



Research gaps in nursing status and interventions – A deductive qualitative analysis of healthcare professionals' perspectives from Swedish childhood cancer care

Cecilia Bartholdson^{a,b,*} , Anna Pilström^c, Pernilla Pergert^{a,d}, Johanna Granhagen Jungner^a, Maria Olsson^{e,f}

^a Dept. of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden

^b Astrid Lindgren Children's Hospital, Karolinska University Hospital, Stockholm, Sweden

^c Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden

^d Centre for Research Ethics & Bioethics, Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

^e LTFUC, Oncology, Sahlgrenska University Hospital, Gothenburg, Sweden

^f Institute of Clin.Sci, Dept. Oncology, Sahlgrenska Academy, Gothenburg University, Gothenburg, Sweden

ARTICLE INFO

Keywords:

Childhood cancer care
Deductive analysis
Healthcare science
Nursing care
Qualitative analysis
Research gaps
VIPS model

ABSTRACT

Purpose: Despite advances within the area of healthcare science in childhood cancer care gaps remain between research and clinical practice, particularly in nursing care. In Sweden, no prior studies have explored healthcare professionals' (HCPs) perspectives on research gaps in this area. Therefore, the aim of this study was to explore research gaps in healthcare science within childhood cancer care in Sweden that HCPs perceived as important. **Method:** HCPs from all six Swedish childhood cancer centres responded to an open-ended question about what questions/needs future research should address to improve the care and nursing of children/adolescents with cancer and their families. Responses ($n = 186$) were analysed using deductive content analysis and categorized according to the VIPS model, which structures nursing data around key care concepts.

Results: HCPs perceived research gaps in two main areas: *nursing status* and *nursing interventions*. Nursing status included communication, nutrition, elimination, physical activity, sleep, psychosocial aspects, and wellbeing. Nursing interventions encompassed participation, support, environmental adaptation, specific nursing procedures, drug administration, and care coordination.

Conclusions: HCPs in Swedish paediatric oncology highlight a broad range of research gaps in nursing care. While there is already existing evidence in some areas, improved implementation strategies are needed to bridge the gap between research and nursing care practice. These findings can help define future research agendas in paediatric oncology nursing.

1. Introduction

In Sweden, approximately 350 children and adolescents (aged 0–19) are diagnosed with cancer each year. These diagnoses encompass a range of cancer types, including blood-related cancers and solid tumours (Socialstyrelsen and Cancerfonden, 2023). The care and treatment are highly specialized and coordinated across six University Hospitals, each hosting a childhood cancer care centre. The centres collaborate closely to ensure that children across Sweden receive equitable access to the latest treatment and participate in research. Thanks to the progress made in research regarding treatment and care over the past decades,

about 85 % of the children survive (Socialstyrelsen and Cancerfonden, 2023). Childhood cancer research includes various types with different goals and methods, such as preclinical- and clinical-as well as biomedical- and healthcare-research. Biomedical research typically focuses on biological mechanisms and medical diagnoses and treatments, while healthcare research aims to understand and improve care practices and patient well-being. Research in the field of healthcare science has been defined as the systematic generation of knowledge aimed at understanding and promoting activities that maintain and improve health, alleviate suffering, and create conditions for a peaceful death (Galea and Abba-Aji, 2024; Pang et al., 2003). Studies in healthcare science also

* Corresponding author. Childhood cancer research unit, Wideströmska Huset, Tomtebodavägen 18a, 17177, Stockholm, Sweden.

E-mail address: cecilia.bartholdson@ki.se (C. Bartholdson).

<https://doi.org/10.1016/j.ejon.2025.102972>

Received 1 July 2025; Received in revised form 26 August 2025; Accepted 27 August 2025

Available online 28 August 2025

1462-3889/© 2025 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

include the effects of treatment and care, resources for care and nursing environments, and studies within various disciplines, such as nursing. Nursing activities represent the practical application of theoretical and research-based knowledge within healthcare science (Meleis, 2011). This integration is echoed in contemporary nursing science models, which describe the generation and application of new knowledge as essential for guiding professional practice and improving patient well-being (Chesak et al., 2022). Applying this knowledge through evidence-based practice is essential for enhancing patient satisfaction, ensuring quality and safety, and supporting professional development in nursing (Välämäki et al., 2021).

Prominent research has been conducted and is ongoing in healthcare science related to children with cancer. However, a significant gap has been identified between the research questions that researchers pursue and the questions that healthcare professionals (HCPs) consider important (Crowe et al., 2015). HCPs working in childhood cancer care have valuable experience-based knowledge to share when researchers and funders decide which clinical questions should be studied. Three recent studies, from the UK and Canada, share a common focus on identifying research priorities in childhood cancer care through stakeholder engagement, particularly involving HCPs. Across all studies, there is a strong emphasis on improving psychosocial support, communication, and family-centred care. The results from the studies also highlight the importance of addressing long-term outcomes, such as survivorship and mental health, and enhancing supportive care practices. Together, these studies reflect a shared commitment to aligning research with the real-world needs perceived by patients, families, and HCPs (Aldiss et al., 2019; Gill et al., 2022; Hwang et al., 2024).

In Sweden a systematic literature review of healthcare science and psychosocial research in childhood cancer care have been conducted (Enskär et al., 2015). The authors emphasized the necessity of shifting the focus towards interventions that can transform empirical research into practical application. The authors also highlighted the importance of presenting results in a concrete and practical way. This ensures that the clinical implications are useful without requiring extensive interpretation (Enskär et al., 2015). However, yet no studies have been performed with the objective to identifying research priorities from the perspectives of HCPs, patients and families in Swedish childhood cancer care. Therefore, the overall objective of a national research project in childhood cancer care is to ensure that future healthcare science research initiatives are grounded in the identified knowledge gaps of key stakeholders. In particular, the engagement of HCPs is critical, not only because they are directly impacted by research outcomes, but also because their insights are essential for shaping research agendas that are both clinically relevant and practically applicable. The aim of this study was thus to explore research gaps in healthcare science, within childhood cancer care in Sweden, that HCPs perceived as important.

2. Methods

2.1. Design

This study is part of a larger national project, with a participatory research approach (Nielsen et al., 2025), using the James Lind Alliance (JLA) method (Nygaard et al., 2019) for identifying and prioritizing knowledge gaps and research questions in childhood cancer care in Sweden. The method is based on patients, relatives, and HCPs working within a specific area agreeing on the most important knowledge gaps within this area. Thus, the JLA method integrates interdisciplinary collaboration, evidence-based practice, patient involvement, and research for change to address complex medical and healthcare problems effectively (Petit-Zeman et al., 2010).

2.2. Procedure

A project group consisting of healthcare researchers and clinicians

belonging to a network for childhood cancer healthcare science in Sweden, was formed to jointly conduct this project. In addition to the project group, 1–2 collaborators were invited from each childhood cancer centre, such as managers and registered nurses, to assist the project group with data collection. In the larger national project three phases will be applied following the JLA method: 1) *Inventory Phase* - data will be collected from HCPs, patients and parents, 2) *Sorting and Compilation of Incoming Proposals*, and 3) *Prioritization Phase*. In this study the two first phases are conducted on data from HCPs perceptions of research gaps, forming a foundation for the larger national project. The two first phases are also presented in this study due to the importance of an efficient and timely approach to disseminate the identified research gaps.

2.3. Participants and data collection

To assess the core question, the formulation of the question was explored using the Think-aloud method in cognitive interviews (Wolcott and Lobczowski, 2021). Five potential respondents from two cancer care centres, including three registered nurses, one nursing assistant and one physiotherapist, considered the question and thought aloud about how they perceived the question and how they would answer. The interviews resulted in the question being revised. After a consensus dialogue, the project group arrived at the following core research question: "Based on your experiences, what questions/needs should future research address to improve the care and nursing of children/adolescents with cancer and their families?"

A member of the project group or a collaborator, presented the project and invited HCPs (Physicians, Registered Nurses and Nursing assistants) from all childhood cancer centres in Sweden (N = 6) to answer the research question. In connection with the presentation, research information was provided, i.e., the purpose of the project, the voluntary nature of participation, and how the data would be handled. After the presentation, a poster was put up with the research participant information and a QR code that directed HCPs to a digital questionnaire. The posters were placed on the wall for approximately a three-month period. At one centre data was collected during a staff meeting and HCPs wrote their perceived research gaps on sticky notes.

2.4. Ethical considerations

This study adhered to ethical principles for research involving human participants. Participation was voluntary, and HCPs were informed about the purpose of the study, and data handling procedures. Data were collected anonymously through open-ended responses, ensuring confidentiality and minimizing any potential risk to participants. No sensitive personal data were collected. As such, the study does not fall under the categories that require ethical review. This approach is consistent with national ethical guidelines for research involving HCPs in their professional roles, where the risk of harm is minimal, no sensitive personal data is collected, and data are handled confidentially.

2.5. Data analysis

All submitted research gaps were compiled in an Excel document and read through by each of the authors, enabling understanding of what the data was about. The authors then coded the data together during two digital meetings, resulting in each perceived research gap labelled with a code. For example, 'Families' experiences regarding the need for psychosocial support during and after cancer treatment' received the code 'Psychosocial support'. Inter-coder reliability was ensured by pilot coding, to align interpretations. To ensure consistency and rigor in the coding process, disagreements between researchers were resolved through discussion during the digital meetings. The inclusion criteria was that the research gaps should answer the aim and thus be about healthcare science within childhood cancer care including care that directly

Table 1
List of Out-of-scope codes.

<ul style="list-style-type: none"> • Children and parents' experiences of the hospital's financial situation • Continue with the development of different [medical] treatments • Genetics • Healthcare professionals' competence • Healthcare professionals' turn over • How can pediatric oncology be adapted to a new medical record system? • How healthcare leaders can be more engaged in research issues • Immunotherapy • Medical Side Effects • Work environment and working conditions

affected the children. The exclusion criteria were that the research gaps were about care that could indirectly affect the children, for example HCP's work environment and competence. Research gaps that were decided in consensus to be out-of-scope (Gibson et al., 2021) were labelled with a code and then sorted in a special list for out-of-scope codes, presented in Table 1. For example, *Work Environment and Working Conditions: Studies that review working conditions, such as staff working hours, paus systems, and workload, to identify factors that can be improved to reduce burnout and increase work morale* received the code 'working environment' and were put on the out-of-scope list.

After that, the first (CB) and the second (AP) author sorted the relevant codes deductively according to the VIPS-model (Ehrenberg et al., 1997). VIPS is an acronym derived from the Swedish words for well-being, integrity, prevention, and safety, which are considered the primary goals of nursing care. The model organizes nursing data using a system of keywords, facilitating the storage and retrieval of information (Ehrenberg et al., 1997).

3. Findings

Six childhood cancer centres and several regional hospitals participated in the project, resulting in responses from 65 healthcare professionals (registered nurses, n = 21; registered specialist nurses, n = 23; nurse assistants, n = 12; other staff, n = 6; and physicians, n = 3). The distribution of responses was similar from four of the six centres and less shares from two of the six centres. Moreover, a smaller portion of responses originated from regional hospitals. HCPs stated 186 (including 12 out-of-scope) healthcare science research gaps that they perceived to be important to improve the care and nursing of children/adolescents with cancer and their families. The research gaps were categorized into the following areas: *Nursing status* and *Nursing interventions*. The keywords in the VIPS model (Ehrenberg et al., 1997) in relation to the perceived research gaps are presented in Fig. 1. Quotes from the respondents are presented to illustrate the perceived research gaps.

3.1. Nursing status

Nursing status included *communication, nutrition and elimination, skin/wounds/mouth, physical activity, sleep, sexuality/reproduction, psychosocial aspects, and wellbeing*.

3.1.1. Communication

Research gaps of communication were related to both *oral and digital communication* and also included different communication situations. The *oral communication* was about language barriers, multi-cultural relations and communication via interpreter. The *digital communication* referred to using mobile applications and visual support in care. Moreover, several respondents described different communication situations as under-researched including communication in palliative care, such as talking with children and their siblings about death. There was also a desire for increased knowledge about how to talk to adolescents about fertility and sexuality in a successful and appropriate way.

As expressed by one respondent: "How and what do they want to

know about fertility and sexuality, how do they want the healthcare system to deliver that information?"

3.1.2. Nutrition and elimination

In the areas of nutrition and elimination, research gaps included how HCPs can contribute to maintaining good nutritional status in patients and how nutritional improvements could be made for patients who do not eat despite sufficient antiemetics treatment and pain relief. One respondent wrote, "Nausea, appetite, good foods to eat. How/what/when do patients prefer to eat?" Questions were posed regarding whether the benefits of a feeding tube could outweigh the disadvantages patients might experience from living with a feeding tube. The research gaps were also about which foods are appropriate during cancer treatment and whether an increased use of rating scales to assess nausea could improve nutritional status. Some research gaps concerned methods to reduce the risk of constipation during cancer treatment.

3.1.3. Skin/wounds/mouth

In the area of skin/wounds/mouth, research gaps were about skin care, scars related to appearance and impact on body image. Furthermore, the research gaps of guidelines to prevent problems with scars were raised. One response was formulated like this, "Skin care, scars, wounds, guidelines around this." Another research gap raised was how quality of life is affected when the skin is affected by various treatments. Some wanted to know more about the importance of touch, e.g. tactile massage for both patients and family members. Several research gaps concerned sores and blisters in the mouth, such as mucositis. Moreover, research gaps concerned how tooth formation is affected when it occurs during the time of cancer treatment.

3.1.4. Physical activity

Physical activity included the need for evidence on how patients should be stimulated to physical activity in a good way. More specifically it was about the research gap of how physical activity affects blood counts during a stem cell transplant. Moreover, it included if physical activity-interventions could attract a teenager out of the hospital room. An example of this is, "Teenagers ... how do you get them out of the room [at the hospital]?"

3.1.5. Sleep

HCPs perceived extensive research gaps concerning the impact of hospitalization on sleep, affecting both patients and their families. Sleep was mentioned repeatedly but almost invariably in a similar way. One respondent wrote "Families/children's sleep at the hospital".

3.1.6. Psychosocial aspects

Psychosocial aspects were identified as a significant area of interest, receiving a large number of suggested research gaps. The core aspects included *education and emotional support*. *Education* - many HCPs emphasized the need for increased knowledge regarding individualized care to improve conditions for social interactions and schooling during cancer treatment. One response was formulated like this: "Preschool/School during treatment - to what extent are children able to attend? What significance does school have? The national recommendations regarding social life - how well do families follow them? What do they [national recommendations] mean for the families? School robots during childhood cancer treatment - how many use them? To what extent are they used when the child has a robot?" *Emotional support* - additionally, research gaps were about strategies to reduce the fear of needles resulting from treatment and how to provide support to families who may decline certain services, such as contact with a counsellor. Moreover, emotional support was about grief.

3.1.7. Wellbeing

Wellbeing included research gaps concerning enhancement of patients' quality of life during their hospitalization, late complications,

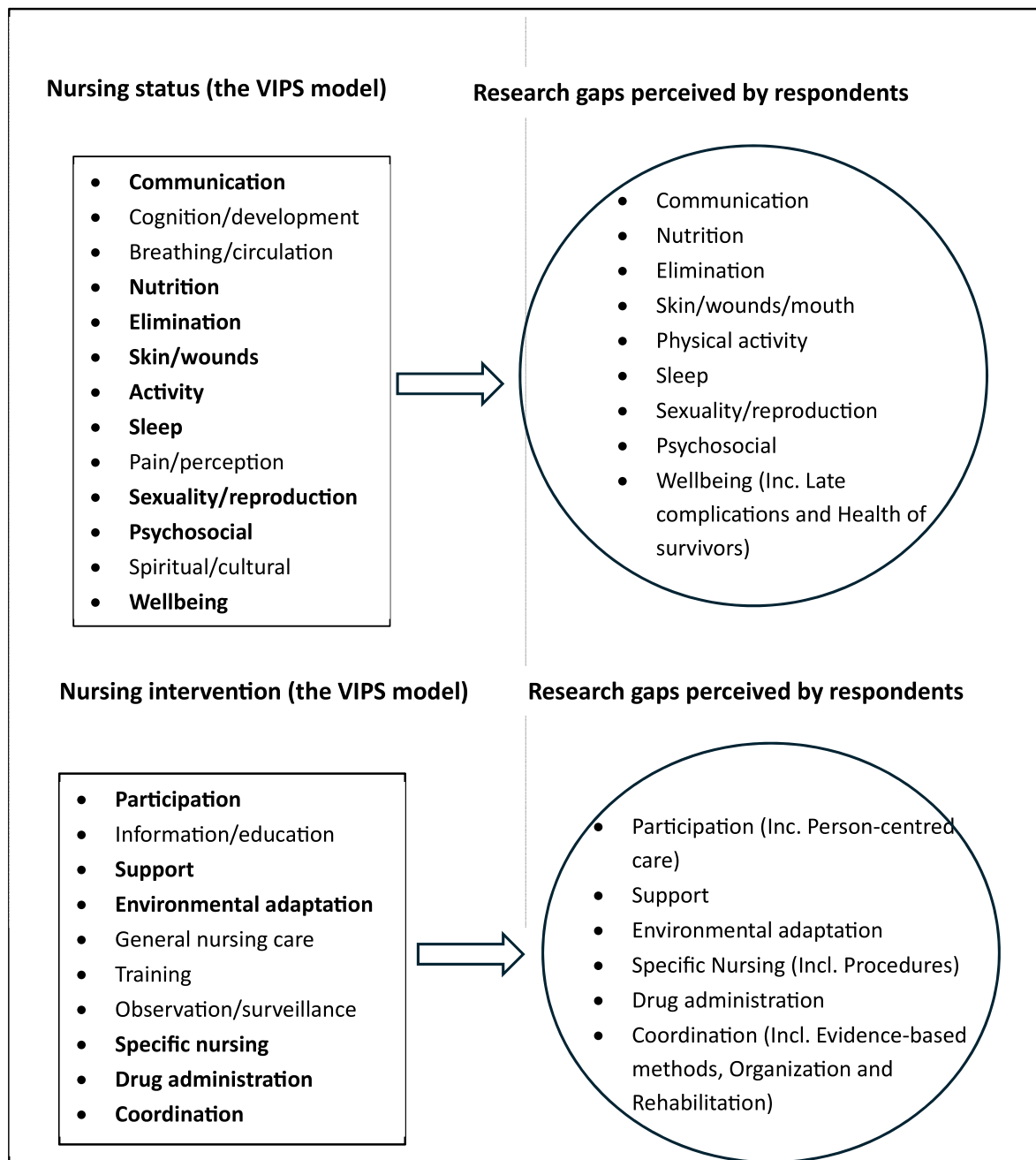


Fig. 1. The keywords in the VIPS model (Ehrenberg et al., 1997) in relation to the perceived research gaps.

and health of survivors. Several respondents wanted more knowledge about late complications on a general level. Some specified that it was about late side effects of newer treatments and how quality of life is affected after cancer treatment as a child. As expressed by one respondent: "Late complications after treatment with new drugs". In general, more knowledge was desired about how the well-being of childhood cancer survivors can be improved.

3.2. Nursing interventions

Research gaps were also identified in relation to nursing interventions, i.e. *Participation*, (incl. *Person-centred care*), *Support*, *Environment adaptation*, *Specific Nursing* (incl. *Procedures*), *Drug administration*, *Coordination* (incl. *Organization*, *Rehabilitation*, *Evidence-based methods*)

3.2.1. Participation

The area of participation included research gaps about both children's and parents' participation and person-centred care. Research gaps for both children and parents were related to how HCPs in general could work to increase patients' and family's participation in their care and specifically in difficult conversations and when facing ethical dilemmas. Focusing on children, research gaps related to person-centred care and where about how person-centred care might enhance the social lives of childhood cancer patients. This included developing strategies to tailor care to the unique needs and preferences of each patient. One respondent wrote, "In today's stressful healthcare environment, I often feel that the focus shifts more toward the medical aspects, and there's not enough time for the person behind the patient." Additionally, facilitating children's own conversations with HCPs was stated crucial for effective communication and ensuring that care aligns with the patient's personal experiences and needs.

Support

The research gaps addressed social support for both the patient and their family. Research gaps were identified about the provision and responsibility of psychosocial support, the specific needs of adolescents, and the optimal treatment for children and adolescents with neuropsychiatric diagnoses in conjunction with cancer treatment. This is exemplified by this quote: "The families' experiences of the need for psychosocial support during and after cancer treatment. How they would like the support to be offered and more research on experiences of the support they have received/not received".

3.2.2. Environmental adaptation

In the area of environmental adaptation, several perceived research gaps were about adolescents at the hospital. HCPs wanted to know more about how adolescents experience the hospital environment and how it could be adapted to stimulate them. One HCP wrote: "A teen-friendly department (how it is adapted to stimulate teenagers, not just the little child)." Additional research gaps addressed the impact of Hospital Clowns' visits to the sick child, their siblings, and guardians, with an emphasis on well-being during hospitalization and the lasting memories post-illness.

3.2.3. Specific Nursing

Several HCPs wanted evidence for their methods used for nursing procedures including *invasive* and *non-invasive procedures*. The *invasive procedures* concerned central venous catheters including the child's perspective on preparation and information before the procedure. Central venous access devices were mentioned many times, indicating a considerable focus on the procedures, complications, and management of these catheters. For example, "CVC/SVP [Central venous catheter/Sub cutaneous venous port] dressing change and needle placement, how often, are today's guidelines research based?" Another research gap pertained to capillary blood sampling in visually impaired patients. This involved understanding the unique challenges and developing specialized techniques to ensure accurate, safe and comfortable blood sampling for these patients. The insertion of nasogastric tubes was also highlighted, with questions about best practices and the potential complications associated with this procedure. Furthermore, there was a question about whether the use of nasogastric tubes is always justified, suggesting a need for criteria to determine when their use is warranted. The *non-invasive procedures* included several research gaps with focus on the use of distraction techniques during medical procedures to alleviate patient discomfort and anxiety. This involved exploring various methods to divert patients' attention effectively. Some research gaps concerned diversion in procedures and how to avoid restraint in connection with a procedure.

3.2.4. Drug administration

The research gaps concerning drug administration included in this study were the ones related to nursing procedures, thus not treatment of illness. HCPs stated a need to evaluate whether the use of local anaesthesia, like lidocaine nasal spray, could improve patient comfort and procedural outcomes related to nasogastric tube insertion. Moreover, the effectiveness of Dexmedetomidine in various medical procedures was another area requiring research to determine its efficacy and potential benefits for patient experiences. As expressed by one respondent: "Is it better to use Xylocaine nasal spray? Does Dexmedetomidine work?"

3.2.5. Coordination

The coordination research gap area included *care coordination*, *evidence-based methods*, *organization*, and *rehabilitation*. HCPs stated a need for developing and evaluating methods for effective *care coordination*, including the concrete implementation of these methods in clinical practice. HCPs further reported that future research is needed to establish robust evidence supporting various coordination strategies.

Suggested research gaps also included non-pharmacological interventions and non-pharmacological treatments, exploring their integration into coordinated care plans. Developing and standardizing guidelines for coordination, particularly in the context of stem cell transplantation (SCT), was additionally essential. Moreover, participants expressed that there was a gap in the evidence-based methods consistent application and the structure for implementing research findings into practice. For example, it was perceived that pain assessment methods required better integration into coordinated care to ensure comprehensive pain management. HCPs also stated a need to investigate how the Convention on the Rights of the Child is adhered to within coordinated care frameworks. Lastly, the consistent application of evidence-based methods across all aspects of coordinated care remains a significant gap according to the participants. Moreover, research gaps were identified in relation to *organization*, including *homecare*, *continuity*, *care structure* and *profession*, referring to where and by whom the child should receive care. Several of the questions concerned homecare. "What wishes do patients have related to care at home and how can opportunities for care at home be increased?" A specific research gap regarding homecare was about success factors for succeeding with complex healthcare of children and young people at home. One respondent expressed it like this: "If children, especially adolescents, can be treated at home, they often hate the hospital." The question of continuity was asked from both HCPs and patient perspectives, and they wanted to know how important continuity is for patients. A further example of a research gap in organization was knowledge about the challenges experienced by less experienced staff as well as patients' experiences of the rounds and whether patients think interventions are missing in healthcare. Finally, the area of coordination included *rehabilitation* after cancer treatment as well as rehabilitation based on a compliance perspective. There were also more specific requests for healthcare research about rehabilitation, for example after radiotherapy.

4. Discussion

Research gaps in healthcare science, perceived as important by HCPs within childhood cancer care in Sweden, have been explored in relation to nursing status and nursing interventions. Important research gaps in nursing status, included communication, nutrition, elimination, activity, sleep, sexuality/reproduction, psychosocial wellbeing, and overall wellbeing. Additionally, research gaps in nursing interventions were noted in areas such as participation, support, environmental adaptation, specific nursing, drug administration, and coordination.

Several of the areas perceived by HCPs as research gaps already have existing scientific evidence. For instance, there is extensive research on communication with children in palliative care (Ayoub et al., 2025; Laronne et al., 2022; Lin et al., 2023) and sexuality has received great attention (Bentsen et al., 2024; Cherven et al., 2021, 2024; Frederick et al., 2019). Additionally, there is increased knowledge regarding the importance of social life and schooling (af Sandeberg et al., 2008), as well as home healthcare for children with cancer (Castor et al., 2018; Hansson et al., 2013). Even if evidence exists in these areas, more research is needed, which could be a reason for the perceived gap. However, it could also be a sign that, although evidence exists, HCPs lack awareness of it and have not engaged in the available research. Several factors may contribute to this gap. Research consistently demonstrates that stress among paediatric nurses is prevalent and multifactorial, with significant implications for mental health, job satisfaction, and care quality. Key contributors include high workload, poor work environment, limited resources, strained interpersonal relationships, lack of support, demanding roles, and financial strain (Pradas-Hernández et al., 2018). In addition to stress and challenging working conditions, a deficient scientific culture, characterized by the absence of structured support for nursing research, may exist within childhood cancer centres. In a cross-sectional study with the aim to

identify barriers to nursing research, respondents (n = 948) reported barriers to research engagement at the individual (lack of research knowledge), unit (limited support from staff and authority to implement changes), and institutional levels (insufficient support systems like protected research time) (Chan et al., 2011). We argue that nursing knowledge and directions on practices are frequently grounded in local traditions and established routines, rather than in critical reflection or an active pursuit of evidence-based practices. To address this issue, one solution could be the integration of doctoral prepared nurses into healthcare organizations. These individuals can play a pivotal role in fostering a culture of scientific inquiry and can provide targeted support in identifying and applying evidence to specific clinical questions. Another solution could be to engage more registered nurses in research, either to take part in established research projects or to become PhD students while working in the clinic. This has also been highlighted in a systematic review aimed at identifying, evaluating, and synthesizing existing evidence regarding the key factors that facilitate or hinder nurses' engagement in clinical research activities (Morrison et al., 2022). We propose that when registered nurses are actively involved in research activities, their awareness and understanding of how evidence is identified and generated increases. This enhanced insight may, in turn, encourage them to seek out and apply evidence more consistently in their own clinical practice. However, not only does this study raise the issue of unawareness of existing evidence, the result of this study also highlights the need for implementation of existing research in the form of guidelines and protocols in certain areas. For example, despite many studies about communication with children about their death, Kreicbergs et al. (2021) regretfully noted that there had been no improvement even though 15 years had passed (Kreicbergs et al., 2021).

Interestingly, this study has identified several research gaps that warrant immediate attention and further exploration. Notably, the impact of hospitalizations on sleep for both children and their parents emerged as a significant yet underexplored area, reinforcing concerns previously highlighted in the literature (Daniel et al., 2024). This may represent a critical area for research, as sleep deprivation can intensify the fatigue already caused by cancer treatment and negatively affect quality of life. Furthermore, the lack of evidence and clinical guidance related to skin care, wound management, and scarring in paediatric oncology was also evident in our findings. This aligns with earlier calls for more focused research in this domain (McNamara et al., 2020), underscoring the urgency of addressing these gaps to improve patient outcomes and care quality. This is an important area to address in research, given the long-term effects of scarring, which can negatively influence young adults' self-perception and impact their social lives (Olsson et al., 2018).

Furthermore, the analysis identified several areas that were not perceived as research gaps in relation to the nursing status areas outlined in the VIPS model. These included areas such as *pain/pain management, spiritual and cultural considerations, cognitive and developmental aspects*, as well as *breathing and circulation*. The exclusion of these nursing status areas as research gaps may be attributed to the extensive studies already conducted, resulting in evidence-based guidelines and protocols that effectively address these issues. However, of particular note is the lack of attention to the spiritual and cultural area since we in Sweden have many patients and families originating from various cultures and countries. Hence, there is a need for increased research in cultural domains to meet the needs of Sweden's new residents, as well as to address areas related to existential concerns of this culturally diverse population. Multi-cultural relations were mentioned in relation to communication via interpreters, which was a perceived gap, but there was too little data about cultures for a separate code. Also, spiritual care was not a separate code but then again, psychosocial aspects include a gap about grief, and communication includes data about communication in palliative care and about death. In addition, within the category of nursing interventions, topics such as *information and education* (including preparation), *general nursing care, training, and observation/*

surveillance were notably absent from the data. This is in contrast with a previous study with HCPs, parents and patients, which found research gaps in communication, coordination of care, information needs, and the lack of adequate information (Aldiss et al., 2019). Regarding general nursing care, as outlined in the VIPS model, this area primarily falls under nursing interventions. It includes assistance with personal hygiene, nutrition, mobility, rest, and sleep; providing patients and their families with relevant information and preparation; monitoring vital signs and symptoms; offering emotional support and presence; and adapting the care environment to promote safety and well-being (Ehrenberg et al., 1997). One could argue that assistance with personal hygiene is often assigned to the parents and might thus not be considered from the HCPs perspectives. We would also like to argue that, for example, nutrition and support are already encompassed within other areas, and that there may be an overlap between certain areas, which could explain why general nursing care did not emerge as a distinct area.

Finally, several topics raised during the study were deemed outside the scope of the current study. These included for example, organizational factors such as HCPs' competence, staff turnover, and the work environment. While the out-of-scope areas, identified in study, are undoubtedly important and may contribute to long-term improvements in childhood cancer care, they were not directly aligned with the study's primary objectives. Consequently, they were excluded from the final analysis. However, the limited research attention to these domains may have implications for care quality and outcomes.

4.1. Method discussion

The study presents several strengths and challenges that are worth discussing. One of the primary strengths of this study is its national scope, which ensures variation in the data. The novelty of the research adds significant value, as it addresses previously unexplored areas. The research team's strong clinical grounding and extensive network further enhance the study's credibility and trustworthiness. The data collection process was designed to compile a comprehensive list and this approach allowed for a thorough and nuanced understanding of the findings. Additionally, the flexibility granted to participants, allowing them to respond in their own words and at their own pace, created valuable opportunities for reflection and consideration of areas that might otherwise have been overlooked. Furthermore, the absence of pressure to produce perfectly worded responses encouraged openness and authenticity. Together, these conditions facilitated the generation of rich data that closely reflected real-world experiences.

Despite these strengths, the study faced some issues. One issue was the limited number of respondents which can be attributed to the high workload at the childhood cancer care centres. Furthermore, the recruitment strategy relied heavily on passive methods (e.g., posters with QR codes), which may have introduced self-selection bias. Moreover, the low number of responses from physicians may contribute to lack of perspectives on research gaps within healthcare science. On the other hand, it is likely that physicians did not respond, because they are more commonly engaged in preclinical and biomedical research. Furthermore, the decision to include an open-ended question posed its own set of issues. While it allowed respondents to express their perspectives in their own words, it also required them to formulate their responses independently, which could have been demanding. The open-ended responses could also have risked revealing personal or sensitive information. Fortunately, none of the respondents had formulated anything revealing this kind of information.

5. Conclusion

This study provides valuable insights into healthcare professionals' perspectives on research gaps in paediatric oncology nursing in Sweden. Using a deductive approach based on the VIPS model, a range of

perceived research gaps in nursing status and interventions were identified, including underexplored areas such as sleep disturbances during hospitalization, skin and wound care, and scarring. The findings reveal a disconnect between existing evidence and clinical awareness, highlighting the need for better dissemination, implementation of evidence-based guidelines, and increased nurse involvement in research. The absence of topics like pain, general nursing care, and education may reflect overlapping categories, underscoring the complexity of defining research gaps. These insights support the development of future research agendas and evidence-based practice. Additionally, further research is needed and this study forms part of a planned national James Lind Alliance project additionally involving patients and family members.

CRedit authorship contribution statement

Cecilia Bartholdson: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Anna Pilström:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Pernilla Pergert:** Writing – review & editing, Visualization, Validation, Software, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Johanna Granhagen Jungner:** Writing – review & editing, Visualization, Validation, Software, Resources, Investigation, Formal analysis, Data curation. **Maria Olsson:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to acknowledge the national network for research in healthcare science within childhood cancer care that created the possibility for the research team to meet and to collaborate. We would also like to thank the collaborators at the centres that facilitated the data collection and finally all the HCPs that made an effort to respond to the research question.

References

- af Sandeberg, M., Johansson, E., Björk, O., Wettergren, L., 2008. Health-related quality of life relates to school attendance in children on treatment for cancer. *J. Pediatr. Oncol. Nurs.* 25, 265–274.
- Aldiss, S., Fern, L.A., Phillips, R.S., Callaghan, A., Dyker, K., Gravestock, H., Groszmann, M., Hamrang, L., Hough, R., McGeachy, D., Morgan, S., Smith, S., Upadhyaya, S., Veitch, H., Veitch, L., Williamson, M., Whelan, J.S., Gibson, F., 2019. Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance. *BMJ Open* 9, e028119.
- Ayoub, M., Lövgren, M., Kreicbergs, U., Udo, C., 2025. Voices of children with cancer and their siblings in the family talk intervention. *Children* 12 (3).
- Bentsen, L., Aagesen, M., Bidstrup, P., Hjerding, M., Pappot, H., 2024. Sexuality, intimacy, and body image among adolescents and young adults with cancer: a qualitative, explorative study. *Support. Care* 32, 219.
- Castor, C., Landgren, K., Hansson, H., Kristensson Hallström, I., 2018. A possibility for strengthening family life and health: family members' lived experience when a sick child receives home care in Sweden. *Health Soc. Care Community* 26, 224–231.
- Chan, G.K., Barnason, S., Dakin, C.L., Gillespie, G., Kamienski, M.C., Stapleton, S., Williams, J., Juarez, A., Li, S., 2011. Barriers and perceived needs for understanding and using research among emergency nurses. *J. Emerg. Nurs.* 37, 24–31.
- Cherven, B., Sampson, A., Bober, S.L., Bingen, K., Frederick, N., Freyer, D.R., Quinn, G. P., 2021. Sexual health among adolescent and young adult cancer survivors: a scoping review from the Children's Oncology Group Adolescent and Young Adult Oncology Discipline Committee. *CA Cancer J. Clin.* 71, 250–263.

- Cherven, B.O., Demedis, J., Frederick, N.N., 2024. Sexual health in adolescents and young adults with cancer. *J. Clin. Oncol.* 42, 717–724.
- Chesak, S.S., Rhudy, L.M., Toftagen, C., Chlan, L.L., 2022. A practice-based model to guide nursing science and improve the health and well-being of patients and caregivers. *J. Clin. Nurs.* 31, 445–453.
- Crowe, S., Fenton, M., Hall, M., Cowan, K., Chalmers, I., 2015. Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. *Res Involv Engagem* 1, 2.
- Daniel, L.C., Catarozoli, C., Crabtree, V.M., Bridgeman, M., van Litsenburg, R., Irestorm, E., 2024. Sleep interventions in paediatric oncology: a systematic review of the evidence. *Pediatr. Blood Cancer* 71, e31202.
- Ehrenberg, A., Ehnfors, M., Thorell-Ekstrand, I., 1997. The VIPS model-implementation and validity in different areas of nursing care. *Stud. Health Technol. Inf.* 46, 408–410.
- Enskär, K., Björk, M., Knutsson, S., Granlund, M., Darcy, L., Huus, K., 2015. A Swedish perspective on nursing and psychosocial research in paediatric oncology: a literature review. *Eur. J. Oncol. Nurs.* 19, 310–317.
- Frederick, N.N., Revette, A., Michaud, A., Bober, S.L., 2019. A qualitative study of sexual and reproductive health communication with adolescent and young adult oncology patients. *Pediatr. Blood Cancer* 66, e27673.
- Galea, S., Abba-Aji, M., 2024. New directions for population health science and scholarship. *JAMA Health Forum* 5, e244566.
- Gibson, F., Fern, L.A., Phillips, B., Gravestock, H., Malik, S., Callaghan, A., Dyker, K., Groszmann, M., Hamrang, L., Hough, R., McGeachy, D., Morgan, S., Smith, S., Upadhyaya, S., Veitch, H., Williamson, M., Whelan, J., Aldiss, S., 2021. Reporting the whole story: analysis of the 'out-of-scope' questions from the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership Survey. *Health Expect.* 24, 1593–1606.
- Gill, P.J., Bayliss, A., Sozer, A., Buchanan, F., Breen-Reid, K., De Castris-Garcia, K., Green, M., Quinlan, M., Wong, N., Frappier, S., Cowan, K., Chan, C., Arafeh, D., Anwar, M.R., Macarthur, C., Parkin, P.C., Cohen, E., Mahant, S., Network, C.P.I.R., 2022. Patient, caregiver, and clinician participation in prioritization of research questions in pediatric Hospital medicine. *JAMA Netw. Open* 5, e229085.
- Hansson, H., Kjaergaard, H., Johansen, C., Hallström, I., Christensen, J., Madsen, M., Schmiegelow, K., 2013. Hospital-based home care for children with cancer: feasibility and psychosocial impact on children and their families. *Pediatr. Blood Cancer* 60, 865–872.
- Hwang, K., Sivaratnam, S., Azeredo, R., Hashemi, E., Jibb, L.A., 2024. Exploring the use of social media and online methods to engage persons with lived experience and healthcare professionals in creating research agendas: lessons from a pediatric cancer research priority-setting partnership. *PLOS Digit Health* 3, e0000181.
- Kreicbergs, U., Pohlkamp, L., Sveen, J., 2021. No impact of previous evidence advocating openness to talk to children about their imminent death. *Acta Paediatr.* 110, 1671–1672.
- Laronne, A., Graneck, L., Wiener, L., Feder-Bubis, P., Golan, H., 2022. "Some things are even worse than telling a child he is going to die": pediatric oncology healthcare professionals perspectives on communicating with children about cancer and end of life. *Pediatr. Blood Cancer* 69, e29533.
- Lin, N., Lv, D., Hu, Y., Zhu, J., Xu, H., Lai, D., 2023. Existential experiences and perceptions of death among children with terminal cancer: an interpretative qualitative study. *Palliat. Med.* 37, 866–874.
- McNamara, S.A., Hirt, P.A., Weigelt, M.A., Nanda, S., de Bedout, V., Kirsner, R.S., Schachner, L.A., 2020. Traditional and advanced therapeutic modalities for wounds in the paediatric population: an evidence-based review. *J. Wound Care* 29, 321–334.
- Meleis, I.A., 2011. *Theoretical Nursing Development & Progress*. Lippincott Williams & Wilkins.
- Morrison, L., Johnston, B., Cooper, M., 2022. Mixed methods systematic review: factors influencing research activity among nurses in clinical practice. *J. Clin. Nurs.* 31, 2450–2464.
- Nielsen, C., Jensen, C.M., Trettin, B., 2025. Epistemological aspects of participatory design studies conducted in the field of health science. *J. Adv. Nurs.* 81, 5151–5162.
- Nygaard, A., Halvorsrud, L., Linnerud, S., Grov, E.K., Bergland, A., 2019. The James Lind Alliance process approach: scoping review. *BMJ Open* 9, e027473.
- Olsson, M., Enskär, K., Steineck, G., Wilderäng, U., Jarfelt, M., 2018. Self-Perceived physical attractiveness in relation to scars among adolescent and young adult cancer survivors: a population-based Study. *J. Adolesc. Young Adult Oncol.* 7, 358–366.
- Pang, T., Sadana, R., Hanney, S., Bhutta, Z.A., Hyder, A.A., Simon, J., 2003. Knowledge for better health: a conceptual framework and foundation for health research systems. *Bull. World Health Organ.* 81, 815–820.
- Petit-Zeman, S., Philpots, E., Denegri, S., 2010. "Natural ground" for medical research charities: public and patient involvement in research funding. *J. Ambul. Care Manag.* 33, 249–256.
- Pradas-Hernández, L., Ariza, T., Gómez-Urquiza, J.L., Albendín-García, L., De la Fuente, E.I., Canadas-De la Fuente, G.A., 2018. Prevalence of burnout in paediatric nurses: a systematic review and meta-analysis. *PLoS One* 13, e0195039.
- Socialstyrelsen, Cancerfonden, 2023. *Cancer i Siffror 2023 [Cancer in Numbers 2023]*. Stockholm, Sweden.
- Välimäki, M.A., Lantta, T., Hipp, K., Varpula, J., Liu, G., Tang, Y., Chen, W., Hu, S., Li, X., 2021. Measured and perceived impacts of evidence-based leadership in nursing: a mixed-methods systematic review protocol. *BMJ Open* 11, e055356.
- Wolcott, M.D., Lobjcowski, N.G., 2021. Using cognitive interviews and think-aloud protocols to understand thought processes. *Feb Curr Pharm Teach Learn* 13 (2), 181–188.