

Who is supporting the parents during their child's cancer treatment?

A qualitative study through the lens of compassion

Nielsen, Camilla Littau; Clemensen, Jane; Callesen, Michael Thude; Jensen, Claus Sixtus; Smith, Anthony C.; Holm, Kristina Garne

Published in:
European Journal of Oncology Nursing

DOI:
10.1016/j.ejon.2024.102534

Publication date:
2024

Document version:
Final published version

Document license:
CC BY

Citation for pulished version (APA):
Nielsen, C. L., Clemensen, J., Callesen, M. T., Jensen, C. S., Smith, A. C., & Holm, K. G. (2024). Who is supporting the parents during their child's cancer treatment? A qualitative study through the lens of compassion. *European Journal of Oncology Nursing*, 70, Article 102534. <https://doi.org/10.1016/j.ejon.2024.102534>

Go to publication entry in University of Southern Denmark's Research Portal

Terms of use

This work is brought to you by the University of Southern Denmark.
Unless otherwise specified it has been shared according to the terms for self-archiving.
If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim.
Please direct all enquiries to puresupport@bib.sdu.dk



Who is supporting the parents during their child's cancer treatment? A qualitative study through the lens of compassion

Camilla Littau Nielsen^{a,b,c,*}, Jane Clemensen^{a,b,c,d,e,f}, Michael Thude Callesen^a, Claus Sixtus Jensen^{g,h,i}, Anthony C. Smith^{d,e,f}, Kristina Garne Holm^{a,b}

^a Hans Christian Andersen Children's Hospital, Odense University Hospital, Denmark

^b Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Denmark

^c Centre for Compassion in Healthcare, Department of Clinical Research, Department of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Denmark

^d Centre for Innovative Medical Technology, Odense University Hospital, University of Southern Denmark, Denmark

^e Centre for Online Health, The University of Queensland, Australia

^f Centre for Health Services Research, The University of Queensland, Australia

^g Research Centre for Emergency Medicine, Aarhus University Hospital, Denmark

^h Department of Clinical Medicine, Aarhus University, Denmark

ⁱ Department of Paediatrics and Adolescent Medicine, Unit for Research and Development in Nursing for Children and Young People, Aarhus University Hospital, Denmark

ARTICLE INFO

Keywords:

Childhood cancer
Compassion
Family care
Oncology care
Paediatric oncology
Parental care
Psychosocial care
Qualitative research

ABSTRACT

Purpose: Parents of children/adolescents with cancer are placed in a state of severe suffering due to serious concerns, fears, and radical daily life changes. Human support is an important source of support for successful coping. This study explored fundamental aspects of parents' daily, social, and personal life during their child's treatment to deepen our understanding of 'who' plays a significant role in supporting parents, and how, and to what extent this support is provided.

Methods: This qualitative study was undertaken in a compassion paradigm, designed and guided by Heidegger's and Gadamer's philosophy and compassionate methods. Data were generated through ethnographic observations (144 h), focus group interviews (n = 2), and individual/couple interviews (n = 16) at two Danish hospitals. Inductive content analysis was used to analyse data.

Results: Overall, support from peers, health professionals, and social networks constituted significant sources of support. Especially peers and health professionals had a continuous support role, which was fundamental for establishing interpersonal closeness and relieving suffering. Sharing responsibilities between parents and among social networks seemed to ease the emotional and practical burden. However, to ensure effectiveness, social networks must be available, outreach, and responsive to needs. Moreover, parents disclosed little self-awareness and resources and options for self-care due to a combination of lack of awareness, time, and space in the hospitals.

Conclusion: Safeguarding interpersonal and interparental understanding and closeness in parental care is essential. One way is building resilience and a broader human-to-human-based safety net around the family, including social networks and professional psychosocial support, advantageously using compassion.

1. Introduction

Suffering is an unavoidable and universal adversity in human life (Feldman and Kuyken, 2011). When confronting serious illness, human beings become particularly vulnerable and in need of care and

compassion for maintaining even basic daily life functions (Perez-Bret et al., 2016). Parenting a child or adolescent (hereafter collectively referred to as "children") with cancer is an extremely demanding and distressing experience (Carlsson et al., 2019; Huang et al., 2023). Everyday life changes substantially, and the parents assume new

* Corresponding author. Hans Christian Andersen Children's Hospital, Odense University Hospital, Denmark.

E-mail address: Camilla.Littau.Nielsen@rsyd.dk (C.L. Nielsen).

<https://doi.org/10.1016/j.ejon.2024.102534>

Received 13 September 2023; Received in revised form 21 January 2024; Accepted 14 February 2024

Available online 24 February 2024

1462-3889/© 2024 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

caregiver roles and responsibilities. To handle all responsibilities related to jobs, potential siblings, social life, home-life chores, and the care of the ill child, family members may be forced to divide their time between hospital and home (Mu et al., 2015), despite their need for family closeness (Darcy et al., 2014). Further comes the confrontation with the child's potential mortality, loss of a "normal childhood", and physical pain, which contribute to parents' grief (Patterson et al., 2004). Thus, parents are placed in a state of severe suffering that comes with an increased risk of developing anxiety, depression, and post-traumatic stress disorder (van Warmerdam et al., 2019).

Parents' mental health post-diagnosis and coping adequacy are associated with family adjustment (Long and Marsland, 2011) and coping abilities (Ljungman et al., 2014), respectively. Adequate coping strategies, especially in the initial treatment stages, are crucial in preventing psychological side effects for the parents (Ljungman et al., 2014). Health professionals (HPs), particularly nurses, due to their often long-term and close contact with the families, have good opportunities to support the parents' coping, increasing the parents' ability to care for themselves and their children (Björk et al., 2009). Professional support is reported to improve parental resilience (Brody and Simmons, 2007; Mu et al., 2015; Mezgebu et al., 2020). So are support from extended family members (Mu et al., 2015; Huang et al., 2023), friends (Mu et al., 2015; Mezgebu et al., 2020), and other significant people in their social network, e.g. in workplaces and local communities (Mu et al., 2015).

2. Aim

This study explored fundamental aspects of parents' natural daily, social, and personal life during their child's cancer treatment to deepen our understanding of 'who' plays a significant role in supporting parents, and how, and to what extent this support is provided.

3. Methods

3.1. Design

This qualitative, descriptive study formed the initial part of a larger project about Compassion in Childhood Cancer Care (CCCC), aiming to improve patient trajectories. It was undertaken in a compassion paradigm, designed and guided by philosophical concepts of Heidegger and Gadamer and compassionate methods. The study was based on the assumptions that suffering is a common human condition (Feldman and Kuyken, 2011), and 'care' is about alleviating suffering in an attentive and affectionate way (Perez-Bret et al., 2016; Trzeciak et al., 2019). This includes being open to, cognitively understanding, and compassionately acting to alleviate suffering (Gilbert, 2005; Raustøl and Tveit, 2023), based on the understanding that all living beings share the desire to be free from pain and affliction (Feldman and Kuyken, 2011).

From the phenomenological notion that the world is as lived by a person and can be taken for granted (Lavery, 2003), we applied an open and sensitive attitude to explore and interpret parents' lived experiences and behaviours. Emotions of the engaging researcher, bringing potential unique insight into understanding particular experiences, and forming responses to those, supported the data generation and data analysis process (Hansen and Trank, 2016). Further, since our understanding is the basic phenomenon in human existence, rooted in historically and culturally lived experiences, interpretation is useful in understanding human behaviour. In the encounter with human beings and the written material, our pre-understandings were challenged, leading to new understandings in an ongoing hermeneutic circular process of horizon fusions (Lavery, 2003). Four researchers (nurses) responsible for this study have pre-understandings embedded in qualitative research in combination with paediatric nursing care. Two of those are also certified ambassadors (facilitators) of Applied Compassion Training (The Center for Compassion and Altruism Research and Education, S. U., 2023). The physician-researcher is a specialist in cancer care, whilst the two

mothers (user representatives), in the final phase of their child's treatment, are regarded as experts in their suffering and coping experiences.

3.2. Participants and Settings

Danish- or English-speaking parents of children under the age of 18 years receiving curative treatment at one of the two included Danish university hospitals were purposively sampled for in-depth interviews. This sample was based on disease-specific data and child and family characteristics to ensure heterogeneity. Through self-created parental networks, we further recruited parents of children, who had completed a treatment protocol (cancer survivors) within the last two years, for participation in focus group interviews. Those parents knew each other prior, intending to establish interpersonal confidence during discussions.

3.3. Data generation

To uncover both unspoken and spoken knowledge, data were generated through short-term hospital-based ethnographic fieldwork and (focus group) interviews. The observation and interview guides were inspired by Spradley (2016) and Brinkmann and Kvale (2018), respectively, as well as a literature review and 30 days of neutral observations in one of the hospitals by the first author before study initiation (Hammersley and Atkinson, 2019). The user representatives in the research group served as pilots to test and confirm the topics and questions included in the interview guides.

Due to participation in emotionally challenging situations of vulnerable families, naturally evoked, fostered, and safeguarded through interpersonal trust, the first author endeavoured to establish trust. This involved the verbal and non-verbal demonstration of personal integrity, respect, humility, and genuine curiosity, aiming to make participants feel that they are experts and their stories valued (Boyd and DeLuca, 2017). Doing so likewise aligned with the author's and compassionate values (Shaw et al., 2020; Sinclair et al., 2021). Moreover, this "humanisation" of the participating author may promote the unfolding of natural processes and behaviours because people behave more spontaneously and naturally toward fellows (Bundgaard, 2010).

3.3.1. Short-term ethnographic fieldwork

Wearing a uniform, following HPs (mostly nurses) during their shifts, the first author passively observed behaviours between families and HPs during rounds, procedures, and other hospital-based activities. The author also moderately participated in activities in the open, shared places around families during their hospital admissions and/or outpatient visits. Participation and observations were carried out all days of the week, including weekends, during the day and evenings. The author first made broad descriptive observations to gain an initial understanding of what was going on, followed by more focused and then selective, descriptive observations (Spradley, 2016). They all concerned the natural daily life involving interpersonal interactions and the surrounding material world, both inscribing social relations and versions of reality (Hammersley and Atkinson, 2019). All observations were recorded as condensed notes and expanded with details immediately after each observation (Spradley, 2016), constituting a narrative. This also included notes on the participating and observing author's sensations, feelings, and immediate thoughts, as recommended by Spradley (2016).

3.3.2. Semi-structured interviews and focus group interviews

Alongside the ethnographic fieldwork, the recruitment of interview participants took place. Therefore, most parents were already familiar with the (intentions and goals of the) CCCC project and the first author, who also conducted the interviews. This provided the author with the opportunity to pursue potential clarifications related to the field observations. The interviews were semi-structured and overall concerned

with uncovering the suffering and human support of parents, through intra- and interpersonal topics relevant to daily life. These included the hospital, home, work, social, personal, family, and marital life during the child's treatment. To encourage trust and a safe space for sharing stories (Hansen and Thorsted, 2022) and gain confidence (Boyd and DeLuca, 2017), parents were encouraged to share personal experiences caring for their child. They were interviewed individually or together with their spouse in their child's hospital room, or at an alternative place in the hospital, depending on the parents' preferences.

The focus group interviews were performed by the first, second, and last authors via videoconference due to the 2019 coronavirus disease (COVID-19) pandemic restrictions. In these focused dialogues, the parents of cancer survivors were reflecting on experiences related to their child's treatment period considering the entire treatment trajectory and overall accomplishment. The intention was to uncover the most powerful events related to intra- and interpersonal topics like those mentioned above. This might include events particularly significant (positively as well as negatively) or of personal importance (Snelgrove and Havitz, 2010). This process might highlight the most prominent (unmet) needs, underpinning the in-depth interview data of parents with a child currently receiving cancer treatment. All interviews were audio-recorded and verbatim transcribed, and the first author's sensations, feelings, and immediate thoughts were noted along the way.

3.4. Data analysis

Data were analysed by the first and last author through a multi-step dialectical process, moving between the whole and its parts. A qualitative inductive analysis approach was applied to obtain rich descriptions of patterns or regularities in the data (Graneheim and Lundman, 2004) with focus on parental suffering and supportive aspects in the natural context of daily, social, and personal life. Initially, the interview transcripts and narratives were gathered into one text and read thoroughly several times to obtain a sense of the whole. The first author included the notes on sensations, feelings, and thoughts, enabling reflection and theorising where possible to explain the particular incidents (Hansen and Trank, 2016). Positioning close to the text, focusing on the manifest content, the text was separately divided into meaning units that were condensed on a low abstraction level with a low interpretation degree (Graneheim et al., 2017). After this process, triangulation and discussion on inconsistencies took place. Based on agreement, the meaning units were abstracted and labelled with codes and subsequently gathered into sub-categories and categories to describe phenomena and enhance understanding. Thereafter, the focus was centred on the latent content, which was interpreted on a low abstraction level with a high interpretation degree to obtain the underlying meanings cutting across categories. This engendered an overarching theme of meaning (Graneheim and Lundman, 2004; Graneheim et al., 2017). There was an open dialogue within the research group, including the user representatives, aiming to discuss overall agreement, reflections, and reach of data saturation. Data saturation was reached when no new or relevant data appeared (Dworkin, 2012), based on the representation of different family structures and illness trajectories. The COREQ checklist was followed for reporting (Tong et al., 2007).

3.5. Ethical considerations

The study was approved by the Data Protection Agency of the Region of Southern Denmark (21/34126) and evaluated by the Ethics Committee of the Region of Southern Denmark (20222000-87), providing an approval waiver. The parents (and HPs who were observed throughout their shifts) received written and oral information about the study, and provided signed consent prior to participation, in accordance with the Helsinki Declaration.

4. Findings

4.1. Study population characteristics

From August to December 2021, 144 h of observations of families and HPs at two Danish university hospitals were carried out. In addition, 16 interviews were completed, evenly distributed between the two hospitals, with 22 parents (16 families) (Table 1), of whom 12 attended as couples and were interviewed together. The average duration of interviews was 46 min (range, 17–67 min). Furthermore, two focus group interviews, each of 2 h duration, with five and six parents (in total 11 families), were conducted by videoconference. All invited parents agreed to participate. Participant characteristics are presented in Table 1.

4.2. Themes

The analysis revealed the following themes, constructed by categories (shown in brackets):

- Living in a parallel world (*A changed daily life and new responsibilities and The significance but challenges of social network involvement*)
- Being in the same boat is relieving unless sailing in different directions (*The significance of a shared understanding and "language" and The strengths and challenges of interparental interaction*)
- Me? There is barely a "me" (*Lack of awareness and space and Few or no resources and options for providing self-care*).

Table 1
Participant characteristics.

Characteristics	Receiving cancer treatment ^a	Post-cancer treatment ^b
Families	(n = 16)	(n = 11)
Relationship between the parents, n (%)		
Cohabiting	14 (87.50)	9 (81.82)
Separated	1 (6.25)	2 (18.18)
Full single parent	1 (6.25)	
Home-living siblings, n (%)	12 (75)	9 (81.82)
Parents	(n = 22)	(n = 11)
Females, n (%)	13 (59.09)	10 (90.91)
Leave of absence to some degree during treatment, n (%)	19 (86.36)	9 (81.82)
Full for one parent	13 (68.42)	8 (88.89)
Mothers	11 (84.62)	7 (87.50)
Children	(n = 16)	(n = 11)
Boys, n (%)	10 (62.50)	5 (45.45)
Age at time of interview ^a /diagnosis ^b in years, n (%)		
0-3	6 (37.50)	6 (54.55)
4-7	1 (6.25)	
8-10	2 (12.50)	3 (27.27)
11-14	3 (18.75)	2 (18.18)
15-17.9	4 (25)	
Diagnosis, n (%)		
Lymphoma		
Non-Hodgkin	1 (6.25)	1 (9.09)
Hodgkin	3 (18.75)	
Neuroblastoma	2 (12.50)	
Nephroblastoma	2 (12.50)	
Brain tumor	1 (6.25)	2 (18.18)
Leukemia		
Acute Myeloid	1 (6.25)	
Acute Lymphocytic	5 (31.25)	8 (72.73)
Osteosarcoma	1 (6.25)	
Co-morbidity ^a , n (%)	3 (18.75)	1 (9.09)
Time since diagnosis ^a /treatment completion ^b in months, n (%)		
≤1	4 (25)	1 (9.09)
2-6	6 (37.50)	1 (9.09)
7-11	4 (25)	4 (36.36)
12-15	1 (6.25)	2 (18.18)
16-24	1 (6.25)	3 (27.27)

^a Metabolic disorder, (genetic) syndromes, and brain damage.

4.2.1. Living in a parallel world

Navigating a fundamentally changed and unpredictable everyday life due to the ill child's treatment and life circumstances was considered living in a parallel world, ruling the ordinary, familiar one. Parents experienced that the majority of people standing outside the parallel world had difficulty understanding the family's current life situation and provided passive rather than active support.

4.2.1.1. A changed daily life and new responsibilities. Although the treatment protocol served as an overall time-limited and structured guide for emotional and practical navigation, it was difficult for all parents to structure their daily life due to the ill child's unpredictable health condition. Most explained that they were living "1 day at a time" and that HPs initially (within the first month post-diagnosis), and sometimes in particular tough periods along the way, stepped in to reconstruct everyday life. This was to ensure the maintenance of basic daily life functioning. Parents generally refrained from planning ahead but grabbed the spontaneous situations for doing activities with the ill child and siblings on good days. This often required help from HPs, as they are the ones familiar with the treatment regimen, including when there is room for social activities. The joy of doing things together benefited the whole family in the sense of accommodating their need for togetherness, which was required for maintaining "the spark of life" within the family. A mother of a cancer survivor explained so:

"Although it is difficult, there must be room for playing and doing things together as a family to maintain the spark of life. If the spark of life is extinguished, you cannot do anything. Even the best treatment cannot save the child then". (parent#2, focus group interview)

With regard to illness-related tasks, mainly hospital-based parents carried a major burden, compared to their mostly home-based spouse, and reported significant stressors and exhaustion. This particularly applied to parents of younger children (before school age) and children with significant disabilities, whose signals were harder to decode and who were more dependent on their parents. However, hospital-based parents were also the ones receiving substantial support from HPs and peers during hospitalisation, which constituted facilitators of successful coping. In contrast, some of the parents who mainly cared for home-life chores, siblings, and their job, expressed difficulties in being fully involved in hospital activities. They often felt alone, which was emotionally challenging when devastating thoughts arose. HPs approached those parents less, compared to their spouse at the hospital, who often also mediated the communication between HPs and the parent at home. The three parents, who, in contrast, mutually shared the responsibilities related to both hospital and home life, were better at balancing the many demands. At one time they could interact with siblings and distance themselves from illness-related tasks for a while by doing normal activities, and at another, they could "have the finger on the pulse" in being directly involved in the child's recovery process. Two of those parents maintained employment responsibilities to some degree and reported significantly greater coping abilities. Moreover, a parent explained their family received support from a municipal-based therapist, who could "see through" the parents and was flexible in helping them structure activities according to their new roles. The therapist succeeded in making the parents talk to and understand each other to make everyday life work.

4.2.1.2. The significance but challenges of social network involvement. In view of the importance of making lives functional, support from social networks was important for the majority of families and considered a facilitator of successful coping. Most parents' social networks consisted of extended family members and friends. Some also experienced their work-related manager and colleagues, taking on an important support role, as well as the local community, e.g., the neighbours, school-teachers, and the parents of their ill children's close friends. In general,

the parents experienced a need for continued contact with their friends and likewise, taking part in their friends' lives too. Unfortunately, some parents experienced close friends refraining from sharing information about their own struggles in life to protect the parents emotionally. This, however, resulted in feelings of exclusion for the parents and was discovered as very painful.

In general, the majority of parents experienced that friends and extended family members had difficulty understanding their needs and how they could provide the best support. Many reported that relatives and friends either were afraid of facing the suffering of the family or did not know what to do and therefore stayed passive or distant. This most often resulted in relatives telling the parents to let them know if any help was needed, which was impossible for the parents though. In fact, they just wanted relatives to act without asking for permission, e.g., cleaning the house, cooking meals that could be stored in the freezer, walking the dog, offering childcare, etc. A hospitalised mother explained her challenges in such matter:

"People from outside the "bubble" [household] do not understand. They cannot. They [relatives] tell me to speak up if I need any help, yet they presume that this is not relevant to a person like me because I always have things under control and my house always looks clean. They should just know (...) They should just do something [help]. In fact, once I finally asked for help, and do you know what? It [helping me] did not really suit their [relatives'] plans [for the day]". (parent#10, couple interview)

In contrast, those who experienced receiving sufficient support from their networks, which was only a few, experienced less stress. The characteristics of these cases were the active roles the extended family, friends, a manager, a colleague, and a municipal-based therapist played, which included active involvement in everyday activities and the perceived suffering of the parents. One parent explained how they, in collaboration with grandparents, took turns to go to the hospital with the ill child, and how the grandparents assumed many of the practical chores at home. The latter source of support was particularly important to the single parent, who had responsibilities for both the ill child and a sibling, but also the home-based parents, who often were on their own, both practically and emotionally.

4.2.2. Being in the same boat is relieving unless sailing in different directions

Socialising and connecting with people who were perceived by the parents to understand the families' current life situation was crucial in alleviating suffering for parents. It provided them with the feeling of not being alone. However, couples who were in a shared position but had very diverse reactions to suffering experienced difficulties in being near, supporting, and relating to each other.

4.2.2.1. The significance of a shared understanding and "language". In addition to the social network's and the spouse's influence, both described above, peers and HPs had a huge impact on parents' emotional self-regulation. Interpersonal interactions often underpinned the parents' ability to apply meaning-making, positive thinking, and reappraisal skills, which were prominent skills used by most parents. This also applied to meeting parents of children with chronic diseases and significant disabilities with whom they were crossing paths in the hospitals, as exemplified by a hospitalised father:

"[...] Then I met this mother pulling her brain-damaged child in a wheelchair, and I recognised that my child at least has the chance of being cured. It is weird, but it made me feel thankful for my child's condition". (parent#7, couple interview)

Peer-to-peer contacts were primarily established within the hospitals' shared areas and were considered therapy for the parents, making some consider the hospital as their "second home". Here, they could share experiences and thereby mirror themselves in worries, concerns,

and emotional difficulties similar to their own, which created a shared understanding and “language”. This provided a sense of togetherness and belonging that helped to mitigate loneliness and build courage and hope, as well as inner strength to keep on fighting. However, not all parents had opportunities for establishing this contact. This applied to some parents of shorter duration treatment trajectories, and those with fewer admissions and more outpatient visits, limiting social interactions and providing feelings of being alone. A parent explained that not establishing any peer-relationships during the child’s treatment had made them feel very lonely, particularly when they approached the end of treatment. This was due to discovering not having anyone to share good advice, worries, and emotional and practical struggles with when being on their own. Furthermore, it applied to some parents in the initial treatment period, who felt overwhelmed observing the feelings of others, withdrawing from any opportunities to interact. However, the peers’ (and HPs’), in general, persistent invitations to join shared activities were encouraging and helped some parents to act and thereby address an unknown need for socialisation. This contact often resulted in the development of close ties with certain HPs, referred to as their “second family”. This was based on the HPs’ demonstration of genuine interest, humanity, and kindness, providing connection in a “shared third place” that goes beyond the professional.

4.2.2.2. The strengths and challenges of interparental interaction. Although parents expressed their long-lasting, “strong” marital relationship was advantageous for understanding and supporting each other when facing this crisis, most expressed interpersonally diverse reactions and responses to suffering. This, also reflecting differences in personality and responsibilities (described above), resulted in diverse needs, as demonstrated by an outpatient-visiting mother:

“Sometimes, when I get home from the hospital, my husband asks questions that I cannot answer. This frustrates him, and he then asks me why I did not think of asking such questions [to the HPs]. I did not, because I was asking other questions... those natural to me”. (parent#12, individual interview)

Sometimes it felt difficult to understand and relate to each other as a couple. In a few cases, to such a degree that the individual parent was left struggling with painful emotions and had to withdraw for a while. One example is the parent who inspected photos taken before the child got ill, ruminating about how life was supposed to be and how the spouse was taking things too easily, which resulted in deep frustrations and feelings of being stuck in and alone with dark thoughts.

4.2.3. Me? There is barely a “me”

The hospital culture was predominately centred on the ill child’s care, involving the parents as caregivers and family members, a paramount source of support in regard to the child’s recovery. However, the parents were physically, mentally, and emotionally burdened people too. They needed but had little or no self-awareness and resources and possibilities for nurturing their well-being.

4.2.3.1. Lack of awareness and space. Since most of the aspects of daily life revolved around and were adapted to the condition of the ill child, this constituted the “natural language” of parents and between people in the wards. During the interviews, most parents disclosed a strong emotional reaction toward being encountered in their good intentions and efforts in caring for their children (demonstrated in the hospital and through their explanations) and being encountered with curiosity toward their vulnerability and need for being taken care of. Self-oriented questions seemed difficult and were rarely answered with words but sadness. It was overwhelming for the parents to receive such intensive, personal attention due to the understanding of their child as the one who is ill (suffering), not them, as well as the recognition of their lack of self-awareness. Parents’ unawareness was also linked to feeling numb, e.g.,

mind-body disconnection or body disconnection through physical detachment from objects like the floor, mattress, etc. Most reacted strongly with sadness toward this feeling of losing themselves, as well as the recognition of feeling lonely and a lack of space for them as humans in all of this happening, as explained by a hospitalised mother:

“This is actually a very lonely time. You know; it feels like there is not really space for me – I am just ‘mom’. Well, I should not complain though because I am not the one who is suffering from cancer”. (parent#5, individual interview)

Many parents experienced that HPs had explicated to them the importance of nurturing their own well-being and likewise encouraged them to do so along the way. A few parents also explained that HPs helped them understand their body’s signals, e.g., that intense feelings of grief can manifest as physical sensations.

4.2.3.2. Few or no resources and options for providing self-care. Despite HPs’ encouragement, it mostly felt impossible for the parents to prioritise themselves for various reasons. Many parents disclosed feelings of extreme exhaustion, a lack of time, and/or poor options to nurture their own needs in daily life. They explained that there were no places in the hospital to isolate themselves for a moment to have a private conversation with their spouse, or to vent out difficult emotions. Parents revealed that they used the hospital carpark to cry and express grief, or that they cried in the shower or silently under the pillow when the child was asleep; all to ensure the child was unaware. Others felt that accommodating their own needs was unmanageable; as if words and deeds are oceans apart. Others again stated that it was overwhelming and that they had no idea how to confront their fears and thus avoided relating to their emotions.

Most parents consulted a hospital-based social worker for important support to handle their job and economic situation, whilst some regularly consulted a hospital-based psychologist for psychological support. Moreover, some found immediate relief in drinking plenty of coffee, and/or smoking cigarettes, even though they had quit smoking years ago. Often, HPs (mostly nurses) identified situations where parents needed a break from the hospital or a therapeutic conversation, for instance, and acted as coordinators, scheduling things and kindly pushing the parents. This was indeed the push needed for some parents to take action, as demonstrated by a mother of a cancer survivor:

“Because I felt so exhausted all the time, my therapist said I had to explain to myself how much it would benefit me to read this book or have that cup of coffee and talk with my friend. She [the therapist] helped me write down the exact time and activity. This helped me a lot to act on it”. (parent#4, focus group interview)

Most parents enjoyed this personal time to do activities with their spouse or friends, read a book, go for a run, etc. Having personal time away from the hospital was, however, not relieving or possible for all parents, although they had the feeling of deeply longing for it. Some felt guilty for not being present and longed for returning to the child’s bedside to be supportive, and some did not have supportive social networks to help them in such circumstances. Conversely, the parent, who experienced sufficient support from the therapist and parents with shared responsibilities or relatives directly involved in everyday life activities, reported greater ability and time to address personal needs.

5. Discussion

This study provides valuable insight into parents’ natural aspects of daily, social, and personal life, highlighting significant sources of support for parents, and how, and to what extent they receive this support. Overall, our findings emphasise the value of as well as the need and potential for further improving human support for parents during their child’s treatment, influencing the phase after treatment as well. As

demonstrated in this study, HPs have a continuous support role in parents' lives in the context of the hospital and the child's care, and therefore primarily target hospital-based parents. In contrast, the municipality-based therapist had a continuous support role for one family concerned with a broader spectrum and function of the family's life, including both the mother's and father's perspectives and support of their individual as well as shared journey. Combined couple and individual support seem very important, seen in the light of the parents' often diverse reactions and responses to suffering and lack of personal awareness. Additionally, peers and social networks related to the personal, social, local community, and work life constituted significant sources of support for the parents. Establishing peer-relationships during treatment was also essential in regard to approaching the end of treatment and being on their own in the transition phase back to a "normal life".

The empirical model of compassion by Sinclair et al. (2021) provides us with an understanding of meanings related to 'shared humanity' feelings among families and HPs and refers to connectedness at a relational level that goes beyond HPs' clinical role. Interestingly, Garg (2023) recently, in general terms, claimed that such human-to-human connections build upon love, whilst HP-patient connections are based on science. These perspectives can explain the parents' understanding of and referral to HPs as their "second family", for instance, acknowledging their beneficence as fellow humans in our study, like other studies (Patterson et al., 2004; Ångström-Brännström et al., 2010; Darcy et al., 2014; Carlsson et al., 2019; Huang et al., 2023). An essential element of compassionately connecting is that it builds on relational understanding (Sinclair et al., 2021). This can explain the developed connection between parents, peers, and HPs through a shared understanding and "language", pointing to the relevance of extending the empirical model by Sinclair et al. (2021) to include peers, as they appear to be a central part of the established hospital community as well. Further, relational understanding, which has to be adjusted between families and their relatives and friends according to the family's new life situation, can explain why it is difficult for relatives and friends standing outside the hospital community to understand the family's situation and thus provide sufficient support. Insufficient support from relatives has been described in a number of other studies (Patterson et al., 2004, Brody and Simmons, 2007, Björk et al., 2009, Džombić and Ogresta, 2020).

In other contexts (but, mainly palliative care), compassion-based interventions to build community targeted social networks and local community actors have been shown to address psychological, spiritual, and social well-being by improving the social capital and interpersonal connections between citizens. This resulted in the promotion of compassionate and caring behaviours (Dumont et al., 2022). In this context, Aoun et al. (2018) found that the social support most often perceived as helpful is the emotional ties to others, the practical help, and the perceived sense of belonging. With respect to our findings, this compassionate community approach activating social networks around the families seems beneficial in providing a path forward regarding the promotion of social connections fostering a safety net based on human connectedness that extends beyond the hospital.

Moreover, cultivating self-compassion has been shown to help improve resilience in parents of children with cancer (Khosrobeigi et al., 2022). In regard to our prominent findings of most parents' poor or lack of self-awareness and self-care, this may be a focus of request. For example, cultivating loving-kindness meditation – that is cultivating a mental state of wishing well and unconditional love and kindness to all fellow beings (Zhao, 2022) – has been shown to enhance positive emotions, resulting in decreased illness and increased social support; both associated with social connection (Seppala et al., 2013). Due to its positive impact on anxiety and depression, emotion regulation, social connections, and building inner mental strength and self-esteem, Zhao (2022) recommends offering loving-kindness meditations to a broader audience facing psychosocial challenges, including in healthcare. Cousineau et al. (2019) support this by highlighting the positive impact

that building self-compassion skills in parents of chronically ill children may have on their application of adaptive coping strategies, including emotion regulation, appraisals, and compassionate attention, to promote parental resilience. Noteworthy to our study, Cousineau et al. (2019) also highlight the influence of family functioning and social support, among other factors, on these processes in their developed conceptual model about the role of compassion and mindfulness in building parental resilience. To this, our study adds valuable knowledge about the impact of different family structures and human support sources on parents' experiences of suffering and coping, influencing their ability to care for themselves and thus their ill child (and siblings). This serves as an important foundation for practical strategies to bridge the human gap between parents and significant other people around the family during the child's cancer treatment, as well as further research.

Recommendations for clinical practice and future research:

- HPs should ensure that necessary support is provided for family members who remain in hospital as well as those at home and encourage the sharing of responsibilities and thus the subsequent burden of the overall experience for the parents.

- As a supplement to HPs' tremendous effort, there is a need for offering a flexible, relational psychosocial support service grounded in daily life, advantageously using compassion. This should focus specifically on acknowledging and navigating the suffering and (personal) challenges linked to parenting a seriously ill child, including interparental communication and understanding, as well as self-awareness and self-care.

- The involvement of extended family members, including friends, relatives, and other significant people to the family should be prioritised, as a means of strengthening social networks, increasing opportunities for practical and emotional support, and communicating needs within the family.

- There is a need for further research to better understand the challenges of social networks and which instances, beyond the hospital, should be involved in the complex process of better integration of social networks in family care.

5.1. Strengths and limitations

The rich and heterogeneous data gained through multiple methods strengthen this study's credibility (Graneheim et al., 2017). Further, the researchers and user representatives agreed on the stage of reached data saturation. Irrespective of whether parents were home-based or mainly living in the hospital during treatment, the interview process gave everyone the opportunity to speak and share their stories. For individual interviews, this meant "her story" or "his story", and for couple interviews, the story they told each other, representing "their story" (Taylor and De Vocht, 2011). This contributed to nuanced data of value to this study, as we investigated parental experiences in both individual and relational contexts of everyday life. These experiences were derived from parents affiliated with two of the four Danish healthcare facilities offering cancer care services for children. Since this study was carried out during the COVID-19 pandemic, it is possible that parental experiences may have been impacted by extraordinary local regulations imposed by health services, such as isolation rules during lockdown periods. Transferability of findings therefore needs to consider different management as well as different healthcare models, including cultural and socio-economic factors.

6. Conclusion

This study demonstrates that human presence is very powerful, and helpful when actively engaged in the daily life and suffering of parents (and the family). Safeguarding interpersonal and interparental understanding and closeness in parental care is essential to alleviate suffering related to their current life situation parenting a child on cancer treatment. Building resilience and a broader human-to-human-based safety

net around the parents (family), including social networks and a flexible, relational psychosocial support service, is one path forward. Applying a compassionate approach seems to be appropriate because compassion appears to be a tool and a mind-set that can improve resilience, and thus emotional presence safeguarding connection and closeness in care to alleviate suffering in parents of children with cancer.

Funding sources

Odense University Hospital, Denmark; University of Southern Denmark, Denmark; Hans Christian Andersen Children's Hospital, Denmark; Lizzi and Mogens Staal Foundation, Denmark [grant number: 2021-0490]; LEGO© Employees' Anniversary Grant 2022, Denmark; The Hede Nielsen Family Foundation, Denmark; and Lån & Spar Foundation, Denmark.

CRedit authorship contribution statement

Camilla Littau Nielsen: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Validation, Visualization, Writing – original draft. **Jane Clemensen:** Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Writing – review & editing. **Michael Thude Callesen:** Data curation, Funding acquisition, Resources, Validation, Writing – review & editing. **Claus Sixtus Jensen:** Data curation, Resources, Validation, Writing – review & editing. **Anthony C. Smith:** Methodology, Validation, Writing – review & editing. **Kristina Garne Holm:** Data curation, Formal analysis, Investigation, Project administration, Supervision, Validation, Visualization, Writing – review & editing.

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

The authors would like to thank all the participants for their support of the project, including Ditte Magnusson and Mette Vedtofte for their great contributions as part of the research group.

References

- Ångström-Brännström, C., Norberg, A., Strandberg, G., Söderberg, A., Dahlqvist, V., 2010. Parents' experiences of what comforts them when their child is suffering from cancer. *J. Pediatr. Oncol. Nurs.* 27, 266–275.
- Aoun, S.M., Breen, L.J., White, I., Rumbold, B., Kellehear, A., 2018. What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliat. Med.* 32, 1378–1388.
- Björk, M., Wiebe, T., Hallström, I., 2009. An everyday struggle—Swedish families' lived experiences during a child's cancer treatment. *J. Pediatr. Nurs.* 24, 423–432.
- Boyd, M., Deluca, S., 2017. Fieldwork with in-depth interviews: how to get strangers in the city to tell you their stories. *Methods in social epidemiology* 239–253.
- Brinkmann, S., Kvale, S., 2018. *Doing Interviews*. Sage.
- Brody, A.C., Simmons, L.A., 2007. Family resiliency during childhood cancer: the father's perspective. *J. Pediatr. Oncol. Nurs.* 24, 152–165.
- Bundgaard, H., 2010. Lærlingen: den formative erfaring. *Ind i Verden. En grundbog i antropologisk metode*. Hans Reitzels Forlag 51–69.
- Carlsson, T., Kukkola, L., Ljungman, L., Hövén, E., Von Essen, L., 2019. Psychological distress in parents of children treated for cancer: an explorative study. *PLoS One* 14, e0218860.
- Cousineau, T.M., Hobbs, L.M., Arthur, K.C., 2019. The role of compassion and mindfulness in building parental resilience when caring for children with chronic conditions: a conceptual model. *Front. Psychol.* 10, 1602.

- Darcy, L., Knutsson, S., Huus, K., Enskar, K., 2014. The everyday life of the young child shortly after receiving a cancer diagnosis, from both children's and parent's perspectives. *Cancer Nurs.* 37, 445–456.
- Dumont, K., Marcoux, I., Warren, E., Alem, F., Alvar, B., Ballu, G., Bostock, A., Cohen, S. R., Daneault, S., Dubé, V., 2022. How compassionate communities are implemented and evaluated in practice: a scoping review. *BMC Palliat. Care* 21, 131.
- Dworkin, S.L., 2012. *Sample Size Policy for Qualitative Studies Using In-Depth Interviews*. Springer.
- Džombić, A., Ogresta, J., 2020. Living "day-by-day": parents' experiences during their child's active cancer treatment. *Hrvatska Revija Rehabilitacijska Istrazivanja* 56, 85–95.
- Feldman, C., Kuyken, W., 2011. Compassion in the landscape of suffering. *Contemp. Buddhism* 12, 143–155.
- Garg, P., 2023. Magic of the touch. *Patient Educ. Counsel.* 106, 210–211.
- Gilbert, P., 2005. Introduction and Outline. *Compassion: Conceptualisations, Research and Use in Psychotherapy*. Routledge, pp. 1–6.
- Graneheim, U.H., Lundman, B., 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ. Today* 24, 105–112.
- Graneheim, U.H., Lindgren, B.-M., Lundman, B., 2017. Methodological challenges in qualitative content analysis: a discussion paper. *Nurse Educ. Today* 56, 29–34.
- Hammersley, M., Atkinson, P., 2019. *Ethnography: Principles in Practice*. Routledge.
- Hansen, F.T., Thorsted, A.C., 2022. At Tænke Med Hjertet: En Grundbog I Eksistentiel Praksisfænomenologi. Klim.
- Hansen, H., Trank, C.Q., 2016. This is going to hurt: compassionate research methods. *Organ. Res. Methods* 19, 352–375.
- Huang, Y., Chen, M., Zhang, Y., Chen, X., Zhang, L., Dong, C., 2023. Finding family resilience in adversity: a grounded theory of families with children diagnosed with leukaemia. *J. Clin. Oncol.* 41(15–16), 5160–5172.
- Khosrobeigi, M., Hafezi, F., Naderi, F., Ehteshamzadeh, P., 2022. Effectiveness of self-compassion training on hopelessness and resilience in parents of children with cancer. *Explore* 18, 357–361.
- Laverty, S.M., 2003. Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *Int. J. Qual. Methods* 2, 21–35.
- Ljungman, L., Cernvall, M., Grönqvist, H., Ljótsson, B., Ljungman, G., Von Essen, L., 2014. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PLoS One* 9, e103340.
- Long, K.A., Marsland, A.L., 2011. Family adjustment to childhood cancer: a systematic review. *Clin. Child Fam. Psychol. Rev.* 14, 57–88.
- Mezgebu, E., Berhan, E., Deribe, L., 2020. Predictors of Resilience Among Parents of Children with Cancer: Cross-Sectional Study. *Cancer Management and Research*, pp. 11611–11621.
- Mu, P.-F., Lee, M.-Y., Sheng, C.-C., Tung, P.-C., Huang, L.-Y., Chen, Y.-W., 2015. The experiences of family members in the year following the diagnosis of a child or adolescent with cancer: a qualitative systematic review. *JBI Evidence Synthesis* 13, 293–329.
- Patterson, J.M., Holm, K.E., Gurney, J.G., 2004. The impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. *Psycho Oncol.* 13, 390–407.
- Perez-Bret, E., Altisent, R., Rocafort, J., 2016. Definition of compassion in healthcare: a systematic literature review. *Int. J. Palliat. Nurs.* 22, 599–606.
- Raustøl, A., Tveit, B., 2023. Compassion, emotions and cognition: implications for nursing education. *Nurs. Ethics* 30, 145–154.
- Seppala, E., Rossomando, T., Doty, J.R., 2013. Social connection and compassion: important predictors of health and well-being. *Soc. Res.: Int. Q.* 80, 411–430.
- Shaw, R.M., Howe, J., Beazer, J., Carr, T., 2020. Ethics and positionality in qualitative research with vulnerable and marginal groups. *Qual. Res.* 20, 277–293.
- Sinclair, S., Bouchal, S.R., Schulte, F., Mt Guilcher, G., Kuhn, S., Rapoport, A., Punnett, A., Fernandez, C.V., Letourneau, N., Chung, J., 2021. Compassion in pediatric oncology: a patient, parent and healthcare provider empirical model. *Psycho Oncol.* 30, 1728–1738.
- Snelgrove, R., Havitz, M.E., 2010. Looking back in time: the pitfalls and potential of retrospective methods in leisure studies. *Leisure Sci.* 32, 337–351.
- Spradley, J.P., 2016. *Participant Observation*. Waveland Press.
- Taylor, B., De Vocht, H., 2011. Interviewing separately or as couples? Considerations of authenticity of method. *Qual. Health Res.* 21, 1576–1587.
- The Center For Compassion And Altruism Research And Education, S.U., 2023. *Applied Compassion Training | ACT* [Online]. California: the Center for Compassion and Altruism Research and Education. Stanford University. <https://ccare.stanford.edu/education/applied-compassion-training/>. (Accessed 19 January 2024).
- Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* 19, 349–357.
- Trzeciak, S., Mazzairelli, A., Booker, C., 2019. Compassionomics: the Revolutionary Scientific Evidence that Caring Makes a Difference. *Studer Group Pensacola, FL*.
- Van Warmerdam, J., Zabih, V., Kurdyak, P., Sutradhar, R., Nathan, P.C., Gupta, S., 2019. Prevalence of anxiety, depression, and posttraumatic stress disorder in parents of children with cancer: a meta-analysis. *Pediatr. Blood Cancer* 66, e27677.
- Zhao, Z., 2022. The influence of loving-kindness meditation on mental health—a systematic review. In: 2021 International Conference on Social Development and Media Communication (SDMC 2021). Atlantis Press, pp. 957–961.