Nordsjællands Hospital
Børne- og Ungeafdelingen

Rigshospitalet

AALBORG UNIVERSITETSHOSPITAL

CONTROL SEMINAR
10. juni 2026

Marianne Olsen, Ph.d.
Ledende overlæge (tidligere)
Afdeling for Børn og Unge med Kræft
Aalborg Universitetshospital

CONTROL

WP12 forskningsgruppe

Ledelse

Marianne Olsen
Chair WP12
Speciallæge, Ph.d
Nordsjællands Hospital

Hanne Bækgaard Larsen
Seniorforsker
Psyko-sociale Forskningsgruppe
Bonkolab, Rigshospitalet

Mette Asbjørn Neergaard
Co-chair WP12
Klinisk professor
Institut for Klinisk Medicin
Aarhus Universitethospital

Medvejledere

Pernille Envold Bidstrup
Seniorforsker
Psykologiske Aspekter af Kræft
Center for Kræftforskning
Kræftens Bekæmpelse

Ayo Wahlberg
Professor
Institut for Antropologi
Københavns Universitet

International samarbejdspartner

Joanne Wolfe, MD MPH
Department of Pediatrics
Harvard Medical School
Boston

Ph.D studerende

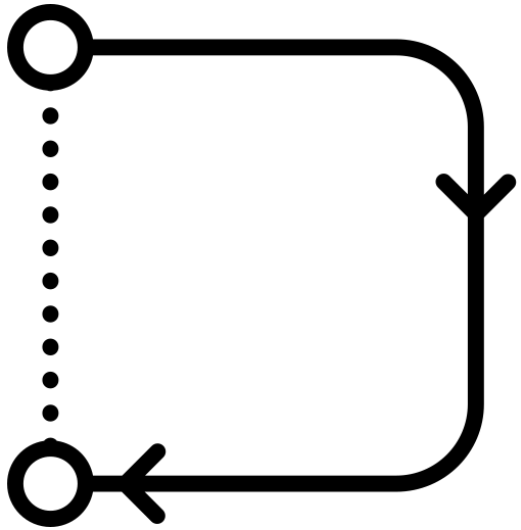
Minna Devantier
Antropolog, Postdoc
Bonkolab
Rigshospitalet

Nanna Maria Hammer
Gæsteforsker, Ph.D
Institut for Folkesundhedsvidenskab
Københavns Universitet

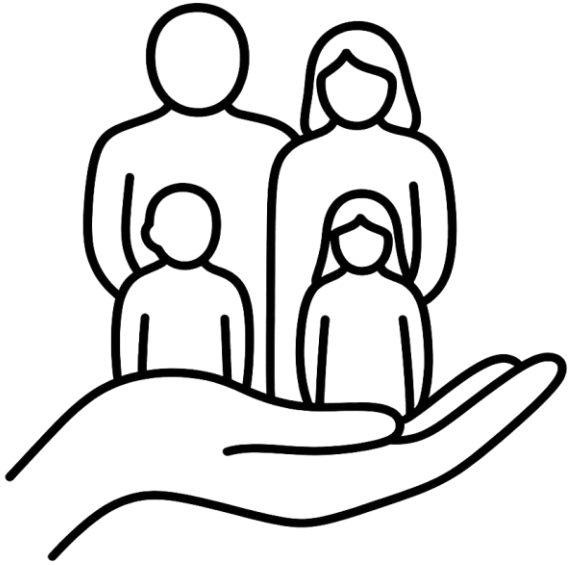
Johanne Aviaja Rosing
Cand.scient.san.publ,
Ph.d.-studerende
Bonkolab
Rigshospitalet

WP12 TIDLIG INTEGRERET PALLIATIV INDSATS

WHO anbefaler, at palliativ indsats til børn og unge starter ved diagnosen og integreres med den sygdomsrettede behandling gennem hele sygdomsforløbet. Målet er bedst mulig livskvalitet for barnet og familien



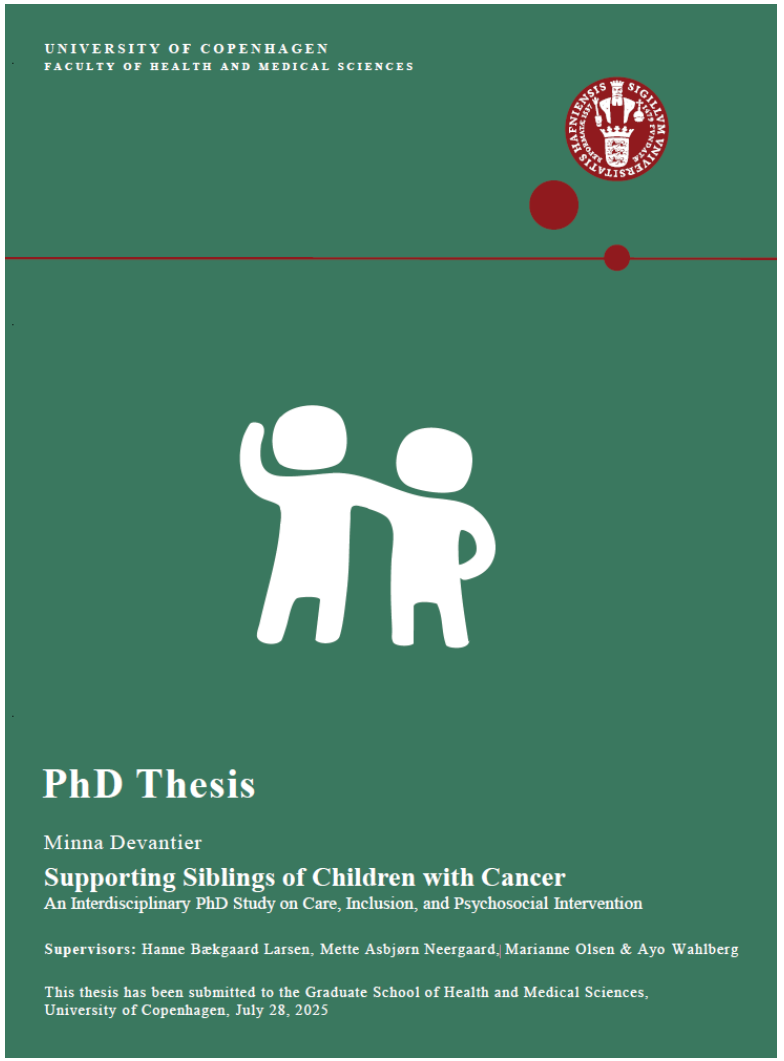
Forskydninger af omsorg og ressourcer



Livskvalitet

Minna Devantier,

Antropolog, PhD



Forsvaret 2025

børne cancer fonden

CONTROL

REGION H Rigshospitalet

Hovedvejleder:
Hanne Bækgaard Larsen
Bi-vejledere:
Mette Asbjørn Neergaard
Marianne Olsen
Ayo Wahlberg

Journal of Clinical Nursing

EMPIRICAL RESEARCH QUALITATIVE OPEN ACCESS

Siblings of Children With Cancer and Th
Across Everyday Life Contexts: A Two-Pl
Study in Denmark

Minna Devantier[1,2] | Mette Asbjoern Neergaard[3,4] | Marianne Olsen[5] | Ayo Wah

[1]Department of Pediatrics and Adolescent Medicine, Copenhagen University Hospital – Rigshospitalet, Co
Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [2]
Care Team, Department of Oncology, Aarhus University Hospital, Aarhus, Denmark | [3]Section for Specialist Pa
University, Aarhus, Denmark | [5]Department of Pediatrics and Adolescent Medicine, Aalborg University H
Anthropology, University of Copenhagen, Copenhagen, Denmark

Correspondence: Minna Devantier (minna.devantier@regionh.dk)

Received: 5 May 2025 | **Revised:** 27 August 2025 | **Accepted:** 3 September 2025

Funding: This work was supported by Kræftens Bekæmpelse (R-257-A14720) and Bernecancerfonden (20

ABSTRACT

Aim: To explore the familial, emotional, social and school-related challenges experier
with cancer, focusing on how these challenges intersect across hospital, home and scho

Design: Qualitative, two-phase, multi-site study.

Methods: Fieldwork was conducted at two distinct paediatric oncology wards, followe
siblings (aged 7–19 years) and 20 parents, recruited through criterion-based sampling.
thematic analysis.

Results: Analysis showed that siblings were often marginalised in hospital life due to
restrictions, rules and physical spaces and (3) perceptions of their presence as 'problem
family life, siblings experienced peripheral roles because (1) they were cared for by othe
(3) faced shifting expectations. At school, siblings encountered (1) limited understandin
insufficient support resources.

Conclusions: Siblings of children with cancer face significant, interconnected challe
frameworks of healthcare, family and school contexts.

Impact: Siblings of children with cancer are often marginalised in their own lives. In l
care should formally and actively include siblings. Nurses are well-positioned to promo
Siblings would benefit from coordinated support bridging hospital, home and school.

Reporting Method: This study adheres to the SRQR Checklist.

Patient or Public Contribution: Parents helped shape the study focus by discussing

WILEY

Journal of Clinical Nursing

European Journal of Oncology Nursing 74 (2025) 102768

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

ELSEVIER

School-based social and educational support for siblings of children with cancer - Siblings' and parents' feedback on an intervention proposal (SUPREME)

Minna Devantier[a], Marianne Olsen[b], Mette Asbjoern Neergaard[c,d], Ayo Wahlberg[e], Natasha Nybro Boensvang[a], Hanne Bækgaard Larsen[a,f,*]

[a] Department of Pediatrics and Adolescent Medicine, Copenhagen University Hospital – Rigshospitalet, Copenhagen, Denmark
[b] Department of Pediatrics and Adolescent Medicine, Aalborg University Hospital, Aalborg, Denmark
[c] Palliative Care Unit and Child & Youth Palliative Care Team, Department of Oncology, Aarhus University Hospital, Denmark
[d] Department of Clinical Medicine, Faculty of Health, University of Aarhus, Aarhus, Denmark
[e] Department of Anthropology, University of Copenhagen, Copenhagen, Denmark
[f] Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark

ARTICLE INFO

Keywords:
Cancer
Childhood cancer
Pediatric oncology
Psycho-oncology
Psycho-social intervention
Siblings
Social support
Qualitative research

ABSTRACT

Purpose: 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. 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 recognised: 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, losing school as a 'free space', and the risk of siblings standing out. 4) Siblings' concerns related to a fear of losing control over the cancer-related information at school and the reactions of peers. 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.

1. Introduction

A sibling's everyday life becomes unpredictable when their brother or sister is diagnosed with cancer (Yang et al., 2016). Family life is divided between home and hospital, and parents' primary focus is on the child with cancer (Long et al., 2018) Accordingly, siblings need to adjust to a new normal with varying degrees of support and attention from facing cancer-related questions within their local community (Prchal and Landolt, 2012). These questions can be difficult for them to answer as siblings lack information about their brother or sister's diagnosis and treatment (Nolbris et al., 2007; Toft et al., 2019) because they are not directly involved in the medical care (Nolbris and Ahlström, 2014; Yang et al., 2016). Siblings may respond to the change within the family, experiencing emotions such as jealousy, anger, sadness, guilt, and

Journal of Advanced Nursing

WILEY

JAN

EMPIRICAL RESEARCH QUALITATIVE OPEN ACCESS

A Nurse-Led, School-Based Social and Educational Intervention for Siblings of Children With Cancer (SUPREME): Process Evaluation of Perceived Impacts

Minna Devantier[1,2] | Mette Asbjoern Neergaard[3,4] | Marianne Olsen[5] | Ayo Wahlberg[6] | Hanne Bækgaard Larsen[1,2]

[1]Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital – Rigshospitalet, Copenhagen, Denmark | [2]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [3]Section for Specialist Palliative Care and Child & Youth Palliative Care Team, Department of Oncology, Aarhus University Hospital, Aarhus, Denmark | [4]Department of Faculty of Health, Aarhus University, Aarhus, Denmark | [5]Department of Pediatrics and Adolescent Medicine, Aalborg University Hospital, Aalborg, Denmark | [6]Department of Anthropology, University of Copenhagen, Copenhagen, Denmark

Correspondence: Minna Devantier (minna.devantier@regionh.dk)

Received: 6 May 2025 | **Revised:** 28 July 2025 | **Accepted:** 15 August 2025

Funding: This work was supported by Bernecancerfonden (Grants 2021-7397, 2022-8140 and 2024-001237).

Keywords: cancer | childhood cancer | nurse | paediatric oncology | psycho-oncology | qualitative research | siblings | social support

ABSTRACT

Purpose: To explore siblings' and parents' experiences of, and perceived impacts of, a nurse-led school-based intervention (SUPREME) for siblings of children with cancer in Denmark.

Design: A qualitative process evaluation.

Methods: Fifteen siblings (aged 6–14 years) and 16 parents were recruited through criterion-based sampling following siblings' participation in the SUPREME intervention. Data consisted of semi-structured interviews and open-ended responses from an evaluation form, and were analysed thematically. Data were collected between May 2024 and February 2025.

Results: The intervention created a sense of normality for siblings by providing age-appropriate and credible information in the familiar school context, thereby strengthening the understanding of the family's cancer journey. The SUPREME nurse played a key role in easing the communication burden on siblings and parents, while also promoting recognition of siblings within the hospital setting as active participants in the family's cancer journey. Additionally, the intervention was perceived to accommodate varying levels of support needs across families.

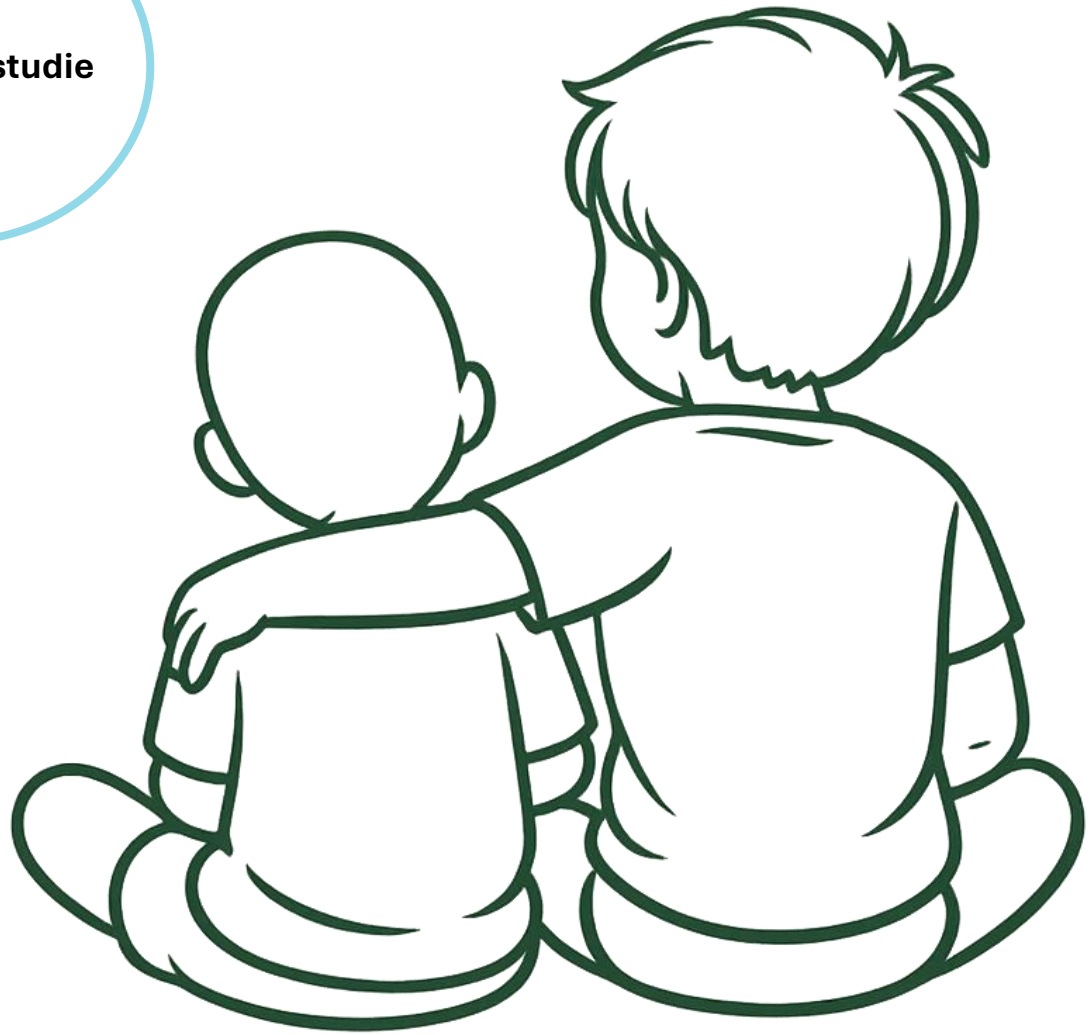
Conclusion: The SUPREME intervention benefited siblings—and, by extension, their families—by equipping siblings with essential information, guiding their class communities on how to offer appropriate support and fostering siblings' inclusion in the family's cancer journey. The SUPREME intervention constitutes a new strategy for accessible, universal siblingship support.

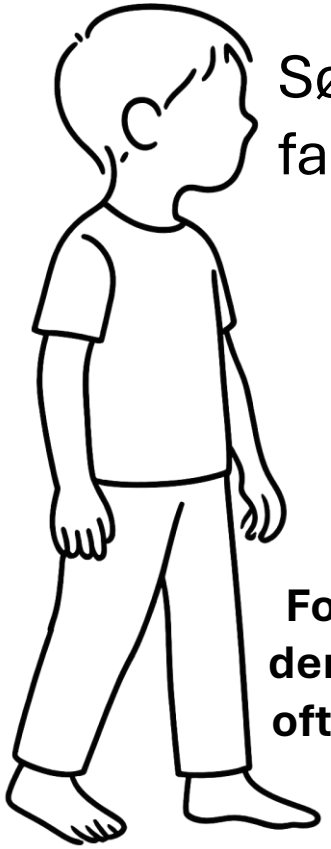
Implications for Profession and/or Patient Care: The healthcare system should formally ensure that professionals working with families affected by severe paediatric conditions provide family-centred care that actively includes siblings.

Impact: *What problem did the study address?* The position of siblings of children with cancer is often complex, as they may simultaneously serve as visible front figures of the family while remaining overlooked. This study explored how parents and siblings of children with cancer experienced participating in a new sibling support intervention.

Søskende til børn med kræft

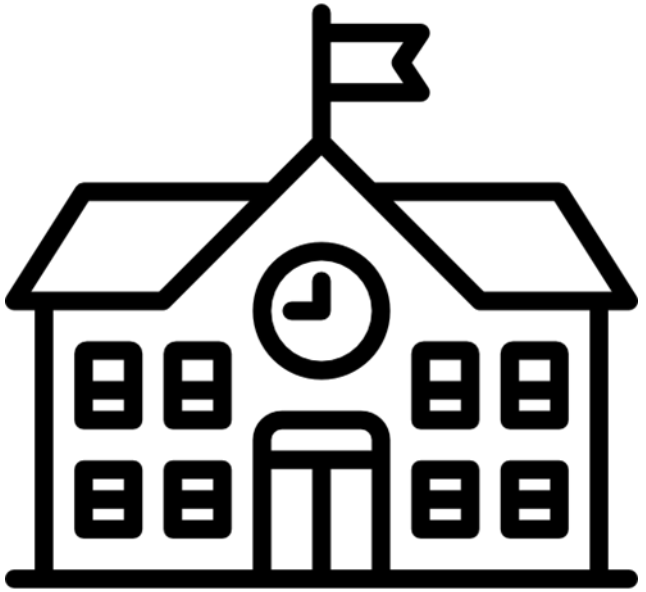
Baggrundsstudie





Søskende er til stede i familiens lokalmiljø

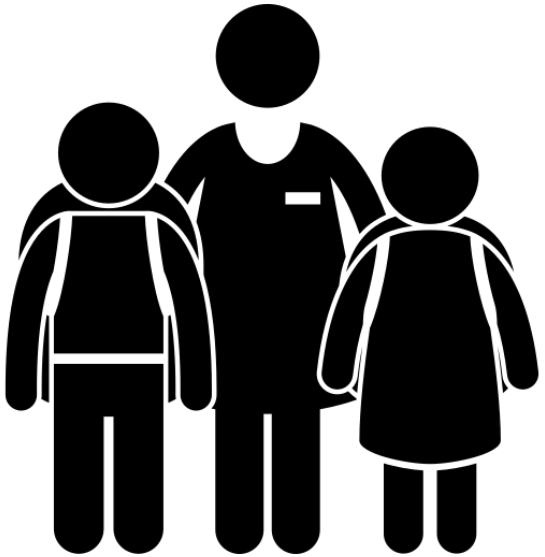
Forventes at passe deres ”normale” liv– ofte som de eneste i familien



Presset på ressourcer

↓

Søskende mødes af utilstrækkelighed



Manglende erfaring og viden om håndtering

Interventionsudvikling

Hvad gjorde vi ved det?

Vi skabte en intervention *med* søskende og forældre

Sygeplejedrevet, hospitals- og skolebaseret intervention

SUPREME

SUPport and social REhabilitation programME for siblings

Intervention (SUPREME)

Samtale

Tæt på diagnosen

Information, tillid og tryghed

Undervisning

Inden for de første to måneder

Børnekræft og praktiske konsekvenser

Samtale

Før anden undervisning

Opfølgning

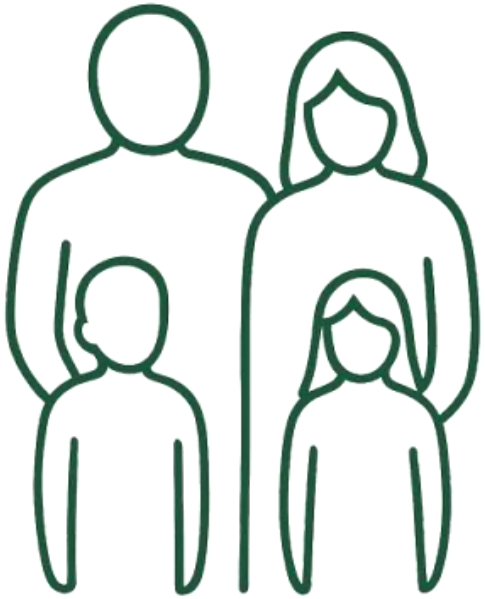
Undervisning

Inden for seks måneder

Sociale og emotionelle konsekvenser

Evaluering

Hvilken forskel gjorde interventionen ifølge familierne?



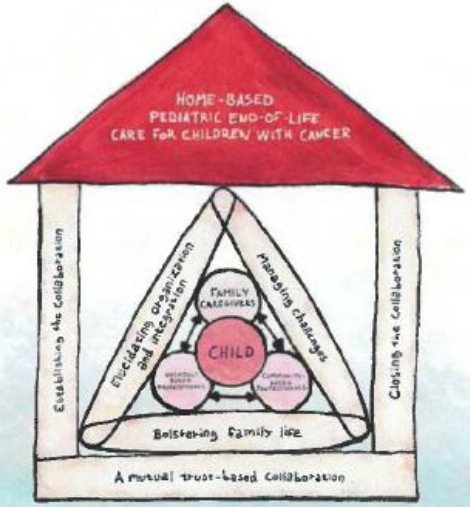
“Nu ved jeg, hvad leukæmi er.”

Søskende, interview

Nanna Maria Hammer

København Universitet,
Post doc

UNIVERSITY OF COPENHAGEN
FACULTY OF HEALTH AND MEDICAL SCIENCES



PhD Thesis

Nanna Maria Hammer

Home-Based Palliative Care for Children and Adolescents with Incurable Cancer and their Families

Supervisors: Hanne Bækgaard Larsen, Pernille Envold Bidstrup and Marianne Olsen

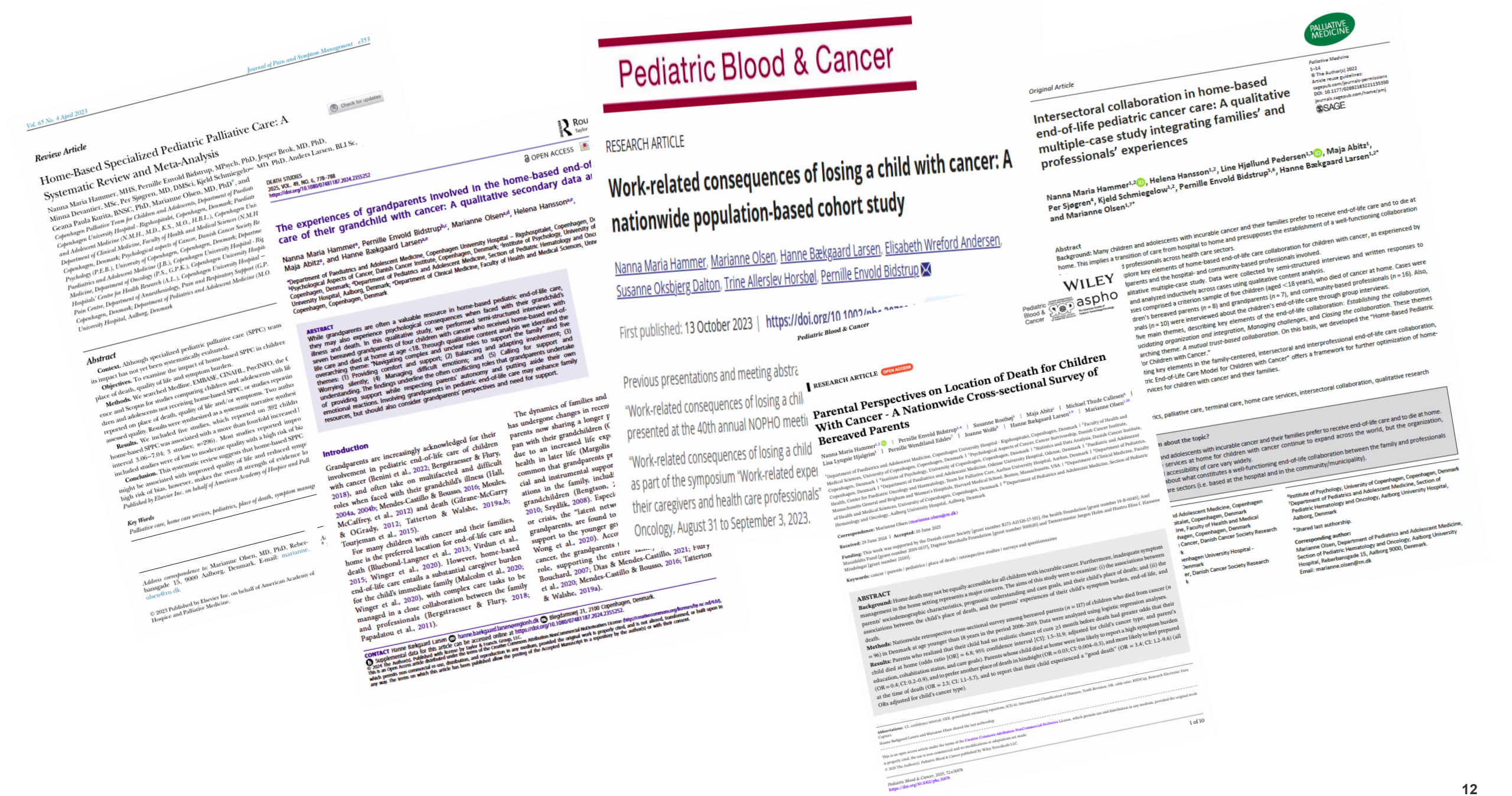
This thesis has been submitted to the Graduate School of Health and Medical Sciences, University of Copenhagen: December 21, 2022

Forsvaret 2022

Kræftens Bekæmpelse
helsefonden
CONTROL

Axel Muusfeldts Fond
Dagmar Marshalls Fond
Tømrermester Jørgen Holm og hustrus Mindelegat

Hovedvejleder:
Hanne Bækgaard Larsen
Bi-vejledere:
Marianne Olsen
Pernille Envold Bidstrup



Journal of Pain and Symptom Management e353

Vol. 65 No. 4 April 2023

Review Article

Home-Based Specialized Pediatric Palliative Care: A Systematic Review and Meta-Analysis

Nanna Maria Hammer, MHS, Pernille Envold Bidstrup, MPsych, PhD, Jesper Brok, MD, PhD, Minna Devantier, MSc, Per Sjøgren, MD, DMSci, Kjeld Schmiegelow, MD, PhD, Anders Larsen, BLI Sc., Geana Paula Kurita, BNSC, PhD, Marianne Olsen, MD, PhD*, and

Abstract

Context. Although specialized pediatric palliative care (SPPC) team its impact has not yet been systematically evaluated.

Objectives. To examine the impact of home-based SPPC in children place of death, quality of life and symptom burden.

Methods. We searched Medline, EMBASE, CINAHL, PsycINFO, the C ence and Scopus for studies comparing children and adolescents with lif dren and adolescents not receiving home-based SPPC, or studies reportin reported on place of death, quality of life and/or symptoms. Two autho assessed quality. Results were synthesized as a systematic narrative synthesi

Results. We included five studies, which reported on 392 childr home-based SPPC was associated with a more than fourfold increased l interval 3.06–7.04; 3 studies; n=296). Most studies reported impro included studies were of low to moderate quality with a high risk of bia

Conclusion. This systematic review suggests that home-based SPPC might be associated with improved quality of life and reduced symp high risk of bias, however, makes the overall strength of evidence lo

Published by Elsevier Inc. on behalf of American Academy of Hospice and Pall

Key Words

Palliative care, home care services, pediatrics, place of death, symptom manag

Address correspondence to: Marianne Olsen, MD, PhD, Rebert- bansgade 15, 9000 Aalborg, Denmark. E-mail: marianne. olsen@rn.dk

© 2023 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

DEATH STUDIES
2025, VOL. 49, NO. 6, 778–788
https://doi.org/10.1080/07481187.2024.2355252

OPEN ACCESS

The experiences of grandparents involved in the home-based end-of care of their grandchild with cancer: A qualitative secondary data a

Nanna Maria Hammer[a], Pernille Envold Bidstrup[b,c], Marianne Olsen[a,d], Helena Hansson[a,e], Maja Abitz[a], and Hanne Bækgaard Larsen[a,e]

[a]Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital – Rigshospitalet, Copenhagen, D [b]Psychological Aspects of Cancer, Danish Cancer Institute, Copenhagen, Denmark; [c]Institute of Psychology, University of Copenhagen, Denmark; [d]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Onco University Hospital, Aalborg, Denmark; [e]Department of Clinical Medicine, Faculty of Health and Medical Sciences, Univ Copenhagen, Copenhagen, Denmark

ABSTRACT

While grandparents are often a valuable resource in home-based pediatric end-of-life care, they may also experience psychological consequences when faced with their grandchild's illness and death. In this qualitative study, we performed semi-structured interviews with seven bereaved grandparents of four children with cancer who received home-based end-of-life care and died at home at age <18. Through qualitative content analysis we identified the overarching theme: "Navigating complex and unclear roles to support the family" and five themes: (1) Providing comfort and support; (2) Balancing and adapting involvement; (3) Worrying silently; (4) Managing difficult emotions; and (5) Calling for support and understanding. The findings underline the often conflicting roles that grandparents undertake of providing support while respecting parents' autonomy and putting aside their own emotional reactions. Involving grandparents in pediatric end-of-life care may enhance family resources, but should also consider grandparents' perspectives and need for support.

Introduction

Grandparents are increasingly acknowledged for their involvement in pediatric end-of-life care of children with cancer (Benini et al., 2022; Bergstraesser & Flury, 2018), and often take on multifaceted and difficult roles when faced with their grandchild's illness (Hall, 2004a, 2004b; Mendes-Castillo & Bousso, 2016; Moules, McCaffrey, et al., 2012) and death (Gilrane-McGarry & OGrady, 2012; Tatterton & Walshe, 2019a,b; Tourjeman et al., 2015).

For many children with cancer and their families, home is the preferred location for end-of-life care and death (Bluebond-Langner et al., 2013; Virdun et al., 2015; Winger et al., 2020). However, home-based end-of-life care entails a substantial caregiver burden for the child's immediate family (Malcolm et al., 2020; Winger et al., 2020), with complex care tasks to be managed in a close collaboration between the family and professionals (Bergstraesser & Flury, 2018; Papadatou et al., 2011).

The dynamics of families and has undergone changes in recen parents now sharing a longer p pan with their grandchildren (C due to an increased life exp health in later life (Margolis common that grandparents pr cial and instrumental suppor ations in the family, includi grandchildren (Bengtson, 2 2010; Szydlik, 2008). Especi or crisis, the "latent netw grandparents, are found to support to the younger ge Wong et al., 2020). Acco cancer, the grandparents role, supporting the entire Bouchard, 2007; Dias & Mendes-Castillo, 2021; Flury et al., 2020; Mendes-Castillo & Bousso, 2016; Tatterton & Walshe, 2019a).

CONTACT Hanne Bækgaard Larsen hanne.baekgaard.larsen@regionh.dk Blegdamsvej 31, 2100 Copenhagen, Denmark.
Supplemental data for this article can be accessed online at https://doi.org/10.1080/07481187.2024.2355252.
© 2024 the Author(s). Published with license by Taylor & Francis Group, LLC.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Pediatric Blood & Cancer

RESEARCH ARTICLE

Work-related consequences of losing a child with cancer: A nationwide population-based cohort study

Nanna Maria Hammer, Marianne Olsen, Hanne Bækgaard Larsen, Elisabeth Wreford Andersen, Susanne Oksbjerg Dalton, Trine Allerslev Horsbøl, Pernille Envold Bidstrup

First published: 13 October 2023 | https://doi.org/10.1002/pbc.30778

Pediatric Blood & Cancer

Previous presentations and meeting abstra

"Work-related consequences of losing a chil presented at the 40th annual NOPHO meeti

"Work-related consequences of losing a child as part of the symposium "Work-related expe their caregivers and health care professionals" Oncology, August 31 to September 3, 2023.

RESEARCH ARTICLE OPEN ACCESS

Parental Perspectives on Location of Death for Children With Cancer - A Nationwide Cross-sectional Survey of Bereaved Parents

Nanna Maria Hammer[1,2] | Pernille Envold Bidstrup[3,4] | Susanne Rosthøj[5] | Maja Abitz[1] | Michael Thude Callesen[6] | Lisa Lyngsie Hjalgrim[1] | Pernille Wendtland Edslev[7] | Joanne Wolfe[8] | Hanne Bækgaard Larsen[1,9] | Marianne Olsen[1,10]

[1]Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital - Rigshospitalet, Copenhagen, Denmark | [2]Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [3]Psychological Aspects of Cancer, Cancer Survivorship, Danish Cancer Institute, Copenhagen, Denmark | [4]Institute of Psychology, University of Copenhagen, Copenhagen, Denmark | [5]Statistics and Data Analysis, Danish Cancer Institute, Copenhagen, Denmark | [6]Department of Paediatrics and Adolescent Medicine, Odense University Hospital, Odense, Denmark | [7]Paediatric and Adolescent Health, Center for Paediatric Oncology and Haematology, Team for Palliative Care, Aarhus University Hospital, Aarhus, Denmark | [8]Department of Pediatrics, Massachusetts General and Brigham and Women's Hospitals, Harvard Medical School, Boston, Massachusetts, USA | [9]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [10]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Aalborg, Denmark

Correspondence: Marianne Olsen (marianne.olsen@rn.dk)

Received: 29 June 2024 | Accepted: 10 June 2025

Funding: This work was supported by the Danish cancer Society [grant number R173-A11326-17-S5], the health Foundation [grant number 19-B-0045], Axel Muusfeldts Fund [grant number 2019-0137], Dagmar Marshalls Foundation [grant number 800020] and Tømrermester Jørgen Holm and Hustru Elisa L. Hansens Mindelegat [grant number 22160].

Keywords: cancer | parents | pediatrics | place of death | retrospective studies | surveys and questionnaires

ABSTRACT

Background: Home death may not be equally accessible for all children with incurable cancer. Furthermore, inadequate symptom management in the home setting represents a major concern. The aims of this study were to examine: (i) the associations between parents' sociodemographic characteristics, prognostic understanding and care goals, and their child's place of death; and (ii) the associations between the child's place of death, and the parents' experiences of their child's symptom burden, end-of-life, and death.

Methods: Nationwide retrospective cross-sectional survey among bereaved parents ($n = 117$) of children who died from cancer ($n = 96$) in Denmark at age younger than 18 years in the period 2006–2019. Data were analyzed using logistic regression analyses.

Results: Parents who realized that their child had no realistic chance of cure ≥1 month before death had greater odds that their child died at home (odds ratio [OR] = 6.8; 95% confidence interval [CI]: 1.5–31.9; adjusted for child's cancer type, and parent's education, cohabitation status, and care goals). Parents whose child died at home were less likely to report a high symptom burden (OR = 0.4; CI: 0.2–0.9), and to prefer another place of death in hindsight (OR = 0.03; CI: 0.004–0.3), and more likely to feel prepared at the time of death (OR = 2.5; CI: 1.1–5.7), and to report that their child experienced a "good death" (OR = 3.4; CI: 1.2–9.6) (all ORs adjusted for child's cancer type).

Abbreviations: CI, confidence interval; GEE, generalized estimating equations; ICD-10, International Classification of Diseases, Tenth Revision; OR, odds ratio; REDCap, Research Electronic Data Capture.

Hanne Bækgaard Larsen and Marianne Olsen shared the last authorship.

Original Article

Palliative Medicine
1–14
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/02692163221135550
journals.sagepub.com/home/pmj

SAGE

Intersectoral collaboration in home-based end-of-life pediatric cancer care: A qualitative multiple-case study integrating families' and professionals' experiences

Nanna Maria Hammer[1,2], Helena Hansson[1,2], Line Hjøllund Pedersen[1,3], Maja Abitz[1], Per Sjøgren[4], Kjeld Schmiegelow[1,2], Pernille Envold Bidstrup[5,6], Hanne Bækgaard Larsen[1,2]* and Marianne Olsen[1,7]*

Abstract

Background: Many children and adolescents with incurable cancer and their families prefer to receive end-of-life care and to die at home. This implies a transition of care from hospital to home and presupposes the establishment of a well-functioning collaboration

d professionals across health care sectors.

plore key elements of home-based end-of-life care collaboration for children with cancer, as experienced by

parents and the hospital- and community-based professionals involved.

alitative multiple-case study. Data were collected by semi-structured interviews and written responses to

and analyzed inductively across cases using qualitative content analysis.

ses comprised a criterion sample of five children (aged <18 years), who died of cancer at home. Cases were

dren's bereaved parents ($n = 8$) and grandparents ($n = 7$), and community-based professionals ($n = 16$). Also,

onals ($n = 10$) were interviewed about the children's end-of-life collaboration: *Establishing the collaboration*,

five main themes, describing key elements of the end-of-life collaboration: *Establishing the collaboration*,

ucidating organization and integration, *Managing challenges*, and *Closing the collaboration*. These themes

arching theme: *A mutual trust-based collaboration*. On this basis, we developed the "Home-Based Pediatric

'or Children with Cancer."

ting key elements in the family-centered, intersectoral and interprofessional end-of-life care collaboration,

tric End-of-Life Care Model for Children with Cancer" offers a framework for further optimization of home-

rvices for children with cancer and their families.

rics, palliative care, terminal care, home care services, intersectoral collaboration, qualitative research

n about the topic?

nd adolescents with incurable cancer and their families prefer to receive end-of-life care and to die at home.

services at home for children with cancer continue to expand across the world, but the organization,

accessibility of care vary widely.

about what constitutes a well-functioning end-of-life collaboration between the family and professionals

re sectors (i.e. based at the hospital and in the community/municipality).

d Adolescent Medicine, Copenhagen
pitalet, Copenhagen, Denmark
ine, Faculty of Health and Medical
hagen, Copenhagen, Denmark
Cancer, Danish Cancer Society Research
k
enhagen University Hospital -
Denmark
er, Danish Cancer Society Research
k

[3]Institute of Psychology, University of Copenhagen, Copenhagen, Denmark
[4]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Aalborg, Denmark
[5]Psychological Aspects of Cancer, Danish Cancer Institute, Copenhagen, Denmark
[6]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Aalborg, Denmark
[7]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark

*Shared last authorship.

Corresponding author:
Marianne Olsen, Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Reberbansgade 15, Aalborg 9000, Denmark.
Email: marianne.olsen@rn.dk

Original Article

PALLIATIVE MEDICINE

Intersectoral collaboration in home-based end-of-life pediatric cancer care: A qualitative multiple-case study integrating families' and professionals' experiences

Palliative Medicine
1–14

DOI: 10.1177/02692163221135350
journals.sagepub.com/home/pmj
SAGE

Nanna Maria Hammer[1,2], Helena Hansson[1,2], Line Hjøllund Pedersen[1,3], Maja Abitz[1], Per Sjøgren[4], Kjeld Schmiegelow[1,2], Pernille Envold Bidstrup[5,6], Hanne Bækgaard Larsen[1,2*] and Marianne Olsen[1,7*]

Abstract

Background: Many children and adolescents with incurable cancer and their families prefer to receive end-of-life care and to die at home. This implies a transition of care from hospital to home and presupposes the establishment of a well-functioning collaboration between the family and professionals across health care sectors.

Aim: To identify and explore key elements of home-based end-of-life care collaboration for children with cancer, as experienced by their parents and grandparents and the hospital- and community-based professionals involved.

Design: Descriptive qualitative multiple-case study. Data were collected by semi-structured interviews and written responses to open-ended questions, and analyzed inductively across cases using qualitative content analysis.

Setting/participants: Cases comprised a criterion sample of five children (aged <18 years), who died of cancer at home. Cases were represented by the children's bereaved parents ($n = 8$) and grandparents ($n = 7$), and community-based professionals ($n = 16$). Also, hospital-based professionals ($n = 10$) were interviewed about the children's end-of-life care through group interviews.

Results: We identified five main themes, describing key elements of the end-of-life collaboration: *Establishing the collaboration, Bolstering family life, Elucidating organization and integration, Managing challenges*, and *Closing the collaboration*. These themes all came under the overarching theme: *A mutual trust-based collaboration*. On this basis, we developed the "Home-Based Pediatric End-of-Life Care Model for Children with Cancer."

Conclusions: By highlighting key elements in the family-centered, intersectoral and interprofessional end-of-life care collaboration, our "Home-Based Pediatric End-of-Life Care Model for Children with Cancer" offers a framework for further optimization of home-based end-of-life care services for children with cancer and their families.

Keywords

Child, adolescent, pediatrics, palliative care, terminal care, home care services, intersectoral collaboration, qualitative research

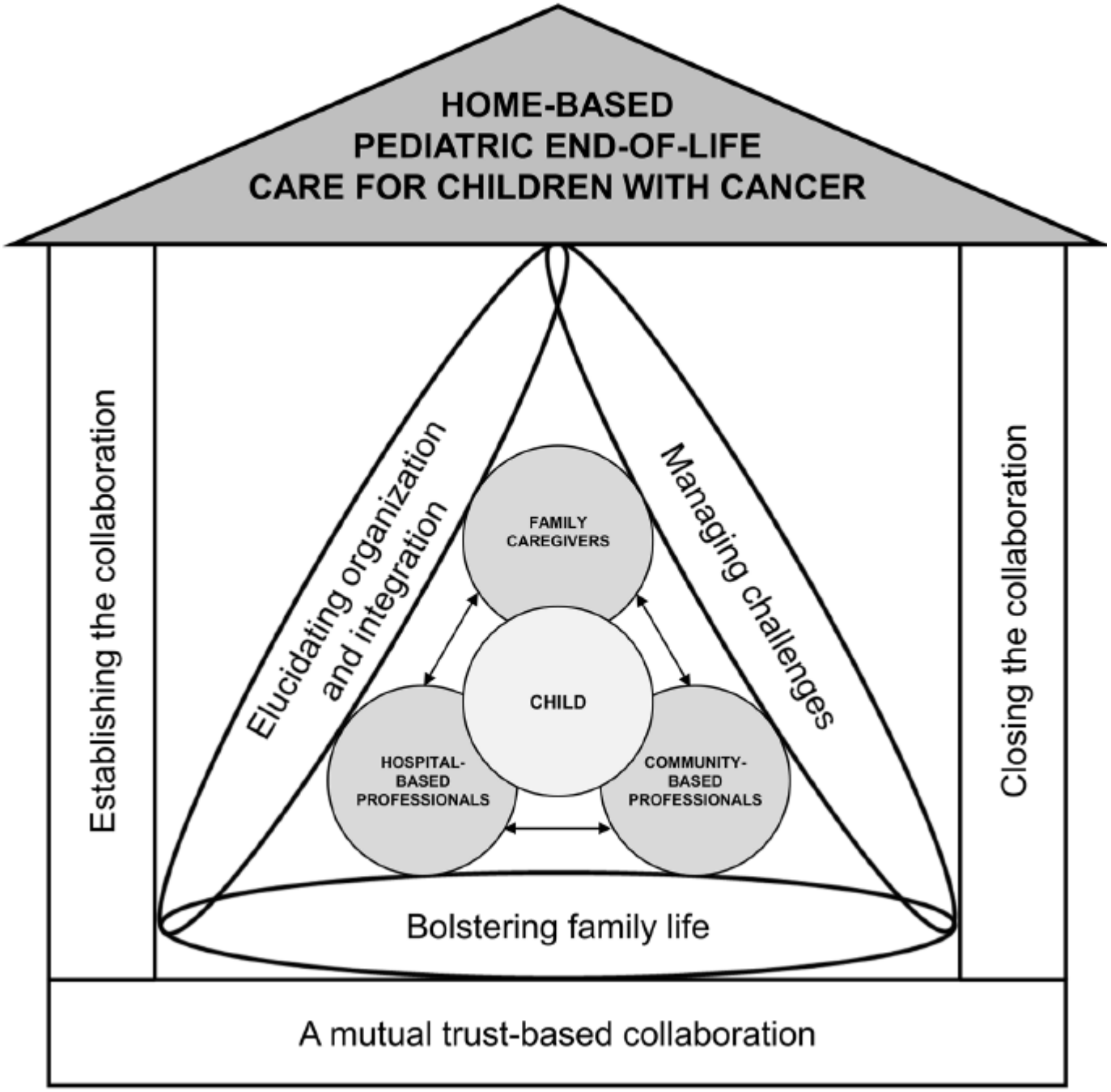
What is already known about the topic?

- Many children and adolescents with incurable cancer and their families prefer to receive end-of-life care and to die at home.
- End-of-life care services at home for children with cancer continue to expand across the world, but the organization, availability, and accessibility of care vary widely.
- Little is known about what constitutes a well-functioning end-of-life collaboration between the family and professionals across health care sectors (i.e. based at the hospital and in the community/municipality).

[1]Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital - Rigshospitalet, Copenhagen, Denmark
[2]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark
[3]Survivorship and Inequality in Cancer, Danish Cancer Society Research Center, Copenhagen, Denmark
[4]Department of Oncology, Copenhagen University Hospital - Rigshospitalet, Copenhagen, Denmark
[5]Psychological Aspects of Cancer, Danish Cancer Society Research Center, Copenhagen, Denmark
[6]Institute of Psychology, University of Copenhagen, Copenhagen, Denmark
[7]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Aalborg, Denmark

*Shared last authorship.

Corresponding author:
Marianne Olsen, Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Reberbansgade 15, Aalborg 9000, Denmark.
Email: marianne.olsen@rn.dk



Pediatric Blood & Cancer

WILEY

Pediatric Blood & Cancer | aspho

RESEARCH ARTICLE OPEN ACCESS

Parental Perspectives on Location of Death for Children With Cancer - A Nationwide Cross-sectional Survey of Bereaved Parents

Nanna Maria Hammer[1,2] | Pernille Envold Bidstrup[3,4] | Susanne Rosthøj[5] | Maja Abitz[1] | Michael Thude Callesen[6] | Lisa Lyngsie Hjalgrim[1] | Pernille Wendtland Edslev[7] | Joanne Wolfe[8] | Hanne Bækgaard Larsen[1,9] | Marianne Olsen[1,10]

[1]Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital - Rigshospitalet, Copenhagen, Denmark | [2]Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [3]Psychological Aspects of Cancer, Cancer Survivorship, Danish Cancer Institute, Copenhagen, Denmark | [4]Institute of Psychology, University of Copenhagen, Copenhagen, Denmark | [5]Statistics and Data Analysis, Danish Cancer Institute, Copenhagen, Denmark | [6]Department of Paediatrics and Adolescent Medicine, Odense University Hospital, Odense, Denmark | [7]Paediatric and Adolescent Health, Center for Paediatric Oncology and Haematology, Team for Palliative Care, Aarhus University Hospital, Aarhus, Denmark | [8]Department of Pediatrics, Massachusetts General and Brigham and Women's Hospitals, Harvard Medical School, Boston, Massachusetts, USA | [9]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark | [10]Department of Pediatrics and Adolescent Medicine, Section of Pediatric Hematology and Oncology, Aalborg University Hospital, Aalborg, Denmark

Correspondence: Marianne Olsen (marianne.olsen@rn.dk)

Received: 29 June 2024 | **Accepted:** 10 June 2025

Funding: This work was supported by the Danish cancer Society [grant number R173-A11326-17-551], the health Foundation [grant number 19-B-0045]; Axel Muusfeldts Fund [grant number 2019-0137], Dagmar Marshalls Foundation [grant number 500020] and Tømrermester Jørgen Holm and Hustru Elisa f. Hansens Mindelegat [grant number 21110].

Keywords: cancer | parents | pediatrics | place of death | retrospective studies | surveys and questionnaires

ABSTRACT

Background: Home death may not be equally accessible for all children with incurable cancer. Furthermore, inadequate symptom management in the home setting represents a major concern. The aims of this study were to examine: (i) the associations between parents' sociodemographic characteristics, prognostic understanding and care goals, and their child's place of death; and (ii) the associations between the child's place of death, and the parents' experiences of their child's symptom burden, end-of-life, and death.

Methods: Nationwide retrospective cross-sectional survey among bereaved parents ($n = 117$) of children who died from cancer ($n = 96$) in Denmark at age younger than 18 years in the period 2006–2019. Data were analyzed using logistic regression analyses.

Results: Parents who realized that their child had no realistic chance of cure ≥1 month before death had greater odds that their child died at home (odds ratio [OR] = 6.8; 95% confidence interval [CI]: 1.5–31.9; adjusted for child's cancer type, and parent's education, cohabitation status, and care goals). Parents whose child died at home were less likely to report a high symptom burden (OR = 0.4; CI: 0.2–0.9), and to prefer another place of death in hindsight (OR = 0.03; CI: 0.004–0.3), and more likely to feel prepared at the time of death (OR = 2.5; CI: 1.1–5.7), and to report that their child experienced a "good death" (OR = 3.4; CI: 1.2–9.6) (all ORs adjusted for child's cancer type).

Abbreviations: CI, confidence interval; GEE, generalized estimating equations; ICD-10, International Classification of Diseases, Tenth Revision; OR, odds ratio; REDCap, Research Electronic Data Capture.

Hanne Bækgaard Larsen and Marianne Olsen shared the last authorship.

ID-nummer_____

SPØRGESKEMAUNDERSØGELSE OM PLEJE OG BEHANDLING AF BØRN MED KRÆFT OG KRÆFTLIGNENDE SYGDOM

Prognostisk forståelse

Hvordan forstår forældre til børn med kræft deres barns prognose, og hvilken betydning har forståelsen for forældre og barn?

Johanne Aviaja Rosing, Ph.d. studerende
Cand.scient.san.publ.
Børneonkologisk Laboratorium
Rigshospitalet

børne cancer fonden

CONTROL

TAK