

DEVELOPMENT AND IMPLEMENTATION OF A FAMILY NAVIGATOR FUNCTION TO ASSIST FAMILIES NAVIGATING THE COMPLEX CANCER TREATMENT

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Background: Cancer treatment for children is intensive and complex and the emotional, psychological, and practical caregiver demand parents face are extensive in addition to maintaining their work or education. Additionally, siblings may suffer from their parent's preoccupation of the sick child. The national cancer strategy encouraged the development of a function to coordinate and support the families navigating the complex cancer treatment, facilitate access to services, and reduce the families' experience of psychological distress.

Aim: The aim of this study was to study describe the development and implementation of a family navigator function (FNF) to help families navigate the complex cancer trajectory.

Methods: In 2020, a multidisciplinary working group was formed. The group developed the FNF based on a previous developed model, interprofessional meetings with medical and nursing specialists, and interviews with specialists in pediatric and adult oncology. After a few months, the FNF was ready to be implemented and regular meetings with family navigators, management, and the working group were held, leading to ongoing adjustments in actions and workflows.

Results/conclusions: Actions for the FNF were identified as: 1) Supporting families with special needs, 2) Managing transitions within and between hospital, municipality, and educational institutions, 3) Establishing support services, and 4) Addressing issues regarding disease relapse. During implementation, we discovered that the family navigators' diagnosis-specific approach was crucial to meet the families' individual needs. Additionally, clear definition and communication of the family navigators' key areas to mono- and interprofessional colleagues were essential to ensure collaboration. Since 2020, the family navigators have supported more than 400 families, and families have provided positive feedback to department management and on social media. We believe that the FNF enhances the families' ability to navigate in their child's complex cancer trajectory and reduces their psychological distress. Further evaluation of the FNF is needed.

FROM A DISORGANIZED DATA CHASE TO A STREAMLINED COORDINATED EFFORT – LESSONS LEARNED FROM THE “ALLTOGETHER” TRIAL

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Background: In 2020, the phase 3 pediatric clinical trial AllTogether (A2G), targeting patients with Acute Lymphoblastic Leukemia (ALL), opened with the pediatric oncology department in Copenhagen. With an annual site uptake of approximately 25 ALL patients and comprehensive trial specific electronic case reports (eCRF), A2G has become a significant task. Data are collected by various healthcare professionals, however, reported by a designated A2G team distanced from the clinic. Hence, securing patient overview and data aligned with ICH-GCPs 5 principles: *At-tributable, Legible, Contemporaneous, Original, Accurate, and Complete* (ALCOA⁺), is challenging.

Aim: This study describes the employment of new workflows to optimize data chase and registration according to the ALCOA⁺ principles.

Methods: Based on ongoing discussions of workflows and data deficiencies between healthcare professionals who registered data, a master Excel spreadsheet was developed in 2023. The spreadsheet aimed to substantiate discussions on urgent optimization and reinforce data and trial overview. Secondly, specific reporting schemes were developed to streamline workflows, optimize inter- and multidisciplinary collaboration, and strengthen data reporting. Finally, to further strengthen collaboration, the A2G team increased their participation in multidisciplinary conferences and leukemia team meetings.

Results: The development and implementation of the master spreadsheet has made data more *Contemporaneous* by securing subject and trial overview. The reporting schemes, used by inter- and multidisciplinary teams, has eliminated the inefficient data retrieval process, and secured the *Legible* and *Accuracy* of the data. The increased clinical presence of the A2G team has strengthened collaboration across disciplines, and the eCRF is now provided with *Complete* data. Hence, workflows are now streamlined, and data fully aligned with ALCOA⁺

Conclusion: Continuous open discussions of deficiencies were pivotal for kickstarting, optimizing and streamlining workflows. We believe that by employing the new optimized workflows, the data chase has become increasingly coordinated and ALCOA⁺ principles secured to a greater extent.

IMPLEMENTATION OF SIMULATION TRAINING OF ACUTE SITUATIONS IN PEDIATRIC CANCER IMPLEMENTATION OF SIMULATION TRAINING OF ACUTE SITUATIONS IN PEDIATRIC CANCER

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Background: Implementation of simulation training for managing acute situations is crucial in preventing fatal outcomes in pediatric cancer. However, implementation of simulation training is a challenge in clinical practice.

Aim: This study aims to identify factors that enhance or hinder implementation of simulation training.

Method: A qualitative design, including a thematically deductive analysis, and the consolidated framework for advancing implementation (CFIR), was used to identify and describe factors affecting implementation. The analysis was conducted by three nurses with two to seven years of experience in facilitating simulation training of acute situations. First, the nurses individually identified factors affecting implementation of the simulation trainings based on their experiences. Second, they analyzed their findings at a small workshop where main factors were discussed and consolidated structured by the domains and constructs of the CFIR.

Results/Conclusion: Four factors enhancing and three factors hindering implementation of simulation training were identified. Enhancing factors: 1) a strong general belief among nurses at the ward that simulation training leads to skills and knowledge due to the practical hands-on design, 2) clear and consistent management support strengthened implementation, 3) positive attitudes from experienced nurses, and 4) ongoing adjustments and adaptability. Hindering factors: 1) hesitancy towards engaging in simulation roleplay, 2) negative attitudes from experienced nurses, 3) unclear summative or formative implementation strategies and implementation goals. The study shows that simulation training of acute situations is highly acceptable and adaptable at the ward. However, some reluctance towards participation in the simulation training exists which might negatively affect the implementation sustainment. To maintain skills and knowledge in the management of acute situations, clearer implementation strategies, implementation evaluations, and outcomes are needed in simulation training.

INTRODUCING NATIONAL EDUCATION DAYS FOR PAEDIATRIC HEMATOLOGY- ONCOLOGY NURSES IN DENMARK

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Background: Each year, approximately 200 Children and adolescents aged 0-18 years are diagnosed with cancer in Denmark. Four pediatric hematology and oncology Centers are responsible for the treatment and care. In 2021 DAPHOS (Danish Pediatric Hematology and Oncology Nursing) was established with the purpose of improving nursing collaboration, nursing development and research across the country.

Objectives/Aim: Based on an increased need of continuously education and development of nursing competencies to ensure the highly complex nursing care, we established National Education Days for nurses. The aim is to share knowledge in nursing care and treatment and to give nurses the opportunity to connect across centers and develop own competencies.

Method: The first two education days was in areas with most shared care between the centers. This decision was verified by participants at the National Multidisciplinary Symposium in 2023. The education days in 2024 were held by the two centers with a specific regional function, (Copenhagen and Aarhus). The themes were stem cell transplantation and CNS/proton therapy. The specific center organized, planned, and hosted the education days, with financial support from the Danish Childhood Cancer Foundation. Specialists from the specific specialty were presenters. Forty nurses from the four centers participated each day. The nurses completed a post evaluation questionnaire to assess the impact of the day.

Results/Conclusion: The participants evaluated the days as beneficial, with an overall positive evaluation of the days as incredibly good and educational, with a proper level. The feedback showed diverse needs, due to different competence levels among participants. The evaluation illuminates the need and value of continuously education in this highly specialized field, where development is rapidly advancing. The positive evaluation has led to implementation of National Education Days twice a year, and the goal is to establish a formal national course in pediatric hematology and oncology nursing.

QUALITY OF LIFE, NEUROCOGNITION, AND MOTOR FUNCTION IN ADOLESCENTS TREATED WITH CNS-DIRECTED THERAPY DURING CHILDHOOD

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Background: Survival rates in childhood cancer are increasing, but many survivors experience neurocognitive side effects to varying severity. Compared to the general population, survivors report lower physical and mental quality of life. In the Southeastern Healthcare Region of Sweden, a comprehensive multidisciplinary follow-up program for childhood cancer survivors treated with CNS-directed therapy is conducted, but there is a lack of effective tools to identify individuals at risk. Survival rates in childhood cancer are increasing, but many survivors experience neurocognitive side effects to varying severity. Compared to the general population, survivors report lower physical and mental quality of life. In the Southeastern Healthcare Region of Sweden, a comprehensive multidisciplinary follow-up program for childhood cancer survivors treated with CNS-directed therapy is conducted, but there is a lack of effective tools to identify individuals at risk.

Objectives/Aim: This study aims to describe self-reported health-related quality of life, cognitive function, and motor skills in adolescents who have undergone CNS-directed therapy for hematologic or malignant disease, primarily outside the CNS. The study also aims to investigate potential associations with background factors to facilitate identifying individuals at risk. This study aims to describe self-reported health-related quality of life, cognitive function, and motor skills in adolescents who have undergone CNS-directed therapy for hematologic or malignant disease, primarily outside the CNS. The study also aims to investigate potential associations with background factors to facilitate identifying individuals at risk.

Method: All adolescents (12–18 years) in the Southeastern Healthcare Region who have received CNS-directed therapy as described, are invited to a multidisciplinary follow-up at H.R.H. Crown Princess Victoria Children’s Hospital. Assessments will be conducted by professionals from each discipline using validated instruments, including PROMIS-25 (quality of life), BOT-2 and the 6-minute walk test (motor function), and WISC-V/WAIS-IV, D-KEFS, and BRIEFAll adolescents (12–18 years) in the Southeastern Healthcare Region who have received CNS-directed therapy as described, are invited to a multidisciplinary follow-up at H.R.H. Crown Princess Victoria Children’s Hospital. Assessments will be conducted by professionals from each discipline using validated instruments, including PROMIS-25 (quality of life), BOT-2 and the 6-minute walk test (motor function), and WISC-V/WAIS-IV, D-KEFS, and BRIEF

(cognition). School performance, emotional health (BECK), and fatigue (PedsQL Fatigue) will also be evaluated.(cognition). School performance, emotional health (BECK), and fatigue (PedsQL Fatigue) will also be evaluated.

Results/Conclusion: Pilot data from 2022 (n=17, unpublished) showed significantly lower physical strength and agility, as well as poorer cognitive function (verbal skills) compared to normative groups. Age at diagnosis influenced outcomes, with younger children at diagnosis exhibiting the greatest cognitive difficulties but reporting higher quality of life compared to the adolescent group. The results of the entire study population will be compiled in spring, 2025.Pilot data from 2022 (n=17, unpublished) showed significantly lower physical strength and agility, as well as poorer cognitive function (verbal skills) compared to normative groups. Age at diagnosis influenced outcomes, with younger children at diagnosis exhibiting the greatest cognitive difficulties but reporting higher quality of life compared to the adolescent group. The results of the entire study population will be compiled in spring, 2025.

The results highlight the importance of structured follow-up for adolescents treated with CNS-directed therapy. This study may contribute to the development of structured follow-up programs, facilitating early interventions and minimizing the long-term impact of late complications on health and health-related quality of life.The results highlight the importance of structured follow-up for adolescents treated with CNS-directed therapy. This study may contribute to the development of structured follow-up programs, facilitating early interventions and minimizing the long-term impact of late complications on health and health-related quality of life.

CAN WE IMPROVE THE INFORMED CONSENT PROCESS IN PHASE 3 PEDIATRIC CANCER TRIALS? A PILOT

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Background/Aim: Sufficient completion of the informed consent form (ICF) in phase 3 pediatric clinical trials is a complex process that occurs in a fast-paced clinical setting and includes multiple healthcare professionals. Faulty ICFs have been collected within our department, and omissions and errors have been identified beyond time targets. In this small-scale pilot study, we aimed to implement and evaluate a new ICF process including an early ICF screening procedure.

Methods: In October 2024, a teaching session took place and an improved ICF process was presented to relevant healthcare professionals. ICF errors and omissions were registered using a screening sheet covering; blank fields, names, dates and signatures, delegation status of the investigator obtaining the ICF, ICF version used, completion, and documentation in the patient's electronic medical health records (EMHR).

Results: From October 2024 to mid-February 2025; 28 ICFs were obtained. In 21 cases, the new ICF process was only partial or not followed. 11 cases had errors and/or omissions: In 7 cases, the screening procedure showed errors and/or omissions related to names and dates. In three cases, the ICF had not been sufficiently documented in the patient's EMHR, and in one case, the ICF had been obtained by a physician without delegated responsibilities. A slightly positive trend regarding fewer errors and omissions was observed over time. Due to the early screening procedure, all faulty ICFs were returned to responsible physicians, and corrected in a timely manner.

Discussion/Conclusion: The poor compliance with the new ICF process indicates that further investigation is needed on how the ICF process can be improved. However, the early screening procedure had a positive impact on completing ICFs in a timely manner, and the relearning aspect of rapidly returning faulty ICFs to responsible physicians may have contributed to a positive trend over time. to establish a formal national course in pediatric hematology and oncology nursing.

CROSS-BORDER ACCESS AND PARTICIPATION IN PEDIATRIC CLINICAL TRIALS – DESCRIBING AND EVALUATING WORKFLOWS.

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Background: Equal access to clinical cancer trials for pediatric patients necessitates cross-border recruitment due to variable trial availability across countries. At the pediatric trials unit in Copenhagen cross-border recruitment accounts for almost half of the patient uptake. Hence a prior study carried out in this unit identified key factors influencing access, including physical and cultural proximity, logistical facilitation, and perceptions of trial participation. The barriers experienced by patients, families, and healthcare providers, underscored the need for enhanced strategies.

Aim: This descriptive study aims to evaluate the workflows and methods employed by the staff in Copenhagen, assessing their impact on trial access and participation relative to the key factors identified.

Methods: Candidates are identified through a network of pediatric oncologists. Our workflow consists of 1. An online meeting prior to the initial on-site visit, engaging all involved parties, to discuss trial details and address concerns. 2. The study nurse (SN) coordinates logistics, including travel and accommodation, and an on-site visit plan. 3. The SN accompanies the patient and family throughout their visit, providing emotional and practical support and interpreters as necessary. 4. The SN facilitates ongoing communication with the patient, family, and local healthcare providers throughout the trial.

Results: The online meeting appears to enhance familiarity and builds trust between the involved parties. It addressed health literacy and attitudes toward trial participation allowing the SNs to adjust to individual needs. Detailed logistical planning by the SN and availability of interpreters seems to enhance the families' feelings of being safe in unknown surroundings. The systematical communication identifies and mitigates sociocultural barriers.

Conclusion: We believe that the workflows that were utilized strengthened equal access to clinical cancer trials for the pediatric patients and addressed the previously identified key factors hindering cross-border trial participation. However more studies are needed to evaluate the patients' and families' perspectives.

EVALUATION OF HOME INTRAVENOUS THERAPY FOR CHILDREN AND ADOLESCENTS WITH CANCER

EVALUATION OF HOME INTRAVENOUS THERAPY FOR CHILDREN AND ADOLESCENTS WITH CANCER

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Background: Home intravenous therapy (HIT) for children with cancer is provided internationally, mostly by a community or home agency nurse. At our department, HIT is provided by a portable pump or injection and initiated at the department and then surveyed or administered by the parents at home and seldom by a nurse. Systematic investigation of HIT can reveal important clinical factors influencing patient outcomes and treatment quality to improve treatment and care.

Aim: The aim of this study was to evaluate the use of HIT and clinical outcomes for children and adolescents with cancer.

Method: Observational study conducted from 2018-2023 at the Department of Paediatric Haematology Oncology in Copenhagen. Data on demographics and HIT for all patients were prospectively registered. Inclusion criteria were children with cancer aged 0-18 years with minimum one course of HIT. The outcomes were number of courses of HIT, medications, days with HIT, days at home without a hospital visit, and complications. Data were analyzed with descriptive statistics.

Results/Conclusion: There were 256 patients included. The median age was 5 years (range 0-18) representing both oncologic and haematologic diagnoses. They had a total of 774 courses of HIT with median number of 2 (range 1-24) per patient. The median duration was 4 days (range 1-384). Patients received HITs for a total of 5933 days, avoiding hospitalization or outpatient visits. Of these, 1996 days were completely free from hospital visits. Nineteen different medications were provided. In total 70 complications were registered and related to venous access (14%), medication (23%), pump (49%), compliance (3%), or other complications (11%). No severe complications were observed.

In this cohort, HIT appears to be safe, well implemented, and fit patients across age and diagnosis. There is a need for improvements in guidelines for both nurses and families, documentation, and data registration.

GAMIFICATION AND AUGMENTED REALITY FOR PHYSICAL ACTIVITY MONITORING IN PEDIATRIC ONCOLOGY: A STEP TOWARDS PATIENT-CENTERED CARE

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Background: Each year, approximately 400,000 children and adolescents worldwide are diagnosed with cancer. Despite the proven benefits of physical activity, inactivity remains a significant issue in pediatric oncology. Gamified applications have shown promise in promoting movement and engagement, yet standardized methods for monitoring physical activity in this population are lacking.

Objectives/Aim: The study aims to identify and evaluate the scope of physical activity monitoring instruments by identifying and evaluating existing approaches. This will serve as a basis for developing and validating an augmented reality (AR)-based approach with interactive game features for tracking physical activity habits in pediatric oncology patients, conducted at the Children's Clinical University Hospital, to support patient-centered care in pediatric oncology.

Method: A scoping review was conducted following the Joanna Briggs Institute (JBI) methodology and reported in accordance with PRISMA-ScR guidelines. Literature searches were performed across PubMed, Google Scholar, ProQuest, EBSCO, Web of Science, ScienceDirect, Scopus, and Cochrane Library, identifying 5,807 records. After screening, 12 studies met the eligibility criteria for inclusion.

Results/Conclusion: This study highlighted the potential of AR-based gamified tools for monitoring and promoting physical activity in pediatric oncology. Building on these findings, future research should focus on integrating a validated monitoring instrument into a digital

AR-based solution and evaluating its feasibility through proof-of-concept testing with patients and caregivers.

GROSS MOTOR FUNCTION IN PRESCHOOL CHILDREN NEWLY DIAGNOSED WITH CANCER—DATA FROM THE REPLAY TRIAL

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Background: Children with cancer experience long-term treatment-related disruptions in gross motor function; however, the potential impairments of preschool children newly diagnosed with cancer remain unknown.

Aim: This study describes gross motor function among preschool children 1-5 years old newly diagnosed with cancer, including the feasibility of gross motor function assessment.

Method: Data from 84 children (50% girls, 39 ± 16 months old) enrolled in the Rehabilitation including structured active play for preschoolers with cancer (RePlay) trial, assessed within the first months from treatment initiation, were analyzed to quantify the feasibility of assessment and gross motor function evaluated by using the stationary, locomotion, and object manipulation domains of Peabody Developmental Motor Scales–2 (PDMS-2).

Results/Conclusion: Thirty-seven children completed the full PDMS-2, and 15 completed at least one domain (n=32 with hematological disease, n=10 with central nervous system tumor (CNS tumor), n=10 with extracranial solid tumor). Reasons for non-completion were pain/physical deficiencies (17%), child's willingness (19%), or logistical issues (20%). Children who completed the full PDMS-2 had a mean gross motor quotient of 78.9 [95%CI: 73.6-84.2], indicating “poor” performance, with 75% of the children performing “below average” or worse. Most children had difficulties with locomotion, with a mean standard score of 5.7 [95%CI: 4.8-6.6], indicating “poor” performance, with 81% of the children performing “below average” or worse. There was a significant difference between diagnostic groups in object manipulation; children

diagnosed with CNS tumors performed significantly worse than children diagnosed with hematological cancers with a mean difference in standard scores of 2.56 [95%CI: 0.51-4.61]. These novel results show that it is possible to conduct gross motor function assessments of preschool children, and preschool children newly diagnosed with cancer have markedly impaired gross motor function—underlining the importance of starting physical rehabilitation at treatment initiation.

IMPLEMENTATION OF DELEGATED RIGHTS FOR NURSES TO ADJUST MAINTENANCE TREATMENT FOR CHILDREN WITH LEUKEMIA OR LYMPHOMA

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Background: In 2021, the outpatient clinic was reorganized into three diagnosis-specific teams (leukemia/lymphoma, solid tumors, and central nervous system tumors). This restructuring allowed nurses to specialize in the care of specific patient groups. To optimize the workflow in the acute lymphoblastic leukemia (ALL) and lymphoblastic lymphoma (LBL) team, we implemented delegated prescription rights (DPR), enabling nurses to adjust maintenance treatments (mercaptopurine and methotrexate). The DPR initiative was inspired by practices at Karolinska University Hospital in Sweden.

Objectives/Aim: This study aims to describe the implementation of DPR for nurses to adjust maintenance treatment for ALL and LBL at the outpatient clinic in Copenhagen.

Method/procedure: The certification procedure to authorize nurses to adjust maintenance treatment was developed by a highly experienced nurse with expertise in pediatric ALL and LBL, a clinical nurse specialist, and the chief physician. Initial certification requirements included chemotherapy administration certification and substantial experience as pediatric oncology nurses. The certification procedure involved: 1) Reviewing guidelines for DPR, medication protocols, treatment schemes, and patient and parent information on maintenance treatment. 2) One hour of teaching by the chief physician, followed by dialogue-based education and case-based training with the experienced nurse. 3) Adjusting five treatment cases, evaluated by a team physician. 4) Certification was granted when the nurse felt confident in the new responsibility, and both the experienced nurse and the chief physician agreed on their competence

Results/Conclusion

Currently, three nurses hold DPR for adjusting maintenance treatment. Previously, all treatment adjustments were managed exclusively by team physicians; now, nurses primarily handle these adjustments, with oversight and verification by a team physician. We believe that DPR enhances time efficiency while maintaining a high standard of maintenance treatment. However, further investigation is needed to assess the long-term impact on treatment outcomes and to confirm sustained safety.

PARENTS' EXPERIENCES OF EVERYDAY LIFE SHORTLY AFTER THEIR CHILD HAS COMPLETED TREATMENT FOR CANCER: A QUALITATIVE STUDY

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Background: Completion of the child's cancer treatment is not only a long-awaited milestone it is also described as a landmark event for the whole family. As survival increases a larger group of parents return to everyday life after their child's cancer treatment. Parents have a large and active role in the child's treatment. Yet, the transition to new everyday life is experienced as challenging with conflicted feelings by parents. The everyday life they once knew is forever changed. Nevertheless, parents must continue to function in roles as complex caregivers, parents, and more.

Objectives/Aim: The aim of this study was to gain insight into the parents' experience of everyday life shortly after their child completed cancer treatment.

Method: A qualitative method within the phenomenological-hermeneutic tradition was applied. Eight semi-structured individual interviews were conducted with Danish parents within the 0-6 month timeframe following their child's completion of cancer treatment. The interviews were analysed using interpretation method inspired by Paul Ricoeur.

Results/Conclusion: Three themes were found: 'To live in a state of alertness between hope and fear', 'From shared to full responsibility – feeling abandoned', 'To gain a foothold while openly expressing emotions'. In the everyday life shortly after the cessation of the child's cancer treatment, parents experienced a vulnerability of being mother and father and a feeling of being alone.

The findings showed that the parents found themselves left with a great responsibility and were unprepared for their emotional response to life after treatment. They experienced inner turmoil as a new condition of their everyday life.

SIBLINGS' LIVED EXPERIENCES OF TRANSITIONS BETWEEN HOSPITAL AND HOME IN PAEDIATRIC ONCOLOGY: A QUALITATIVE STUDY

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Background: Childhood cancer profoundly affects the entire family, with siblings experiencing significant changes throughout the cancer journey. Transitions between paediatric oncology treatment centres and homes pose particular challenges, fragmenting family life and heightening uncertainty. Understanding siblings' unique experiences of these transitions is essential for informing care practices and developing tailored support interventions.

Aim: This study aims to explore how siblings of children with cancer experience transitions between hospital and home.

Methods: A phenomenological-hermeneutic approach was employed to capture the lived experiences of eight siblings of children with cancer. Semi-structured interviews, supported by photo-elicitation methods, were conducted in the siblings' homes. Interviews were audio-recorded, transcribed verbatim, and analysed using Nvivo software. The analysis was guided by Paul Ricoeur's theory of interpretation, which provides a philosophical framework for understanding the deeper meanings in siblings' narratives.

Findings: Three overarching themes on hospital and home transitions emerged: Grappling to find a new family position situated in the periphery, The risk of sudden family separation left with uncertainty and Adapting to a changing siblingship shaped by the illness. Frequent hospital-to-home transitions posed new life circumstances in the well-known family life, where attention was centred around the ill child.

Results/Conclusion: This study provides insights into how siblings adjust to the frequent disruptions caused by cancer treatment. The findings highlight that siblings are deeply affected when family members fluctuate between hospital and home settings, and the demands on siblings to adjust and adapt to unpredictable family separations are high. While siblings strive for family closeness, they often feel distanced and placed in a peripheral role, navigating uncertainty and worries.

FACTORS INFLUENCING THE SMOOTH TRANSITION FROM PAEDIATRIC ONCOLOGY TO ADULT ONCOLOGY

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Background: With improvements in pediatric healthcare, the smooth transition from pediatric oncology unit to adult oncology unit is becoming very significant in achieving wellbeing of our patients. The transition from pediatric oncology to adult oncology can be challenging and complex process for many young people. Here are some key issues that can arise during this transition: emotional and physiological challenges, differences in care philosophy, age-related and developmental differences, continuity of care and coordination, health insurance and financial issues, fertility and sexual health, adapting to new medical protocols, long-term survivorship care. To address these challenges, it is essential to have structured transition programs in place, where the adolescent and their family can prepare well in advance for the shift. Programs that focus on both medical and physiological needs alongside strong communication between pediatric and adult oncologists are crucial for ensuring a smooth transition.

Objectives/Aim: To describe the main challenges and issues patients encounter while shifting from paediatric to adult department.

To investigate the factors influencing the smooth transition from paediatric oncology to adult oncology.

Methods: 1. Systemic review of the scientific literature; 2. Qualitative research: anonymous questionnaire survey. Respondents (N=9): family members or significant others of patients who shifted from paediatric to adult department.

Results/Conclusion: The most common challenges and issues patients encounter while transition from pediatric to adult oncology are related to emotional and psychological challenges, differences in care philosophy, age-related and developmental differences. The most relevant factors influencing the smooth transitions from pediatric to adult oncology are continuity and care coordination and adapting to new medical protocols.

NURSING INTERVENTIONS FOR PEDIATRIC PATIENTS WITH CANCER AND THEIR FAMILIES: A SCOPING REVIEW

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Background: Clinical nursing care is essential in pediatric oncology. The body of nursing interventions targeting pediatric oncology patients and their families has grown in recent years.

Objectives/Aim: The aim was to develop a comprehensive overview of the available nursing interventions for pediatric oncology patients and their families, outline the characteristics of the interventions, and identify any knowledge gaps.

Method: This review was conducted in accordance with the JBI guidelines and included the following databases: Scopus, PubMed, CINAHL, PsycINFO, and Embase. The following inclusion criteria were applied: peer-reviewed studies written in English, Danish, Norwegian, or Swedish from 2000 onward and reporting on pediatric patients with cancer and/or family members of a pediatric patient with cancer who received non-pharmacological and non-procedural nursing interventions provided by a pediatric oncology hospital service. Critical appraisal was achieved using the Mixed Methods Appraisal Tool.

Results/Conclusion: Among 2762 studies, 26 met the inclusions criteria, comprising 25 unique nursing interventions. 89 % had been published from 2013 onward. Interventions were clustered into four main types: psychosocial, educational, informational and physical. The studies were characterized by considerable diversity in terms of intervention content, components, timing and delivery mode. 60 % of the interventions were targeted parents among whom mothers were highly overrepresented (75 %). 16 % adopted a family-centered focus.

Conclusion: This review contributes to building a more comprehensive understanding of the evidence base within pediatric oncology nursing research. This field is evolving and nursing interventions holds the potential to support families with childhood cancer across various phases of their treatment trajectory. We identified a need to develop interventions with a family-centered focus, targeting both patients and family members. A gap exists in reporting of the intervention development process and intervention characteristics.

SIBLINGS OF CHILDREN WITH CANCER AND THEIR CHALLENGES IN AND ACROSS THEIR EVERYDAY LIFE CONTEXTS – A TWO-PHASE STUDY IN DENMARK

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Background: When a child is diagnosed with cancer, their siblings' everyday lives are affected, and they often experience a variety of psychosocial consequences. However, the literature describing siblings' challenges is inconclusive, especially when comparing qualitative and quantitative studies.

Aim: This study explored the challenges of school-aged siblings of children with cancer across the hospital, home, and school contexts to understand how these challenges interrelate and manifest in siblings' everyday lives.

Methods: Our study employed a comprehensive two-phase approach, consisting of ethnographic fieldwork at two geographically distinct pediatric oncology wards in Denmark, followed by semi-structured interviews with 11 siblings (aged 7-19 years) and 20 parents of children with cancer recruited using criterion-based sampling. The data were interpreted using content analysis.

Results: Siblings were at the periphery of family life at the hospital due to: 1) family logistics, 2) hospital induced restrictions, rules, and physical spaces, and 3) perceptions of their presence as 'problematic', ultimately limiting their access. Within the home-based family life, siblings' position shifted to peripheral due to: 1) being cared for by others than

the parents, 2) a subordination of their experiences and needs, and 3) an expectation of them enduring excessive demands. At school, siblings' position changed due to: 1) classmates and teachers lacked an understanding of the siblings' situation, and 2) resources for adequate support were insufficient.

Conclusion: The challenges described by siblings and parents align with existing literature, but our study extends the current understanding by highlighting the interrelated nature of these challenges and the various contexts in which they occur. Based on our findings, we suggest that siblings would benefit from support initiatives that integrate the hospital, family, and school.

SUPPORT FOR SIBLINGS OF CHILDREN WITH CANCER – SIBLINGS’ AND PARENTS’ FEEDBACK ON AN INTERVENTION PROPOSAL (SUPREME)

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Background: Siblings of children with cancer experience the consequences of their brother or sister’s disease and treatment firsthand, often causing social and school-related difficulties.

Aim: This study aimed to gather parents’ and siblings’ feedback on a proposal for a school-based social and educational support intervention for siblings with the goal of tailoring the program to meet the needs of siblings.

Method: Adopting a criterion sampling strategy, we conducted interviews with 20 parents and 11 siblings, aged 7-19 years, of children with cancer. During the interviews, we introduced a proposal for a school-based intervention as part of a co-creation design. Data were examined by content analysis.

Results: The analysis showed that both parents and siblings recognized: 1) the need to inform the class about the family's situation, 2) the need for the timing and content of the support to align with the family's stage in the cancer journey. 3) Parents' concerns centered on potentially imposing experiences on siblings, preserving the school as a free space, and the risk of siblings standing out. 4) Siblings' concerns focused on the flow of cancer-related information at school, avoiding victimization, and ensuring that their experiences were validated. The final SUPREME intervention involved clarifying family meetings before two educational, nurse-led school visits addressing challenges relevant to siblings' academic and social lives.

Conclusion: The participants' responses to the intervention proposal played a key role in shaping the final intervention, encompassing valuable insights into precautions necessary for implementing school-based support for siblings of children with cancer.

WHEN A HEALTHY CHILD DONATES STEM CELLS TO A SEVERELY ILL SIBLING - PARENTS EXPERIENCES

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Background: When the potential stem cell donor for a seriously ill child is a healthy sibling below the age of 18, Swedish parents have the legal responsibility to decide on behalf of the donor child. This decision may present challenges, as parents have to balance the needs of the seriously ill child in need of cure, and their healthy child, who needs to undergo medical procedures, in a situation where the outcome remain uncertain.

Aim: To explore parents' experiences and ethical considerations during the donation and transplantation process when two children in the same family are involved, one as a donor and the other as a recipient.

Methods: Individual interviews were conducted with 18 parents of 13 healthy minor donors following successful hematopoietic stem cell transplantations. Data were analyzed using qualitative content analysis to capture parents' experiences.

Results: Parents were living with the constant threat of losing a child while navigating an uncertain future and coping with unpredictability. Their primary focus was ensuring that the ill child received cure, and thus, they often did not experience conflicting loyalties. Parents struggled to cope with family life amidst chaos, despite feelings of inadequacy and fragmentation of the family during hospitalizations. Parents expressed a need for both tangible and emotional support throughout the process.

Conclusion: The study highlights the importance of ensuring a process grounded in healthcare ethics, suggesting presence of a designated donor advocate for minor donors. The findings also emphasise necessity of mandatory psychosocial support for parents during paediatric stem cell transplantation procedure to enable them to prepare emotionally and practically for challenges they may face, regardless of outcome of the process.

UNDER-RESEARCHED AREAS IN PAEDIATRIC ONCOLOGY NURSING - SWEDISH HEALTHCARE PROFESSIONALS PERCEPTIONS

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Background: During recent decades research within paediatric oncology nursing has progressed significantly, also in Sweden. However, it is not clear whether the research have answered the questions that healthcare professionals (HCPs) find most important and the areas they lack scientific evidence in. Sometimes there is a gap between ongoing research and what is going on in clinical daily life.

Objectives/Aim: The aim was to identify research areas in pediatric oncology nursing that HCPs perceive important and under-researched.

Method: This study constitutes the first phase of a James Lind Alliance Priority Setting Partnership. Data collection started in March 2024. HCPs at all paediatric oncology centres (N=6) in Sweden were invited to participate in the study by scanning a QR code, to access a digital form. The digital form included information about the study, 2 sociodemographic questions and the question: “Based on your experiences, what questions/needs should future research address to improve nursing care of children/adolescents with cancer and their families? Data was analysed using a qualitative descriptive approach. Questions and needs were coded into subject areas.

Results/Conclusion: Subject areas for future research was identified in relation to 1) *Nursing status* including communication, nutrition/elimination, skin/mouth, physical activity, environment, sleep and psychosocial aspects; 2) *Nursing interventions* including procedures, children and parents participation, personcentered care as well as coordination; 3) *Organisation* including homecare, continuity, care structure and profession; 4) *Post cancer experiences* including late complications, survivorhealth and rehabilitation.

HCPs seem to want to engage in impacting future research areas. Even if there are existing research in some areas, HCPs might not be aware of the evidence, or they perceive the area to be under-researched. In the next phase, the perspectives of children and parents will be collected. Data from all stakeholders will be compiled to form co-created future research areas in paediatric oncology nursing.