by mixing in qualitative results

Research Questions / Aims

In order to enhance interpretation of both data types and gain a deeper understanding of this existential and devastating human experience of losing a child, the aim now is to connect the two data analyses to interpret how the qualitative results explain and depict particular quantitative results, specifically:

- What specific parental experiences might explain either extreme negative or positive experience ratings?
- What main differences exist between positive and negative parental perspectives in relation to the six quality domains that guided the questionnaire survey and interviews?

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Karin Zimmermann, Katrin Marfurt Russenberger	PELICAN II Sequential exploratory mixed-methods design	PELICAN II questionnaire survey and interviews.	Caracelli and Greene, as cited in Creswell and Plano Clark et al. [6], of extreme case analysis, i.e. extreme cases of one type of data are examined with data of the other type to refine the initial explanation for the extreme cases [6].	University of Basel, PPHS Stipend Award, extension stipend.

Study Titel and Duration

Transition to Home (TtH) after Preterm Birth: Pilot Testing an Advanced Practice Nurse (APN)-led Model of Transitional Care (2017 - 2019)

Research Questions / Aims

Our study will evaluate the organizational and financial **feasibility and cost effectiveness** of the TtH model for infants born preterm by measuring the impact of an Advanced Practice Nurse (APN)-led intervention at the Children's University Hospital Bern. The intervention focuses on improving parental mental health and well-being, on infant growth and development, and on lowering overall costs. We will gather data and then adapt and test the model within a longitudinal interventional comparative effectiveness study, and prepare it for other Cantons in Switzerland to implement.

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Natascha Schütz Hämmerli Eva Lucia Cignacco Müller	Pilot Study including a randomized controlled trial, qualitative research and a cost-effectiveness study part	questionnaires surveys data extraction from hospital records interviews focus group interviews	RCT: linear regression models, mixed-effects linear models, mixed-effects repeated-measures linear model Interviews and Focus Groups: Thematic analysis (Braun and Clark, 2006) For the cost-benefit analysis, we will calculate Net	n.a.

Study Titel and Duration**Specialised Paediatric Palliative Care: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings (SPhAERA) (2019-2023)****Research Questions / Aims**

This study's overall target is to evaluate the effectiveness of SPCC and to report on its potential to improve patient-, family-, health professional-, and healthcare-related outcomes.

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Karin Zimmermann	This is an interventional multi-centre study with a Type 1 hybrid design, i.e. testing a clinical intervention (comparative effectiveness study) while gathering information on its delivery and implementation.	Data will be mainly collected through questionnaire surveys and chart analysis.	Mixed effect regression models will be used to account for the clustering effect due to the dyadic structure of parents	SAMW ssp/sgp and SwissPedNet Kristian Gerhard Jebsen Foundation

Study Titel and Duration**Caring for Patients with Neuromuscular Diseases in Switzerland (Care-NMD-CH Project) (2020-2021)****Research Questions / Aims**

To investigate the current interdisciplinary care situation for patients living with Neuromuscular Disease (NMD) and their families involving Care Management

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Veronika Waldboth Barbara Grädel	Mixed Methods	Qualitative (interview data) and quantitative data (chart review, survey, outcome measures)	qualitative data analysis; descriptive and inferential statistics and multilevel analyses (linear mixed models)	ongoing Fundraising

Study Titel and Duration**Development of an interprofessional complex intervention and feasibility study to improve the management of procedural pain in neonates (2017-2020)****Research Questions / Aims**

Aim 1 : Develop an interprofessional complex intervention for management of procedural pain in neonates by including experts in the field, and parents.

Aim 2 : Determine the feasibility and acceptability of the intervention of the interprofessional healthcare team in terms of collaboration, adherence, mobilized resources, perception of barriers and facilitators.

Aim 3 : Determine the acceptability of the intervention by the parents in terms of satisfaction, needs, experiences and preferences in managing their child's pain.

Aim 4 : Evaluate the intervention on the process and clinical outcomes for neonates

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Colette Balce	Pilot pre-post feasibility study using an embedded concurrent design with quantitative and qualitative parts	Data will be collected through questionnaire surveys (quantitative data) and interviews, focus group (qualitative data)	Descriptive, comparative, thematic analysis	ABREOC, Advisory Board della Ricerca scientifica dell'EOC

Chronic Critical Illness in pediatric intensive care unit: assessment of patients characteristics and resources use, and family psychosocial outcomes and needs (2018-2021) (OCToPuS 1-2)**Research Questions / Aims**

To provide specific information on CCI childrens' care characteristics and how they differ from non-CCI children

To measure the impact of CCI hospitalizations on family members over time

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Chantal Grandjean Anne-Sylvie Ramelet	Retrospective predictive Longitudinal convergent mixed-methods	National database Chart review Questionnaires Interviews	Descriptive, comparative, longitudinal, predictive analyses	Fondation Marisa-Sophie GETINGE Fondation Livio-Glauser Stiftung Pflegewissenschaft

Study Titel and Duration**Clinicians and intensive care units determinants of care for Chronic Critically ill patients in Pediatric Intensive Care in Switzerland: a cross-sectional study (OCToPuS 3)****Research Questions / Aims**

To describe clinicians' determinants: socio-demographics, professional experience, job satisfaction and moral distress

To describe PICU interdisciplinary collaborative practice

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Anne-Sylvie Ramelet Chantal Grandjean	Multicenter prospective, cross-sectional and correlational	Online questionnaires	descriptive, predictive analyses	None

Study Titel and Duration**The effectiveness and family experiences of interventions promoting partnership with families in pediatric and neonatal intensive care units on family and patients' outcomes: a mixed methods systematic review protocol (OCToPuS 4)****Research Questions / Aims**

To conduct a mixed methods systematic review that examines the effectiveness and family experiences of interventions that promote partnerships between parents and the multidisciplinary healthcare team in pediatric and neonatal intensive care units.

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Anne-Sylvie Ramelet Chantal Grandjean	Mixed methods systematic review			

Study Titel and Duration**The pain, sedation, delirium and withdrawal practices in pediatric intensive care units and the development of an integrated assessment tool****Research Questions / Aims**

To describe current practices and variations to the management of pain, sedation, delirium and withdrawal as compared to international clinical recommendations

To synthesize the evidence on instruments for assessing pain, sedation, delirium and withdrawal

To develop an integrated tool to assess the four symptoms based on evidence-based practice recommendations

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Anne-Sylvie Ramelet	3-phased longitudinal observational design	Survey Integrativereview Tools development		None

Study Titel and Duration

HomeAfterNICU project

Research Questions / Aims

To develop an application to support families after NICU discharge

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Anne-Sylvie Ramelet	App development			Fulbright Scholar Program

Predictive monitoring for bloodstream infections, necrotizing enterocolitis and sepsis in a Swiss neonatal intensive care unit: a retrospective case control study

Research Questions / Aims

To determine the degree of association between high HeRO® scores and culture-proven sepsis in the NICU of the CHUV.

To describe the HeRO® profile of infants with sepsis as well as their associated sociodemographic data

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Anne-Sylvie Ramelet	Case-control	Retrospective database	simple, multiple regression	None

Study Titel and Duration

Educational videos for parents of children with atopic dermatitis: The EduDerm Study (2019-2022)

Research Questions / Aims

To test in a pragmatic Randomised Control Trial (RCT) the effectiveness of video-based education in regards to QoL, disease severity and worries and beliefs about topical cortico-steroids (TCS) for parents of children 0-5 with AD.

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Brunner Corinne Barbara	Schlüer Anna- Pragmatic RCT	Questionnaires, clinical investigation, chart review, literatur search	Descriptive statistics	Stiftung Pflegewissenschaft

Study Titel and Duration

Explore and develop a severity tool for Incontinence Associated Dermatitis (IAD) in neonatal population. (2019-2023) The EduDerm study"

Research Questions / Aims

To adapt and to clinically validate a tool that aims to assess the severity of IAD in the neonatal population after the diagnosis has been confirmed. A prerequisite to this study is the recently validated GLOBIAD tool for measuring IAD in the adult population.

AFG Member and/or PI	Design	Data Collection	Analysis	Funding
Dunk Annemarie (AUS) Barbara	Schlüer Anna- prospective observational study	Questionnaires, clinical investigation, chart review,	Descriptive statistics	

Forschungsregister AFG Pädiatrische Pflege

Study Titel and Duration

Adoleszente mit einer chronisch entzündlichen Darmerkrankung Erlebnisse und Bedürfnisse aus der Betroffenenperspektive

Research Questions / Aims

Welche Erfahrungen und Erlebnisse machen Adoleszente, die eine CED haben, mit ihrer Erkrankung?

AFG Member Supervisor	Design	Data Collection Sample	Analysis	Funding
MSc/MAS - Student Senn Beate; Schlier Anna-Barbara; Marty Mirjam (2019-2020)	Eine Theorieskizze, angelehnt an die Grounded Theory	8 Jugendliche	Qualitativ	NA

Study Titel and Duration

Transition to Home Teilprojekt

Research Questions / Aims

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AFG Member Supervisor	Design	Data Collection Sample	Analysis	Funding
MSc/MAS - Student Schütz Natascha; Schlier Anna-Barbara; von Gunten Geraldine (2019-2020)				

Schütz Natascha; Schlier Anna-Barbara;
von Gunten Geraldine (2019-2020)

Study Titel and Duration

Evaluation et traitement de la douleur en pédiatrie : collaboration entre professionnels de la santé (2018-2020)

Research Questions / Aims

Décrire les comportements de collaboration entre les professionnels de la santé dans la prise en charge de la douleur de l'enfant à l'hôpital.

AFG Member Supervisor	Design	Data Collection Sample	Analysis	Funding
MSc/MAS - Student Anne-Sylvie Ramelet, Laura Rio, Pascale Ullmann	Descriptive	Multidisciplinary pediatric healthcare professionals	descriptive comparative	NA

Study Titel and Duration

Validation of the Paediatric Palliative Screening Scale

Research Questions / Aims

To further validate the PaPaS Scale with real patient data by testing it in four Swiss children's hospitals. Specific aims of this validation include the assessment of inter-rater reliability, convergent, concurrent, and predictive validity
To determine whether the PaPaS Scale meets the criteria of a valid instrument for healthcare professionals to identify children and families with PPC needs.

AFG Member Supervisor	Design	Data Collection Sample	Analysis	Funding
MSc/MAS - Student Karin Zimmermann Selina Benz	Validation study	Children with life-limiting conditions at enrolment into the SphaERA study.	Inter-rater reliability Convergent, concurrent, and predictive validity	NA