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WORKING PAPER ON THE NURSING SCIENCE SYMPOSIUM 2024

Improving Research Impact for Families Experiencing Acute-Critical Illness

Methodological Insights and Takeaways From the Nursing Science Symposium

University of Zurich, Institute for Implementation Science in Health Care (IfIS)
University Hospital Zurich, Center for Clinical Nursing Science (ZKPW)

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About this Working Paper

This working paper summarises the findings and discussions from the first Nursing Science Symposium, which took place at the University of Zurich on 19 January 2024, with 70 participants including nurses, physicians, psychologists, and ethicists. The paper is a reflection of the collaborative efforts of the nursing science and interdisciplinary community in addressing critical healthcare challenges faced by families across the lifespan today.

The Nursing Science Symposium aimed to share the latest methodological insights in research, focusing on families experiencing acute-critical illness, drawing on national and international experiences from different disciplinary perspectives. It built and expanded collaborations between researchers, clinicians and innovators involved in family intervention and implementation research. The specific aims of the symposium were to:

- Build a transdisciplinary and interprofessional community of researchers and clinicians / practitioners committed to improving healthcare for families.
- Promote scientific / scholarly dialogue relating to family health research and practice within health and healthcare.
- Enable methodological advances and innovations in family health intervention and implementation research.
- Highlight research areas for future collaborative intervention and implementation research in the field of family health.



A look inside the auditorium where the Nursing Science Symposium was held.

Using examples from their own research, five contributors shared novel methods and orientations for improving quality of research, and for promoting its translation into services that benefit families:

Dr. Nancy Kentish-Barnes, Sociologist & Co-Director of the Famiréa Research Group, APHP Nord, Hospital Saint Louis, Medical Intensive Care Unit, Paris, France

Prof. Dr. phil. Martina Roes, Professor for Nursing Science and Health Care Research at the Department of Nursing Science, Faculty of Health, University of Witten/Herdecke, Speaker and Senior Research Group Leader Implementation Science and Person-Centered Dementia Care at the German Center of Neurodegenerative Diseases (DZNE), Witten, Germany

Chantal Britt, Patient Expert and Advocate, President of Long Covid Switzerland, and Research Associate at the Competence Centre Participatory Health Care, Bern University of Applied Sciences, Switzerland

Prof. Dr. Anne-Sylvie Ramelet, Professor at the Institute of Higher Education and Research in Healthcare (IUFERS), Faculty of Biology and Medicine, University of Lausanne and Nursing Research Consultant at the Department Woman-Mother-Child, CHUV Lausanne University Hospital, Switzerland

Dr. sc. nat. Oliver Gruebner, Lecturer and Senior Researcher at the Faculty of Health Sciences and Medicine, University of Lucerne and at the Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Switzerland

This working paper is intended to serve as a resource and inspiration for researchers, practitioners, and policymakers alike.

Institute for Implementation Science in Health Care (IfIS)
Center for Clinical Nursing Science (ZKPW)

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Welcome Address by Professor Beatrice Beck Schimmer

In her welcome address, Professor Beatrice Beck Schimmer, Vice President Medicine Zurich, and Member of the Executive Board of the University of Zurich, outlined three key themes relevant to the symposium: Implementation, Nursing and Higher Education, and Patients and their Families.

First, Beck Schimmer highlighted the significance of scientific research and its implementation into practice settings in the field of medicine, nursing, and healthcare in general. She referenced Walter Siegenthaler, a former Swiss professor of internal medicine, who once said: "The current state of knowledge is the current state of error." This sentence, she argued, means that what we know today is not necessarily the entire truth – as scientific knowledge changes and evolves over time. To illustrate this point, Beck Schimmer referred to historical misconceptions such as the belief that going outside with wet hair causes a cold or that reading in poor light damages eyesight. She then emphasised the role of evidence-based medicine and implementation science in driving this progress. Beck Schimmer advocated efforts to bridge the gap between knowledge generation and its implementation into real-world healthcare at scale.

Beck Schimmer then pointed out the ways the landscape of nursing and higher education is changing, highlighting the expanding demands on health professionals due to demographic shifts of the population, chronic illness burden, and technological advancements. She stressed the need for academic education for nurses, and the potential of new roles such as nurse practitioners as essential in addressing the evolving health needs of patients and families in a dynamic healthcare environment and to ensure healthcare for all.

Beck Schimmer also outlined the significant impact of illness not only on patients, but also their families, recognising the challenges they face with an ill family member. She highlighted the crucial role of nursing science in improving health outcomes and providing support to patients and families during times of illness.

Beck Schimmer thanked all attendees for their dedication to the healthcare field. She expressed her confidence in the healthcare workforce to engage in collaborative efforts and innovations that drive meaningful advances in healthcare, ultimately leading to improved health outcomes and well-being for all.



Professor Beck Schimmer gave the welcome address and introduced the main topics of the symposium.

Introductory Remarks by Professor Rahel Naef

In her introductory remarks, Professor Rahel Naef, who hosted the symposium, introduced family-focused healthcare research, then identified existing research gaps, and briefly outlined the research focus of the Implementation Science in Nursing Research Group.

What is family-focused healthcare and research?

Family-focused healthcare is a specialty within nursing science, sharing with other health and social science disciplines the intent to improve family health and healthcare. Specifically, it aims to:

- Strengthen family literacy and capacity for self-management and self-care.
- Decrease family suffering, burden, and negative health consequences.
- Improve family functioning and well-being.
- Ensure equitable access to healthcare that values family input and expertise while also offering necessary engagement and support structures.



The University of Zurich on the day of the Nursing Science Symposium.

Families, defined as the patient and those close to him or her from his or her perspective, play a key role in patients' well-being and recovery, in symptom and disease management, as well as enabling functioning in everyday life in any life cycle. At the same time, Naef acknowledged that family systems face challenges associated with uncertainty, burden, and losses associated with illness and caregiving situations. A considerable proportion of family members experience their own physical and mental health problems arising from these stressful illness and caregiving situations, resulting in specific information, communication, and support needs. The aim of family interventions and support services is therefore to enable families (patients together with those close to them) to understand the illness, develop skills in illness and symptom management, learn new roles, and manage everyday life as a family system facing multiple challenges.

Family-focused research aims to generate knowledge in these areas. Naef referred to Suzanne Feetham (2018), a first-generation family nurse researcher, who, over 40 years ago, outlined the following objectives for family research:

- Advance knowledge of the family to improve care and outcomes.
- Determine sustainable interventions to improve outcomes.
- Inform policy to sustain change that advances health and well-being of families.

Naef described how family health research has proliferated over the last decade, generating an impressive body of knowledge regarding family health and family healthcare. Earlier research investigated family needs, family function and roles, and family experiences of illness and healthcare. Subsequently, research focused more on developing and examining family support interventions, services, and programmes, including the formal testing of their clinical effectiveness. More recently, the implementation of research knowledge on family health into routine health-care has gained momentum.

The need for family-focused intervention and implementation science research

Naef then drew attention to the important questions remaining to be researched, despite significant advances, such as how to best ensure existing research evidence be translated into effective services and integrated into health systems at scale, or how to conduct research to make a difference to families across the lifespan, who have different backgrounds, live in diverse constellations, and different geographical areas.

Intervention and implementation research on family health interventions are often complex and difficult to undertake due to the vulnerability and diversity of families and burdens associated with research participation. According to Naef, important methodological questions predominate, for example, about data collection and analysis (such as the need for sensitive family health outcomes and their valid measurement to assess effectiveness), on the choice of data sources or informants, as well as on the statistical analysis methods that could account for the multiplicity of voices and perspectives present within a family.

This underscores the need for scholarly dialogue, methodological discourse, and mutual learning to move the field of family health intervention and implementation research forward and to accelerate the implementation and delivery of effective, evidence-informed and equitable services for families. This is reflected in the research focus of the Implementation Science in Nursing Research Group. It has set the aim of advancing knowledge and the impact of research in adult family health, family-focused nursing interventions, and the effective implementation of evidence-based (family) nursing practices into clinical care predominantly in the areas of acute-critical illness, bereavement, and cognitive impairment. Methodological innovations in care models and methodology, including participatory research processes, have evolved as further research foci in recent years.

Building a Programme of Intervention Research Focusing on Families' Experience in ICU: Methodological Learnings From the Famiréa Research Group

Dr. Nancy Kentish-Barnes, sociologist and co-director of the Famiréa Research Group at Hospital Saint Louis in Paris, France, was the first contributor of the morning session. She presented insights from an impressive programme of research using both quantitative and qualitative approaches to design and test family support interventions targeting those who experience the death of a loved one in critical care. She discussed key learnings that arose from three research projects involving bereavement support and intervention research methodology.

Research project 1: Complicated grief after death of a relative in the intensive care unit

The aim of the first project was to understand the experience of losing a loved one in the intensive care unit (ICU). This prospective observational study evaluated the impact of the ICU end-of-life process on families' bereavement psychological symptoms using follow-up research calls one, three, six and twelve months after the patient's death. The study found that complicated grief disorder affects up to 50% of individuals and highlighted four risk factors related to the end-of-life process in the ICU: 1) not saying goodbye to the patient, 2) being present at the time of death without adequate support, 3) dissatisfaction with doctor communication, 4) patient symptom management. This study was the first to show that ICU clinical practices, including communication and support, are associated with psychological burden in bereaved family members, demonstrating room for improvement in support and care (Kentish-Barnes et al., 2015). The qualitative approach in this study also showed the importance of communication, including both verbal and nonverbal: communication is not a detail but affects the family's experience in the short and long term.

Two important methodological lessons were learnt: firstly, as response rates were extremely high, the study sought to better understand the willingness of bereaved families to participate in the follow-up interviews. Results of this sub study by Kentish-Barnes et al. (2015) show that the follow-up research was an opportunity to express themselves and feel supported as many families felt isolated during bereavement. The study shows there is a very fine line between research and support. The work of the researchers should not add to the burden of family members, which is why the researchers decided to be trained in basic bereavement support. Secondly, as it became clear that participation went beyond mere data collection, offering families the possibility of expressing themselves and feeling supported, Kentish-Barnes and her team recognised the importance of developing interventions to support bereaved family members. In particular, the perceived lack of support from the ICU team, unanswered questions, few opportunities to say goodbye and feelings of isolation called for a new intervention. This led to Research project 2, which investigated the potential a condolence letter might have in alleviating the emotional burden experienced by families.

Research project 2: Effect of a condolence letter on grief symptoms among relatives of patients who died in the ICU: a randomised clinical trial

The research team of Kentish-Barnes developed a condolence letter intervention involving several key components. The content of the letter was carefully crafted to encompass five essential domains: naming the deceased and acknowledging the loss, mentioning the patient as a person, recognising the relative and their role in the patient's life, proposing concrete help with contact information provided, and demonstrating empathy and understanding of the family's grief. The letter was handwritten and co-signed by the doctor and nurse who oversaw the patients' care during their ICU stay, adding a human touch to the communication. It was tested in a randomised controlled trial in 22 ICUs in France that assessed the impact of condolence letters on reducing psychological burden in 242 bereaved family members (Kentish-Barnes et al., 2017).

Surprisingly, the study found that condolence letters not only had no impact on the mental health of family members one month post death, but even increased the risk of developing depression and post-traumatic stress-related symptoms at six months. In addition, the experience of receiving the condolence letter was explored in a qualitative study which was instrumental in understanding why the intervention did not work. The study results revealed that the condolence letters may have been sent too early, and sometimes generated doubts among the bereaved family members as to the clinicians' motivation. The letters, while well-intentioned, were not always perceived as providing meaningful support, particularly if family members sought to interact with ICU clinicians after receiving the letter. It became apparent that the healthcare providers were not adequately prepared to provide the additional support implied by the condolence letters. This study was a learning curve for the research group: first, because it confirmed that all interventions need evaluation, and second because it taught the Famiréa Research Group that designing an intervention requires anticipating possible long-term impacts of that intervention on families and ICU clinicians. The integration of both quantitative randomised controlled research and qualitative methods was crucial in comprehending the impact mechanism of the condolence letter. This was especially important given the unforeseen outcomes stemming from the intervention.



Dr. Nancy Kentish-Barnes started the morning session with a presentation about a programme of intervention research focusing on families' experience in ICU.

Research project 3: A three-step support strategy for relatives of patients dying in the intensive care unit: a cluster randomised trial

The results of the first two research projects informed the design of a three-step support strategy (Kentish-Barnes et al., 2022), an intervention to improve end-of-life communication and support for families in end-of-life situations within ICU settings. The intervention consisted of three key steps offered by ICU physicians with the involvement of nurses:

The first step consisted of providing support to families before the patient's death by means of an end-of-life family conference. The second step focused on providing support to families during the dying and death process of their loved one. The third and final step was a post-death interview with the bereaved family.

The intervention emphasised the importance of communication, both verbal and non-verbal, including empathetic support at all three steps. The intervention aimed to alleviate distress through effective communication and support, to foster resilience, and to facilitate coping among bereaved family members.

It was tested in a cluster randomised trial design, with 875 participants enrolled across 34 ICUs, and found a reduction in both the frequency and intensity of complicated grief, as well as post-traumatic stress-related symptoms. The qualitative results revealed that communication, empathy, and supportive interactions were central to the intervention's success. Particularly, families stressed the significance of the third step, i.e. the post-death interview.

Based on these three research projects that employed quantitative and qualitative data to evaluate the intervention, Kentish-Barnes advocated a comprehensive and inclusive approach to healthcare intervention research and practice. She emphasised the importance of using diverse methodological approaches and multiple perspectives to understand intervention effectiveness or the lack thereof. The qualitative studies identified the central role of effective communication within family support interventions in ICUs.

Overall, Kentish-Barnes highlighted the importance of mixed methodology studies to provide in-depth and complementary results, which helped to design interventions for RCTs. She emphasised how important it is to give family members a voice, that they should be included in further studies as partners to provide feedback on developed tools and strategies as well as on study design. Enhancing the post-study follow-up period involves delivering feedback to participating ICU teams regarding the study outcomes. In instances of positive results, encouraging the implementation of the intervention into routine practice is of vital importance. According to Kentish-Barnes, this might be the means by which the gap between research and practice could be bridged.

Nancy Kentish-Barnes

Dr. Nancy Kentish-Barnes is a sociologist specialised in critical care and healthcare research. With Professor Elie Azoulay, she co-directs the Famiréa Research Group, a multidisciplinary research group, based at Hospital Saint Louis in Paris, dedicated to understanding the experiences of families in ICUs. Kentish-Barnes has played a pivotal role in observing and improving support provided to family members of ICU patients across France and internationally. With over 80 original publications, Kentish-Barnes' research primarily focuses on communication, end-of-life care, bereavement support, and

family-centred care in intensive care settings. She has served as the principal investigator for numerous randomised controlled trials in these areas. In recognition of their impactful work, the Famiréa Research Group, including Kentish-Barnes, received the prestigious Galien Coup de Coeur prize from the Patient Support Jury in 2020. In addition, Kentish-Barnes co-leads the recently launched VITAL, a new initiative of the European Society for Intensive Care Medicine that partners with patients and family members to improve patient and family-centred care in ICUs.

Addressing Complex Implementation Challenges in Family-Focused Dementia Care

Due to the snowy weather circumstances preventing her travel, the second contributor joined the symposium virtually. In her keynote address, Professor Martina Roes explored the intricacies of implementing family-focused dementia care, with a specific focus on social determinants of health, health disparities, inequity and inequality. A central question in her contribution revolved around the unintended reproduction of structural inequalities, and the need to focus on equity as an essential concern within implementation.

Social determinants of health, health disparities, inequity, and inequality

Roes presented the concepts of social determinants of health, health disparities, inequity, and inequality to ensure a common understanding among the audience. She emphasised the intricate interplay between these factors and their impact on healthcare delivery and outcomes. Further, she underscored the significance of addressing social determinants of health, disparities, and inequities in the context of family-focused dementia care. While numerous studies have explored interventions – such as interventions for family caregivers and social determinants of health –, there has been a notable gap in implementation science regarding these concerns. Last, but not least, Roes highlighted the potential of implementation science to address disadvantages, inequity, and inequality within healthcare systems.

Social determinants are the conditions in which people are born, grow, live, work and age. They include factors such as socioeconomic status, education, neighbourhood environment, and access to healthcare. Essentially, they shape our health outcomes. Health disparities are differences in health outcomes between groups of people. These differences can be influenced by factors such as race, ethnicity, gender, socioeconomic status and geographic location. Health disparities often result from social inequalities. Inequality refers to differences that exist but may not necessarily be unfair or unjust. Inequity refers to unfair differences or disparities that are avoidable and unjust. In the context of healthcare, inequities and inequalities can arise due to systemic discrimination, lack of access to resources or unequal distribution of healthcare services.

Roes introduced two common models used in discussions on social determinants of health, each offering valuable insights into the factors shaping health outcomes. The first model covers several essential domains, including education; healthcare access and quality; neighbourhood and built environment; social and community context; and economic stability. Factors such as early childhood education, access to health services, quality housing, social relations, and economic resources play pivotal roles in determining health outcomes (Kuehnert et al., 2021).

Additionally, Roes discussed a [model proposed by the World Health Organization \(WHO\)](#), which emphasises the need to consider the socioeconomic and political context when examining social determinants of health. This model underscores the importance of addressing blind spots in understanding how broader societal factors influence health disparities.

Roes then highlighted the significant impact of socioeconomic status on individuals' access to healthcare services, emphasising that the professionals providing care often overlook socioeconomic factors due to organisational constraints. She stressed the need for implementation teams to take responsibility for addressing these disparities when translating research knowledge into healthcare systems.

The Covid-19 pandemic served as a catalyst for recognising societal inequities, with numerous studies revealing disparities in healthcare access based on geographical and socioeconomic factors. According to Roes, this heightened awareness underscores the necessity for a fresh approach to addressing healthcare disparities.

Roes argued that traditional assumptions regarding caregiving burdens, particularly the burden on women, have changed in light of societal norms, prompting a re-evaluation of analytical approaches. Furthermore, implementation efforts should not commence only after intervention research is completed. In her role as a dementia and implementation researcher, Roes stressed the importance of sensitivity to the inequalities present when living with dementia, or when designing interventions. She also recognised the potential for unintended consequences resulting from thoughtless intervention designs that may exacerbate existing disadvantages. It is also important to integrate sensitivity to dementia-related challenges into implementation efforts to ensure equitable outcomes for all individuals involved. If neglected, inequalities that were overlooked in the intervention design or testing will be reproduced and worsened with implementation.



Professor Martina Roes addressed the complex implementation challenges in family-focused dementia care during an online presentation.

Implementation science to address disadvantages, inequity, and inequality

A special focus of the presentation was the fundamental responsibility in implementation science to address health inequities. Roes proposed three paradigms for examining inequality:

Firstly, Roes discussed the Paradigm of Using Existing Data. This approach involves leveraging existing datasets, such as clinical studies and national datasets, to understand health inequities and their impact on implementation outcomes. By doing this, researchers can tailor strategies to help marginalised groups and make sure everyone gets the care they need.

Secondly, Roes emphasised the Paradigm of Including People with Disadvantages in implementation studies. This approach highlights the importance of including diverse and minority communities, as well as other underrepresented or disadvantaged populations in implementation research efforts. By increasing the participation of underrepresented groups in research teams or specific projects, researchers

can better understand how different groups are affected and make sure that interventions work for everyone. Roes emphasised the importance of inclusivity in dementia research, highlighting the need for diverse perspectives at the table. She stressed the necessity of simplifying research processes to ensure accessibility for all involved, acknowledging the challenge of reducing complexity. Roes urged researchers to develop sensitivity in their communications and to seek representation from researchers who reflect the populations they work with.

Finally, Roes highlighted the Paradigm of Implementation Research focusing on experience of inequities. This paradigm centres on targeting implementation research and efforts exclusively on populations that experience high levels of disparities. By working directly with these communities and listening to their needs, researchers can create interventions that really make a difference and help close the gap in healthcare. As a qualitative researcher, Roes underscored the need for reflection on research methodologies. She expressed concerns about the lack of connection between research and the target population, emphasising the creation of generalisability rather than reaching the intended audience.

By incorporating these paradigms into implementation science, researchers can work towards ensuring that interventions are effective, inclusive, and equitable for all individuals and communities affected by dementia.

Overall, Roes advocated a paradigm shift in understanding evidence-based research to facilitate a smoother transition into practice and ensure interventions are effectively implemented.

Martina Roes

Prof. Dr. phil. Martina Roes is Site Speaker and Senior Research Group Leader of the German Center for Neurodegenerative Diseases (DZNE) and a Professor for Nursing Science and Health Care Research at the University of Witten/Herdecke in Germany. Previously, she has been a Professor for Nursing Science at the University of Applied Sciences in Bremen. She holds a PhD from the University of Bremen. Roes has been a Robert Bosch Foundation Fellow (PhD) and a Commonwealth Harkness Research Fellow (PostDoc). Roes' research focuses on implementation science and person-centred dementia care, and the question of how innovations and interventions are best integrated into healthcare in sustainable ways. She is the Principal

Investigator of several large studies and has published extensively in that field. She has been actively engaged in the scientific community and professional organisations for several years. She is a Fellow of the American Association of Nursing (FAAN), a Board Member of INTERDEM, a Fellow of the Gerontological Society of America (GSA), and a member of the DZNE Patient Council. Additionally, she is a founding member of the Society for Implementation Research Collaboration and a member of the European Implementation Collaborative (EIC). Roes is also a member of the Scientific Advisory Board at the Institute for Implementation Science in Health Care, University of Zurich.

Research Co-Production: Perspectives of a Patient, a Family Member, and a Researcher

After the lunch break, Chantal Britt took the stage, first to offer a personal perspective on her experience with partnerships between professionals and patients and their families in healthcare and research, particularly in critical care settings. This was followed by methodological reflections on patient and public involvement and engagement in research, stressing the need for a paradigm shift towards partnership models.

Personal journey: navigating health challenges

Based on her own experience of being a patient and family member, Britt, who is the president of Long Covid Switzerland and a research associate at the Competence Centre Participatory Health Care, Bern University of Applied Sciences, shared her families' illness and healthcare experiences from 2017 through to today. Britt provided multiple examples of challenging situations she encountered in her role as daughter-in-law, daughter, mother and person living with long covid, across various care settings. Issues included not being taken seriously or not being believed, resulting in healthcare that failed to address medical needs, increasing the family's disease burden and suffering. These, to a certain extent traumatic, experiences and encounters within the system led Britt to question the quality of care, the lack of patient engagement and shared decision-making in critical care settings. She urged the implementation of participatory approaches within healthcare, in which patients and family members are recognised as experts in their own care. Her own experiences prompted the decision to actively advocate better care, not just for herself and her family, but also for fellow patients. Britt stressed that she did not become a patient expert out of choice, but out of necessity.

Britt then asked the audience: "If you could ask a patient only one question, what would it be?" In her view, the pivotal question health professionals should always ask is: "What matters most to you?", emphasising the importance of understanding patients' unique needs, perspectives and priorities, particularly in critical care settings.

Importance of patient and public involvement and engagement (PPIE) in research

Britt argued that actively engaging patients and their families is essential in order to develop projects that ask relevant research questions with the potential to have an impact and improve care outcomes. One of several useful models that inform PPIE is the Montreal Model by Pomey et al. (2015). It is a conceptual framework describing the relationship between patients and healthcare professionals on a continuum from passively informing patients to working with them in a partnership. The Montreal Model aims to understand the dynamics and challenges arising on different levels, i.e., the individual, institutional or policy level, when patients actively engage in healthcare. The core idea is that effective collaboration between patients and healthcare professionals can lead to better health outcomes and more meaningful, relevant care. The model emphasises the importance of partnerships in which patients are not merely seen as passive recipients of healthcare services but are actively involved in decision-making processes shaping their own healthcare. It explores various aspects of this participatory relationship, including communication between patients and healthcare professionals, mutual recognition of knowledge, competence and experience, and the challenges that may arise when implementing such partnerships. Overall, the Montreal Model supports a better understanding of the dynamics and potential of participatory relationships between patients and healthcare professionals, with the aim of promoting improvements in healthcare delivery based on this concept. While the model has gained visibility across Switzerland, Britt criticised its limited implementation in healthcare settings, particularly at institutional and policy levels in German-speaking parts of Switzerland. Overall, she stated, PPIE is still underdeveloped in the Swiss healthcare system.

According to Britt, participatory research moves beyond merely “conducting research about” patients and their families as subjects, to “conducting research with” them as active partners. The objective of participatory research is to maximize the participation of those whose life or work is to be investigated and potentially transformed. In participatory research, people with lived experience hold responsibility and influence decisions about outcomes, design and interpretation, thereby actively shaping the project. This differentiates it from other forms of research where people are consulted on projects that have already been developed without their input. The overarching goal of any participatory research endeavour should be to enhance both the health outcomes and overall experience for patients, their families, caregivers, and users of healthcare and social services, as well as for the broader community and society.

Principles, methods, and paradigms of participatory research

Britt highlighted ten principles of participatory health research: it is (1) participatory; (2) locally situated; (3) a collective process; (4) a dialectical process characterised by messiness; (5) collectively owned; (6) critically reflexive (7); it produces knowledge which is local, collective, co-created, dialogical and diverse; (8) generates local evidence based on a broad understanding of generalisability; (9) strives for broad impact, and (10) aims for transformation through human agency (International Collaboration for Participatory Health Research, 2013). Britt further illustrated the broad continuum of engagement when carrying out PPIE and the levels of participation (i.e., collective action, co-learning, consultation etc.) as outlined by Wright et al. (2013). Britt emphasised the distinction between a method and a paradigm, suggesting that participatory research should not only be used as a method, but as a guiding principle to engage and empower patients to co-produce knowledge. She advocated a paradigm shift towards a democratic approach that prioritises patient perspectives over a utilitarian logic approach. Also, she emphasised the importance of embracing the messiness of participatory research and adapting research to feedback from patients and their families.



In her interactive session, Chantal Britt emphasised the importance of participatory approaches in healthcare, advocating working with patients and family members as partners.

Examples of participatory research

Britt introduced the Research Agenda of the Long Covid Citizen Science Board (LCCSB) by Ziegler et al. (2022) and shared three ongoing projects in which patients, partners, and healthcare professionals worked together. The aim of the first project was to investigate whether patients and family members can be more actively involved in decisions about the use of physical restraints within a hospital setting. This project engaged members of the hospital's patient advisory board and professionals who shared their experiences and views regarding the feasibility and acceptance of such an approach. Britt then presented another project involving assessing the impact of travel costs to dialysis centres on kidney patients. In this project, an advisory board consisting of patients, partners, and healthcare professionals were actively involved in ensuring that patients' views, needs, and concerns were included. The third project Britt described was a programme on chronic pain (Project PrePaC – Prevention of Pain Chronification) with the aim of preventing chronification by improving interprofessional collaboration. In this ongoing project, a sounding board consisting of patients, family members and healthcare professionals is involved in ensuring that patients' needs and views are reflected in the development of a care pathway as well as education and information tools for the public and professionals in order to reduce the risk of chronification.

Participatory research – dos and don'ts

Britt provided practical recommendations for dos and don'ts in facilitating PPIE, emphasising transparency, respect, and trust-building. On the part of the facilitator, it is crucial to be realistic and cautious about expectations and resources. Transparency should be maintained by clearly communicating motivations, purposes, and the expected level and role of involvement. Open communication channels should be fostered throughout the research process, and a variety of opportunities for participation should be provided to accommodate various needs and preferences. Additionally, it is essential to recognise and value the knowledge, competencies, and skills of all those involved, building their confidence and competence in contributing to the research. Trust can be established by creating safe and respectful environments for all participants. Conversely, barriers to effective patient involvement include tokenism, where participants are included in name only, without genuine engagement. Exploitative practices should be avoided. Participants' expertise should be respected, and their contributions valued. All participants should be treated equally, without marginalising certain groups or marking individuals as different. Lastly, meaningful participant engagement should take precedence over saving resources or time.

Britt concluded by sharing healthcare experiences that contrasted with the many difficult situations she had encountered. Thanks to the attentive care of her oncologist and family physician, for example, Britt's mother was able to pass away in a manner respecting her wishes: peacefully, with dignity, at home, and at the time of her choosing. This serves as an example of the lasting positive impact that compassionate healthcare professionals and patient-centred care can have on individuals and their families.

Chantal Britt

Chantal Britt is a patient expert and a research associate with the Competence Centre Participatory Health Care at Bern University of Applied Sciences BFH.

Since 2020, Britt has been living with the consequences of long covid, fuelling her dedication to address the challenges faced by patients with chronic invisible diseases in our healthcare, social security, and research funding systems. Britt, a science communicator by background, is the co-founder and president of Long Covid

Switzerland, a patient organisation promoting the recognition of long covid and other postinfectious conditions. Her advocacy extends beyond her organisation's topics as she serves as a patient involvement expert on numerous boards and expert panels, including those of the Swiss National Science Foundation, EUPATI Switzerland and Swiss Patient Organisation SPO. In March 2024, she received the Viktor Award as the most outstanding personality in Swiss healthcare in 2023.

Doing Research with Families in Vulnerable Situations: Key Considerations when Designing Family Studies in Acute-Critical Settings

Anne-Sylvie Ramelet, Professor and Head of the PhD in Nursing Sciences Program at the Institute of Higher Education and Research in Healthcare (IUFERS) within the Faculty of Biology and Medicine at the University of Lausanne, led a session on child and family vulnerability and its implications for research design, particularly within the paediatric intensive care unit (PICU) environment. She outlined various vulnerabilities in children with complex chronic critical illness, pointing out family challenges when experiencing hospitalisation in PICU. She then outlined certain key concerns for researchers interested in improving healthcare and outcomes for families whose child lives with medical complexity.

Vulnerability and chronic critical illness

Emphasising the significant resource investment and myriad stressors inherent in paediatric acute-critical care, Ramelet highlighted the diverse vulnerabilities confronting families, such as: physical, psychosocial, cognitive vulnerabilities, and vulnerabilities arising from a specific life situation, illness and care trajectory, and individual characteristics. Children with complex chronic illness in need of acute-critical care have multiple vulnerabilities (Edwards & Goodman, 2022) and may require prolonged intensive and specialised healthcare attention. Despite being relatively rare, the mortality rate among these children is disproportionately high, with many passing away in hospital settings (Håkanson et al., 2017). These patients require specialised paediatric care and may face extended hospitalisations in tertiary care centres.



Throughout the day, the audience engaged in stimulating discussions.

The lifelong impact of chronic conditions that began at birth underscores the importance of addressing paediatric health needs to enable healthy adulthood. Ramelet showed findings from a survey by Park et al. (2023) of 45 WHO-EU member states, revealing that while most countries have strategies in place to address child and adolescent health issues, only 39% prioritise early identification of developmental impairments in children arising from a complex chronic conditions-related illness. This highlights the disparities in healthcare accessibility and the need for targeted interventions tailored to each family's unique circumstances. She referred to the ecological model of family stress in paediatric critical care by Hagstrom (2017), a conceptual model that reflects the contemporary PICU environment and factors likely to be important to the population of children with long stays, depicting the varying environments within which families function.

Definition of family and family challenges arising from hospitalisation

As children often lack the capacity to decide for themselves, responsibility for decisions lies with the family, usually the parents / legal guardians, and is therefore defined from their perspectives. Quoting Davidson et al. (2017), Ramelet defined family as individuals who provide support and have a significant relationship with the patient, whether related or unrelated. Ramelet underscored the need to incorporate diverse family structures, including minority groups such as rainbow families, thereby contributing to the diversity of family living arrangements encountered in PICU contexts [[see US Estimates of Same-Sex Households for 2019](#)].

Ramelet acknowledged the challenges children and families face when dealing with hospitalisation, particularly the uncertainty regarding diagnoses. Families are confronted with various challenges and influences in their daily lives, including (1) activities such as medical visits and presence during hospitalisation, assistance with homework, seeking financial help, and managing other administrative tasks for social support, (2) relationship dynamics encompassing communication, emotional attachment, sexual health, and participation in social activities, or (3) socio-economic factors such as discontinuing work. It is typically expected that either the mother or father remains with the child in the hospital, with parental leave often utilised in such situations. Notably, there is still a trend of more mothers taking parental leave (Borrescio-Higa & Valdés, 2022, Roser et al., 2019).

Key factors when designing family studies in acute critical care settings

Ramelet's research focuses on understanding the paediatric acute-critical care context and its impact on children and families, as well as on examining the dynamics of child-parent relationships.

Ramelet emphasised several crucial factors encountered when designing studies centred on families in acute-critical care settings. She pointed out the importance of understanding the relationship between the child and family, specifically, highlighting how any disruptions in family functioning can negatively affect the child's development and recovery. Additionally, Ramelet advocated the use of theoretical frameworks, such as the Medical Research Council framework for complex interventions, to guide the development and evaluation of healthcare interventions (Skivington et al., 2021). It provides a structured approach to the development, implementation, and evaluation of complex interventions in healthcare. The framework comprises four main phases: development phase, pilot and feasibility phase, evaluation phase, and implementation phase. Each phase involves specific steps and guidelines to ensure that the research is conducted effectively and that the results contribute to improving healthcare delivery.

In her presentation, Ramelet included results of the OCToPuS research programme, which followed the MRC guidance for complex health interventions and was the first of its kind in Switzerland, conducted in all accredited Swiss PICUs. The OCToPuS study consists of four sub-studies, with Ramelet presenting the results of OCToPuS 1 and 2 in more detail:

OCToPuS 1: Psychosocial outcomes in mothers and fathers of chronic critically ill children

In OCToPuS 1 (Grandjean et al., 2024), a retrospective longitudinal study in eight accredited PICUs in Switzerland, the aim was to measure perceived stress, sources of stress in PICUs, and family functioning, using a validated questionnaire. The results showed high levels of stress experienced by parents throughout and after hospitalisation, with sources of stress primarily related to the child's appearance, emotional responses, and parental role alteration. Family functioning was found to be low throughout hospitalisation, decreasing significantly after 30 days, particularly among mothers. The study emphasised the importance of reducing the negative impact of PICU stays on parents' psychosocial well-being through early emotional parental support and addressing individual needs throughout and after hospitalisation.

OCToPuS 2: Sources of Stress, Family Functioning, and Needs of Families With a Chronic Critically Ill Child: A Qualitative Study

This quantitative and qualitative study by Grandjean et al. (2021, 2024) was conducted to describe and explore in-depth, specific PICU-related sources of stress, family functioning, and the needs of families with chronic critically ill children during hospitalisation. Conducted in eight paediatric intensive care units across Switzerland, this study involved 199 families with chronic critically ill children, 31 of whom were interviewed. The quantitative results indicated impaired family functioning and high stress in parents. The interviews revealed five overarching themes: high emotional intensity, PICU-related sources of stress, evolving family needs, multifaceted family functioning, and implemented coping strategies. Parents reported experiencing high negative emotional responses that affected family functioning, highlighting the crucial role of healthcare providers in meeting parental needs, providing emotional support, reinforcing parental empowerment, and facilitating high-quality care coordination.



Professor Anne-Sylvie Ramelet led an interactive session on child and family vulnerability and its implications for research design, with a particular focus on the paediatric intensive care unit (PICU) environment.

Key considerations when designing family studies in acute-critical settings

After introducing the OCToPuS study, Ramelet described key considerations when designing family studies in acute-critical settings. Ramelet discussed Patient and Public Involvement (PPI) as part of the preparation of one interventional study, which was supported by a Swiss National Science Foundation (SNSF) PPI grant, and which focused on the family engagement framework in research. This framework delineates several roles for families in research:

The first is the Family Advisor, who offers advice and insights at particular points, such as reviewing grant applications or providing feedback on study materials. Second, the Family Partner actively collaborates throughout the research journey, contributing as a co-investigator or providing expertise in study design and implementation. Ramelet emphasised the key concept of co-design / co-production, which focuses on collaboration between researchers and knowledge users throughout the research process, from developing the research question to interpreting results and disseminating findings. Co-production of research increases the likelihood that the results of a project will be relevant to end-users, thereby improving the possibility of uptake and application. Finally, the Lived Experience Educator role involves sharing personal experiences to educate researchers, research staff, and trainees. This may include conveying family stories during meetings or workshops and disseminating research findings to diverse audiences.

Evidence-based data that supports interventions and family support tailored to meet the needs of both parents and siblings in these situations do exist. According to Ramelet, presence, participation, engagement, and empowerment, and families' control over decisions and actions are essential in order to effectively support families in healthcare. Being present allows healthcare providers to participate in care activities, fostering engagement and empowering families. This active involvement bridges the gap between support interventions and family empowerment. The effectiveness of such interventions, however, remains unclear to date. A recent review by Barnes et al. (2024) investigated the efficacy of interventions fostering partnerships between parents and multidisciplinary healthcare teams in paediatric and neonatal intensive care units, along with their impact on family experiences. Of the 48 studies, 43 targeted families in neonatal intensive care. Only five interventions were designed for families in PICU, which yielded inconclusive results due to high heterogeneity between interventions.

Ramelet also addressed the challenges of participant recruitment in family studies in the context of PICUs, noting the subsequent high level of engagement once individuals were involved. Additionally, she stressed the importance of defining the study's target population, including criteria such as the definition of family, the number of family members involved, and the types of relationships analysed. These considerations are vital for conducting comprehensive research on family engagement within healthcare contexts.

Anne-Sylvie Ramelet

Anne-Sylvie Ramelet is a Professor and Head of the PhD in Nursing Sciences Program at the Institute of Higher Education and Research in Healthcare (IUFRS) within the Faculty of Biology and Medicine at the University of Lausanne, Switzerland. Additionally, she serves as Nurse Consultant for Pediatric Nursing Research at the Woman-Mother-Child Department at Lausanne University Hospital (CHUV). With over 15 years of experience as a registered nurse in neonatal, paediatric, and adult intensive care, both in Switzerland and Australia, Anne-Sylvie brings a wealth of practical expertise to her academic roles.

Her research and teaching focus on family support in paediatric and neonatal critical

care settings, as well as in general paediatrics. Ramelet's work emphasises developing family support interventions to empower families with critically ill children, addressing their specific needs. She has authored over 100 publications in peer-reviewed journals, reflecting the interdisciplinary and international nature of her research.

Ramelet is an active member of various professional organisations, including the European Society of Paediatric and Neonatal Intensive Care, in which she is currently the Nursing President-elect. She is also involved in the Partnership for Maternal, Newborn and Child Health on behalf of the International Council of Nurses and former Director of the BEST JBI Centre of Excellence to promote evidence-based healthcare.

Methodological Innovations in Family (Nursing) Research: Using Digital Health Platforms to Improve Family Health

Dr. sc. nat. Oliver Gruebner, a lecturer and senior researcher at the Faculty of Health Sciences and Medicine, University of Lucerne, presented valuable insights into family-focused research and healthcare using digital health platforms. In his plenary session, Gruebner highlighted the challenges faced by families dealing with paediatric neuromuscular diseases (NMD) such as Duchenne Muscular Dystrophy (DMD). He then expanded on the role of digital platforms in supporting affected families, family research, and healthcare within the context of DMD.

Gruebner's presentation focused on three key objectives: (1) exploring the types of digital platforms used by families affected by paediatric NMDs leading to severe disabilities, including the reasons and concerns associated with their utilisation; (2) discussing the common consequences and challenges for resilience in patients and family members; and (3) eliciting practical needs, concerns, and opportunities regarding the use of digital platforms to support affected families.

Drawing from his personal experiences as a parent of a child diagnosed with DMD and as president of Duchenne Schweiz, a patient organisation supporting families affected by DMD, Gruebner was able to not only offer a researcher's perspective but also insights from a family and patient organisation perspective. He began his presentation by painting a vivid picture of the emotional turmoil families face upon receiving a diagnosis like DMD. For the family, learning of such a life-threatening diagnosis for their own child is often unexpected and considered a traumatic experience with mental health consequences for the entire family. For those navigating the complex landscape of NMDs such as DMD, life presents a remarkable array of mental, physical, social, and mobility challenges. In addition, these challenges are not uniform; they are compounded by disparities stemming from socioeconomic, employment, and political factors. The resources available to tackle these challenges are often suboptimal. Technical, social, and practical barriers loom large, casting a shadow over the path to effective support. However, when these individuals turn to the digital world for support, the information and aid provided there are often unsatisfactory and can even be unsuitable, as online resources and digital platforms sometimes contain information that may be difficult to process or inappropriate for that moment, unnecessarily increasing the psychological burden on the families concerned (Gruebner et al., 2022, 2023).

As a digital epidemiologist, Gruebner co-initiated the "Rise" project, which sought to raise awareness of mental health among patients and families affected by paediatric NMDs leading to severe disability. Through this project, Gruebner and his team aimed to address the emotional challenges faced by families dealing with such diagnoses, acknowledging the significant impact these conditions can have on mental well-being. The "Rise" project involved two main methodologies: A) scoping review on parent / caregiver digital platform use in diseases with childhood onset disability and B) a transdisciplinary workshop on DMD which involved families, clinicians, and researchers, followed by the Swiss Duchenne Conference.

Diseases with childhood onset disability

The scoping review primarily focused on self-help or parent / caregiver-led digital platforms. The review encompassed a thorough examination of literature from five academic databases, specifically targeting English-language articles published within the last decade. The results revealed several key findings. Various types of digital platforms were identified, including social interaction options such as digital places, as well as search engines, health-related apps, and medical websites. The reasons for utilising these platforms were multifaceted, with users seeking information retrieval, social support, and access to objective, up-to-date, and reliable information, and guidance. However, concerns were also

identified regarding privacy issues, the digital divide, language barriers, and perceived suboptimal advice attributed to the lack of empathy from medical professionals (Gruebner et al., 2022).

Duchenne Muscular Dystrophy (the patient's journey)

The second methodology involved a transdisciplinary workshop, where the findings of the scoping review were discussed. The workshop included clinicians, representatives from patient organisations, affected families, and researchers from nursing, data, and social sciences, among others. The outcomes of the workshop were then presented at the Swiss Duchenne Conference with the aim of discussing the findings with its participants, which brought together participants from clinical practice, psychology, nursing, patients, family members, and caregivers (Gruebner et al., 2023).

The results highlighted the progressive nature of DMD, starting with early developmental abnormalities and leading to a loss of muscle strength, particularly affecting walking ability between the ages of 10 to 12 years. As the disease progresses, patients require increasing levels of care and support, including assistance with activities such as eating and moving. By around 20 years of age, upper extremity function is typically lost, necessitating full-time care. The life expectancy ranges from 30 to 40 years.



Dr. sc. nat. Oliver Gruebner spoke about the usability of digital health platforms in improving family health.

Numerous social challenges accompany the progression of DMD, including issues related to living in the nexus between the child's development and the disease progression at the same time, social exclusion, stigma, care-related challenges such as organising therapy sessions, as well as structural and financial obstacles. Additionally, patients and families face psychological challenges, such as the potentially traumatic diagnosis experience, feelings of isolation, and difficulties in navigating the overwhelming amount of information available on digital platforms.

Concerns and needs related to digital platform use included the desire for social and professional support, credibility, and trust, as well as privacy and informed consent. Opportunities for digital platforms include promoting social inclusion, facilitating organisation and care management, and providing various forms of social support. Gruebner emphasised the importance of political decisions in implementing these technologies, aligning with the UN Convention on the Rights of Persons with Disabilities and UN Sustainability Goals.

Key insights regarding use of digital platforms

Gruebner highlighted the following key insights regarding the use of digital platforms to support families grappling with progressive health challenges:

The imperative for safe, reliable, and expert-guided information dissemination on digital platforms is paramount. Given the complexities associated with conditions such as DMD, access to accurate and trustworthy information is vital for informed decision-making and care management.

Furthermore, accessible digital platform data offers new methodological avenues, for example through the application of natural language models to detect patients' specific emotions, stress, or hope in relation to the family and the patient and their respective challenges and needs, which may inform the design of digital health interventions (Tušl et al., 2022, Fadda et al., 2022, Edry et al., 2021).

Psychosocial and relationship-based digital interventions are indispensable. Beyond merely offering medical information, digital platforms should provide avenues for emotional support, counselling services, peer networks, and mental health resources tailored to the unique needs of patients and their families.

Adopting a family-centred approach is essential in digital health and social care initiatives. Acknowledging the interdependence of family members' experiences and needs ensures that support services are comprehensive and inclusive, catering to the holistic well-being of the entire family unit. Further research is warranted to evaluate the efficacy of digital platforms in fostering resilience among affected populations. Understanding how these interventions can enhance individuals' coping mechanisms and adaptability to challenging circumstances is crucial for developing effective support strategies tailored to the specific needs of patients and their families.

Overall, Gruebner's conclusions underscored the potential of digital platforms to provide holistic and personalised support for families navigating progressive health challenges and disabilities. By addressing information needs, offering psychosocial support, prioritising family dynamics, and promoting resilience, digital interventions have the capacity to significantly enhance the well-being and quality of life for patients and their families.

Oliver Gruebner

Dr. Oliver Gruebner is a lecturer and senior researcher in Public Health and Quantitative Methods at the Faculty of Health Sciences and Medicine, University of Lucerne. He is also president of Duchenne Schweiz, a patient organisation that supports families affected by DMD. Previously, he led the Digital Health Geography Research Group at the Department of Geography, University of Zurich (UZH). Gruebner is a member of the UZH DSI Health Community and the Swiss School of Public Health.

With a background in health geography, Gruebner's research focuses on the intersection of digital and physical environments and their impact on population mental health. Utilising methodologies from digital epidemiology and geography, he has contributed to over 50 publications. Gruebner recently investigated digital platform use in families living with paediatric neuromuscular diseases.

Wrap-up Session: Developing Family Nursing Research in an Interdisciplinary Context: What is Next?

In the concluding “Wrap-up Session” of the Nursing Science Symposium, contributors and participants engaged in a reflective dialogue on key learnings and future directions for family-focused research within an interdisciplinary context. The symposium’s core questions framed the discussion: How do we best improve research impact for families across the lifespan who experience acute-critical or persistent health challenges?



The engaged participants of the symposium contributed to valuable discussions and exchanges.

Throughout the discussion, the importance of engaging patients, families, and underrepresented groups in research was emphasised, highlighting the need for more collaborative approaches to research that value diverse perspectives and partnership models. The use of research methodologies that allow for the development and testing of equitable and tailored interventions and care programmes reflecting diversity in needs and life circumstances across the lifespan was also emphasised. Attendees and contributors also recognised the significance of interdisciplinary collaboration and larger programmes of research in order to achieve impact across health systems. Lastly, the potential of digital platforms to revolutionise healthcare delivery and research was highlighted. Takeaway messages included:

Create partnerships with patients and family members: Moving forward, the community discussed the need to support, empower and fund initiatives that promote partnerships between patient and family member experts with researchers. Patient and public involvement and engagement was held to be underdeveloped, particularly within the Swiss system, requiring a paradigm shift towards a more participatory understanding of healthcare and research design, enabling shared ownership and governance. Therefore, the need to build capacity and infrastructure to enable early engagement and nurturing of long-time collaborations between patients, family members, researchers, and policymakers was identified in both research and service provision.

Address social determinants of health to ensure equity: The panel discussed the need for more attention to family vulnerability and diversity in order to avoid the reproduction of inequality and injustices in health (care) knowledge, service, and implementation design. Social determinants and disparities that shape individual and family health needs, experiences, literacy, and accessibility (or lack thereof) should be built into research programmes and new healthcare intervention and implementation projects, despite multiple methodological challenges, to advance equity in healthcare research and service, was the conclusion.

Build-in adaptability when designing family-focused health interventions: According to the discussion, in order to address diversity and disparities, new family-focused interventions and healthcare programmes, which are often developed in the context of research, need to be designed in a way that allow them to be tailored to diverse family constellations, situations, and locations across the lifespan. Based on the presented research, those core interventions that were perceived as beneficial and resulted in positive health outcomes combined healthcare practices such as listening, communication, interaction, and empathy.

Discussions also centred on improving health promotion and prevention within the health system, with an emphasis on the crucial role of family members, parents, and close friends. Participants emphasised the usefulness of understanding family as a comprehensive, interactive system that is essential to the individual child's or adult person's health. The importance of seeing family as an integral part of the healthcare system, rather than passive users or an "add-on" was stressed, with a call for more proactive involvement and engagement across populations, life-course, and health systems.

Use of diverse research methodologies to advance family health and well-being: The contributions gave testimony to the value and added benefit of combining quantitative, and more controlled research approaches with qualitative, exploratory research methodologies to determine and explain intervention benefits as well as unintended consequences, or even harm. The discussion emphasised the value of longitudinal, multi-, and mixed-method research programmes to develop or redesign, evaluate and implement interventions.

Capitalise on the digital transformation: The use of digital platforms to develop community-based, accessible, and reliable family support structures that meet families' diverse needs, which may appear differently in the early stages versus later in an illness trajectory, provides a resource which is still untapped within the health system. Targeted use of such digital platforms was suggested to provide information, education, and to empower families who are faced with a new diagnosis or live with ongoing health challenges, particularly in light of their use being a societal trend. In addition, openly accessible, digital platform data offers new methodological avenues, for example, through the use of natural language models, to better understand illness narratives and needs, which in turn may inform digital health intervention development.



In the "Wrap-up Session", contributors and participants reflected on key learnings and future directions for family-focused research within an interdisciplinary context.

Concluding Remarks by Professor Petra Brysiewicz

Prof. Dr. Petra Brysiewicz

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Given the recent global pandemic, a symposium to focus on “Improving research impact for families experiencing acute-critical illness” is indeed timely. In writing the concluding note for this symposium describing methodological insights and takeaways for this area of research, I am privileged to be able to revisit the key themes and understandings shared during this important meeting.

This inaugural, multidisciplinary symposium showcased the collaborative efforts of researchers, clinicians and innovators (experts from France, Germany and Switzerland), in addressing critical healthcare challenges faced by families. This symposium created a wonderful opportunity to bring researchers together to discuss and to highlight the critical role nurses play in improving health outcomes as well as recognition of the impact of illness on patients and their families.

The symposium considered the importance of families to the healthcare system and the evolution of family health research (especially within the field of acute care), as well as exploring how to advance the field while acknowledging that traditional caregiver burden assumptions are changing, and that family structures are indeed diverse. The importance of communication between all health professionals and the patient and family members was emphasised, as well as the need to provide holistic and personalised support, and for a digital platform to be safe and reliable.

The presentations served to highlight the implementation of research findings into real world healthcare. Reflections were raised regarding the latest methodological insights and conducting research that emphasizes the importance of the use of mixed method studies and further investigation of the social determinants of health in this research field. Research in this area should strive to explore and gain further understanding of health disparities as well as the influence of socioeconomic factors.

There is a need to think about research in this area as not being “just research” but rather that researching families can actually be a therapeutic experience for families, as well as having unexpected and unintended consequences of proposed supportive interventions. The symposium discussed shifts within this research field into partnership models, namely, patient and public involvement and engagement in research, as well as the need to actively engage patients and families in the research to increase meaning making. In fact, doing research “with them” and in so doing, embracing co-learning and the messiness of participatory research, all the while working to ensure transparency, trust building and respect.

Indeed, as we navigate the complexities of medicine, nursing, and healthcare, we must remain vigilant in our pursuit of evidence-based practices while at the same time acknowledging the inherent uncertainties that accompany progress while appreciating the continuous nature of scientific knowledge. The imperative to bridge the gap between knowledge generation and implementation resonates profoundly, urging us to transcend the confines of academic research and affect tangible change in real-world healthcare settings. It is hoped that this symposium provided resources and inspiration for family research globally as well as highlighting the implications and challenges for implementation science. The need to decrease research complexity and be more inclusive, to reduce the research mystique, was stressed.

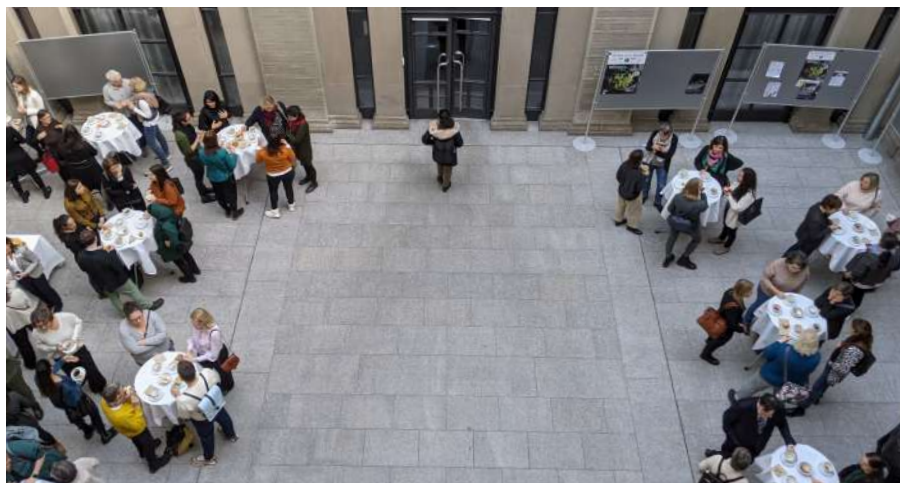
Finally, let us carry forward the lessons learnt from a variety of contexts globally within the spirit of inquiry and collaboration that has defined this symposium. May we remain steadfast in our commitment to excellence, guided by the principles of compassion, integrity, and innovation while we embark on the process of addressing critical healthcare challenges faced by families and the critical role nurses play in improving health outcomes.

Acknowledgements

When I was appointed to the professorship of Implementation Science in Nursing during the early days of the Covid-19 pandemic, we witnessed the dramatic impact of the pandemic on families, as the smallest societal unit, particularly within health-care. We experienced the consequences of families' physical exclusion from health-care institutions, such as hospitals and long-term care. The delivery of family-focused nursing and healthcare became extremely challenging. Families were unable to get the support they needed, nurses and healthcare workers were limited in their ability to engage with family members and others close to the patient in order to support patients' health and well-being, and to partner with families in providing care. The need for better translation and integration of existing evidence into family-focused nursing and healthcare, together with a need to innovate care delivery to families, became even more pressing (Naef & Monteverde, 2021).

During that time, it was impossible to come together physically in one room to discuss family health research and its real-world implementation to improve care. It has therefore been a great honour to be able to host this first Nursing Science Symposium at the University of Zurich in January 2024 with a focus on family-centred health intervention and implementation science research across the lifespan. I would like to thank the participants, contributors, and supporters of the symposium:

- The over 70 participants for their interest and time.
- The contributors (in alphabetical order): Beatrice Beck Schimmer, Chantal Britt, Oliver Gruebner, Nancy Kentish-Barnes, Anne-Sylvie Ramelet, Martina Roes for the excellent presentations and contributions, and their agreement to share their insights with a wider audience.
- The organising committee (in alphabetical order): Lea Dahinden, Saskia Oesch, Marco Riguzzi, Irene Rilko, Torsten Schwalbach, Simone Sutter, Lotte Verweij.



Break time is used for further discussion at the Lichthof of the University of Zurich.

I would also like to acknowledge the invaluable support of the Swiss Society for Intensive Care Medicine (SSICM), Swiss Association for Nursing Science (VFP/APSI) and Palliative.ch for communicating and disseminating information on the symposium within their society and networks. UZH alumni provided financial support, for which we express our sincere appreciation. We would also like to thank Careum Publishing for enabling the release of this working paper.

I am personally extremely grateful to the many supporters and promoters of Nursing Science at the University of Zurich, which is a relatively young academic discipline within the Faculty of Medicine. In spring 2020, the Assistant Professorship for Implementation Science in Nursing was established with the support of Careum Foundation, the Zurich University of Applied Sciences, School of Health Sciences, and the University Hospital Zurich, Directorate of Nursing. The Professorship is affiliated with the Institute for Implementation Science in Health Care at the Medical Faculty, founded in 2019, and includes a cross-appointment to the Center for Clinical Nursing Science at University Hospital Zurich.

I would like to thank the members of my research group and colleagues at the Institute for Implementation Science in Health Care and at the Center for Clinical Nursing Science at the University Hospital Zurich for their collaboration. I would also like to acknowledge the nurse leaders who have promoted nursing science at the University Hospital Zurich over the last three decades, leading the Center for Clinical Nursing Science: PD. Dr. Dr. Silvia Käppeli (1989-2010, then called Center for Development and Research in Nursing), Prof. Dr. Rebecca Spirig (2010-2013), Dr. Maria Schubert (2013-2015), and Prof. Dr. Heidi Petry (since 2016).

Zurich, in April 2024

Professor Rahel Naef

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Appendix: Symposium Programme Overview



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USZ Universitäts
Spital Zürich

Description

This symposium aims to share latest methodological insights in research focusing on families experiencing acute-critical illness, drawing on national and international experiences from different disciplinary perspectives. It will build and expand collaborations between researchers, clinicians, and innovators involved in family intervention and implementation research. Using examples from their own research, contributors will share novel methods and directions on improving quality of research, and for promoting its translation into services that benefit families. The aims of the symposium are:

- To build a transdisciplinary and interprofessional community of researchers and clinicians / practitioners committed to improving health care for families.
- To promote scientific / scholarly dialogue about family health research and practice within health and health care.
- To enable methodological advances and innovations in family health intervention and implementation research.
- To highlight research areas for future collaborative intervention and implementation research in the field of family health.

Everyone interested in the symposium topic is warmly welcome to attend. The symposium is targeted towards researchers, practitioners and clinicians interested or involved in research, as well as master and doctoral students in the field of nursing science, medicine, psychology, health sciences and other disciplines related to family health.

Contributors

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Dr. sc. nat. Oliver Grübner, Group Leader Health Geography at the Department of Geography and at the Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Switzerland



Program

09:00	Registration
09:15	Welcome Rahel Naef, Host, University of Zurich
09:20	Welcome address from the University of Zurich Beatrice Beck Schimmer, Vice President Medicine Zurich, University of Zurich RAA-G-01
09:30	Introduction and overview to the symposium Rahel Naef, University of Zurich & University Hospital Zurich RAA-G-01
09:45	Keynote 1: Building a programme of intervention research focusing on families' experience in ICU: Methodological learnings from The FAMIREA Example Nancy Kentish-Barnes, Famiréa Research Group, Hospital Saint Louis, Paris RAA-G-01
10:30	Coffee break Lichthof
11:00	Keynote 2: Addressing complex implementation challenges in family-focused dementia care Martina Roes, DZNE & University of Witten/Herdecke RAA-G-01
11:45	Networking Lunch Lichthof
13:15	Interactive session 1: Research co-production: Perspectives of a patient, a family member, and a researcher Chantal Britt, Patient expert and advocate, Bern University of Applied Sciences RAA-G-01
14:00	Interactive session 2: Doing research with families in vulnerable situations: Key considerations when designing family studies in acute-critical settings Anne-Sylvie Ramelet, University of Lausanne & CHUV RAA-G-01
14:45	Walk & talk – grab your coffee as you go Lichthof & Outside
15:30	Plenary session: Methodological innovations in family (nursing) research: Using digital health platform to improve family health Oliver Grübner, University of Zurich RAA-G-01
16:15	Wrap-up: Developing family nursing research in an interdisciplinary context: What is next? All contributors RAA-G-01
17:00	End of symposium

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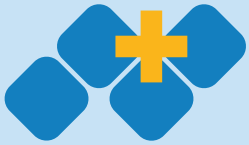
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